### INTERACTIVE WEB APPLICATION FOR EVIDENCE-BASED MEDICINE TRAINING

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SUMMARY - The education in spirit of practicing evidence-based medicine represents the first step in implementation of the concept in daily activity. Two educational strategies in evidence-based medicine education, a directed intervention and a self-directed one, for fourth-year undergraduate medical students at the Faculty of Medicine, "Iuliu Hatieganu" University of Medicine and Pharmacy, Romania were studied. The methodologies used and the comparison between the intervention strategies on evidence-based medicine training are presented.

#### INTRODUCTION

The evidence-based medicine (EBM) concept, introduced by Guyatt & all in 1991 [1] and define as conscientious, explicit, and judicious use of the best evidence in making decisions about the care of individual patients [2], imposes the translation of knowledge resulted from research in daily individual decisions.

Evidence-based medicine education represents the first step in implementation of the concept into practice [3]. Comparing with no intervention, short EBM educational strategies proved to be able to transfer knowledge and sometimes to improve critical appraised skills for medical students [4], residents [5] and physicians [6].

#### 2 Аім

The aim of the research was to evaluate two educational strategies in evidencebased medicine education, a directed intervention and a self-directed intervention, for fourth-year undergraduate medical students at the Faculty of Medicine, "Iuliu Haţieganu" University of Medicine and Pharmacy, Romania.

#### 3 MATERIAL

Two interventions in evidence-based medicine training were studied: (1) a traditional intervention (a mini-course, two-hours), and (2) a self-directed intervention (interactive web curriculum; three month self-directed training <a href="http://vl.academicdirect.org/medical\_informatics/EBM\_Rom/EBMRom.chm">http://vl.academicdirect.org/medical\_informatics/EBM\_Rom/EBMRom.chm</a>) [7]. Both educational interventions covered the steps of practicing evidence-based medicine; computer-assisted curriculum enclosed deepen knowledge, clinical problem with or without solutions, links to evidence-based medicine resources in native languages and in English.

#### METHOD

The aim of the study was presented to a series of fourth-year undergraduate medical students at the Faculty of Medicine.

All students had possibility to chouse one of the presented interventions on evidence-based medicine education.

The students were considered to be eligible for the study if: (1) attended to the presentation; (2) complete the baseline characteristics form; (3) Complete the consent form for participation at a least one educational intervention in evidencebased medicine.

The consent form for the participants to the interactive web evidence-based medicine training imposed the access to an individual computer with CD-ROM. Knowledge and skills about evidence-based medicine concepts, searching techniques and critical appraisal of evidence was measured in both intervention groups at the end of the intervention using: z a paper-based questionnaire of eighteen true/false questions (with five problem-based questions) for the group which participate at the mini-course;  $\varkappa$  a tutor-assisted online forty-five multiple-choice questionnaire (fifteen problem-based questions) for the group which participate at self-directed intervention.

The participant's characteristics were summarized and the comparisons of the two groups were performed according with the type of variable and its distribution by the use of t-test, Mann-Withney U test, Statistica 6.0, at a significance level of 5%. The 95% confidence intervals for proportions were calculated with a method based on the binomial distribution hypothesis [8].

Ninety-six fourth-year medical students decided voluntary to enroll into the study: fifty-six students enroll to the mini-course on EBM and forty students enroll to follow the interactive curriculum on EBM.

**RESULTS** 

The characteristics of the students included into the study, summarized by intervention group are in table 1.

Table 1. Characteristics of students included into the study				
	Group		Total (n = 96)	
Characteristic	Directed (n = 56) Self-directed (n = 40) Percent (%) [95% CI] Percent (%) [95% CI]		Percent (%) [95% CI]	P-value
Gender				.743 <sup>†</sup>
Female	64.29 [50.03-76.75]	67.50 [50.06-82.44]	65.63 [55.22-74.99]	
Age (years old)				.235
21	19.64 [10.75-32.11]	32.50 [17.56-49.94]	64.58 [54.18-73.95]	
22	69.64 [55.39-82.11]	57.50 [40.06-72.44]	10.42 [5.22-18.74]	
23	10.71 [3.60-21.40]	10 [2.56-22.44]	25 [16.68-34.36]	
Previously heard about EBM	25 [14.32-37.47]	55 [37.56-69.94]	37.5 [28.14-47.91]	.003
Access to computer				.713
Easy	44.64 [30.39-58.90]	42.50 [27.56-59.94]	43.75 [33.34–54.16]	
Relative easy	19.64 [10.75-32.11]	32.50 [17.56-49.94]	25.00 [16.68-34.36]	
Difficult	30.36 [17.89-44.61]	20.00 [10.06-34.94]	26.04 [17.72-36.45]	
No access	1.79 [0.03-8.90]	2.50 [0.06-12.44]	2.08 [0.01-7.28]	
I don't know	3.57 [0.03-12.47]	2.50 [0.06-12.44]	3.13 [1.05-8.32]	
Access to Internet				.676
Easy	33.93 [21.46-48.18]	27.50 [15.06-44.94]	31.25 [21.89-41.66]	
Relative easy	25.00 [14.32-37.47]	45.00 [30.06-62.44]	33.33 [23.97-43.74]	
Difficult	35.71 [23.25-49.97]	22.50 [10.06-37.44]	30.21 [20.84-40.61]	
No access	1.79 [0.03-8.90]	5.00 [0.06-17.44]	3.13 [1.05-8.32]	
I don't know	3.57 [0.03-12.47]	0.00 [n.a.]	2.08 [0.01-7.28]	
<sup>™</sup> Chi-square₁; Mann-Withney U test; n.a. = not a				

The statistics of correct answers gave by the two group of directed and self-directed educational interventions in evidence-based medicine are in table 2. Note that all students previously received training in research methodology, epidemiology, and statistics.

The average of the proportions of correct answers in self-directed

group (0.844, n = 40) was significantly greater (P = .0174) compared with the average of the proportions of correct answers in directed group (0.617, n = 56). The results of analyzing the number of students which give a specified number of correct answers, for directed and self-directed interventions according with the following criterions: more than or equal with correct answers:

- (1) 50% ( $\geq$  9 for directed intervention,  $\geq$  23 for self-directed intervention);
- (2) 60% (≥ 11 for directed intervention, ≥ 27 for self-directed intervention):
- (3) 70% (≥ 13 for directed intervention, ≥ 33 for self-directed intervention);
- (4) 80% (≥ 15 for directed intervention, ≥ 36 for self-directed intervention) are in table 3.

Table 2. Results of educational evidence-based medicine knowledge assessment

	Group		
	Directed (n = 56) [95%CI]	Self-directed (n = 40) [95%CI]	
Number of questions (type)	18 (true-false statement)	45 (MCQs with five options)	
Average	11.11 [10.59–21.70]	37.90 [37.21–75.11]	
Standard Deviation	1.91	2.15	
Median	11	38	
Minimum	7	32	
Maximum	16	42	
MCQs = multiple choice questions; 95% CI = 95% confidence intervals			

Table 3. Results of comparison between directed and self-directed interventions in evidencebased medicine

	Group				
Criteria	Directed (n = 56)		S	elf-directed (n = 40)	P - value
	No.	95% CI <sub>p</sub>	No.	95% CI <sub>p</sub>	
≥ 50	51	[0.8039-0.9640]	40	[0.9006-1.0000]	.0552
≥ 60	32	[0.4289-0.6961]	40	[0.9006-1.0000]	< .001
≥ 70	11	[0.1075-0.3211]	39	[0.8756-0.9994]	< .001
≥ 80	4	[0.0182-0.1783]	36	[0.7756-0.9744]	< .001
95% CI <sub>0</sub> = 95 % confidence intervals for proportion of students which gave more than x % correct answers					

#### **CONCLUSIONS**

The study reveals that the interactive web approach was efficient and effective in undergraduate students' education, suggesting that may be an alternative method for teaching evidence-based medicine. However, more research comparing the proposed method with other educational models applied on residents and practitioners are necessary. Also, critically appraisal skills on searching the best available evidence and evidence assessment, as well as evaluation of the professional behavior in spirit of inclusion of the best available evidence into daily medical decision, and long-term effects on patient outcomes are necessary to be investigated.

#### **ACKNOWLEDGEMENTS**

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### The Effect of Graphic Features of Web-based Health Communication On User Evaluation and Psychological Wellbeing

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The Effect of Graphic Features of Web-based Health Communication On User Evaluation and Psychological Wellbeing Background: The use of peripheral communication elements such as humor appeals or background music/graphics can influence user attitude toward communication [1-3]. Online health communication often presents potentially threatening information to health information seekers. Moreover, health information is typically sought by users when they face either actual or perceived health threats, which often generate psychological distress. Therefore, optimal design of web-based health communication should ideally provide pertinent information while at the same enhance users' psychological wellbeing. Based on existing literature [4-5], we expect that the use of positive peripheral elements in web-based health communication such as pleasant background images can enhance users' psychological wellbeing as well as acceptance of the communication. Objective: We examine the effect of positive peripheral visual features of web-based health communication on users' affective experience and evaluation of the website. Methods: 40 healthy women were randomly assigned to visit one of the three versions of a health communication website, which were identical in verbal messages, but differ in peripheral visual features: color or black-and-white (BW) pictures of pleasant natural scenery, or no picture. Pre-test shows that the color pictures are more pleasant than the BW version. The websites were evaluated in terms of organization, ease of finding information, speed of loading, and usefulness of information. Psychological wellbeing was measured by self-reported affect in response to the website. Results: The color version were perceived to have a better organization than the BW version (p < .03), easier to find information than both the BW version (p < .06) and the no-picture version (p < .001), and higher usefulness of information than both the BW version (p <.04) and no-picture version (p <.002). Further, participants reported more pleasant affect after viewing the color than the BW and no-picture website (Ps < .02). Finally, the effect of the visual features on evaluation and psychological wellbeing appear not be cognitively mediated, as participants' retrospective evaluation of the pictures per se did not differ between the color and BW versions (p > .20). Conclusion: The use of positive peripheral visual elements can enhance users' evaluation of the website and psychological wellbeing.

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### The RealU: A Web-based Intervention To Reduce College Smoking

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Background: The college years represent an opportunity to intervene to limit escalation in cigarette use and encourage early cessation. Working with the University of Minnesota's Boynton Student Health Service, the goal of this project was to test a web-based intervention to reduce cigarette smoking by UM Twin Cities undergraduates. Methods: This is a two-group prospective randomized controlled trial. Potential participants (any smoking past 30 days) were identified via internet health screening survey and invited to enroll. Individuals randomized to the RealU intervention group were offered a \$10 incentive to make weekly visits to the study site to (1) track their cigarette use, (2) take an interactive quiz to learn about their lifestyle and smoking habits, and (3) view an on-line college life magazine with general lifestyle and smoking related content. Outcomes include 7-day abstinence at weeks 6, 12, and 20 evaluation points and 30-day abstinence at week 20 (with carbon monoxide (CO) validation). Results: Invitation email was sent to 25,000 UM undergraduates yielding 6492 completed surveys (26% response) identifying

1857 smokers (29% prevalence) of whom 517 enrolled (usual care=260, RealU=257). Weekly participation exceeded 89% (range 89%-98%). The prevalence of 7-day abstinence from smoking in the RealU group was higher than in the control group at 6 (42% vs. 25%, p < .001), 12 (42% vs. 33%, p < .05), and 20 weeks (59% vs. 38%, p < .001). The rate of 30-day abstinence at week 20 was also higher in the RealU (40%) vs. usual care (23%, p < .001). CO validation showed low rates of underreporting (<1%) with no difference between the groups. Conclusion: Internet health screening is an effective means to identify large numbers of college smokers. The RealU on-line intervention achieved and sustained high participation rates, reduced the 7-day point prevalence of smoking, and increased 30-day abstinence.

### Knowledge-Based Teleinterpretation of Hepatitis Serology Test Results

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Background: Automated interpretation of any combination of laboratory test results of a specific medical field such as hepatitis serology - including rare and frequent, or even inconsistent, combinations - contributes to quality assurance in patient care, enhances the productivity and efficiency of medical work, and may also reduce costs in health care. A knowledge-based system for the interpretive analysis of hepatitis serology test results, named Hepaxpert, that covers any combination of hepatitis A and B serology test results was developed, tested, and routinely applied at one of the laboratories of the Vienna General Hospital [1]. Later its knowledge base was revised, extended to include hepatitis C serology, and discerned from its surrounding software. The established Hepaxpert knowledge modules [2] now comprise 64 possible combinations of test results for hepatitis A, 61440 possible combinations for hepatitis B, and 16 possible combinations for hepatitis C serology. Objective: The general aim is to incorporate the Hepaxpert knowledge modules into a multi-lingual web-based system to allow for teleinterpretation of any hepatitis A, B, and C serology test result from any part of the world. The specific aims are twofold: first, the Hepaxpert knowledge modules will be integrated into a web server application to allow the input of test results via a web browser; second, the Hepaxpert server application should be able to process Hepaxpert queries without going through a browser interface; it should be possible to send serology test results packed into a web-standard protocol query to the Hepaxpert server and return the respective interpretive text by the same technical pathway. Methods: The present Hepaxpert knowledge modules include a clearly arranged knowledge representation and an efficient inference method by structuring the knowledge domains into equivalence classes and using index calculation to access the respective interpretive text [1]. The main inference step will include pre- and post-processing. These knowledge modules offer input and output structures used to fill the given laboratory test results in coded form into the input and return the textual interpretation in the output structure. Results: The web version of Hepaxpert [3] is currently available in the German and the English language. It is linked to a number of medical web sites dealing with hepatitis, laboratory medicine, and patient education. Its browser-less version is routinely used at the Franz Josef Hospital in Vienna, Austria. The laboratory information system of the laboratory department of this hospital forms a query record based on HTML, sends it via HTTP to the Hepaxpert intranet web server, gets the interpretation returned, and includes it in the laboratory result sheet sent to the referring physician after verification. Conclusion: Teleinterpretation of hepatitis serology test results, either through a browser interface or in the browser-less mode through a network query, provides valuable support for the medical decision-making process and for quality assurance, especially in cases of rare and inconsistent laboratory findings.

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### Medical Intelligence Service Provider Based On Interconnected, Cooperating Medical Decision Support Systems

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Background: Knowledge-based medical decision support systems (MDSSs) were shown to be useful in patient care, especially when fully integrated into hospital or laboratory information systems, patient data management systems for intensive care, or medical practice software systems for the practitioner [1]. In order to remain medically up to date, the knowledge bases must be continually revised, extended, and made accessible to their sites of application. In addition, MDSSs are offered via the World Wide Web, to be accessed through a web browser or, browser-less, in order to receive queries and automatically return answers within a network-based communication protocol. Objective: The general aim is to establish a web application that not only offers single, autonomous MDSSs but also provides an array of interconnected, mutually supportive MDSSs. By doing this, parts of, or the entire, medical decision making process in patient care is mimicked. For example, an MDSS that assists in the clinical differential diagnostic process in hepatology, a field of internal medicine, might generate - on the basis of jaundice, enlarged palpable liver, and increased bilirubin levels - the hypothetical diagnosis of hepatitis, among others. Hepatitis serology laboratory tests will now be required in order to confirm or exclude a viral cause for the inflamed liver. The one system (internal medicine) demands information from the other system (laboratory medicine) and, if available, incorporates these results in its own decision. Methods: As shown previously [1], software-based medical knowledge modules are well suited to form the core of MDSSs. A next step is taken by providing a web interface that exhibits the different medical specialities as components that interact with each other, as (specialized) physicians do in actual medical situations. The components are backed by medical knowledge modules for the respective speciality. Calls for switching from one MDSS to the next and back, if appropriate, are triggered by the respective MDSS. Results: Based on several autonomous MDSSs (Rheumexpert [2], Hepaxpert [3], Thyrexpert [4], and Toxopert [5]) that have been routinely applied, a general web-based interface showing the specialities of internal and associated laboratory medicine is established. In this methodological and technical study, a blackboard system was used: it serves as a common communication platform between clinically oriented systems and systems for the analysis of laboratory test results. Conclusion: We report the initial steps taken to establish a web-based medical intelligence service provider that includes MDSSs for the many large and small specialities of practical medicine, and also follows the information and decision flow in actual patient care by means of interconnected, mutually supportive MDSSs.

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### Techniques for Customizing Patient's Diagnosis User Interface

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This paper proposes an approach of introducing a specific user interface (or diagnosis screen) to enter efficiently patient's diagnosis details. We discuss various aspects and techniques for providing efficient way to enter diagnosis details in efficient manner. However, there are few facilities in user interface development that are being covered and analyzed. We discuss methods for providing automatic data view by focusing on efficient design and effective viewing strategies so that user can fill up related information with less typing efforts. Various drag and drop window-screens will be provided to enhance various user interface styles. Data manipulation and data extraction features are introduce to manage a link with user interface for the user's better interaction.

### Telecardiology System Using Internet and Picosatellite Connections

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Background: We have designed an experiment to research the performance of the telecardiology system using internet and picosatellite connections for telemedicine, the principal interest is to bring medical services to isolated communities Objective: The objective of this research is to evaluate the performance of a telecardiology system on internet and picosatellite networks. Materials: A fully functional telecardiology system was used on internet and network simulation system. Methods: the telecardiology system are composed by acquisition, compression and error control modules, we send compressed ecg data through internet to the ground station of the picosatellite network, later the data are sending to the satellite, they are received at the other ground station in remote place and transmit on internet to the hospital where there are medical specialist for analisys and diagnosis. Finally this communication process is used to return diagnosis data to source place where there is the patient. Results: We send compressed data through internet later we uses data for simulitating satellite transmission using matlab communications tollbooks, as a result some doctors in Bogotá carried out observations to the results with ecg reconstructed in reception and they concluded that it is acceptable the ecg waveform for diagnosis. Conclusions: Using internet and picosatellite networks will enable the develop of integrated networks in order to establishing the infrastructure with the capability to develop space activities for special purposes on medicine. it is possible to take ecg data of a patient from remote place for attending the principal necessities of medical services in the community.

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### Disability Informatics: Meeting the Needs of People with Disabilities

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Disability Informatics is an emerging field that seeks to better understand how individuals with disabilities can use information technology and information systems to address any functional issues they encounter, improve their self-efficacy and empower them to be as independent as any other person. Disability Informatics research often involves identifying and addressing the



particular needs and requirements of particular populations of people with disabilities when utilizing general information systems. One of the main solutions is then educating and raising awareness of these issues to information technology professionals and the healthcare IT industry. In many instances, accessible information systems are also advantageous to the non-disabled population. In fact, one of the major reasons for considering universal design principles and accessibility in design is that everyone is subject to different types of functional limitations in various environments, e.g., design requirements for noisy environments are very similar to those for people with hearing impairments, and for environments where is not safe to look at a device (such as driving a car) are very similar to those for people with visual impairments. But whereas these systems provide a convenience or make something easier for the general population, they are essential for populations with disabilities to function independently. An introduction to Disability Informatics will be presented, along with research examples and an overview of the need for accessible design requirements.

### Computer Games and their Relation with Psychosomatic Factors Among Adolescents

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Games play an essential role in the psychosomatic development of children.I n recent years, however, computer games have occupied much of childrens leisure time. This study evaluates the impact of computer games on various aspects of psychosomatic developement. This study investigated how computer games affect different aspects of developement.METHODS:this is a descriptive analytic study of 1498 school age adolescents (11-17 years )in Isfahan.Iran.The tools of research were clinical interview and questionnaire. Datd were analyzed using T-test, Man-Whitney test and Logistic Regression.RESULTS:There was a significant relationship between computer games overinvolvement and level of activity ,socialization,abstraction,aggression and self -confidence.Sex was an important factor among computer game players. Sports computer games were the commonest form of games played(23.3%), while fictional and problem solving games were the least common. No relation was found between computer games and somatic and verbal factors.DISCUSSION:Results indicated inceased levels of aggression and emotional hyperarousal among heavy users.Because of the high level of self\_confidence and socialization in this group ,there is no evidence to suggest that computer games have any adverse psychological or social effects.

### Stakeholder Perspectives On the Development of a Virtual Clinic for Diabetes Care

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Background: The development of the internet has created new opportunities for health care provision, including its use as a tool to aid the self-management of chronic conditions. Diabetes is one such condition and internet-based interventions may be particularly appropriate for use with young people, 20% of whom fail to attend routine appointments at clinic. There is considerable research evidence that internet-based health interventions have been successful in reaching and working with young people; for example in smoking cessation [1], eating-disorder prevention [2] and cystic fibrosis [3]. In addition, a report of a small study which pilot-tested the feasibility of allowing patients with type 2 diabetes to co-manage their condition from home showed proof of concept for internet-based co-management of diabetes for adults [4]. This paper reports on the development of an internet-based 'Virtual Clinic' as an innovative way to help people with diabetes manage their condition. The Virtual Clinic allows a person with diabetes to communicate with their healthcare providers, find information about their condition, and share information and support with other users. It is enhanced by being based on the behavioural theory of self-efficacy from psychology [5]. Objective: To present the results of a detailed consultation with a variety of stakeholder groups in order to identify what they regard as the desirable, important and feasible characteristics of such a system. Methods: 1.

3 focus groups with people with diabetes recruited through a local diabetes clinic 2. 5 qualitative interviews with health care professionals from the clinic (3 doctors, 2 nurses) 3. E-mail consensus gathering with those using internet-based systems for other chronic conditions (asthma, epilepsy, ME, mental health) 4. Workshop to gather expert consensus on the use of IT to improve the care of young people with diabetes Results: Stakeholder groups identified the following important characteristics of an internet-based Virtual Clinic: being grounded on personal needs rather than only providing general information; having the facility to communicate with, and learn from, peers; providing information on the latest developments and news in diabetes; being quick and easy to use. This paper discusses these characteristics in light of a review of the relevant literature. The development of a virtual clinic for diabetes which uses these principles, and which is based on self-efficacy theory, is described. Conclusions: Involvement of stakeholders is a vital early stage in the development of a complex intervention. Stakeholders have clear and relevant views on what a virtual clinic system should provide, and these views can be captured and synthesized with relative ease. This work has led to the design of a system that is able to meet user needs.

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### Joint Effort of Internet, Quit-line and Primary Care In Smoking Cessation

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Tobacco smoking is the single most preventable cause of death in the western society[1], demanding effective intervention strategies. Smoking cessation is considered one of the most important aspects of tobacco control [2]. In European comparison Iceland has been in the lead in tobacco control (i.e. legislation and price) except for smoking cessation. Studies have shown that doctors and nurses in primary healthcare are lacking support systems to effectively provide smoking cessation [3]. The use of modern technology is widespread in Iceland, with 86% having access to the internet (mostly broad band) and 98% of homes having access to mobile phones [4]. Due to wide spread access to modern technology there is a great potential of using the internet and telephone in smoking cessation. The current project is run by the Public Health Institute of Iceland. The aim is to integrate an interactive website, proactive telephone quitline and the primary health care. The interactive website offers facts, various tests, a diary, FAQ's, tailored advice and discussion forums for people attempting to quit. Furthermore the site provides social support. The website visitors are encouraged to use the national quit-line and their local primary health care for further support. The quit-line is both reactive and proactive and assists both the public in tobacco cessation and acts as support for health care professionals in their tobacco cessation work. The service is provided by specially trained nurses and is a mixture of behaviour therapy, motivational interviewing techniques, and pharmacological consultation. Callers are encouraged to use the website and their local primary health care for further support. The primary health care professionals are offered training in motivational interviewing as a smoking cessation technique. Furthermore they are encouraged to refer patients to the website and the quit-line as well as getting support and advice concerning their work. Joint efforts of an interactive website, a quitline and the primary health care may maximize the effect of smoking cessation on a national level. Data indicates that GPs having access to a quitline are more likely to provide smoking cessation service at their clinic [5]. The evaluation of the project will include process evaluation, which components are mostly used and by whom, as well as evaluation of the efficacy of the service. Our vision is that an interactive website, proactive quit-line and primary healthcare units build a network where each component can work together, support each other and refer people to the appropriate agent in the network for further support.



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### An Automatic Communication System Between Nursing Home and Residents' Families

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Introduction: If your family member or relative resides in a nursing home, you will worry if the resident is doing fine or not. In such case, you will feel reassured if you get periodical daily reports from the nursing home to know if the resident is doing fine. But, such communication tends to be neglected except emergency, because nursing home staffs are tied up for their daily work. We studied a dementia's wandering patterns in a nursing home, using an automatic monitoring system with IC tags. Observation studies on wanderings action are conducted in three nursing homes in Japan and South Korea. This system which was intended to automatically record wondering observation results also recorded dementia elders' routine actions. Therefore, we can also use this system as an automatic reporting system for residents' families. Method: Several trigger fields were set up in a nursing home and nursing home staff and the residents wore IC tags. When an IC tag is in a trigger field, it transmits its ID and the trigger field ID, which tells the information about "Who", When" and "Where". The information is automatically recorded and classified according to ADL. A summarized daily profile is sent to a family of a resident by e-mail. Results: We developed two systems, one is to automatically record daily profiles by using IC tag system and the other is to send them by e-mail. Discussion: This automatic monitoring system through the use of IC tags improves the communication between a nursing home and residents' families, providing information on a daily basis for families without increasing the burden on nursing home staff. Reference: 1. Ashida N., Makimoto K. Nozaki C., Nakagawa M., Suzuki M. and Kawahara T.: A Monitoring of Wandering Behavioral Pattern of Senile Dementia with IC Tag.,3rd APT TELEMEDICINE Workshop 2005, Proceedings p80-84,2005 2. Ashida N., Ashida Y., Takagishi Y. and Kawahara T.: The Survivor Search System using an IC Tag,4th APT Telemedicine Workshop 2006 p220-224, Pakistan 25-26, Jan 2006.

# Web-based Information Services for the Nationwide Model Project Against Hospital Infection

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Introduction: The Internet has been increasing its importance as an information collection tool. Nevertheless, reliable and good web sites tend to contain a massive amount of information and have complicated structures, which provides poor accessibility of desired information. We promoted the nationwide model project against hospital infection with the aims of 1) establishing the system for medical institutions so that they can consult specialists on a daily basis about hospital infection prevention through the specialized consultation service desks which are set up in different regions, and 2) connecting these regional desks with the International Medical Center of Japan with intent to transfer consulted cases online to the center so that the cases can be gathered to construct the system which is designed to provide information about remedies and safeguards. In Japan, it is difficult to have hospital infection cases reported, but, many

research papers about hospital infection are written overseas. We extracted and summarized those anecdotal reports to create a database for Web-based information provision. This study is to report such Internet-based information gathering and provision for hospital infection prevention. Method: The following three systems were constructed to gather and provide information about hospital infection prevention on the Web. 1. Nosocomial infection report system to gather consultation cases nationwide 2. Database of summaries of papers on nosocomial infection 3. Reliable search engine which specializes in hospital infection Result: The nosocomial infection report system of Item 1 is operated only among registered institutions. The systems of Item 2 and 3 which are designed for web applications are experimentally operated at the following address. http://www.health-db.net/infection/index.asp Moreover, the text analysis was performed on the contents which contained particular sentences. Coded data acquired from such contents were used for searches and the cross-disciplinary survey. Discussion: Many manuals have been developed based on the CDC guideline in recognition of importance of preventive measures against hospital infection as a part of medical risk control. But, it is pointed out that the majority of them are like schoolbooks and require further decision to be made in the field without providing adequate instructions. It is also pointed out that they do not always provide a clear "definition of infection" which immediately becomes necessary in developing safeguards and remedies to "do what in which case." Prevention of hospital infection inevitably requires not only manuals but also the knowledge-based applications in selecting a solution based on cases. Gathering information from many web sites is also necessary in addition to gathering case examples, however, it frequently takes time to verify the reliability of information (if it is an official announcement, knowledge, or a personal view) when such information is obtained on the web site which is hit by a versatile search engine. Therefore, the development of a reliable, specialized search engine is desired.

# Factors Affecting Electronic Health Care Records Adoption and Success In Fertile Crescent Developing Middle Eastern Countries

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Title: Factors Affecting Electronic Health Care Records Adoption and Success in Fertile Crescent Developing Middle Eastern Countries. Background: "The lack of access to basic healthcare continues to stifle social and economic advancement in many parts of the developing world."[1] Moreover, IT improved many industries according late research (2004-2006) in developing countries but not in the health care industry. This even applies to developed countries.[2] Thus, this research seeks to further our knowledge of Healthcare Information and Communication Technology Systems (EHCR) adoptions in Fertile Crescent countries of the Middle East(Lebanon, Syria, Jordan & Iraq. Researching EHCR factors leading to successful adoption in The Fertile Crescent countries will create a panoramic and practical picture and vision for healthcare executives, healthcare IT professionals, healthcare researchers and officials in the governments responsible for finance and health policy in these countries as well as agencies and other international organizations to take action towards bridging gaps for achieving optimal and affordable health information and communication technologies as EHCR. As a conclusion, this research will promote collaborative efforts for creating a reliable, timely, high quality and affordable health care in the region. Objectives: It is argued that there is an identifiable cluster of factors that "predispose" hospitals to adopt EHCR in general [3, 4]. In particular, this investigation focuses on assessing and estimating the relationships between Environmental factors (economical, political, etc...) and "extent and success of EHCR adoptions" and the relationships between organizational factors and "extent and success EHCR adoptions" in the hospitals of which is nearly most inclusive and representative sample of the region's hospitals that treat approximately three quarters of the population. Moreover, it focuses on the relative importance of environmental and organizational factors with respect to "extent and success of EHCR adoptions". Methods: Descriptive multivariate hypotheses are proposed, hence multivariate regression analysis are employed in order to evaluate factors' correlation magnitude with EHCR adoption and success in the Fertile Crescent region. The two main dependent variables are the "extent of EHCR adoption" and "EHCR adoption success". The former refers the measure of adoption as sum of percentages of adoption levels and components of EHCR-supported functions performed in a hospital because it reflects the level of commitment to EHCR adoption and the factors associated with it. The latter is a summary



percentage measure of the extent to which EHCR functions is perceived to be hospitals' needs[5]. Data collection includes the use of on-site structured and open ended interviews of hospital departments' managers of "A" five stars accredited 200> beds' hospitals within counties of the region. Thus the sample includes hospitals whose clients account for more than 75% of the population of these countries. Analysis: This research analysis thus is not only quantitative, but also results are leased out through our comprehension of related literature and qualitative information collected through site visits and interviews. Conclusions: Data collection will start from the beginning of March 2006 and end at June 2006. So real conclusions will data analysis, results, discussion and conclusions will be updated at the end of June 2006

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### Interactive Webcasting + Audioconferencing + Media **Archiving for Medical ELearning**

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Peter Wolf, Univesity Of Toronto Background: The standard approach to enhancing medical multimedia communications at a distance is videoconferencing [1]. Although videoconferencing ideally provides high-quality transmission of moving images

and voices symmetrically among various sites, in practice it is limited to a small number of sites, is critically dependent upon having good bandwidth, and rarely incorporates effective mechanisms for archiving sessions in ways that allow flexible access to the content. Objective: We shall present an alternative approach, the use of highly interactive webcasting with integrated conferencing and the automatic Web publishing of structured, navigable, and searchable archives. We shall articulate the pedagogical and technical issues involved in enabling effective remote participation in events transmitted in this manner. Methods: In our poster and demonstration we shall exhibit key features of the design of our technology, which is called ePresence Interactive Media [2-5]. We shall illustrate use of the system by discussing how Computer Science graduate students and faculty from five Canadian universities used ePresence to participate in a Computer Supported Collaborative Work course offered at the University of Toronto during the fall semester 2005. We shall also summarize the experiences of a number of medical schools, hospitals, and medical research groups (University of Toronto, Memorial University of Newfoundland, Northern Ontario School of Medicine, Toronto Rehabilitation Institute, the Waterloo Institute for Health Informatics Research, and the Centre for Global eHealth Innovation) using the ePresence technology.\* Results: Particular emphasis will be placed on six themes: 1) we shall report on the use of VoIP to enable voice questions and discussion periods; 2) we shall discuss how we facilitate interaction between remote webcast participants and participants at Toronto through text chat and experimental "awareness servers"; 3) we shall describe how remote students as well as those present in the lecture room also tune into the webcast and use the chat feature to communicate among themselves; 4) we shall enumerate the challenges of hosting lecturers from locations other than Toronto, which now happens increasingly often; 5) we shall review the importance of ePresence's flexible retrospective access to archived presentation via structured, navigable, searchable archives; and 6) we shall discuss the software distribution approach which involves open source publishing and the formation of a contributing community of users. Conclusions: Because of its scalability, resilience in the face of vagaries of Internet traffic, and ability to integrate with conference and web publishing, medical schools should increasingly consider interactive webcasting systems for eLearning and for distance education.

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- \* For example, Memorial University of Newfoundland Faculty of Medicine reports that it "has found ePresence to be an excellent tool for dissemination of educational presentations. Busy faculty and students in a geographically dispersed setting have traditionally found it difficult to attend educational presentations and "rounds". ePresence realizes the potential of the Internet to economically and efficiently address faculty and student needs.

### Multimedia Biographies for Individuals with Alzheimer's Disease and their Families

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Background: This work stems from the increasing recognition of the beneficial effects of reminiscence for senior citizens [3, 5], and seeks to enhance the ability of individuals with Alzheimer's disease (AD) and their families to reminisce. Objective: The aim of the project [1-2] is to develop methods for constructing life history multimedia of persons with AD, and to evaluate Alzheimer's patients' responses to observing their life stories, as well as the impacts that creating such biographies has on family members. Our work differs from Project CIRCA [4] in that we explicitly focus on personal information, whereas CIRCA developed multimedia that are generic to a specific locale. Methods: Two daughters of a 91-year-old woman receiving institutional care agreed to participate with informed, signed consent. The daughters provided information about their mother's life through stories, still pictures, and home videos. Using video editing software a preliminary 7-minute video history was constructed. The video was shown to the daughters and based on their feedback a 40-minute nonlinear video was completed and published on a DVD. The DVD was shown to Jenny on three separate occasions and her verbal and non-verbal responses were filmed for subsequent analyses. The daughters were given a copy of the Jenny's video history and were instructed to show the video to Jenny as often as possible and record their observations of her responses. Six month and one year follow-up interviews with the daughters and videos of Jennie's responses were recorded and analyzed. Results: Content analysis of transcribed interviews with Jenny's daughters and analyses of Jenny's video responses showed that Jenny's overall response to viewing the video history was positive as indicated in both her verbal and non-verbal reactions. Jenny views the DVD often and it continues to give her delight, apparently enhancing her sense of identity and improving the mood with which she interacts with family members. The biography has also had a significant impact on the daughters' relationship their mother. They report positive reflections on past family experiences, re-evaluation and reconnection to their mother, and a greater acceptance of their mother's disease. Conclusions: Since then, with the help of support from the U.S. Alzheimer's Association, we have begun production of an additional six biographies, all of which should be completed by the time of the conference. Our presentation will include results from all seven cases.

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### Combined On/offline ECG Monitoring of Heart Failure Patients with Automated Nonlinear Risk Prediction

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Background: The telemedicine management of chronic heart failure patients is very important for the patients and for cost savings of repeated hospital admission. Our internet medical server collects the two forms of ECG registrations. The bedside, 12 lead ECG were acquired during night, the online GPRS ECG monitoring was used at daytime [1]. The remote automated analysis software contained a QRS and ST slope wavelet detector. Using the alarm function in the cases of arrhythmia or ST-segment displacement the online ECG monitoring via internet could start. Objective: The aim of our study was to find a method to forecasting disease worsening at home in heart failure patients. The complex math calculations were done in the telemedicine centre. Methods: The prediction is based on the calculation of correlation dimension (CD) of heart rate intervals analysis using three methods: pointwise method of Grassberger (M-1) [2], Farmer (M-2) [3], and the "point" estimate (PD2) of Skinner (M-3) [4]. In general, all methods determine the logC(r,n)/log r slopes (C(r,n) is the cumulative number of all vector difference lengths within a range (r), and n is the number of vector difference lengths), and the linear slope represents the scaling feature. The PD2 method does not use all possible vector lengths, the nref value is fixed. The PD2 is a rough estimate of the CD, the slope in the linear scaling region is less precise, but this loss is compensated for by its lack of sensitivity to data nonstationarities and size. 74 postinfarction patients with heart failure (NYHA III-IV) were monitored weekly for 24 months. Our internet server calculated with 1-2 hours delay the correlation dimensions, comparing these data with the previous ones. In the case of lowering the CD under the cutoff value, the patient was alarmed, and immediate (within 6 hours) medical visit was performed. During the two years follow-up (74 with (G1), and 74 age-matched control group without (G2) telemedicine management) 14 deaths in the G1, and 29 in the G2 group were observed (p < .01). Results: The sensitivity, specificity, positive and negative predictive accuracy of the CD values in predicting all-cause mortality with these cutoff values were for M1: 62, 74, 49, 88%, for M2: 50, 82, 52, 83%, for M3: 72, 75, 68, 81%. In the G1 group, the Kaplan-Meier survival curves were compared with log-rank analysis: for M1 the CD cutoff value of 2.1, for M2 1.9, and for M3 1.3 was showed significant difference (p <0,014, < .01, and < 0,001, respectively). During the 24 month follow up, the hospital re-admission rate was 38/74. This value was 118/74 in the non-telemedicine managed heart failure patients (p < .001). Conclusions: The major finding of the study is that the frequent internet monitoring of heart rate is capable of predicting fatal and non-fatal outcomes not only in statistical way, but as an individual forecasting. Our result confirms the importance of non-linear analysis of heart beat intervals. The three ways of calculating the correlation dimension work excellent, the fine and rough methods help each other in the cases of noise and nonstationarities. All of the telemedicine managed patients had 3 days e-visits, where during the "chat" consultation the relevant clinical signs and symptoms were compared to the ECG data, collected via internet, that might improve the managing strategies.

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### Collecting Tobacco Use Information with a Web-Based Family History Tool

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Background: We report here on an extension to a family health history collection and interpretation tool to gather information about tobacco usage. Diagnosis and risk assessment of heritable conditions utilizes family health history. We originally developed HealthHeritage, a patient-driven web-based tool to collect, update and interpret family health histories for 89 hereditary conditions, to assist health consumers or patients and their physicians [1-3]. Tobacco use is widely acknowledged to be an important, preventable environmental aspect of health [4] and an important risk factor for many conditions in HealthHeritage. We added tobacco usage by individuals and by their family members to this family history tool. Objective: Here, we extend the original HealthHeritage to include the collection of personal and family tobacco usage history and conduct a formative evaluation of this data collection. This evaluation assesses comprehension and ability to answer these tobacco use questions including details important for risk assessment and research. Methods: Based on an evidence-based literature review by medical specialists, we added tobacco use as a risk factor for 9 cancers (e.g. pancreatic, bladder, and kidney cancer) and 14 conditions in the area of cardio-/neuro- vascular disease (e.g. atherosclerosis). We also developed a separate tobacco use risk assessment to address significant health risks associated with tobacco use that, although not currently shown to be strongly hereditable have important health implications. Our tobacco use questions resulted from a review of the literature assessing tobacco risks and several national health surveys. We chose to combine the NHLBI Atherosclerosis Risk in Communities (ARIC) survey, and the National Health Interview Survey (NHIS) as they were the most extensive in their tobacco related questions. This met an important stakeholder need, to include comprehensive data collection for medical researchers. We conducted a pilot evaluation of these tobacco use questions with 20 health information consumers who were patients in a Family Medicine department with a history of tobacco use. Participants were given a paper-based version of the tobacco questions; this version used screenshots of the web-based questions with instructions added to allow self-guided completion. After answering the survey participants completed a post-survey interview. This interview clarified participant comments and questions, and went into depth about potential survey difficulties (e.g. difficulties with calculations, amount known about a relative's tobacco use). Results: Results include overall ease with the question content including comprehension and respondent's ability to answer. Some difficulties were identified in certain subsets of participants (e.g. older individuals) in areas such as recall of tobacco usage dates and information about their relatives. Conclusion: Our effort to integrate personal and familial tobacco use history into a comprehensive family history provides a tool with potential utility for in primary care and public health research. Our pilot evaluation suggests that, for these respondents, collection of personal and familial tobacco use history with detail sufficient for risk assessment and research is possible. We discuss recommendations to enhance data collection in these areas where recall was difficult and the potential educational impact of the survey itself on participants.

### Online Patient Self-Reporting of Toxicity Symptoms During Chemotherapy

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OBJECTIVES: To determine whether lung cancer patients can be engaged to report their own toxicity-related symptoms during chemotherapy. METHODS: The NCI's Common Terminology Criteria for Adverse Events (CTCAE) schema for 12 common symptoms was adapted into a web-based patient-reporting system, accessible from computers in outpatient clinics and from home computers. Outpatients with lung malignancies beginning standard chemotherapy regimens were invited to enroll. During a 16-week observation period, participants were encouraged to login and report symptoms at each follow-up visit, or alternatively to access the system from home. Severe toxicities entered into the system (grade 3-4) triggered emails to the primary clinical team. RESULTS: 108 patients were approached, with 23 refusals due to anxiety (n=4), unwillingness to use a computer (n=5), or no perceived benefit (n=6). All 93 enrollees completed an initial login. At each subsequent appointment, most enrollees (80-85%) reported symptoms using the online system, with a mean of 7 visits per patient (range 1-16). 79/93 (85%) logged in at more than two-thirds of appointments. Only 12/93 (13%) voluntarily logged in at least once from home, with a mean of 10 logins among home users versus 6 among non-home users. Utilization was significantly associated with prior Internet experience but not with age, cancer type, ECOG score, income, or education level. 121 severe toxicities were entered into the system, including 17 from home users, which were delivered via email to treating clinicians for consideration of interventions. CONCLUSION: Lung cancer patients are capable of reporting symptoms experienced during chemotherapy via the web, but may be less willing than other populations to use computers, and less apt to self-report from home. Assessment in other populations, in a clinical trial setting, and comparison of patient versus clinician symptom reporting are being performed in separate studies.

### If You Build a FAQ, Will they Come? Evidence-based Online Health Information Vs. Propaganda

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Contrary to most people's beliefs, the health risks from smokeless tobacco (ST) are very low, roughly 1% that from smoking (1). Most popular information, particularly that on the Web, grossly overstates the risk. In particular, it is usually suggested that the risk is similar to that of smoking (2, 3, 4). This has substantial health implications because encouraging inveterate smokers to switch to ST, thereby reducing their risks by almost as much as quitting entirely, is a promising "harm reduction" strategy, but most consumers are prevented from learning this. Attempts to persuade anti-tobacco activists to make their messages more accurate have proven ineffective to date. As an alternative strategy, we have embarked upon a project that will directly challenge the misinformation with online, accurate, evidenced-based information. The cornerstone of this is a FAQ (a set of extensively hyperlinked "frequently asked questions" pages) that, along with other related material, will be posted at our smoking-cessation website, www.tobaccoharmreduction.org (5) in May 2006 (the site is currently beta). We will actively promote the website among opinion leaders and through inexpensive popular channels. The FAQ is designed to communicate with educated laypeople and opinion leaders who are not subject matter experts (e.g. physicians) who are convinced that ST is a major health hazard by the prevalent inaccurate claims about the topic. As such, the content is designed to not just provide accurate information but to explicitly acknowledge and respond to common claims. Realizing that most readers will be predisposed against our message, we try to anticipate their doubts and respond with evidence, as well as explicit evidence-based arguments against the predispositions. The success of our message in the face of overwhelming misinformation will depend on our ability to help readers appreciate the scientific evidence, rather than consider this a "he said, she said" battle of competing experts that they cannot make sense of. This will prove a test of both our ability to communicate that message and internet users' ability to appreciate it. We realize that any short-term success is likely to be limited to the most sophisticated and patient readers. This is not a research project, but we will attempt to assess our audience and gather feedback. The website will include a voluntary sign-in which collects basic demographic information and discussion forums. The latter will be particularly important because they will let us judge reactions to our information, hone our arguments, and collect more frequently asked questions to answer. By the time of the conference, in addition to being able to report on our strategy and content, we should be able to provide some assessment of early success based on forum

feedback, counts of page hits, links from other websites, and search-engine prominence. In addition to potentially helping nicotine users switch to a reduced-harm alternative, our website will prove a test of whether a focused evidence-based response can compete with dominant misinformation from ostensibly authoritative sources. (1) Tobacco Advisory Group of the Royal Physicians. Protecting smokers, of [http://www.rcplondon.ac.uk/pubs/books/protsmokers/index.asp] Accessed March 28, 2006. (2) Phillips, CV, Wang, C & Guenzel B. You might as well smoke; the misleading and harmful public message about smokeless tobacco. [http://www.biomedcentral.com/1471-2458/5/31] BMC Public Health 2005, 5:31 Accessed March 28, 2006. (3) Waterbor, JW, Adams RM, Robinson JM, Crabtree FG, Accort NA, Gilliland J. Disparities between public health educational materials and the scientific evidence that smokeless tobacco use c a n c e r s e s [http://www.leaonline.com/doi/pdfplus/10.1207/s15430154jce1901\_08?cookieSet=1] Accessed March 28, 2006. (4) Kozlowski LT, O'Conner RJ: Apply federal research rules on deception to misleading health information: an example on tobacco a n d cigarettes. [http://www.publichealthreports.org/userfiles/118\_3/118187.pdf] Public Health Reports 2003, 118:187-192. Accessed March 28, 2006. (5) Phillips, CV & Bergen PL. Tobaccoharmreduction.org. [http://www.tobaccoharmreduction.org] Accessed March 28, 2006.

## The Virtual Consulting Room: An Intuitive Solution To Bridge the Eternal Divide Between Primary and Secondary Care

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Background: Public healthcare in the United Kingdom is currently failing to meet the expectations of patients and healthcare professionals [1-3]. The primary method for general practitioners (GPs) to obtain a consultant opinion is referral to a specialist outpatient clinic. The disequilibrium between supply and demand has resulted in a bottleneck at the primary-secondary care interface. The inability to support rapid communication between healthcare professionals is partly responsible for delays in patient care. The provision of easy access to specialist help should be a key component of the National Health Service (NHS) information technology strategy [4-5]. Objective: With the participation of 250 healthcare professionals from The Royal Free Hampstead NHS Trust, a unique multi-speciality, internet-based, Virtual Consulting Room\* (VcR) has been developed. The aim of the study was to evaluate the implementation of the VcR within primary care. Methods: Each VcR speciality hosts four modules providing incremental access to local specialist knowledge. These modules are patient journeys, frequently asked questions (FAQ's), specialist e-helpdesks and speciality-specific referral templates. Patient journeys follow an algorithmic design which distils specialist knowledge and disentangles process from detailed background knowledge. This allows GPs to visualise the specialist's thought processes and helps navigate the user through unfamiliar territory. The starting point for each of the 370 journeys is a sign or a symptom, and the user has access to 1400 derivative pathways to guide each step in the patient's management. The supporting information can be exposed by rolling the cursor over the relevant box. Further layers of consultation include FAQ's, access to a specialist e-helpdesk and printable referral templates. All modules are technically supportable for all specialities, but, for the purposes of the study, the e-helpdesk and a printable referral template were only available in Gastroenterology. In order to protect patient's confidentiality, personal data, such as name and healthcare record number, remained anonymous. Participating GPs were offered the opportunity to freely add an icon to their desktop computers which provided online access to the VcR by any browser. Data was obtained using web-tracking software and a questionnaire. Results: Following a letter of invitation to 22 local general practices, 13 requested internet access



to the VcR. GPs connected freely to the VcR by an icon which they added to their desktop. No special training was provided. Over the 2 month monitoring period, the VcR was consulted by 34/58 GPs (58.6%) and there were 177 consultations (mean of 22.1 consults per working week). Every mouse-click during the virtual consultation was recorded as a "hit". There were a total 35,244 hits (mean of 4405.5 hits per week) averaging 199.1 hits per GP visit (indicating considerable exploration) and 881.1 hits per working day. All departments in the VcR were visited. The four most frequently visited specialty homepages were Gastroenterology (40), Dermatology (21), Cardiology (19) and Accident & Emergency (19). Within Gastroenterology (the only speciality offering all four levels of consultation), the modules visited were: patient journeys (20), specialist helpdesk (12), referral templates (11) and FAQ's (7). Thirty one of 58 GPs (53.4%) responded to the questionnaire and 17 classified themselves as users. Of these, 14/17 (82.4%) reported that the VcR was easy to use and 15/17 (88.2%) found it a good educational tool. Thirteen of 17 (76.5%) found the patient journeys useful in practice and 7/17 (41.2%) reported that consulting the patient journeys improved patient care. The referral templates and e-helpdesk functions were considered useful by 5/17 (29.4%) and 3/17 (17.6%) of respondents respectively. Conclusions: Our preliminary results indicate that the VcR is easy to install, requires no training to use, is educational and has the potential to influence patient care. Facilitating health care professionals' communication through the VcR might alter practice and influence the primary-secondary care bottleneck.

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### The Internet for Health, Beyond Information Exchange

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The Internet for Health, Beyond Information Exchange The 21st century will be one of proactive health promotion, with the Internet as a cornerstone of success. In 2003, the Internet surpassed the physician as Canada's primary source for health information[1]. The objective was self-diagnosis (37%), confirmation of the doctor's diagnosis, accessing medical research, or contacting others with the same health condition. This phenomenon is propagating globally. Reliability of health information on the Internet, however, remains a concern. Endorsement by a recognized expert, affiliation with a credible organization, and third party accreditation are criteria to determine validity. Following MIT's example, other institutions, such as John's Hopkins Bloomberg School of Public Health, have implemented opencourseware initiatives that allow access, use and translation of their course materials. The American Association of Medical Colleges hosts a repository for peer-reviewed educational materials[2]. Inspired by the open-source software movement, Connexions[3], permits anyone to contribute, manipulate or update educational materials, but also provides the ability to brand by institution or disciplinary body. In addition to increasing demand for health information and services, the nature of health knowledge and practice is changing. Advances in genetics and imaging are transforming individual medicine. Emerging issues such as SARS, BSE, antimicrobial resistance and the threat of avian influenza have underscored the interaction among humans, animals, their food and the environment. Medical knowledge will continue to become more integrated with information from other disciplines such as genetics, engineering, computer science, geography, meteorology, communication and behavioral sciences. As it is impossible to master all the relevant disciplines, health professionals will have an interpretive role as part of an integrated health team. The goal is not just longevity, but the total years of quality health and life. Although many recent headlines have been devoted to emerging infectious diseases, it is projected that 73% of deaths worldwide will be attributable to non-communicable diseases (eg. cardiovascular disease and cancer) by the year 2020[4]. The three leading causes of global disease

burden in 2020 are expected to be ischemic heart disease, depression and road traffic accidents. Hence, there will be a growing emphasis on lifestyle and behavioral changes to improve physical and mental well-being. Simulations may offer a safe and effective means of modeling and practicing behaviors for effective patient interactions. The medical landscape is becoming increasingly complex due to advances in knowledge, sophistication of diagnostic tools and technologies, shifts in the burden of disease, recognition of the role of environmental factors and demands of an aging, educated population for greater involvement in their health[5]. This complexity can only be met with a collaborative approach to discovering, organizing, analyzing and validating medical information and developing new ways to impart healthy behaviours. As the health team expands and embraces the health-seeker (or their advocate) as members, the Internet is evolving from a purely informational to a functional role. The global supply chain of disease must be met with an equally global and interconnected response for health.

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#### **ECDC** and the Future of Public Health

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Keynote Speech: eCDC and the Future of Public Health Length: 1 hour Abstract: Hear how the Centers for Disease Control and Prevention (CDC), an international leader in the health arena, is impacting lives through the advancement of technology. Dr. Jay Bernhardt, Director of CDC's National Center for Health Marketing, will discuss the agency's movement to incorporate a variety of eHealth technologies into its activities, communications and public initiatives, and the implications this will have on the future of public health. The use of web and multimedia channels for communicating science-based information in accurate, relevant and meaningful ways will be discussed. In addition, learn how the CDC is using these media to respond to public health emergencies, as well as interact with the media, its partners, and the general public. Examples from current national and international public health issues, such as Avian Flu, will be discussed.

### From Hand To Mouse: Qualitative Results for Online Multimedia Informed Consent for Clinical Trials

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Traditional paper-based enrollment of eligible cancer patients into clinical trials is difficult, time-consuming, and expensive. Clinical trial investigators have yet to use electronic media to effectively and consistently present clinical trial consent information to patients, while tracking patient use patterns. A few small evaluation studies or single attempts to create electronic or multimedia informed consents have been attempted [1, 2]. Online multimedia interactive informed consent for clinical trials was developed with an SBIR grant from NCI after literature review and iterative contact with key informants. Developed and approved for trials by IRBs at 2 comprehensive cancer centers, and fully beta-tested, this patent-pending process addresses problems cited for paper-based informed consent. Qualitative results from key informants include: Sponsors recruitment time , multiple site monitoring; IRBs - uniform presentation, real-time enrollment data; Investigators - documentation of use, liability protection against claims of non-consent, improved subject-investigator interaction; more efficient recruitment and retention of subjects [3] and Patients



- language and literacy level barriers; [4] values clarification, self-assessment tools, and maintenance and enhancement of patient-staff interactions [5]. Study of online informed consent uses identical language and organization of paper-based IRB-approved consent. Effectiveness of knowledge transferred and perceived understanding is measured, as well as recruitment times, rates, and levels of compliance. Patient preferences, clinical trial coordinator observations, and IRB responses and concerns are recorded and monitored. Tracking of amendments and reconsenting of current subjects is facilitated and documented efficiently. Data on use of the online informed consent is tracked through the secure back office administrative section. Investigators and trial managers can review data on individual patient time spent on the consent and by section, subjects in the consent process, data on enrollment per site and per investigative staff member. Patient questions and concerns are collected to be addressed before the final in-person consenting process. Open-ended interviews with key informants revealed areas of concern during the consenting process for clinical trial staff. Interviews focused on: similar and contrasting needs of investigative staff and patients, issues arising from the transition from paper-based to electronic consent formats, and components of the current process that are essential to maintain. SecureConsent<sup>TM</sup> provides secure online multimedia informed consent across sites, countries, and languages. The IRB-approved consent incorporates multimedia explanations of unusual words and research concepts, patient-focused self-assessment and values clarification, with an optional audio track for aural as well as visual learners. The back office administrative tool offers staff an evolving overview of the consent process by tracking individual, study, and site usage levels. Qualitative research from all stakeholders will be illustrated through demonstration of both the patient informed consent site, www.secureconsent.com, with the Sponsor/Investigator back office tool. 1. Fureman I, Meyers K, McLellan AT, Metzger D, Woody G. Evaluation of a video-supplement to informed consent: injection drug users and preventive HIV vaccination trials. AIDS Education and Prevention 1997; 9(4):330-41. 2. Jimison HB, Sher PP, Appleyard R, LeVernois Y. The use of multimedia in the informed consent process. Journal of American Medical Information Association 1998; 5(3):245-56. 3. Food And Drug Administration. Clinical trials of medical treatments: Why volunteer? September 1998. Publication No. 98-1294; 6 pages. 4. Hochhauser M. Compliance vs Communication. Clarity 2003; 50:11-19. 5. Simon CM, Kodish ED. "Step into my zapatos, doc": understanding and reducing communication disparities in the multicultural informed consent setting. Perspectives in Biology and Medicine 2005; 48(1 supplement): S123-S138.

### Response To An Internet Survey of Men Who Have Sex with Men In Peru

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Background: As in many other parts of the world, the HIV epidemic in Peru is concentrated among men who have sex with men (MSM) [1]. The availability of free Highly Active Antiretroviral Therapy (HAART) for HIV-infected individuals in Peru makes it imperative to develop strategies to reach at-risk individuals who have not been tested for HIV [2] and may represent untreated cases. The availability of Internet access through 'cabinas públicas' (commercial cybercafés) may represent a cost-efficient and convenient means of identifying high-risk MSM and providing online HIV/STI prevention messages [3,4]. Objective: To assess interest in free HIV-testing and to gather local information about sexual risk behaviors for HIV/STI among Peruvian MSM. Methods: We developed an online survey of HIV/STI risk behaviour, which was advertised on a Peruvian website frequented by MSM seeking sex partners online. We used two nearly identical banner ads; one advertised an incentive of a free HIV/syphilis test at our clinic 'Vía Libre' and the other was unincented. The ads were displayed randomly and were linked to identical online surveys. Results: During the first 11 weeks (January-March 2006), 1075 men completed the survey, with 62% having responded to the banner ad that offered free testing.

The mean age of the sample was 26 years (SD: 7.24; range 15-55). Commercial cybercafés were used by 57% of participants to access the Internet. The majority of respondents were homosexual (73%), with the remainder identifying as bisexual. Among all individuals who reported that they were not HIV positive, 45% (446/996) had never had an ELISA test. Participants who had never tested for HIV tended to be younger (P < .001) and less educated (P < .001) than those who had previously tested. Compared to those who had tested previously, participants who had never tested had a high frequency of casual partners (44% vs. 37%; P = 0.01) and more anonymous partners (26% vs. 23%; P = 0.01). Untested respondents had higher frequency of unprotected anal intercourse (59% vs. 50%; P = .02) and higher frequency of sex with partners met initially online (70% vs. 64%; P = 0.049). Those who had previously tested were more likely to discuss HIV before having sex with their most recent sexual partner (44% vs. 20%; P < .001). Both groups reported favorable attitudes towards online modalities for accessing HIV/STI prevention messages, such as Web pages, chat rooms, emails, e-groups, and cell phones. Conclusions: Absence of a previous HIV test in Peruvian MSM seeking sex partners online is related to high-risk sexual behavior. The presence of these risk behaviors suggests that some of these men may be unaware of their HIV-positive serostatus, and are therefore not accessing available HAART. The differential response rates to the two advertisements, however, suggest that Peruvian MSM are interested in freely available HIV/STI testing. It appears that the Internet is an acceptable and cost-efficient means of reaching high-risk MSM and delivering testing and prevention messages.

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### Predictors of Dropout and Correlates of Cessation Among Individuals Using An Internet Smoking Cessation Program

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Background: Studies of behavior change using Internet platforms are plagued by low subject retention rates. Objective: To examine predictors of study drop out and cessation. Method: We invited smokers who were registering as new members of an online smoking cessation website to participate in the study. Interested persons provided informed consent and completed baseline surveys. One week prior to month six, a letter was mailed to participants reminding them of their commitment to participate and confirming their email address. At month six a survey invitation was emailed with a link to the survey. Non-responders were sent reminder emails five and ten days later to encourage them to complete the survey. Survey data included demographics, smoking history, current smoking, and motivation to quit. Data were obtained from the website regarding use of site features. Results: Of the 824 participants, 45% were men. Average age was 35 years (range 18-77), 88% were white, and most reported either having "some college" (43%) or "high school" (25%) education levels. Responses to the follow up email were; 16%, 9% and 9% (1st - 3rd emails); a a total of 34% follow-up completion. Analyses regarding predictors of study drop out showed women (x2(2)=2.89, P=0.54), and those who set a quit date (x2(1)=12.5, p < .001) were less likely to drop out. Less education (P = 0.06)and higher baseline smoking rate (P = 0.06) were slightly predictive of drop out. Among website use data, total logins (p < .01) and use of the Quit Date function (p < .001) were predictive of remaining in the study. Among study completers abstinence at month 6 was 27%. Among continuing smokers, the largest group (22.6%) had been able to quit for <24 hours, 20% had quit one week, and 19% had quit for over 90 days. Participants made an average of 2.8 quit attempts (SD=4.8) during the study. Among continuing smokers, smoking rates were reduced from baseline by 24%. Motivational stage (x2(4)=22.5, p < .001) and smoking rate at baseline (F[1,250]=3.3, P = 0.68) were predictive of success in quitting smoking at follow up. No differences were observed for gender, age or education. Data from the website showed that use of the site, including total logins (F[1,250]=6.4, p<.01), time spent online (F[1,250]=9.7, p < .001), and page views (F[1,250]=10.8, p < .001) were each predictive of cessation. Conclusions: Among completers, cessation rates were comparable to face-to-face counseling interventions with extensive (> 90 minutes) contact



time (U.S. PHS, 2000). The abstinence rate seen in this study is similar to those seen in studies of the nicotine patch and bupropion, in which all participants are required to use medication. While study completion rates were disappointing, they are consistent with other published studies of Internet interventions for smoking cessation (e.g., Feil et al., 2003; Lenert et al., 2004; Cobb et al., 2005). Study retention and smoking cessation may be improved by the development of techniques to increase site utilization.

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### The Content, Quality and Usability of Smoking Cessation Treatments On the Internet

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Background: The explosive growth in access to the Internet suggests that the Internet may be a viable channel through which we can reach and treat the large population of smokers who are unlikely to use other modes of intervention. Objective: To use guidelines from the U.S. Public Health Service (U.S. PHS, 2000) to assess the quality of interventions for smoking cessation that are available on the Internet. Method: PHS guidelines were codified into two instruments to record intervention content and rate quality of the website intervention contents. Content was divided into eight Key components and quality was rated on coverage of key components, accuracy and website interactivity. Usability guidelines established by the U.S. National Cancer Institute were used to develop a third instrument to assess website usability. Eleven Ph.D. or MD -level specialists in smoking cessation and tobacco research reviewed websites. Reviewers were selected for their clinical or scientific experience, familiarity with the PHS guidelines and current research interests or clinical specialization in tobacco treatment. No reviewer had consulted for or had any financial interest or involvement with any of the websites they were assigned to review. Results: Of the 202 websites identified in searches 77% did not provide direct intervention on the Internet and were excluded from analyses. Forty-six websites were included in this review. Results of usability assessments showed mixed results. Websites were visually well organized and used consistent graphical design, however, reading difficulty averaged above the 8th grade level. Most websites (87.5%) recommended pharmacotherapy for smoking cessation, 40% assessed nicotine dependence and 43% provided guidelines and instructions for the use of medications. However, over 80% of websites provided no coverage of one or more of the key components of tobacco treatment recommended in the guidelines. Ironically, the areas receiving the least coverage were those most amenable to the interactive capabilities of the Internet, such as providing tailored, personalized advice to quit and arranging follow-up contact. Conclusions: Smokers seeking quality tobacco dependence treatment on the Internet may have difficulty distinguishing among the numerous websites available. Websites that provide direct treatment often fail to fully implement treatment guidelines and do not take full advantage of the interactive and tailoring capabilities of the Internet. Despite the importance of social support in the process of quitting smoking, few sites used chat rooms, electronic message boards, on-line counselor support (e.g., email) systems or other on-line support groups. The interactivity that can take full advantage of tailoring interventions to the needs of individual smokers is under-utilized despite research supporting its efficacy (Abrams, Mills, & Bulger, 1999). At a minimum, Internet treatment should be responsive to changes in guidelines, current treatment practices, known side effects, available medications and other aspects of smoking cessation treatment that can change over time.

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### Distance Learning Strategy: Continuing Medical Education On Evidence-based Medicine – Implementation At Cluj County

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Introduction: In Romania, continuing medical education is mandatory for all specialties, being necessary two-hundred credits every five years [1], credits obtained through continuing medical education activities such as courses, symposiums and congresses accredited by the Romanian College of Physicians. In accordance with European Union trends in creation of e-Health [2] and implementation of evidence-based health care [3], training in evidence-based medicine become a necessity in Romania. Objective: According with the specification of Romanian College of Physicians regarding distance learning continuing medical education an eighteen-hour curriculum on evidence-based medicine curriculum was developed, accredited and applied at primary care physicians in Cluj County. Methods: The core evidence-based medicine concepts were integrated together with additional evidence-based medicine resources in the curriculum and were presented as distance learning course to the Cluj County family physicians at the October 2005 meeting. Thirty-one physicians enroll voluntary to the course and received training materials. Pre- and post-course surveys were applied to assess the physicians' knowledge and attitude on evidence-based medicine. All participants completed the surveys at the beginning and completion of a one month period of evidence-based medicine training. Data were summarized using the Statistica 5.5 software; the comparisons were done with Wilcoxon test. Results: The access to a computer and to the Internet was classified on a scale from 1 (easy - in the consultation room) to 5 (I had no idea what are you talking about). Most of the participants classified the access to a computer as easy (29%, 95% CI [14.2, 48.0]) or relative easy (29%, 95% CI [14.2, 48.0]), and the access to the Internet as difficult (33.3%, 95% CI [15.6, 55.3]) or no access (33.3%, 95% CI [15.6, 55.3]). The medical journals most frequently consulted by the physicians are British Medical Journal Romanian edition and Medical Life, both in Romanian language journals which contain most of the time clinical cases, experts' opinions and pharmaceutical advertisings. Responses at the pre- and post-course survey on evidence-based medicine demonstrate that the distance learning curriculum was effective in giving the core evidence-based medicine knowledge. The evidence-based medicine knowledge from the completion of the course was significantly improved comparing with the knowledge at the beginning of the course (p < .05, imposed significance level: 5%). Conclusion: Having evidence-based medicine core knowledge do not means that the physicians will change their daily routine by including the best available evidence in medical decisions, but it is the first step in formatting the Romanian primary health care physicians in the spirit of practicing evidence-based medicine.

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### E-Facilitation of Healthy Behavior Change: An Evaluation of Group Online Learning

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Introduction—Risk behaviours such as smoking, excessive alcohol use, poor diet and lack of exercise account for 50% of preventable mortality. Regrettably, evidence-based guidelines in primary care help only a minority of patients change their risk behaviors. When these "proven" interventions fail, practitioners are left with the challenge of helping these patients. Practitioners can use the concept of motivational practice to move beyond the limits of scientific evidence



by helping patients develop their own personal evidence about change. However, practitioners need first-hand experience of developing such evidence for themselves before they can work effectively with patients. Objective—To evaluate the impact of the Motivate Healthy Habits online learning program on helping a group of ten practitioners improve their own health habits. Methods—The MHH online course uses an e-process learning system; in others words, the instructional design of this software is tailored around the needs of the learning process described in the MHH guidebook. This process can be used to address any risk behavior. An e-health facilitator provided guidance to a group of practitioners who worked through a semi-structured journaling process that addressed the following tasks and learning exercises: Task A-Clarify Issues about Change 1. Use a decision balance 2. Assess your competing priorities 3. Assess your energy to change 4. Assess your motives for change 5. Assess your confidence and ability to change Task B-Lower Your Resistance 1. Assess your priorities 2. Compare your priorities 3. Think how your health behavior over time 4. Make a list of substitutes for your benefits 1. Consider future events happening now 2. Change your values 3. Change your views about change 4. Look at your "excuses" for not changing 5. Transfer motivation toward another behaviour Task D-Make Plans for Change 1. Overcome negative self-talk 2. Use your strengths 3. Take a time-out 4. Suppose a miracle happened tomorrow 5. Find exceptions in how you behave 6. Build your confidence to change 7. Increase your ability to change 8. Understand addictions 9. Select your goals 10. Prevent relapses Each practitioner kept a private online journal about improving their health habits (e.g., increase exercise, eat healthy diets, reduce weight). The e-health facilitator wrote a feedback note (with comments and probing questions) after each practitioner completed the tasks listed above. Before and after completing the course, all participants rated their motivational process variables (using the 0-10 scale) and their readiness to think and to take action in order to make inferences about how this complex process intervention affects the outcome. Evaluation—Practitioners enhanced their conceptual understanding about the change concepts and motivational process variables, such as resistance and motivation to change based on what they thought and how they felt; their perceptions about risk, benefits and harms; and different motives (based on self-determination theory). This reflective learning process helped practitioners identify their themes and issues for their ongoing work on health behavior change.

## Screening for Diabetic Retinopathy In Urban and Semi-urban Areas In Canada Through Telemedicine.

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Introduction: We present the results of screening for diabetic retinopathy for known diabetics through telemedicine throughout Canada. Description:Through a telemedicine project, fundus imaging of known diabetic persons was performed through screening health days held in pharmacies in Quebec, Saskatshewan, Manitoba, Alberta and British Columbia. Clinical data, visual acuity were obtained an diabetic retinopathy education provided by a nurse. The clinical data and images were encrypted and transmitted to a Data Centre through a safe and secure protocol. Through secure digital imaging software, retina specialists assessed the images and the clinical data and provided their recommendations . A report was sent to all involved physicians in the patient's care. All patients were notified of their results; positive screening lead to the organization of a timely appointment with their own ophthalmologist they often had neglected to see or an ophthalmologist in their area if they were not followed by any ophthalmologist. Results: A large number (68.8%) of non compliant diabetics to screening guidelines (over 2 years since last examination or never any dilated eye examination) were recuperated through this approach and the presence of some level of diabetic retinopathy was detected in 22.5% of the screened patients with 1.8% needing to be followed-up/ treated urgently Insufficient image quality in at least one eye in 0.7% of the cohort highlighted

the effectiveness of this teleophthalmology system in a mass screening strategy for diabetic retinopathy. Incidental findings requiring urgent ophthalmologic attention were found in 0.6% of the cohort. The savings of examinations for diabetic retinopathy (85.6%) to ophthalmologists who can better use their time and expertise to the benefit of truly diseased diabetics are important. Conclusion: This model for mass screening for diabetic retinopathy with telemedicine in known diabetics efficiently reaches under-serviced diabetic populations in urban and semi-urban areas . It provides medical quality diabetic retinopathy screening and timely ophthalmologic follow-up and/or treatment. It favors the development of multidisciplinary collaborations between ophthalmologists and other physicians involved in the care of diabetic patients. Significant incidental findings associated with screening highlight the need for experienced ophthalmologic competences in exercising diabetic retinopathy screening within a teleophthalmology approach.

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### An Online Tool for Identifying Patterns In NIH Funding for Research

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Progress in the diagnosis and management of medical conditions depends heavily on research targeting these conditions, and a preponderance of this research is funded by the National Institutes of Health (NIH). As new public health concerns emerge, they must compete with existing research agendas for funding from this limited source of funds. The ability to accurately track the pattern of funding by the NIH becomes crucial to researchers and health care planners in their efforts to direct research activities to particular areas of concern. While the NIH provides periodic summary data on the activities of its institutes and agencies, these reports do not allow for well-focused inspections that can usefully inform health policy. We have developed a tool that provides researchers and health planners online access to records and reports that enable effective and timely tracking of NIH funding activities. In a "proof of concept" project, we constructed a database of all NIH funded research projects on pain, nausea and dyspnea during the 3 year period 2003-5. We then developed an interactive tool for searching for specific projects or submitting structured queries to obtain reports tailored to answer particular questions of interest to researchers or policy planners in these areas. Having established the procedures for creating this tool, we hope to expand its applicability to other medical conditions.

# A Prospective Study In 7707 Overweight Individuals of the Effects of Internet-based Personal Dietary Advice Combined with An Online Community

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Background: The need for cost efficient weight loss modalities increases. Dietary advice by professionals on the Internet may be able to induce significant weight loss in overweight individuals. Online community support can be the 2006 alternative to support groups and weekly meetings. Aim: To quantify the effect of an online service for weight loss. Method: Assessment of self-recorded data from all persons registered 1st January - 31st December 2004 at the website www.slankedoktor.dk (slimming doctor). Intervention: Included participants entered weight, height and age at first registration and were allocated in groups



of 20-30 subjects of matched gender and target weight loss. Qualified dieticians, physiotherapists and doctors provided Internet-based personal advice at a monthly cost of average US\$35. Participants recorded weight, diet and exercise on a regular basis and were able to anonymously share their personal experiences with group members and professionals. Results: 7707 persons entered the study (women n=6690, men n=1017). At inclusion the BMI (mean±SD) was 29.4± 4.9 kg/m2 and age was 39.7± 12.2 years. The follow up period was 133± 104 days. 298 subjects were excluded due to insufficient data and three due to pregnancy. The weight loss was 3.9± 4.3 kg, women 3.7± 4.1 kg and men 5.2± 5.3 kg. The subjects (n=2769) with BMI > 30 kg/m2 had a reported weight loss of 4.9± 7.0 kg. In 711 (9.6 %) subjects no weight loss was observed. Conclusion: Personalised online advice in combination with an online community may provide cost effective weight loss in motivated overweight subjects. However objective outcome documentation is still needed.

### Design of Vision-based Human Computer Interfaces for Health Applications

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The field of computer vision focuses on the development and implementation of algorithms which allow computers to "understand" image and video data at various levels depending on the task at hand. Task-oriented image "understanding" may offer assistance to human perception, cognition and decision-making, such as in computer-aided diagnosis systems, or may enable more natural ways for human-computer interaction (HCI) in perceptual interfaces and in pervasive computing systems. Such vision-based technologies find promising applications in several areas of health care, including but not limited to image-based diagnosis and therapy planning, minimally invasive surgery, assistance and support for people with disabilities and elderly. HCI design for medical applications is a difficult problem. Gosbee and Ritchie [1] built a hierarchical model of clinician acceptance of technology in an attempt to identify basic reasons why physicians and other care providers are not eager to accept HCI technology in their daily work routine. Considering this model, it is expected that a successful integration of computer vision algorithms in human computer interfaces for health applications should consider both user-centered and task-based design paradigms. In return, these paradigms influence the basic assumptions as well as the algorithmic development of computer vision techniques. As an example, fully automatic 3D segmentation of anatomic structures in medical images has not succeeded yet in gaining clinical acceptance in diagnosis procedures, since end-users (i.e. radiologists) do not have control over the segmentation results. This tutorial discusses vision-based human computer interfaces for several key-fields in health care: - data visualization for image-guided diagnosis, therapy planning and minimally invasive surgery, - perceptual interfaces for the operating room. The emphasis will be on the contribution of the embedded computer vision techniques to the usability and usefullness of interfaces for each specific domain. Computer vision techniques have already proven their usefulness and usability for the design of research-oriented graphical user interfaces. It is expected that clinical acceptance will improve with advances of 'going filmless' in screening, diagnosis and therapy planning. The use of computers for inspecting images will probably trigger the use of interactive tools that augment the visualization options and improve the speed of diagnosis and planning. Vision-based perceptual interfaces are currently among the latest trends in video games. As in the case of virtual reality applications, it is predictable that mature technologies and vision algorithms used in games will become transferable and/or adaptable to health applications. Multimodal interfaces integrating voice and visual recognition are also a promising alternative to the "assistant-in the-loop" approach in image-guided surgery.

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### Semi Automatic Ontology Based Knowledge Extraction and Search for Medical Algorithms From Web Documents

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Introduction: KnowBaSICS-M (Knowledge Base System for Intelligent Computational Search in Medicine) is a Knowledge Base System providing basic help to clinical doctors and algorithm researchers, when attempting to reach the algorithmic solutions of Medical Computational Problems (MCPs). It is a tool for providing unstructured and widely scattered medical information related to computational algorithms by enabling authors to insert new MCPs and algorithmic solutions into the Knowledge Base (KB). KnowBaSICS-M also links a knowledge extraction tool with MCP ontology. The extraction tool extracts knowledge from particular online documents that refer to algorithmic solutions of MCPs (like www.medal.org) by matching it with the given classification structure of MCP Ontology. Methods: MCP Ontology has proved that most of the needs of MCP KBs are covered by employing an ontological approach by using Ontology Web Language (OWL). The code development was based on open-source development platforms, tools and technologies, like the 'Protege' ontology editor, the 'Eclipse' open-- source Integrated Development Environment, the Unified Medical Language System (UMLS), a medical lexical knowledge source and a set of associated lexical programs. One of the most important functions is the search process. For effective searching, Information Retrieval algorithms estimating the similarity among MCPs and requested MCPs were used, while automatic extraction of terms as keywords for the Quested MCP was performed through the UMLS Metathesaurus. Results: Knowledge Author Users using the advance Java Client can have full access and manage the MCP Ontology and the clinical user can search for algorithmic solutions and implementations by describing the MCP in a natural language upon using the Web Client. For the search process the Similarity Threshold is set at around 47%, since the Precision and Recall characteristics are approximately 81% and 72% respectively, numbers that are considered quite satisfactory. Discussion: The high rates of precision and recall characteristics of the search processes shown by the system may be attributed to the relatively small total number of MCPs present in the current version of the KB and also to the precise and careful MCPs' description exhibited by our test users. Though our initial experiments are showing promising results, a more extensive evaluation is needed, in order to complete and extend these first observations. The overall performance of KnowBasics-M in terms of usability, user friendliness and precision / recall features is satisfactory. Thorough use of such an application is expected to enhance task automation, cost containment and quality services in medical care, while at the same time medical research and high quality medical education by means of focused problem based learning are going to be benefited at a considerable rate.

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### Multimedia Approaches To Informed Consent and Patient Decisions Making

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Please note: this is an NCI requested product demo.



### Influencing Knowledge, Self-efficacy, and Readiness To Improve Dietary Behavior In a Rural Tri-ethnic Adult Population with a Nutrition Education Website

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Introduction The Internet will realize its potential as a channel for health education if it can deliver content that confers knowledge, positively influences expectations, and moves users toward implementing positive health behaviors. Internet health communication has produced positive changes in diet-related outcomes [1-3], but these evaluations have not been conducted in rural settings and rarely with multi-ethnic populations. Methods A nutrition website intended to increase the intake of fruits and vegetables (FV) was evaluated with a tri-ethnic sample of 768 adults (65% Hispanic, 9% American Indian, 26% White; 88% female) in a rural region in the American Southwest. Adults were individually randomized to treatment or control in a pretest-posttest trial, with in-person pretesting and telephone posttesting (n=479, 62% follow-up). The website was developed following Social Cognitive Theory and the Diffusion of Innovations Model and through formative research and website usability testing. Results Statistically significant improvements were evident in stage of readiness to eat more FV (estimate=0.234, P = 0.036 adjusted for covariates; estimate=1.685, P = 0.024 for positive change) but not in knowledge of the 5 a Day recommendation (estimate=1.463, P = .074) or self-efficacy expectations for eating 5 servings daily (estimate=0.057, P = 0.427 each day; estimate=0.015, P = 0.845 on busy days) in analyses adjusted for pretest value. Adults who used the website more (measured by time spent on site) had greater knowledge (estimate=1.008, P = .041), improved self-efficacy expectations (estimate=0.004, P = 0.028 on busy days), and more positive change in stage of readiness (estimate=1.010, P = 0.016). Discussion The nutrition website moved adults toward increasing their intake of fruit and vegetables but being assigned to use the website did not improve their knowledge or self-efficacy expectations. However, changes on the latter two variables were in the expected direction; the higher than expected posttest attrition may have under-powered the comparisons on these variables. Low use of the website by some adults may have undermined the effectiveness of the website [4], as greater use was related to improvements in knowledge and self-efficacy beliefs, as well as positive changes in readiness. Achieving website use may be a challenge in rural settings which often have poorer Internet infrastructure and technical support than urban areas, but efforts need to be directed at strategies to improve exposure [5]. 1. Oenema A, Tan F, Brug J. Short-term efficacy of a web-based computer-tailored nutrition intervention: main effects and mediators. Ann Behav Med 2005;29:54-63. 2. Papadaki A, Scott JA. The Mediterranean eating in Scotland experience project: evaluation of an Internet-based intervention promoting the Mediterranean diet. Br J Nutr 2005;94:290-298. 3. White MA, Martin PD, Newton RL, Walden HM, York-Crowe EE, Gordon ST, Ryan DH, Williamson DA. Mediators of weight loss in a family-based intervention presented over the internet. Obes Res 2004;12:1050-1059. 4. Eysenbach G. The law of attrition. J Med Internet Res 2005;7:e11. 5. Slater MD. Operationalizing and analyzing exposure: the foundation of media effects research. Journalism and Mass Communication Quarterly 2004;81:168-183.

### Challenges In the Evaluation of Chronic Diseases EHealth Initiatives

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Challenges in the evaluation of chronic diseases eHealth initiatives Chronic conditions such as diabetes, asthma and coronary artery disease account for up to 75% of costs of health care systems in Canada, the US and the UK; the indirect costs of lost productivity, pain and suffering are often much higher. Traditional care paradigms designed to respond to acute episodic illness do not serve the needs of patients with chronic conditions. In response, the Chronic Care Model (CCM) was developed to improve the care of patients with chronic conditions. This model was developed by Dr. Ed Wagner, and is based on medical evidence that specific interventions, such as self management, patient educatoin, case managers, multi-disciplinary care teams and automated decision support tools have beneficial effects on patient outcomes. Moreover, systematic reviews of such interventions suggest a synergistic effect when the interventions are combined. (www.improvingchroniccare.org) In 2003, Improving Chronic Illness Care and a small group of experts updated the CCM to reflect advances in the field of chronic care. Currently, there are several controlled studies on implementation of the model. Recent literature has identified a move towards the development of CCM evaluation frameworks and the need to evaluate the model's implementation and sustainability. Our presentation will use case studies, based on our research, to discuss the approaches that have been taken by various stakeholder groups to evaluate eHealth initiatives in chronic disease. In addition, we will discuss the challenges of evaluating chronic disease initiatives and provide recommendations on how to improve the evaluation process of such initiatives. Sources Cretin, Shortell, Keeler (2004). An Evaluation of Collaborative Interventions to Improve Chronic Illness Care-Framework and Study Design. Eval Rev. 2004 Feb;28(1):28-51 Kushniruk, A. W. & Patel, V. L. (2004). Cognitive and usability engineering methods for the evaluation of clinical information systems. J Biomed. Inform., 37, 56-76. Rush, B. Ogborne, A. (1991). Program logic models: expanding their role and structure for program planning and evaluation. The Canadian journal of Program Evaluation, 6, 95-106. Shaw NT. (2002). "CHEATS": a generic information communication technology (ICT) evaluation framework. Computers in Biology and Medicine 32, 209-220. Wagner EH. (1998) Chronic disease management: What will it take to improve care for chronic illness? Effective Clinical Practice. 1:2-4.

## The Hospital-at-Home: Advanced Remote Monitoring of Home Hemodialysis

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Background: The complexity and risks associated with complex hospital-at-home services can be significant. An example of a complex hospital-at-home service is nocturnal home hemodialysis. Patients can dialyse more frequently than with traditional hospital therapy, achieving better health outcomes [1] and lowering the cost of delivery [2]. If this new form of delivery is to be widely deployed, it is felt that the use of remote monitoring is required to reduce the associated risks and to improve patient adoption [3]. Methods: A patient-centric design method was used, beginning with ethnographic interviews of dialysis patient groups (nocturnal hemodialysis (NHD) and conventional hemodialysis (CHD)). In addition, 150 dialysis patients were surveyed regarding their perceptions of NHD therapy and remote monitoring. Peritoneal dialysis (PD) patients were added to the survey group as a further comparison. These data were used to inform the design of the remote monitoring support system. Results: The level



of agreement was high regarding the need of remote monitoring: CHD patients (mean of 4.06 on a 5-point Likert scale, SD of 1.13) and PD patients (mean 3.96, SD of .92). The NHD patients showed less agreement (mean 3.17, SD of 1.55). Multiple ANOVA comparisons showed this difference as significant (P = 0.008 vs CHD, P = 0.026 vs PD). During interviews, NHD patients qualified their answer by stating that the need was only in the first few formidable months after initiating home treatment. Following that, they feel the need diminishes unless the patient is not medically stable or is elderly. Although it was expected that NHD patients would express greater confidence in executing the therapy  $(P=0.004~vs~CHD,\,P=0.001~vs~PD)$ , they expressed no significant differences in the amount of anxiety related to a potential adverse outcome while undergoing home therapy (P = 0.302 vs CHD, P = 0.277 vs PD). This indicates a need for improved support of patients undergoing NHD therapy. This approach informed the design and development of the system, which elements ultimately included: • real-time monitoring of dialysis and physiological parameters • bloodline disconnect sensing • low-light pan-tilt-zoom IP camera The system transmits dialysis and physiological data back to the home dialysis centre via VPN. These data are processed by a clinical decision support system, where rules are applied, alerts generated, and transmitted to on-call clinical staff. The staff will receive the alerts via handheld device and respond as needed. Conclusion: The delivery of complex health services in the home will likely require some form of remote monitoring to mitigate risk and to improve patient adoption. This patient-centric approach to the design allows for other applications of the system, including chemotherapy, TPN, and palliative care.

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### **Diabetes Telemanagement**

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Purpose The primary objective of this pilot demonstration is to determine whether diabetic patients with high blood pressure, using a mobile communication device to monitor their blood sugar levels and blood pressure, are at lower risk of dangerous complications related to their condition. The secondary objectives are to assess the level of patients' adherence to the schedule of home (self)-monitoring and the usefulness, practicality, and cost-effectiveness of the system to health care providers. The added challenge is the implementation in two different settings: the large urban area of Toronto, and the northern rural community of Chapleau, Ontario. Each has differing patient profile and telecommunication infrastructure, which need to be accommodated through the telemanagement system. Methodology Bluetooth-enabled medical devices are used to transmit date to a mobile device (cell phone or PDA). The mobile device relays data back to a data repository, where rules can be applied and alerts generated. These alerts are sent to the family physician by fax (in the absence of an EHR) and to the patient by automated text or phone messages. Local health personnel will instruct patients on the proper method of measuring blood pressure and blood sugar at home. The patients will be provided with a bluetooth-enabled validated blood pressure and blood sugar devices and the mobile phone (Toronto) or PDA (Chapleau) running a custom application for secure retrieval and transmission of the patient data. The patients will be asked to take their blood pressure and blood sugar levels at least twice weekly in the morning and evening. The system is designed to remind patients by text or voice message to take their home readings if they fail to adhere to the preset schedule. Results/Outcomes Thirty patients have been recruited since December 2005 in the Toronto area. Chapleau patient will be recruited in February 2006. Both sets of patients will be tracked for four months. The primary measure of intervention efficacy will be changes in blood pressure readings and hemoglobin A1C level from the baseline to the last (4 month) visit. At the end of the study all patients will be scheduled for two visits to the health clinic one week apart for blood pressure measurements following exactly the same protocol as described for the baseline blood pressure evaluation. The patients will also have their blood hemoglobin A1C level measured again. Secondary outcome measures will be an assessment of: 1) the frequency of home measurements to determine adherence with the pre-specified monitoring schedule, and 2) the questionnaire

given to the health care providers to determine the usefulness of the system as an aid in managing high blood pressure and diabetes. Conclusions This on-going study may be viewed as a demonstration of a technology that is applicable to a wide variety of chronic diseases and conditions such as heart failure, asthma and depression and builds on the demand for new and more effective ways to improve chronic disease management.

### Avian Influenza: Evaluation of European National Surveillance Institutes Information On the Web

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Background: Avian influenza is a highly contagious disease of animals caused by viruses that normally infect only birds and, less commonly, pigs and other mammals, spreading worldwide through migratory routes of wild birds. The current outbreaks of influenza in birds, which began in South-East Asia in mid-2003, are presently infecting Europe and Africa as well. These are the largest and most severe outbreaks on records and are of particular concern for human health, due to two main risks: the possibility of direct infection when the virus passes from poultry to humans, and the possibility for the virus to change into a form that is highly infectious for humans and thus mark the start of a pandemic. [1] [2] Objective: The purpose of this paper is to consider the European National Surveillance Institutes (ENSI) web sites, listed by the European Commission with an eve to the structure of information on avian influenza. [3] The analysis has been carried out through pre-defined criteria. Methods: The European web sites have been analyzed through criteria such as home page topical information availability, functionality of internal search engines and presence of topic-related links. In the English version, links to WHO, OIE and other international web sites have been evaluated as well as links to statistical data, news and FAQ section or similar formats, RSS feed, etc. [4] [5] Results: Preliminary results of avian influenza information search, on a sample of 25 web sites, show that: 80% have at least a partial English version; 44% show the topic on the home page; 48% include a FAQ section or similar formats; 16% allow the users to be interactive. Conclusions: Official web sites make information available to a variety of recipients such as laymen, health workers, decision makers, internet community, being a focal point within health information system. More attention should be paid to meet end-user needs, particularly to make the websites more consumer-oriented, focusing on guidelines for prevention and control measures.

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### A Discourse Analysis of Risk Information In Prominent Web Health Resources

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Background Screening test results are notoriously difficult to understand; in particular, professionals and lay people alike tend to over-estimate the reliability of positive test results [1]. Much of the available consumer health information does little to address this widespread misconception, presenting information in ways that make it difficult to comprehend, and in some cases even omitting



information about test performance that is critical for a complete understanding [2]. These resources, therefore, do little to promote informed decision making regarding screening test participation. One possible reason is that the resources presuppose participation: that is, they may be designed to support a presumed decision to participate rather than to provide the balanced information that consumers require to make an informed decision. Objective The present study examines consumer health information resources regarding a variety of screening test to determine whether these resources promote active consumer participation in a decision process, or whether they instead construct the decision of whether to take a screening test as a 'fait accompli', serving instead to support this presupposed decision. Methods Information resources regarding four different screening tests were selected from MedlinePlus and analyzed using qualitative content analysis methods. The four screening tests were: 1) Maternal Serum Screening for Down Syndrome (MSS); 2) Screening Mammography for breast cancer (SM); 3) HIV screening (HIV); 4) PSA testing for prostate cancer (PSA). The four tests differed in whether they targeted women or men (MSS for women only, SM primarily for women, HIV primarily for gay men, and PSA for men only) and whether the detection of the condition served individual and/or social goals (SM and PSA screen for conditions that are constructed primarily as individual issues, while MSS and HIV also have social implications (the first with respect to potential costs to the health care system, the second with respect to the possibility of transmission)). Results Our results indicate that the focus and even content of screening test information differs depending on whether the target audience is male or female, and whether the condition is constructed primarily as an individual issue or one with larger social implications. Among the resources we examined, those concerning the PSA test (male audience, individual issue) are best constructed to support informed decision making on the part of the reader; other resources are less likely to provide complete and unbiased information, and less likely to construct the consumer as an active participant the decision of whether to take the screening test. Conclusions Our analysis indicates that much of the online consumer health information regarding screening tests conforms to the biomedical discourse identified by Dixon-Woods, with the primary goal of provider-directed 'patient education' rather than 'patient empowerment' [3]. This perspective is particularly evident in resources directed primarily toward women, and in resources regarding tests with more evident social (as opposed to individual) benefit. It appears, therefore, that the goal of many of these resources is to promote test participation, rather than support informed decision making [4].

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### Health Information Needs of the Low Income Elderly

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Elderly adults are one of the last demographic groups to begin using the Internet to locate health information1. Those elders who do use the Internet to locate health information are predominately white females who own a computer with a broadband connection, have high levels of locus of control, high self efficacy in terms of computer use and possess a college degree or some form of post-graduate training2. How and to what extent seniors having low income and educational status use the Internet for health care purposes remains poorly understood. More importantly, providing low income elderly with the ability to locate and retrieve valuable health information can enhance the type and quality of care they receive from their health care provider. This paper will describe "The Elderly and the Internet: A Partnership in Health" an outreach program designed to train and analyze how low to moderate income elderly adults use the Internet to locate, retrieve, and evaluate health care information. The program is an interdisciplinary joint effort between Duquesne University's School of Health Sciences, the School of Nursing, the School of Pharmacy, and the University Library. The program centers on the development of a local area network comprising five personal computers within two nurse wellness centers.

Each nurse wellness center has been integrated within a low income residential high rise located in economically depressed areas of downtown Pittsburgh. Each network has been connected to the Internet using a high speed DSL connection. The program allows residents to volunteer to take part in the training/research program. Residents who volunteer participate in a five week course that provides them with skills needed to locate Internet based health information. Training modules in the course include: Introduction to the Internet and the personal computer; finding basic health care information; finding drug and alternative medicine information; using search engines to locate health information/finding quality of care information, and evaluating Internet based health information. The hands on instruction residents receive from University faculty, VISTA volunteers and six year pharmacy students enrolled in a patient education course contributes to the program's strength and distinguishes it from other similar initiatives. Residents have access to the labs on a daily basis. To evaluate the effectiveness of the program, several factors related to resident perceptions are being collected. These perceptions include: locus of control, opinions regarding health information and behavioral involvement, levels of anxiety toward computers, and self efficacy toward the use of the computers. To determine how often residents use the computers to locate health information, residents will participant in a series of interviews and complete an Internet usage survey nine months after completing the training program. This paper will describe the program in detail and report initial findings. 1. Campbell RJ, Nolfi DA Teaching Elderly Adults to Use the Internet to Access Health Care Information: Before-After Study J Med Internet Res 2005;7(2):e19 <URL: http://www.jmir.org/2005/2/e19/> 2. Campbell R. Older women and the internet. J Women Aging 2004;16(1-2):161-174.

### Sharing Electronic Patient Records Using a Peer-to-Peer Infrastructure

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Introduction Electronic Patient Record (EPR) has become an essential tool for accessing in an efficient manner to information regarding patient health history and personal data, required by administration, medical doctors and researchers. Recent efforts for defining standard guide line for EPR compilation, electronic representation and accessing control have been guided by the importance of tracing any information about history of patient, but also by the necessity of monitoring expenses supported by local and central governments. Indeed, an EPR contains data about the various hospitals the patient visits, e.g. for surgery or special examination, the family genetic pathologies, clinical treatments, but also personal information regarding incomes necessary for (eventual) bills. Treatments and response to drug types can also be used by researchers to derive information on clinical effects (outcomes) research. Decisions in health care often need to be taken by integrating and comparing data coming from heterogeneous data sources. For instance, information may be found in different data repositories such as family doctors records, hospitals databases, and national health system repository, each one with their own data structures. Moreover, single patient records may be stored by using different identifiers on the different data sources. Methods Often EPRs are organized in a stand-alone way and decisions are taken by using only individual local data, resulting in incomplete information. To enable effective decision-making, clinical and organizational levels (administration) need to access to distributed data, and need to consider schema heterogeneity, and access policies. Heterogeneity can be faced by using a mediator-based approach where a mediator defines a global schema, and queries against the global schema aremapped to queries defined on the local data. Recently the use of XML as a standard language for data exchange has been proposed for EPR sharing. Decentralized and peer-to-peer approaches for data access and integration have been proposed for EPRs based on XML representation. Peer-to-Peer (P2P) systems are largely used to share information among remote and distributed data sources. This approach has rapidly grown up for data sharing. Indeed, each data source is managed by a peer node that maintains its own autonomy and shares resources with other nodes, using Internet for communication. Nevertheless, sharing data and accessing remote ones, requires that each peer node must know the data structure of the other ones. Nevertheless, currently the problem in EPRs sharing is that no common standard has been adopted. Results This paper proposes an hybrid P2P



architecture allowing different health centers (e.g. hospitals, primary doctors, etc.) to share information about patient records. Due to lack of common EPR structure, and to allow an efficient access to aggregate information, we do not propose any new EPR structure, but a meta-Electronic Patient Record (meta-EPR) containing representative data extracted from each EPR. The meta-EPR is an XML-based data structure that allows to obtain information about different clinical practices, such as therapy response time, number of patients cured for a specific disease (e.g., lung cancer). Meta EPRs are obtained by extracting data from local EPRs using extraction rules defined in a wrapper module based on a logic language. The meta-EPRs are shared into a peer-to-peer network where each hospital has a super peer node containing the meta-EPR, and the reference to a set of local peers, each one allowing to access to local and remote data (e.g. from a department). Discussion Medical doctors belonging to a department may query the meta-EPRs stored in the super peer database or search for meta-EPRs of different hospitals. Last search is performed through the super peer node that is in charge of communicate with the other super peer nodes. For patients moving among departments (e.g., from the cancer to the surgery department) or among different hospitals, doctors may need to rapidly access to recent and relevant information about their health state. The proposed architecture has been fully implemented and tested on three hospital nodes. The main goal of the system is to support outcome research on a regional and national basis.

### Accessible and Usable Graphical User Interface for An E-health Web Platform

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Background: Aging of the population has become a world trend [1] and actual health care systems have to face up with its consequences, mainly represented by chronic diseases. Studies show that such diseases contribute approximately to 59% of 56.5 million total reported deaths in the world and 46% of the global burden of disease [2]: moreover important economical resources are spent in the care of them. Risk factors causing chronic diseases could be easily prevented, and the active collaboration of the patient would have a really crucial importance. For this purpose, there is the need of truly personalised health care systems which can push and motivate the patient, preventing relapses and enforce therapy compliance. Objective: The aim of this work is to build an high accessible and usable Graphical User Interface for an e-health web platform that allows to reach the highest portion of the population as possible, being accessible and user-friendly to every kind of patient, including people with special needs and disabilities and people with little skills on ICT, from a PC or a mobile device. Methods: The design of such GUI was conducted taking into account principles of usability and accessibility. Usability is a subjective way to measure the effectiveness, efficiency and satisfaction in using a system or a product [3]. In our system this is achieved by having built a simple and clear page structure, where the information is clearly presented and easy to find. Commands and actions are limited in number and rightly associated to specific functions, making the system intuitive and easy to use, without any kind of previous training. Accessibility plays an important role in user interfaces, especially giving to people with special needs and disabilities the possibility to access the system without any obstacles or barriers. For this purpose, our user interfaces is compliant with the recommendations given by the WAI [4], presenting information with alternative descriptions, making possible to special browsers to cover all the possible ways to render the same information (visible, audible, touchable). Finally, last and W3C compliant technologies like HTML and CSS are used [5]. Results: The user interface developed provides information in a simple and high usable way, enhancing user satisfaction when using the system. Furthermore, our system provides users with a novel and very useful functionality: the personal assistant. It guides users providing them with personalized messages regarding their position in the system, instructing on how to use the different functionalities, and showing the necessary priority messages from the system. Moreover, following WAI recommendations, an AA level of accessibility is achieved. This enables users with special needs and disabilities to access the system with their specific web browsers, from PC or mobile device, without limitations in the information received. Conclusions: The graphical user interface presented in this paper is a perfect mediator between the e-health system and patients, providing them motivation to move toward a positive and active attitude in health prevention. Moreover, it results flexible and independent by the specific system architecture or implementation.

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### EHealth Services for Family Caregivers of Dependent Elderly People: An Exploratory Spanish Case Study

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Background: In Spain, the person mainly responsible for the care of elderly dependents at home is still the woman of the house[1]. Although her social and cultural profile hardly favor her integration within the society of information and knowledge, the services afforded by eHealth may be a valuable tool for two reasons; to attain a level of information necessary for them and to enable them to care for themselves and the other members of the family more effectively. Objective: To examine the possibilities for help that Internet can provide to those looking after elderly dependants and evaluate the suitability of the eHealth services aimed at the requirements of family caregivers, in order to propose improvements for the better use of these services. Methods: We undertook a qualitative research project in two phases: A. Ethnographic needs study of the requirements of family caregivers by means of in-depth interviews and observation (10) and discussion groups (3). B. Study of the eHealth services for family caregivers of elderly dependents using Google searches and reviews of the web sites selected (10). Results: The family caregivers studied had important requirements concerning information, education and support related with the care they give to other members of their families, with their own care and with the use of information technology and internet. The few web sites for family caregivers of elderly dependents mostly provided health information poorly related with their needs. Conclusions: At the present time, eHealth services fail to provide much help to Spanish family caregivers of elderly dependents. A series of strategies needs to be developed to enable persons involved in social and health care to benefit from the advances in information technology and communication and abandon their digital isolation.

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# Psychotherapy and E-therapy: The Integration of Traditional Techniques and New Tools In Clinical Settings

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Introduction: in the last years the rapid development of the Internet and new communication technologies has had a great impact on psychology and psychotherapy. Psychotherapists seem to rely with more and more interest on the new technological tools such as videophone, audio and video chat, e-mail, SMS and the new Instant Messaging Tools (IMs). All these technologies outline a stimulating as well as complex scenario: in order to effectively exploit their potential, it is important to study which is the possible role played by the Internet-based tools inside a psychotherapeutic iter. Methods: the clinical outcome of different clinical trials carried out inside the San Giuseppe Hospital (Istituto Auxologico Italiano, Italy) will be outlined stressing the possible added value of a new integrated clinical protocol (including Virtual Reality and Internet based tools) in comparison with traditional approaches (such ad cognitive-behavioural psychotherapies) for the treatment of eating disorders (in particular binge-eating disorders) and anxiety ones (in particular anxiety and panic disorders). A rationale about the possible use of Virtual Reality is provided. Results: The major aim of this paper is to provide a framework for the integration of old and new tools in mental health care. Different theoretical positions about the possible role played by e-therapy are reported showing the



possible changes that psychotherapy will necessarily face in a cyber setting. In particular the use of Virtual Reality is described as an example of clinical application matching old (and functional) practices with new (and promising) media for the treatment of different mental disorders. Discussion: Future scenarios (such as "Ambient Intelligence" based ones) will be discussed in order to better match "technology" and "psychology" in the mental health care field looking for new clinical applications.

## Use of Web-based Health Counselling Service Among Finnish University Students

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Background: Among Finnish people of working age, young adults are the most active users of email and the Internet. University students use ICT even more actively than young adult population on the whole. The Finnish Student Health Service (FSHS) provides primary health care services to ca. 140,000 university students in Finland. Services includes also a web-based health counselling service through which general practitioners, nurses, and dental care professionals give instructions and advice on health and illnesses to anonymous students. The service free of charge covers following topics: sexual health, asthma and allergies, travelling medicine and vaccinations, oral health, and mental health. Objective: Our study was designed to examine factors that differentiate between users and non-users of a web-based health counselling service among Finnish university students. Methods: This study was carried out made as a part of the "Student Health Survey 2004", a national mailing survey among Finnish undergraduate students aged 19-35 years. The population size was 101,805 and the study sample 5,030. The response rate was 63%. Statistical analyses were conducted using the  $\chi^2$  test. Results: 12% of respondents had used FSHS' web-based health counselling service. Compared to non-users, users were more likely to be female (14% vs. 8%, p < .001), and were studying in Helsinki area (18% vs. 9%, p < .001). Compared to female non-users, female users reported more often >5 health cares visits in the past 12 months (11% vs. 7%, p < 0.001). Compared to male non-users, male users had more frequently (30% vs. 20%, P = 0.019) been diagnosed for asthma or allergies. There were no between group differences in self-reported global health status (excellent/good, only fair, or poor). Conclusions: Female gender, study residence in Helsinki area, higher numbers of health care visits, and diagnosed asthma or allergies were associated with the use of a web-based health counselling service. More research data are needed to evaluate the role of a web-based health counselling service as supplementing or substituting the traditional forms of health services.

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### **Creating Training with In-house Experts**

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Talaria sells educational products that help healthcare institutions meet regulatory in-service requirements and improve the quality of services. The Builder is Talaria's core software application. The Builder allows in-house content experts to efficiently create educational content and offers branched logic, user tracking, pre post testing, and a customizable learning management system. The software is web-based and supports audio and video presentations. The Builder allows customers to use in-house experts to significantly reduce the cost of creating educational programs and customized learning management systems. The Builder is currently used by a number of large customers and references are available.

### Solution Usability Assessments: A Novel Approach for Ensuring Online Electronic Health Record (EHR) Adoption

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The potential of online electronic health record (EHR) systems to reduce medical errors, improve patient care and decrease healthcare costs, can only be realized if they are successfully adopted. Yet the usability of these systems, while recognized as critical for successful adoption [1], continues to take a back seat to functional and technical requirements. Not only are online EHRs implemented without being evaluated for how well they meet user needs, how easy they are to use or how well they match workflow, they are often required to interface with additional or existing systems that also have not been exposed to usability evaluations. The resulting integrated solutions that health care practitioners are required to contend with often make use of multiple interfaces with inconsistent terminology and behaviour. This increases the mental workload of the users as well as the required training and support. In addition, inconsistencies in the way information is entered or reviewed can lead to errors or incomplete records which could adversely impact patient care. The Solution Usability Assessment methodology was developed by the Healthcare Human Factors team at University Health Network (UHN) to address the issue of evaluating the usability of a solution that comprises of multiple vendor products, each with differing interfaces, mental models and navigation schemes. The process of evaluating the usability of a complete and interoperable EHR solution presents significant challenges compared to evaluating individual vendor products, particularly when multiple and disparate systems are involved. The goal of Solution Usability Assessment is to determine how well a given solution meets the needs of end users in terms of workflow optimization, ease of use and patient safety. The specific focus is on areas of intersection or overlap between the front end user interfaces of different vendor applications in a solution, with respect to consistent behaviours, common terminology and metaphors, as well as equivalent help and efficiency tools. In addition, unnecessary or confusing redundancies are identified and examined. Solution usability assessments are performed by a minimum of two usability experts and involve initial heuristic assessments of individual vendor applications comprising the solution. Heuristic assessments involve the systematic inspection of interfaces for conformance with Usability Heuristics developed for user interface design [2], for medical devices [3], in conjunction with First Principles of Interaction Design [4]. These assessments provide direction for the integrated solution assessments by identifying areas of focus. For example, heuristic breaches identified in individual vendor products will be re-assessed in the context of the entire solution to determine the potential impacts on the user workflow, ease of use and patient safety. Additionally, solution usability assessments involve mapping the information architecture of the solution. The focus is to identify navigational inefficiencies as well as information redundancies and deficits. The Solution Usability Assessment methodology has been employed to evaluate the usability of the "Physician Office of the Future" solution being developed by the eHealth Collaboratory project [5].

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### The WHO International Clinical Trials Registry Platform: Promoting Science and Ethics Through Increased Transparency

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Selective reporting of clinical trial results is known to be widespread, and recent high-profile cases have demonstrated the potential impact of suppressing negative findings in healthcare. In order to restore public trust in clinical research, it is clear that transparency and accountability must be strengthened through trial registration and results reporting on public electronic databases. The World Health Organization (WHO) established the International Clinical Trials Registry Platform (http://www.who.int/ictrp) in August 2005 with the primary objective of ensuring that all clinical trials worldwide are uniquely identifiable through a system of public registers, and that a minimum set of results is made publicly available. This presentation will highlight the current policies and progress of the WHO Registry Platform, as well as outline the technical and practical challenges of implementing global trial registration. WHO Registry Platform policies apply to all research studies that prospectively assign humans to one or more interventions, regardless of study design or intervention type. For a trial to be considered fully registered, all 20 items in the WHO Trial Registration Data Set (Version 1.0) must be recorded in a national, regional, or international Primary Register that meets acceptable standards for content, technical capabilities, quality assurance, and administration. A WHO Search Portal to identify trials across Primary Registers will be developed to meet the needs of patients, scientists, and other healthcare workers. Although internet technology has made it simpler to record, search, and share information about trials on a global level, many challenges remain to be resolved. As a single trial can be registered multiple times on the same or different registers, a reliable mechanism must be established to detect and 'deduplicate' such entries. Use of a single data interchange standard would simplify the identification of duplicate entries across registers. A Universal Trial Reference Number will then be assigned to each globally unique trial. Some stakeholders have argued against immediate disclosure of registered trial data to protect competitively sensitive information. A policy on the timing of public disclosure of registered trial information will be finalized in the coming months to balance the need for timely transparency with the protection of competitive advantage. Finally, global compliance, oversight, and capacity building must be considered in WHO Registry Platform policies, which will be re-evaluated and refined periodically as the complex field of trial registration continues to evolve.

### Innovative Tool for Cancer Education: The Asian and Pacific Islander Cancer Education Materials Web Portal

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The Asian and Pacific Islander Cancer Education Materials (APICEM) web portal, launched on March 24, 2006, is perhaps the first online portal for English-fluent health care providers and community-based organizations to search for and retrieve printed lay-oriented cancer education materials designed for Asian and Pacific Islander populations residing in the U.S.A. in 12 Asian or Pacific Islander languages and in English particularly customized for Native Hawaiians. APICEM was developed to meet the need for health care providers and community-based organizations who serve limited-English proficient Asian and/or Pacific Islander patients or clients, and who desire medically accurate cancer education printed materials developed for lay audiences in Asian and Pacific Islander languages as well as English language materials culturally tailored for Native Hawaiian lay audiences. This web portal is collaboration

between the U.S. National Cancer Institute (NCI)-funded Asian American Network for Cancer Awareness Research and Training (AANCART) with the support of the National Cancer Institute and the American Cancer Society. Additionally, all of NCI's community network programs focused on Asian Americans or Native Hawaiians or other Pacific Islanders: [American Samoa Community Cancer Network (ASCCN); The Asian Community Cancer Network (ATECAR); 'Imi Hale (The Native Hawaiian Cancer Network); and Weaving an Islander Network for Cancer Awareness Research and Training (WINCART)] focused on Asian American or Native Hawaiian and other Pacific Islanders endorsed and in some cases, contributed materials for the web portal. During this presentation, the APICEM web portal will be demonstrated and the latest statistics on its usage will be reported. Lessons learned and future directions will be shared.

# User-centerd Design of a Digital Knowledge Medium To Support Family Caregivers of Brain Injury Survivors

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Background: When caring for a family member who suffers a brain injury, family members often need to share the care. While the family is learning to cope with the injury, each member must rearrange his or her own schedule as well. We envision a computer system that can aid in this transition period, and continue to support family members in managing care amongst themselves in the years to come. Designing a computer system for use in the context of healthcare requires knowledge from the health and computer science fields. Objective: This paper describes our experiences of integrating the knowledge in both fields to design and evaluate a digital knowledge medium [1] that aims to ameliorate the burden of managing care schedules for families with a member who has brain injury. A digital knowledge medium is an electronic device that supports thought, coordination, and planning. Method: Computer system interface and system design involves iterative design to ensure that the device supports the user [2,3]. Because caregivers are stressed mentally, physically, and financially, it is paramount that design choices are well-executed. This paper illustrates the strong need for lockstep design, where each design choice is validated with the family and specifically targeted for their circumstances. The design progressed in three stages. First, we conducted needs assessments with three families using stakeholder interviews, artifact assessment, and environment assessment. Second, the needs assessment data were analyzed using stakeholder, artifact, task, scenarios and requirement analysis techniques. We used the analysis results to develop a design concept. Finally, two caregivers and two case managers validated the design concept in interviews. They performed representative tasks using two prototypes. Their performance and difficulties with the tasks were observed. Results: The results showed that primary caregivers who were busy had to perform complex tasks to schedule and coordinate helpers. The nature of coordination and the network of helpers frequently changed. The results surprised us with new user needs. In the artifact analysis, we learned the importance of translating traditional artifacts like calendar and white board into the new digital counterparts: caregivers perceived the new design useful and easy to use because familiar metaphors were chosen. In the usability study, we learned why caregivers had difficulties using some functions by carefully examining conceptual similarities and differences between the designers and caregivers. We added three new functions to enhance the design. The validation study showed that the new design was perceived as useful, easy to use and consisted of important functions. Conclusions: Our experience shows that ehealth technologies can be integrated into the caregiving cycle through user-centred design techniques. This project also demonstrates how a collaborative study can promote cross-germination of design and evaluation methodologies between the fields of human-computer interaction and occupational therapy.

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### Family Caregivers' Needs of Internet-based Services: A Survey of Caregivers of Brain Injury Survivors In Ontario

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Background: Brain injuries often result in long term disabling consequences [1]. Family members of brain injury survivors who are in need of support services may not be able to access them. Among other traditional support services, caregivers have expressed an interest to access services supported by Information Communication Technologies [2]. Objective: To investigate the needs of internet-based support services by family caregivers of brain injury survivors in Ontario. Methods: All family caregiver members, including internet users and non-users, of one provincial and one regional brain injury organizations were invited to participate in a mail survey. Core questions asked the caregivers to choose new internet-based services that they would like to receive. Results: A total of 157 internet users participated. The response rate was 39%. A typical internet user was female, aged 41-60, provided moderate to heavy care for a family member in a post-acute long-term recovery stage. Most caregivers preferred information about programs (73.9%), brain injury (67.5%), and caregiving (64.3%). Approximately half preferred to email health professionals (56.7%) and to obtain website lists (55.4%). They were less interested in email exchanges with other caregivers (35.7%), a message board (22.9%), or a chat group (19.7%). Logistic regression analyses showed that caregivers' preferences were affected by their prior experiences of internet, email, and chat group uses (P < .01). If caregivers had experiences in searching brain injury information on the internet, they were more likely to prefer information-based support. If they had experiences in emailing someone about brain injury, they were more likely to prefer email-based support. Conclusions: In Ontario, family caregivers of brain injury survivors have accepted to use the internet as a medium to receive support services. Their readiness to accept the service is consistent with studies about technology readiness: people are not always ready to make too great a jump in information communication technologies. Failure of adoption is more likely to occur when the users' readiness is ignored in the system design [3]. Also, the extent to which users perceive a system as useful predicts how they eventually accept and use the system [4]. Therefore, when designing ehealth services for family caregivers of brain injury survivors in Ontario, an easy-to-use information website can serve as the basic resource. The base service can be expanded to include email services and message board at a later stage for subgroups of caregivers who are ready to use the services.

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# What Prevented Family Caregivers From Accessing a New EHealth Service? – a Study of Chinese Family Caregivers of People with Alzheimer Disease

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Background: Family caregivers who take care of a family member with Alzheimer Disease often need support services. Yet, not all of them can access services because of geographic location, time, or other constraints. To address these service gaps, a new ehealth program was designed to provide professional support services to Chinese caregivers via the Internet at a time convenient to them, using a language of their choice. A number of studies have evaluated the use of communication technologies to provide caregiver support services that show moderate outcome results in terms of reducing caregiver stress and burden

[1 - 4]. In some studies accessibility issues were addressed but few investigated the specific barriers to accessing technology-based support programs. Objective: This paper reports on the extent and characteristics of the barriers that prevent family caregivers from accessing a new ehealth support service. Methods: The sample was identified from the membership list of two ethno-specific (Chinese) day treatment programs for persons with dementia in Toronto, Canada. Each caregiver was contacted by phone and a screening interview was held. Interviews were conducted in the language preferred by the caregiver (Cantonese, Mandarin or English). If caregivers declined the offer to participate their reasons for refusal were recorded. Results: A total of 132 caregivers were identified. They were mostly the daughter (40.9%) or son (34.1%) of the care-recipient and Cantonese speaking (87.1%). Sixty-nine (52.3%) did not qualify for the program because, a) they did not have computers/internet or knowledge of how to use them (47.8%), b) the care recipient was being admitted to a nursing home (21.7%), c) caregivers refused to engage in the telephone screening interview (17.4%), and other reasons such as passed away or moved out of the country (13.0%). Sons or daughters were eight times more likely than spouses to qualify for accessing the service (p < .005). Many spouse caregivers did not have computers or internet access. With regard to language it had been expected that Mandarin speaking Chinese families would have greater need for the service due to their more recent immigrant status. Compared with Cantonese speaking families the Mandarin speaking families were ten times less likely to qualify for the ehealth program (p <.004). Many did not qualify for the program because we were unable to contact them for an interview after numerous trails. Discussion: With increasing use of technology for the delivery of health services to families in the community the challenge is to address the barriers to access to these services. Families who do not have computers or access to the Internet would need to be provided with this equipment. In addition they would need to be trained to use software so as to access e-health service web sites and engage in interactive communication with professional caregivers.

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### Web-Based Tools Help Fight TB In Taiwan

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Background: Among communicable diseases, tuberculosis (TB) is a leading cause of death worldwide, killing 2 million people each year. TB in Taiwan is a major public health issue as well. In 2004, the mortality and incidence rates of TB in Taiwan were 4.2 and 74 per 100000 population, respectively. Compared to the TB mortality and incidence rates in the United States (0.5 and 5 respectively) and Japan (4 and 30 respectively) in 2004, there is much room for Taiwan to improve TB control. A major system redevelopment project in 2001 marked the beginning of a continuous effort in converting the existing system to be web-based. Web-based modules developed to-date include case notification, case management for hospital personnel, automatic indicator-based monitoring of total quality management, automatic alert via cell phone to designated health officials, management of medications, and online professional development. Objective: The objective was to evaluate a web-based National TB Register system designed for health care professionals to report accurate, timely and reliable data as part of TB surveillance and case management. Methods: The performance of this system was evaluated in terms of improvements in follow-up of TB treatment cohorts and the compliance of notification timeliness. Results: The enhancements have resulted in significant system usage. Currently, this system is used by 832 institutions, 5128 individuals in Taiwan with an average of 210000 logins annually. With implementation of internet tools, improvements in the following areas have been observed: (i) the trend for the reduction of defaulted and transferred out patients in 2001-2003 treatment cohorts, (ii) the trend for the increase of compliance of notification



timeliness (34% in 2001, 84% in 2002, and 99% in 2003, P<0.0001). Conclusions: TB surveillance and case management involve a large number of specialized personnel and public health agencies. While Internet-based tools have been shown to effect improvement in TB outcome, it is a major challenge, from a system development of view, to understand users' requirements and to build a consensus among all users as to what tools and associated priorities need to be developed.

# An Innovative E-system for Integrated Management and Monitoring of International Multicenter Clinical Studies.

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INTRODUCTION: Management, monitoring and quality control of multicenter, international clinical studies and trials are complex and resource consuming. Electronic (off-line) and on-line Case Report Forms (CRF) are now sometimes used thus shifting the burden of data entry to the individual participating center/investigator. Still, study monitoring relies on human resources that have to travel to different sites and/or follow complex data verification procedures. AIM:To overcome these limitations, time constraints and related costs, we developed a real-time, on-line framework for the collection, control and verification of CRFs and study management forms; as well as for real-time study progress monitoring and quality control procedures. METHODS:No single data management or office automation package is capable of fulfilling all the complex requirements for these tasks, thus we used a set of commercially available platforms and tools. The core of the system is an industry standard SQL database/management platform (Oracle 9i) and its on-line web-portal. RESULTS: This combination provides the electronic CRF for the study granting each individual investigator access to, and only to, his/her cases while providing immediate feedback with first tier warning such as inconsistencies, incompleteness of data, upcoming and overdue deadlines (i.e. Follow-ups). In real-time the study monitor can access all data from all investigators to perform control procedures on data completeness and deadlines, thus issuing e-mail warnings. We obtained a higher level of integration and control by developing sets of real-time procedures, reports and charts that query the on-line database through a secure ODBC connection. The front-end and development tools include a database querying and reporting application (DataEase 6.5 RADD), a set of highly integrated "executive" reports (Crystal Reports) and several tables and summary charts (Graph Pad Prism4). Several security layers have been implemented: server access control policies, SSL, data codification and encryption. We have applied this framework to an ongoing case-control international project: the First Acute Myocardial Infarction (FAMI) Study, which has enrolled over 1000 cases and controls in Italy, China and Scotland to study the inflammatory, genetic and environmental pathogenetic components of acute myocardial infarction in three populations. We hence developed 32 relational tables, the corresponding data-entry forms and over 40 control reports. As a result, this integrated managing system enabled study monitors and the steering committee to remotely manage 31 centers and over 1000 patients and

### Evaluation of the Functionality of Subscription and Free Online Drug Information Databases

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Evaluation of the Functionality of Subscription and Free Online Drug Information Databases Background: As the amount of drug information rapidly expands and technology improves, online drug information databases are increasingly being utilized by healthcare professionals to help answer their questions and many individuals and institutions have invested substantially in them [1,2]. Subjective reviews of these online drug databases are plentiful in the literature, but no published systematic evaluations are available. Objective: The objective of this study was to systematically evaluate the functionality of seven of the most commonly used online drug information databases. Five subscription and two free online databases were assessed according to scope, completeness and ease-of-use. Methods: Fifteen categories (e.g. drug dosing, drug interactions, mechanism of action, side effects, and over-the-counter drug information) of drug information questions were identified as important to healthcare professionals based on the published literature and the Nova Southeastern University Drug Information Centers' records of queries by primary care providers [3]. The number of questions placed in each category was weighted with more important categories receiving more questions. A grand total of 158 pairs of representative questions and answers were created by the authors to populate the categories. Scope was assessed by the presence or absence of an answer for each question. A 3-point scale was used to evaluate completeness, and ease-of-use was measured by the number of clicks or steps necessary to reach the answer. Scores were reported for each of those three categories. Additionally, a composite score of the three facets was generated by weighting the scope 70% and completeness 30%. Then, the ease-of-use score was subtracted from the weighted value to determine the final score. Descriptive statistics and Chi-square were used to summarize the evaluation components and make comparisons between databases. Scheffe's multiple comparison procedure was used to determine statistically different scope and completeness scores. The composite score was subjected to sensitivity analysis to investigate the effect of the choice of percentages for scope and completeness. Results: The ranking for the databases from highest to lowest, based on composite scores was Clinical Pharmacology, Micromedex, Lexi-Drugs, Facts & Comparisons Online, ePocrates Premium, RxList.com, and Epocrates Free. Differences in scope produced three statistical groupings with Group 1 (best) performers being: Clinical Pharmacology, Facts & Comparisons Online, Lexi-Drugs and Micromedex, Group 2: Epocrates Premium and RxList.com and Group 3: Epocrates Free (p < .05). Completeness scores were similarly stratified with Clinical Pharmacology, Facts & Comparisons Online, and Micromedex being the best performers followed by Lexi-Drugs and then the remaining databases (p < .05). Collapsing the databases into two groups by access (subscription or free), showed the subscription databases performed better than the free databases in the measured criteria (p < .001). Conclusions: Online drug information databases vary in their ability to answer questions in a variety of categories. Clinical Pharmacology, Micromedex, Lexi-Drugs, and Facts & Comparisons Online were the top ranked online information databases based on the composite score. Additionally, the databases that require a subscription outperformed the free online databases.

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#### Mobile Healthcare for Adherence: Business Considerations

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This work proposes a cost/benefit analysis for developing mobile healthcare solutions that could improve chronically ill outpatient adherence (also known as compliance) to prescribed medical regimens. The paper begins by briefly discussing the importance and consequences of insufficient patient adherence and the modalities of mobile information technology that could address this critical issue. Medical and non-medical savings are identified that could result from adherence-enhancing initiatives, balanced by investment and operating costs. The work substantiates the importance of business evaluation of any such initiative, and suggests directions for future research.

# The Role of the Medical Librarians In the Organization of Integrated Knowledge Systems for Health Personnel and Consumers

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Internet has led to new systems of information retrieval and diffusion in all fields, also in medicine. Health workers, patients and citizens can freely have access - on the Net - to useful information resources, like those concerning clinical protocols. Many international organisations such as NLM, OMNI, CISMEF adopt rules and codes of conduct to validate biomedical information and have organised quality portals. Many standards, such as the MESH thesaurus and UMLS, have been produced by the libraries for a deep indexing and an effective information retrieval, and are currently used by the most important biomedical Web sites. The Dublin Core (ISO Standard 15836-2003) for the integration of information deriving from heterogeneous archives has also been developed by the libraries. The use of standards guarantees the interoperability defined as: "functional interconnection and interaction"... "the ability to exchange information and mutually use the information which had been exchanged" (91/250/EC). Librarians have always been involved with the management of knowledge. The libraries' network is essential in order to guarantee universal access to health information and to contribute to overcoming the 'digital divide' and 'second-level digital divide'. Libraries offer space and competence for people wishing to retrieve information tailor-made to their needs. trends of the Future evolution'strends are towards the constitution of integrated informative archives, using metadata, and the development of multilingual access. Therefore the old models of separate computerization have been superseded by the new models of integrated information oriented towards different categories of customers Biomedical libraries and documentation centers are, therefore, in a "pole position" with regard to the development of integrated knowledge systems for health personnel and consumers. In Italy there are some initatives using standards and guidelines for the quality and accessibility of information, among these a comprehensive patient information resource: Azalea, multicentre project of a digital library for patients, their relatives and the general public contains almost 1831 bibliographic records - 67 protocols,81 bibliographical citations, 949 electronic resources - 224. web site descriptions, 596 full text online full-text documents for patients, 553 main oncological associations, 1422 total ..... The Azalea Team, a pool of professionals coming from the seven research institutes specialized in oncology organized in a network (Alliance against cancer) is working to implement the digital library in a co-operative way. Azalea is a "hybrid" library integrating different kinds of documents: booklets, articles, links to web sites, association schedules. Furthermore the clinical trials are included in the archive, in a friendly readable version for patients. Azalea has developed an original method of evaluation to apply not only to electronic resources (web sites etc) but also to paper-based documents. Librarians, psychologists and oncologists are involved in the evaluation process, by means of grids, originally designed on the basis of internationally accepted criteria. The Italian Ministry of Health is currently funding the SICOP project (Information Communication System in Oncology for Patients) in order to create a network of Libraries for patients and to investigate the applicability of optimal patient information and communication models

# Development of a Health Portal: Applying Re-usable Knowledge Kernels To Provide Adaptive and Personalized Health Information and Medical Education

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Background: Appropriate delivery of medical knowledge delivered through the web to targeted audiences requires constant review of and adaptation to users' behaviour to optimize the accessibility, scope and depth of medical content. The Knowledge Kernel Framework was designed to manage and translate medical knowledge using a transformative and transportable approach that is primarily directed by the user and originated by the author(s) of a Knowledge Kernel. Methods: A Knowledge Kernel is a self-contained unit that packages and integrates medical knowledge with the means to organize, adapt and transform it according to the on-going needs of a user or community of users. The knowledge contained in the Kernels can be obtained from browsing or issuing a query to a repository of existing kernels for an application area (e.g. medical education). Returned kernel fragments can be modified and recontextualized by the end user in order to customize a "personalized" Kernel or they can be used to create new Kernels. The framework was developed using XML and Java standards and allows reconfiguration and extension of existing kernels. Whenever a search retrieves medical content without satisfying what the user is looking for, a Kernel can correct itself by aggregating and combining the content from other Kernels in the network. In this manner, the ongoing and dynamic development of a Kernel can be shaped and formed by the user to the point a Kernel has been sufficiently transformed to generate a brand new Kernel that can potentially be used to start a new repository, or contribute to other repositories of Kernels on the Web. Results: The approach has been applied to developing repositories of Knowledge Kernels in several domain areas, including development of a Northern Health Web portal designed for access by local clinicians and laypeople, as well as plans for use of the framework in providing context-sensitive medical information to medical students in an innovative northern medical program. The approach taken to evaluation involves application of remote usability engineering methods (termed "televaluation"), which is an approach involving remote collection of usability data (including results from automated logging and event-triggered pop-up questionnaires) from end users of a system [1]. The evaluation plans currently include remote monitoring of end users creating Knowledge Kernels, as well as tracking of use of Knowledge Kernels in the both the Northern Web Portal and the Northern Medical Education program. In addition, a subset of users will undergo laboratory-based usability testing of the application using an approach described in [1]. Preliminary evaluation has indicated that the approach is technically feasible, with detailed analysis of the usability of the approach ongoing. Conclusions: With the proliferation of knowledge obtainable over the WWW, new approaches to the configuration and access of medical and health knowledge are needed. The Knowledge Kernel approach we have developed appears to be technically feasible and is currently being applied successfully in several health related projects.

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# Coping with Dental Anxiety and Phobia Through Online Support

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Background: Dental anxiety and phobia can have a profound impact on the lives of individuals. Firstly, the phobia often leads to avoidance of the stimuli (the dental context) which can have a deleterious effect on oral health [1]. Secondly, patients report significant psychological and social consequences of their phobia; shame, guilt and embarrassment are common experiences with research indicating that patients often report widespread negative social life effects and a threat to self-respect and well-being [2,3,4]. In recent times, there has been a marked increase in the number of individuals who are searching for health-related information, advice and support on the Internet. In particular,



online support groups have become a popular vehicle through which individuals affected by a range of health-related issues can discuss, share and explore their collective experiences. To date, however, the extent to which such online groups have assisted those coping with dental anxiety or phobia to overcome their fears remains unclear. Objective: The aim of this study was to investigate the impact of a dental phobia online support group on the self-reported anxiety of its participants. In addition, to explore using a qualitative methodology the experiences of those who have chosen to access the group. Methods: Participants were 93 members of the Dental Fear Central network who were invited to visit a website hosting an online questionnaire. Participants were required to acknowledge their consent to participate through the submission of a unique password. The questionnaire included socio-demographic information, views on the efficacy of the online support group as well as the Modified Dental Anxiety Scale [5]. Results: Scores on the MDAS scale ranged from 6-25 [Mean = 19.81; SD = 5.02). In total, 65 (69.9%) scored 19 or above [which indicates dental phobia]. There was no difference between males and females with regards total MDAS scores, nor any association with age. In total, 61.3% considered that the online group had either 'greatly' or 'somewhat' lessened their phobia/anxiety, 36.6% considered it had 'stayed much the same' and only 2.2% 'somewhat' or 'greatly' increased. Comparing those individuals who reported the online group to have 'lessened' their anxiety with those whose had 'stayed the same', there was a significant difference on the overall MDAS score (Means = 18.56 vs. 21.78; p <.01). Results also indicated that individuals whose anxiety had lessened, had lower anxiety across all items on the MDAS (p <.05) except the 'scale and polish' item. Findings from the qualitative phenomenological analysis revealed five emergent themes which represented the main motives for accessing the support network and its perceived benefits: 'I needed work done', 'I'm not alone', 'I can finally talk to someone', 'Learn from others' and 'I feel empowered and ready to try'. Conclusions: Participation in the online support group appeared to reduce feelings of anxiety and concern towards dental treatment. The use of such groups may provide a useful tool through which dental anxiety/phobia may be treated.

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## (Behavioral Health Panel) Translating Evidenced-based Behavioral Health Interventions Into E-health Modalities

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Panel Overview: Increasingly, research suggests the Internet provides the platform for the next generation of health promotion initiatives and behavioral health interventions. In some experimental studies, Internet-based programs are not only feasible, but are efficacious compared to no treatment or attention controls. Such computer-delivered interventions mimic the education or interventions that mental health professionals would provide by: (1) employing computer-mediated approaches that tailor personally-relevant information to the patient or health consumer, and (2) allowing for real-time feedback and updating of risk assessment or motivational feedback. Thoughtful formative research and testing can ensure high quality content and programming so that initial investment in a development of computer-based approach is sensible. Further, online behavioral health interventions can reach a large target audience at relatively low cost over the long term. However, the success of such innovative approaches relies heavily on solid theoretical frameworks and the success of traditional evidence-based approaches in behavioral health treatment modalities. Translation of traditional methods into e-health interventions presents both and challenge and an opportunity. Three programs will be discussed: (1) Internet-based STD/HIV prevention for college students by Sarah Lord, PhD, Director of College Health Programs at Inflexxion, Inc.; (2) Web-based cognitive-behavioral treatment for insomnia, by Dr. Gregg Jacobs, internationally known expert in congitive behavioral treatment for insomnia, Harvard Medical

School; and online psychosocial support for infertile couples, by Tara Cousineau, PhD, Research Scientist, Women's Health Programs, Inflexxion, Inc. Each panelist will discuss the evidence-based approach for each e-health intervention, preliminary or prior research that informed the development of online intervention, formative processes involved in using web-based formats in program development, and relevant outcome data on program effectiveness. Panelist 1: Sarah Lord, Ph.D. MyStudentBody STD: Web-based Sexual Risk Prevention for College Student Sexually transmitted infections (STI) among young people are a significant public health concern (CDC, 2002). An estimated half of all new cases of STIs occur among adolescents and young adults (Weinstock et al., 2004). This study describes the formative research underlying development of a media-rich, interactive online sexual risk prevention program for college students (MyStudentBody STD: MSB-STD). Elicitation research was conducted with representative stakeholders of the target population (students, peer educators, LBGT advocates, and college health staff) to identify critical STI prevention information, motivation, and behavioral skill needs, as well as successful education strategies for reaching students. This formative work, in conjunction with an empirical-based conceptual model for sexual risk reduction, informed development of a prototype Web program. Usability and acceptance testing of the prototype with potential end-users strongly supported the feasibility of the approach for reaching students, in terms of both content and delivery. End-user feedback helped refine development of a fully functional program. MSB-STD was evaluated in a randomized, controlled trial with three hundred sixteen students. Participants were randomized into intervention or control conditions. At 6-month follow-up, MSB participants showed significantly greater improvements in knowledge and attitudes, and demonstrated significantly higher intentions to carry and use condoms relative to controls. MSB participants were also over three times more likely than controls to use condoms with any partner. Results indicate that early formative work to tailor prevention material to a target audience is critical to the development of effective technology-based prevention programming. Panelist 2: Gregg, D. Jacobs, PhD An Online, Interactive Cognitive Behavioral Therapy Program for Insomnia Insomnia affects almost 60 % of adults at least a few nights per week and one-third on a nightly basis. It is associated with impaired daytime functioning and significant increases in health care costs, particularly chronic use of sleep medications. Although pharmacotherapy is the most frequent treatment for chronic insomnia, cognitive-behavioral therapy (CBT) is now recommended as the first line treatment due to its superior long-term efficacy, lack of side effects, and greater efficacy in direct comparisons. Unfortunately, CBT has not been available to the vast majority if insomniacs due to a severe shortage of CBT clinicians. In order to make CBT more widely available, we translated a therapist-delivered CBT protocol that has been empirically validated in a randomized clinical trial into an online, dynamically interactive CBT program for insomnia (www.cbtforinsomnia.com). This six session, 6 week online program incorporates an interactive sleep diary and progress summary to provide individualized, dynamic CBT guidelines and techniques. The program sets goals, tracks goals and compliance with behavioral techniques, and tracks changes in sleep. A recent clinical outcome study on 50 users who completed the program showed that 93% of almost nightly users of sleeping pills reduced their medication use, 66% reduced use of sleep medication to less than twice per week, and 40% stopped using medication entirely. Additionally, average sleep duration increased from five hours per night to almost 7 hours per night. These results significantly exceed those reported in randomized clinical trials involving sleeping pills and therapist-delivered CBT and suggest that this online, interactive CBT program for insomnia may be the most effective first-line treatment for chronic insomnia. Panelist 3: Tara Cousineau, PhD InfertilitySource.com, Online Psychosocial Education and Support for Infertile Couples An online program, InfertilitySource.com, was developed for couples seeking medical treatment for fertility problems and informed by theories of social learning, cognitive appraisal and stress inoculation. The goal of the program is to prepare patients for the medical journey by employing various self-assessment and cognitive behavioral skill building around the psychosocial issues unique to infertility. In general, most fertility patients enter the treatment process with a sense of hope and optimism and do not anticipate prolonged treatment or consider that mental heath counseling may be needed. Many patients do, however, spend considerable time on the Internet searching for infertility information and support, suggesting that the Internet may offer both an opportunity and innovation in quality programming. Extensive formative research with patients and health professionals contributed to program content, including the validation of an infertility self-efficacy measure, which was used as a tailoring mechanism for feedback and prioritizing content for individual users. InfertilitySource.com was developed and tested in an efficacy study where 296 patients (185 women, 111 men) were randomized into either the online intervention or no treatment control group. Initial data for the first 124



patients that completed the one-month follow-up assessment suggest that the program was successful in several domains. In particular, women exposed to InfertilitySource.com significantly improved scores on measures of fertility-related sexual concerns and overall psychosocial fertility problems. These results suggest that formative content development process with patients and experts contributed to the success of the intervention and that the online formats in behavioral medicine are viable.

# Targeting E-health Obesity Prevention for Youth: Balancing Evidence Based-Approaches with Audience Appeal

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With increasing access to computers and the Internet across all age groups, obesity prevention programs are beginning to expand into online modalities. The opportunity to reach children and adolescent via online programming has arrived. Consider that 99% of US public schools now have access to the Internet and 59% of children and adolescents (5-17 years old) go online daily. Use of the Internet capitalizes on the wide availability of computers and Internet connections at schools, while offering students private, self-paced, and tailored health information. The climate is particularly ripe for addressing nutrition in youth. Indeed, the high prevalence of overweight and obese children in industrialized nations has become a major concern. In the US, for example, the percentage of overweight school-age children has nearly quadrupled in the last 30 years. This is largely due to poor diet and physical inactivity. It is important to recognize that in the majority of cases, obesity is a preventable health condition. In response to the obesity epidemic, national prevention campaigns have been developed, e.g., "Five A Day for Better Health" is sponsored by the National Cancer Institute, the CDC, and the fruit and vegetable industry, and encourages Americans to eat at least 5 servings of fruit and vegetables (F&V) per day. Efforts to support this campaign are important, based on the well documented association between diet and life threatening, yet preventable, health conditions. Unfortunately, the vast majority of children do not consume the recommended five servings of F&V per day. On average, children eat 2.8 servings of vegetables and fruits combined per day. The question prevails, however, how can educational settings be maximized to encourage the current generation of children to engage in healthy eating behaviors in a way that appeals to them? One way is via the Internet. This workshop will address integrating technology with nutrition education and obesity prevention by introducing participants to three Internet-based programs, each developed for a specific youth segment. In this workshop strategies for program development and evaluation will be addressed. Applications to other health promotion areas of interest to participants involved in program development for youth will be addressed. Educational Goals: The focus of this workshop will be to describe three online prevention programs designed to increase healthy eating as models for e-health interventions. With funding from the National Institutes of Health, these programs include: Trouble on the Tightrope: In Search of Skateboard Sam, a fully animated mystery game geared toward 5th and 6th grade school children to promote a healthy lifestyle and body image; Jive for Five, a online program to promote increased F&V intake in high school aged children, and MyStudentBody.com/Nutrition, a comprehensive online program to promote healthy nutrition and physical activity in college students. All three programs make use of computer-mediated messaging and feedback to personalize, target and tailor relevant health information to the individual and are designed to appeal to each youth segment. The development of these programs included significant input from children, teachers and health professionals to ensure program quality and appeal. Participants will: 1. Learn the latest information on prevention programs in nutrition and obesity and the advantages of using online technology across age groups; 2. Gain knowledge about formative research that engages the target audience and informs program development; 3. Gain knowledge about e-tailoring approaches and messaging for youth and the importance of interactivity as represented by three programs in obesity prevention and nutrition education. Attendees: Those with an interest in e-health promotion initiatives with youth audiences, health professionals and researchers. and product developers. Level of content: intermediate. Prerequisites: none. Audiovisual: LCD, Internet-access Ref: A similar workshop geared toward prevention of eating disorders has been developed for the 2006 International Conference on Eating Disorders, Academy of Eating Disorders, Barcelona, Spain, June 8, 2006, entitled: Decreasing Risk for Eating Disorders across the

Developmental Spectrum: Multimedia Tools for Children, Adolescents, and College Students by Debra L. Franko, Ph.D. and Tara M. Cousineau, Ph.D.

### Determinants of Adolescents' Exposure To An Internet Delivered Intervention

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Purpose: To study factors that determine exposure to an intervention delivered through the Internet. In this context, exposure means that people stay on the website and make use of its functionalities. Methods: A total of 35,104 adolescents filled in the monitoring questionnaire. Three days afterwards, they could obtain their individually tailored feedback. They had to log on, to make use of the functionalities. Multilevel analyses were used to identify what the characteristics are of adolescents who make use of functionalities. Results: In total, 18,732 adolescents (55.7%) logged on to the website and 1,535 adolescents (4.6%) clicked on at least one link to obtain more information or a tailored advice. Those who have a higher intention to change behavior in an unhealthy way are more inclined to click on links with regard to smoking and alcohol consumption. With regard to fruit consumption, those who have a higher intention to change behavior in a healthy way are more inclined to click on a link to obtain tailored advice. Conclusions: With regard to smoking and alcohol consumption, interventions should focus on changing existing intention into an intention to change behavior in a healthy way. With regard to fruit consumption, interventions should enforce transition from intention to behavior. There is still a big gap between logging on and clicking on links, due to hyperlink lay-out and users' preference to stay "on-site".

# The Development and Evaluation of a Miscarriage-related Website for Women and their Partners Following Early Pregnancy Loss: A Pilot Study

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Background: Miscarriage carries for women and partners risks of psychopathology and readjustment. Emotional sequelae are commonly not recognised by health professionals resulting in dissatisfaction with provision of care, including information. The Internet offers a medium for delivering healthcare information tailored to needs of individuals. Hardwick & Mackenzie. 2003 suggested that most existing miscarriage-related websites failed to provide accurate and reliable information when compared with the Royal College of Obstetricians and Gynaecologists (RCOG) guidelines. This study aims to: (i) develop a website tailored specifically to meet the needs of women and partners post-miscarriage, and (ii) assess the feasibility of an adequately powered online randomised controlled trial (with a "preference" option) to evaluate the effectiveness of a web-based intervention to facilitate psychosocial readjustment. Methods: A 14-month pilot study. The design and development of the website met RCOG guidelines, with content shaped by a Needs Assessment Survey. A study pack giving access to the registration site was given to eligible participants. Online consent was obtained with demographic and study details recorded. Baseline assessments were obtained from two online questionnaires, the Hospital Anxiety and Depression Scale (HADS), and the Medical Outcomes Study 36-item Short Form (SF-36). The allocation to either the intervention group (IG) (access to the website) or non-intervention group (NIG) was by a computerised randomised process. A "preference" option enabled a change of group allocation. On completion of registration, participants were then reminded they would be contacted at 3-months post-registration to complete follow-up assessments. Primary outcome related to: (i) methods of recruitment, (ii) willingness to participate, and (iii) acceptability of the randomisation outcome. Secondary outcome related to the efficacy of the intervention at 3-months post-registration (HADS, SF-36) and perceived helpfulness of the website.



Results: Of the 239 receiving a study pack, 61 women and 7 men accessed the registration site. Approximately half were randomly allocated to the (IG (n=34). Of those, 17 (50%) requested reallocation to the IG. Of the participants randomly allocated to the IG, 2 (6%) endorsed their preference to be reallocated to the NIG. At 3-months post registration significant differences in the IG had were observed for six of the eight SF-36 domains as well as the mental health summary score compared with their scores at baseline. These significantly lower scores were HADS anxiety (P = 0.005) and HADS depression (P = 0.001). At 3-months, significantly higher scores were found for the SF-36 domains of "physical role" (P = 0.009), "bodily pain" (P = 0.029), "vitality" (P = 0.001), "social functioning" (P = 0.001), "emotional role" (P = 0.003), "mental health" (P = 0.001), and the "mental health summary score" (P = 0.001). No significant differences were identified in relation to the NIG for the same measurements. The majority of users endorsed the overall helpfulness of the website content. Conclusions: This pilot study supports the feasibility of conducting a multi-centre controlled trial to rigorously evaluate the efficacy of this miscarriage-related website.

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# Telemedicine-Delivered Tobacco Treatment for Rural Smokers: A Pilot Study

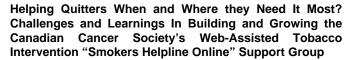
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Background: Rural U.S. smokers have poor access to tobacco treatment. Objective: To conduct a pilot study to assess the feasibility and acceptability of a telemedicine-delivered intervention. Methods: Medical students on rural preceptorships recruited 11 smokers from 3 remote rural primary care clinics. All participants were provided with smoking cessation pharmacotherapy, which was coordinated with their primary care physician. Counselors at an urban tertiary care hospital delivered four counseling sessions via webcam and high-bandwidth telecommunication software to each participant during scheduled visits to their physician's office. Results: We provide interim results here; end of study data will be provided at the conference. Participants were middle-aged (mean age= 44) and mainly female (60%). By the third session, one smoker had quit. Among those still smoking, average cigarettes smoked per day dropped significantly. Participants kept 86% of their appointments at the scheduled time. Counseling sessions lasted an average of 33 minutes. Most (89%) participants reported they would be willing to participate in future telemedicine trials. Conclusions: Smokers and clinic staff were highly satisfied with, and adherent to, office-based telecounseling. We believe this is because telecounseling is novel, is conducted in the physician's office which uplevels the importance of quitting, and because they got to skip the queue for the physician - there was no wait time. Study counselors liked being able to view participants and felt they established better rapport with participants compared to telephone-based counseling. These results supported an application for funds to conduct a large-scale trial of telemedicine for rural smokers. 1) Center for Medicare and Medicaid Services. Medlearn Matters: Smoking and Tobacco Use Cessation Counseling, MM3834. Center for Medicare and Medicaid Services. Available at: http://www.cms.hhs.gov/medlearn/matters/mmarticles/2005/MM3834.pdf. Accessed November 21, 2005. 2) Cronk CE, Sarvela PD. Alcohol, tobacco, and other drug use among rural/small town and urban youth: a secondary analysis of the monitoring the future data set. Am J Public Health. May 1997;87(5):760-764. 3) MMWR. Physician and other health-care professional counseling of smokers to quit--United States, 1991. MMWR. November 12, 1993 1993;42(44):854-857. 4) Glasgow RE, Orleans CT, Wagner EH. Does the chronic care model serve also as a template for improving prevention? Milbank Q. 2001;79(4):579-612, iv-v. 5) Currell R, Urquhart C, Wainwright P, Lewis R. Telemedicine versus face to face patient care: effects on professional practice and health care outcomes. Cochrane Database Syst Rev. 2000(2):CD002098.



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Background: Smoking is a leading cause of death in Canada, yet 5.4 million (21%) of Canadians continue to smoke. Due to their accessibility and 24-hour availability, Web-Assisted Tobacco Interventions (WATIs) have considerable potential to facilitate both cessation attempts and anonymous peer support. The Canadian Cancer Society (Ontario Division) operates and maintains Smokers' Helpline and the Smokers' Helpline Online, an interactive and personalized WATI based on the Stages of Change. The WATI also offers a Support Group moderated by the Smokers' Helpline trained Quit Specialists. Objective: With the growing popularity of anonymous online support, public and private organizations are increasingly offering these services. This presentation will attempt to outline some of the key challenges and lessons learned in offering online support in order to create better practices for managing online communities. Discussion: Smokers' Helpline Online (SHO) was launched on March 31, 2005 as a complement to the traditional telephone counseling offered at Smokers' Helpline. Between March 31, 2005 and March 14, 2006, 2,308 smokers self-registered with the SHO. Self-reported data sets were collected via the Canadian Cancer Society's customized SQL database. Support Group usage patterns were determined via WebTrends® reporting software. Smokers' Helpline Quit Specialists were trained on the use of WebTriage® support software in order to moderate their online support group for smokers. Lessons learned include: - Managing shifting requirements throughout the support group lifecycle, from methods for an initial "seeding" period, through growth and maintenance. - Anticipating special requirements during particularly heavy usage periods, for example the period immediately following the New Year and during the heavily promoted "Driven to Quit Challenge". - Handling non-compliant participation, including strategies for respectfully maintaining a balance between free expression of the often unpleasant experiences and feelings that naturally occur in the quitting process, while maintaining a publicly funded site. The results of the presentation are intended to contribute to the growing body of better practices for establishing and maintaining effective WATIs, and possibilities for applying these experiences to other eHealth programs. Conclusions: There may be significant pressures for staff moderating and managing online support programs that include shifting and specialized requirements, user behaviour, and public profile. Standards should be developed that meet program needs and can be applied consistently throughout the program lifecycle. Staff should be provided with training to assess situations and apply standards, recognizing that a learning curve exists that may require additional problem-solving and management support, depending on circumstances.

### Design, Structure and Growing Dinamics of An Online Website of Consumer Oriented Health News and Education In Spanish

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Introduction: Since may 2000 we have been running a consumer oriented health website based on a general information newspaper [1]. Aims and method: we described the design, structure and development of this website and its relationships with the rest of the online newspaper and the health weekly supplement. Traffic results and analysis of news updating are used to describe the change of paradigm in health information within a national newspaper from an archive oriented website to a front running health section based on internet. Results: a weekly health section has been active on paper since 1991. The



electronic version was first posted online on 2000 [2]. During the following years a new section was created on an annual basis starting with AIDS in 2002 [3], cancer in 2003 [4], pain and tobacco in 2004 and neurosciences in 2005 [5]. A clear growing pattern has been achieved for every section. Due to its connection to a very successful general information website, traffic results for www.elmundosalud.com are higher than other more conventional or monographic online health resources. From 2 editors at the beginning, the web site is currently employing 10 people on a regular basis as well as a number of collaborators as medical experts for the different sections. Revenues come from the pharmaceutical industry in various forms. Independence about contents is guaranteed through a written contract specifying absolute freedom of initiative for the web. The website is permanently updated. Conclusion: Our growth model a viable evolution from a printed version to an online tool which has changed the health information standards within the second largest national newspaper in Spain. Economic stability and sustained growth can be achieved with consumer oriented health information and education online. The business model is based on a general health information resource hosting independent sections with identical cloned structures appearing as soon as independent financial support is recruited for each project. Traffic is guaranteed by the placement of this global resource as an specific section of a general information website.

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# Creation of An Online Joint Project for the Treatment of Tobacco Addiction Between a Consumer Oriented Health Website and a Hospital Based Tobacco Unit

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Introduction: Between november 2004 and january 2006 the online health section of Spanish newspaper El Mundo [1] developed an online interactive tool for the treatment of tobacco consumers together with specialists on nicotine addiction from Hospital Carlos III (Madrid). Starting January 2006 and synchronic with a new restrictive legislation about smoking on public and working places approved by Spanish government, a new site called Vida Sin Tabaco was launched, hosted on web address www.vidasintabaco.com [2]. Aims and method: To evaluate the impact of online program Vida Sin Tabaco on tobacco and nicotine addiction treatment [3]. Since launching we have gathered complete statistics and data from users and specialist involved in the treatment in order to measure the quality of work and its progress. The site has a supporting role to a Tobacco Unit from Hospital Carlos III (Madrid). There are two pneumologist, two psychologist and one nurse from this hospital involved in the online treatment. They check the medical data of the patientes, choose the right therapy and monitor its evolution. They can communicate with registered users through email or even by phone if necessary. There is also one editor from the tobacco section of the health website of Spanish newspaper El Mundo involved in the project. Results: In the first three months, more than 18.000 users registered to Vida Sin Tabaco. A total of 1.353 users quit during the allocated treatment period. There is no follow up information for 1.447 registries. As of March 29th there were 13.835 subjects on therapy. These figures represents an amount of patients almost 15 times higher than the usual number of patients treated in 2005 at the same Tobacco Unit from Hospital Carlos III. Most of the users (14.578) access the online program through Spain. There are patients from 58 countries. Apart from Spain, the geographic region which is more represented is South America (Mexico, 724 users; Chile, 730; Colombia, 298 and Argentina, 293). A partial analysis of 10.164 cases shows that 4.251 patientes where treating addiction withouth drugs; 1.472 users receive nicotine gums; 1.442 received transdermal patches and 559 takes bupropion. The others follow other combinations. Conclusion: Online treatment resource for tobacco addiction Vida Sin Tabaco has expanded significantly the scope of a Tobacco Unit from a Hospital in Madrid from around 1.000 patients per year to more than 15.000 in the first three months since both the site and a new

national law about tobacco use were implemented. With a rigid control from a group of specialist, tobacco online treatment can be administered effectively even to remote populations with Internet access [4].

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### Collaborative Virtual Working Environments for Medical Expertise Sharing

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Background: In several professional and highly specialized contexts there is an increasing need to share, combine and exploit what is deemed "expertise", that is knowledge, methods, approaches and theories, but also studies, discoveries and so on. In a high technological and frenetic society, the common dissemination channels are not anymore sufficient, while innovative Collaborative Work Environments (CWEs) able to provide advanced supporting services for the everyday activity of professionals become essential. The medical domain is particularly starving of "knowledge sharing". Our experience, in fact, revealed that the research initiatives in the healthcare context are mainly focused on "data" instead of "knowledge", i.e. on designing suitable databases of profiles and procedures, as well as defining precise standards and protocols, with the goal to provide interoperability and seamless interaction among the actors operating in this environment. However, there is the increasing necessity of innovative solutions based on the concept Virtual Working Environments (VWE) where distributed, heterogeneous and complementary resources and know-how can be shared and combined with the goal to offer added-value services to the end-users [1-3]. Objective: Medical services should allow, on one side, the patients to be actors of a "Virtual Hospital" accessible everywhere and anywhere to get and provide information, and, on the other side, the domain professionals and decision makers to count on a distributed and reliable platform of services to support their daily activity and the diagnostic processes. Methods: The objective will be achieved by exploiting a wide range of complementary technologies, **GRID** knowledge-based middleware/"upperware" infrastructures, under the technological and business perspective of the Ambient Intelligence paradigm [4], thus achieving interoperability, good performances of the services provided and reliable results, which are typically mandatory requirements especially in the medical context. Results: A CWE framework has been designed and will be tested on selected use cases. This is a knowledge-oriented architecture able to adapt to the characteristics of the specific application context thanks to a multilevel infrastructure: at the lower level, the GRID-enabled middleware guarantees connectivity, interoperability and integration, while at higher level the intelligent middleware can be tailored on a specific application. The efficacy of the proposed solution will be proved by implementing added-value services for supporting advanced diagnostic processes in the cardiovascular field. Conclusions: We propose an ICT architecture implementing a CWE to enable the realisation of a "Distributed Virtual Hospital" accessible everywhere and anytime by professionals, patients, and interested people. The cardiovascular field represents a perfect test-case for the CWE: cardiovascular clinicians, in fact, make wide use of imaging techniques for diagnostic purposes, which usually lead to the acquisition of large image sequences not easy to be examined by the experts. Therefore, the automatic processing of the events monitored represents an important support for the diagnosis. Moreover, each medical centre belonging to CWE might be more specialized than others on a clinical protocol, on a specific examination or on a particular pathology. It is, therefore, desirable that an interactive diagnostic support system for image analysis could exploit the knowledge provided by different centres.

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### Integrated Multimedia Medical Data Agent In E-Health

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1. Introduction E-Health can be viewed as an emerging field in the intersection of medical informatics, public health and business, referring to health services, information delivered through the Internet and related technologies, as described in ([1]). The main improvements the E-Health raises are the improving care efficiencies between General practitioner's (GP), hospitals, and the patients by increasing the quality of clinical communication. Currently, there is increase in demand for remote access and interoperability to the information systems of the hospitals (ISH) that mainly consists of following systems. The objectives of this paper are to address the problems of system interoperability that goes beyond just the information systems connectivity but allow components to share and distribute medical data efficiently internally or externally from the hospital environment. 2. Methods and Results 2.1. Method Previous research on information systems used in hospital tends to divide in two categories: PACS (Picture Archiving and Communication Systems) development and the integration of the information system. Researches in PACS have lead to successful implementations and results. The potential for PACS to communicate with outside network of the hospital environment is desirable and possible with the rapid advancement in Information Technology. Secondly, the system integration has been focused on addressing the structure and development of the integrated system architecture as described in ([2]). In this study, we present a client -server system consisting of web enabled data browser to communicate to a server that consolidates the HIS. The client-server architecture is defined as follows. The server is connected to the various information systems and receives input from these systems that is parsed and stored in the database. The client then queries to this server, extracting the required information. 2.2. Server Application: Multimedia Medical Data Agent (MMDA) MMDA is an agent to the ISH that requires integration with the hospital departments IS to archive interoperability. It acts as a broker, performing an integration service on behalf of all the system components, and as a client-server for web-based medical data browser (MD-Browser) application. In other words, the MMDA consolidates the ISH by indexing all the data used in the ISH. The indexing is performed with an "information shelling" parsing method. 2.3. Information Shelling The method of "information shelling" is for the representation of medical data. This uses the concept of metadata its definition is defined according to IEEE Mass Storage System and Technology Committee's ([3]). 2.4. Client Application: Medical Data Browser (MD-Browser) The client in this client-server system is the use of web-based MD-Browser. This is an image viewing and patient record display application that supports the two most popular Web browsers.

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### Relationship of Participant Engagement and Exposure Measures To Successful Behavior Change In a Web-Based Smokeless Tobacco Cessation Program

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Background: Published research on the use of Web-based behavior change programs is growing rapidly. Web-based programs offer myriad opportunities to unobtrusively measure ways that participants access (expose themselves to) program content. This inquiry can help us better understand ways to encourage program engagement [1] and to guide the development of more effective interventions. Objectives: We examine the relationship between outcome and measures of participant exposure to ChewFree.com, a large two-armed randomized controlled trial of a Web-based program for the cessation of smokeless tobacco (ST; use of chewing tobacco and/or snuff). Methods: Elsewhere we have described the recruitment methods and baseline participant characteristics for the 2,375 ST users who participated in the ChewFree study [2]. Measures of participant engagement (including exposure) were unobtrusively captured from both the Enhanced condition (interactive, tailored, and media-rich Web-based ST cessation program) or a Basic condition control website (static, text-based ST cessation website) including measures of e-mail prompting, participant visits (their number, duration, and pattern of usage over time), and webpage viewing (number of views, types of pages viewed, and Web forum postings) [3]. Additional self-reported measures of participant engagement were obtained at the 6-week follow-up assessment. Point prevalence and repeated point prevalence outcome measures of self-reported tobacco abstinence were obtained at 3- and 6-month follow-up assessments. Results: Participants in the ChewFree.com Enhanced condition made more visits and spent more time accessing their assigned website than did participants assigned to the Basic website condition. In addition, exposure data demonstrated that Basic condition users thoroughly accessed program content, indicating that the condition provided a meaningful, face-valid control to the Enhanced condition. Relationships between exposure measures and tobacco outcome are explored in detail. Conclusions: Our results underscore the utility of carefully measuring program engagement and exposure as predictors of outcome in understanding which participants respond better to Web-based health behavior change programs. This type of evaluation is particularly important for Web-based intervention like ChewFree.com that are purposefully designed with minimal entry requirements in order to reach as many potential participants as possible. This project was funded by The National Cancer Institute R01-CA84225.

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## E-Clinical Trials Supported By a Service-Oriented Architecture

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Background: The complexity of the clinical trial (CT) process involves high investments in the research of a new drug or procedure. In order to reduce costs, there has been a wide development of ICT products, which support various activities within the CT process (protocol authoring [1], gathering and processing of CRF [2], management of patient enrolment). A need of integration and re-use of these eterogeneous products is evident. Objective: In this paper we propose an architecture derived from a business-oriented model and supported by a service-oriented infrastructure in order to achieve greater flexibility, adaptability to new requirements and interoperability between applications, platforms and organisations involved in the entire CT process. Such an architecture can



integrate legacy ICT products, allowing service discovery and composability of existing services in business processes, which provide the CT stakeholders with new, customised services. Methods: We consider the whole CT research as a business [3]. As any other business a CT has its own objectives (i.e. safety and efficient treatment) and carries out a business process that starts with the protocol defintion and ends with the evaluation of CT results. The process uses agents and resources to achieve these objectives, and needs a continuous activity of planning, monitoring, and coordination to elevate its performance especially regarding its objectives. At the base of any process definition and improvement there is a process model. We described such a model in UML [4] and used it to identify small logical units of activity, select those which can be automatised, and expose their interfaces as web services. Finally, the identified services are mapped on a service-oriented architecture [5]. Results: We define a software architecture, which allows interoperability between various organisations partecipating to the CT as well as definition and design of new processes that use existing services to provide new services for customised CTs. Conclusions: A software architecture is proposed as a framework to integrate legacy products used as ICT support of the CT process and improve the adaptability of the whole process to environment changes, usually new requirements and business rules.

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# Using the Internet To Reduce Risk of HIV-Infection In Steady Relationships: A Randomized Controlled Trial of An Online Tailored Intervention

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OBJECTIVES Relationships are a high-risk setting for HIV-infection. This paper describes the development and efficacy-testing of an online theory-based tailored intervention which prepared single gay men to practice safe sex with future steady partners—labeling it the 'cognitive vaccine approach'. METHODS The target was the promotion of negotiated safety (NS): steady partners testing for HIV and reaching agreements to either be monogamous or to only have safe sex outside the relationship in order to have safe unprotected anal intercourse with each other. The intervention content was based on the information, motivation, behavioral-skills model and the intervention was tailored according to knowledge, motivation, and skill-related deficiencies of each participant. Condom use was promoted as the default alternative for NS. Using an online randomized controlled trial we examined the effects of a tailored versus non-tailored version of the intervention. The cognitive effect (i.e. response efficacy, intentions, and perceived behavioral control (PBC) was measured directly after the intervention and, after 6-months, the behavioral effect (i.e. NS and condom use) via e-mail follow-up. RESULTS Online recruitment produced 1013 single gay or bisexual men. The median age was 33 (SD=11.1). Analyses revealed that both tailored and non-tailored interventions increased response efficacy (p <.001), but only the tailored intervention increased intentions to practice negotiated safety and to use condoms with future partners (p <.05). No effect was found for PBC. Follow-up on behavior indicated that the men in the tailored intervention were more likely to practice NS with their new partner (OR=10.50, 95%CI 1.19-92.72). Intentions to practice NS at time 1 mediated the intervention effect on behavior. CONCLUSIONS The online tailored intervention significantly increased NS behaviors at a six months follow-up and rendered the cognitive vaccine approach effective. The motivational component of the intervention seems to have been the most effective one in inducing behavioral change.

# Qualitative Sexual-Health Research Online: Usability and Acceptability of Online In-depth Chat-interviews with Webcameras

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GOAL This study examined the self-reported usability and acceptability of in-depth chat interviews online using web-cameras to study sexual-health behavior and cognitive-behavioral barriers to safe sex among Dutch youth. METHODS Two male and two female interviewers conducted in-depth chat interviews with 104 males and 99 females aged 14-24. Visual contact via web-cameras was maintained between interviewer and interviewee throughout the interview. No audio contact was possible. The majority of participants communicated via their home computer. The end of each interview was dedicated to standardized questions regarding the research experience. RESULTS According to participants, the relative anonymity online and the familiarity of being in their own environment made it easier to answer personal and intimate questions. Seeing the interviewer and the studio environment through the web-cameras reduced feelings of distrust participants usually had for 'strangers' online. In comparison to face-to-face interviews, participants found it easier to give honest answers concerning sexuality during online contact than in the presence of a 'real' interviewer. Time gaps between questions and answers that occur while chatting gave participants time to think, ask for clarifications, and calmly formulate their answers. "Typing things is easier than saying things", commented one participant, and others commented that typed questions were easier to understand than questions presented orally. Participants were concerned whether privacy and anonymity could be guaranteed online. Distrust was frequently noted: "are you really who you say you are?" Finally, parents, siblings or other factors in the interviewee's environment have occasionally interfered with the interview. CONCLUSIONS According to the interviewees, online in-depth interviews with webcameras can facilitate communication on sensitive issues such as sexuality. If issues of trust in the interviewer are properly addressed, the perceived advantages of online interviewing seem to surpass the disadvantages

# Retrieving E-Health Research: The Challenge of Accessing the Knowledge

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Background: Internet-based health interventions have become a viable means for delivering health care and health information to patients. The efficacy of e-health interventions is receiving considerable attention from researchers in numerous fields of inquiry. As part of a larger meta-analysis study, the totality of peer-reviewed publications reporting efficacy studies of Internet-based health interventions published to date were retrieved and analyzed. Objective: To identify the database search term or terms that present the greatest probability of locating peer-reviewed efficacy studies of Internet-based health interventions. Method: This research involves the systematic retrieval and analysis of peer-reviewed publications describing efficacy trials of Internet-based health interventions and the keywords associated with those publications. A total of 28 academic databases were searched using keyword-only, subject-only and full text search options. Searches were performed utilizing the search sequence "Internet AND health AND intervention AND outcome". Articles retrieved were matched against eligibility criteria for the meta-analysis and only studies that met these requirements were retained for inclusion in the study. The keywords stored by the various database suppliers were transferred to a relational database and analyzed for frequency across the study population of literature. The frequency of keyword appearance, composite keyword appearance and journal category was computed for each keyword. Results: Initial search returns utilizing the keyword-only and subject-only search methods were minimal. Full-text searching returned over 1,000 publications that were then manually reviewed for inclusion. After manual review, 161 publications reporting randomized trials of Internet-based health interventions were retained for the final study. Keywords were associated with 128 of 161 articles that qualified for inclusion in the study. A total of 1368 keywords were associated with these



articles. Of the 1386 keywords, 624 were found to be unique keywords. The most common keyword was the key 'human', found in 72 of the study publications. Journal categories spanned nine specific disciplines from cardiac medicine to education. Conclusion: We sought to develop a list of high-value keywords to provide guidance in retrieving relevant e-health intervention publications. Expectations were that a number of keywords commonly associated with the field, e-health, would result from the analysis of keyword data retrieved from the various bibliographic databases. That expectation was not met by the data collected. When total keywords, by category, were further analyzed for uniqueness, interesting information emerged. Specifically, within the category of intervention type, keywords were unique 324 out of 498 times. We believe that this wide range of keyword assignment to a limited number of articles would lead searchers to expend significant amounts of time in accessing the research. Within the scope of this investigation, we found that keyword-only searching was not useful in retrieving e-health intervention study publications. In our experience, using keywords or Boolean logic, returned in excess of 400,000 citations, most of which were not relevant. Although a high percentage of articles within the bibliographic databases (75%) had keywords assigned and a large number of keywords were associated with each article (11), keyword-only searching accounted for zero publications found. Implications for the research community are discussed.

### Information Partnerships for Gateway Websites Panel Session

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Web gateway sites link to information on other websites. The reliability and presentation of health information is important to all users, but there are particular issues for consumers in making informed decisions about their own health care. To ensure the quality of information, gateway owners may set up information partnership agreements with the source website owners. How well do these agreements achieve their aims? Can quality be assured without a formal agreement? The panel members will describe the partnership models considered and used in the UK's NHS Direct Online, the Canadian Health Network and Australia's HealthInsite. A review of other health gateway websites in Australia, Canada, the US and Europe will be presented, looking at how each gateway sources information from other agencies and how quality assurance is maintained. Specific topics to be explored will include: the credibility of gateway websites and the value of government support or management; the quality assurance processes used by different gateways and other accreditation agencies; levels of quality assurance for different types of information; levels of quality assurance for different audiences (consumers, health professionals and others): developing partnership agreements and trust between the gateway owner and partner site owners or other information providers; supporting community organisations to meet quality standards; and maintaining quality assurance as websites change. The session will conclude with some real case scenarios of the challenges faced by website owners in maintaining acceptable quality within tight budgets. The audience will be encouraged to contribute ideas on prioritising quality criteria and to discuss the risks of compromise either by gateway sites or by partner sites.

### A New Model for the Promotion of EHealth

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Introduction Preventing or delaying illness and death from chronic disease is possible [1]. Many of these diseases can be prevented or ameliorated through education that encourages behaviour changes [2]. New Information and Communication Technologies (ICT) tools and applications are also seen as having a potential to support an enhanced access to health information in general and indeed, to the health system itself in particular [3]. Characteristics such as

the tailoring of messages, instantaneous feedback, appeal or engagement are potential advantages that can provide and that may be of enormous benefit to attain behaviour change. Methods This paper proposes a new model that provides assistance in understanding the reasons why individuals would accomplish and maintain a healthcare change in their lifestyle by means of new ICT. Achieving a lifestyle change by the use of new technologies is a multifold issue that can be broadly addressed by analysing, in parallel two dimensions: the individuals' attitude towards their health condition and their approach and readiness to monitor and change their attitude by the use of ICT. Tailoring both the channel and the content of the message has proven essential for persuading individuals to change their health behaviour [4]. In order to personalise information, a well-known methodology was followed [5]: Results Our work has been to conceive and develop a model that explains the different stages the user is at both in terms of the perception of healthcare and of the use of technology to perform any desired or recommended change. In order to place the user at each dimension a set of questionnaires were designed and implemented. These questionnaires assisted us in understanding what personalised information needs to be provided according to the stage the user is at as well as to other variables (such as age, cultural background, etc). The novelty of this model is that it proposes a general framework that may be applied to the conception, design and evaluation of any e-health application. Moreover, it can be applied to different application targets (medical informatics, public health informatics, etc) and to different audiences (healthy individuals, patients, professionals, etc) as it proposes an enhanced user modelling process by taking into account both healthcare behaviour aspects as well as technological issues, which up to this moment, have not been taken into account and may be part of the explanation of e-health uptake failure in the healthcare field. Discussion The application of this model promotes the empowerment of the individuals by providing tailored information, as well as guidance, monitoring, through ICT and it will certainly make an impact on health-related behaviour. Besides, it will allow understanding some of the reasons of the success or failure of different e-health platforms. Overall, this model is likely to provide deeper insights into the process of improving e-health so it can meet ongoing individuals' needs and become an increasingly valued part of health care services. The validity of the model has been tested on expert individuals and evaluation results are presented in this paper. [1] World Health Organisation, 2005. Facing the Facts: solving the chronic disease problem. [2] U. S Department of Health and Human Services. The Health Benefits of Smoking Cessation; centers for Disease Control, Centers for chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 1990. Report No (CDC) 90-8416. [3] The Euser Project. eUser -Workpackage 1: Conceptual and Analytical Framework. D1.1: eUSER Conceptual and Analytical Framework (Part A and Part C). European Commission, 6th Framework Programme. Contract number: IST-2002-507180. [4] Kukafka, R., (2005). Tailored Health Communication. In consumer Health informatics, Editors, Lewis D., Evsenbach, G., Kukafka, R. et al. Springer, 2005. ISBN 0-387-23991-x. [5] Kreuter M., Farrell D, Olevich L, et al. (2000). Tailoring Health Messages: Customising Communication with Computer Technology. Mahwah, NJ: Lawrence Erlbaum, 2000.

# Internet-Based Quality Control of Cervicovaginal Screening In the Region Friuli – Venezia Giulia

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Part of the quality assurance process in Pathology is carried out through aptitude tests made usually on glass slides, which should be examined by the subjects and their answers should then be compared with the consensus diagnoses of an expert panel. This is in turn achieved by making glass slides circulate among Institutions, or by gathering together people to be examined in sessions occurring during Congresses or seminars. Examples of the cited approaches are the NEQAS UK breast screening scheme and the European QUATE aptitude test. In Italy, healthcare quality assurance is carried out at regional level, under the control of the regional Healthcare System. Unfortunately, glass slides are unique and fragile, thus it is difficult to have the people examined on the same material, in particular when it is of cytologic kind. A solution comes with digital pathology: as digital slides can be replicated and distributed through networks or removable media, they could overcome the glass slide uniqueness and fragility



(Demichelis 2002). In 2004, the Healthcare Authority of the Region Friuli -Venezia Giulia started an explorative action to evaluate the adoption of digital slides into their cervicovaginal screening programme. After a preliminary feasibility experimentation (Della Mea 2006), a programme has been set up in order to: i) acquire 30 PAP test slides selected from the regional archives; ii) train to the use of digital slides about 40 cytotechnicians in six regional cytopathology laboratories, by means of a training slide set; iii) ii) distribute 25 digital slides on DVD-Rom for the sake of performance; organize a regional meeting to compare digitally obtained results to consensus data. Slides were acquired and viewed with a previously developed software (eSlide), which during the programme has been also further developed. During the programme, problems arose regarding computers and monitors available in the laboratories (old, without DVD readers), so that while traning has been correctly carried out, the full quality assessment round has still to be made, waiting for an upgrade. However, cytotechnicians acceptance and interest after training was good, so that we are confident in an effective adoption of the technology, which will be also used for quality control on breast histology.

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# Access To Quality Information On Bioethics In Italy: An Analysis of Available Internet Resources

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Background: Bioethics is an intensely discussed issue in Italy both in public debate and within academic and government institutions. Access to reliable and up-to-date information is essential in this field and the availability of information tools can ensure the exchange of knowledge and ideas, encourage moral reflection on medicine and scientific progress, and stimulate research in relevant areas [1]. Internet plays a key role in disseminating information and in the process of communication between citizens and governmental agencies. Accordingly, the Italian Parliament has recently passed several important laws which are qualifying Italy as one of the most advanced countries in the field of e-government. Nevertheless, while Italian e-government policy, has been focusing attention on online interactive services, it has at times neglected the objective of making public sector information available in a simple, efficient and consistent way. Public information is scattered over many different websites, and it is therefore often difficult to find [2]. Objective: a. To provide, in view of a future European network, a directory of Italian Internet information resources on bioethics that is similar to that provided by foreign institutions in their countries [3, 4]. b. To analyze the quality of government, academic, educational and non-governmental organization websites in terms of accessibility, usability, accuracy and exhaustiveness of information. The analysis was carried out according to the general principles proposed by MINERVA, a European network set up to create an agreed common platform for digitisation of cultural and scientific content [5]. c. To verify web availability of full-text documentation such as laws, guidelines, position statements and reports, and of information tools such as databases, glossaries and e-journals. Methods: A survey was carried out by means of a questionnaire sent to ethical committees of hospitals and local health authorities, and to other related institutions in order to verify their information sources. A web search was performed using the main search engines and exploiting advanced search options (i.e. searching the Italian term for bioethics in the title of pages, selecting only Italian language websites, finding pages that provide links to other significant pages). Results: a. Design of a dedicated website (SIBIL - Sistema Informativo per la Bioetica In Linea - Online Bioethics Information System), linking to relevant Italian quality informational and educational resources. b. An analysis of the identified websites showed that: 41% are official websites, 11% are academic or educational and 48% belong to non-governmental institutions. Significant information is concentrated on public source websites (67% of databases, 100% of terminological tools such as thesauri and glossaries). Compliance to accessibility regulations is incomplete for almost 90% of websites, of public or non-public origin. c. 94% of public source websites include the full-texts of laws, opinions and other documents. All specialized bioethics journals are of non-public origin and 100% of them have a website with a table of contents and abstracts. Only 14% of the articles are open-access. Conclusions: The majority of ethical

committees (65%) are located in the Northern and Central Italian regions, while 81% of clinical trials occur in the same areas. Results of our questionnaire showed that only 9.6% of responding centres have the possibility of consulting fee-based electronic resources [6]. Internet and open access documents are therefore a key resource, especially for those regions where the information infrastructure is inadequate.

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# Open Peer Review and New Measures of Journal Status: Is the ERevolution In Biomedical Publication Moving forward Or Back?

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This panel will debate recent developments brought by the eRevolution in Biomedical Publication. Part 1: Open Peer Review Pro: Dr. Ellis will outline how open peer review for all medical and scientific literature is now possible using www.journalreview.org. He will argue that open peer review benefits readers, authors, editors and publishers. Con: Dr. Dellavalle will highlight the potential pitfalls of open peer review such as the inadequate screening of commenter credentials and statements, and the benefits that confidentiality provides the peer review system. Part 2: Impact factor vs. y-factor Pro: Dr. Bollen will argue for replacement of impact factor by a novel measure of journal status--the y-factor which accounts not only for frequency of citations but also (analogous to Google's page rank algorhythm) for citation quality.1 Con: Dr. Dellavalle will argue the merits of maintaining the use of impact factor for judging journal status.

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### Internet Based Smoking Cessation Programmes: Examining Smokers' and Ex-smokers' Attitudes

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Background: Internet is a useful medium for delivering services to the wider population. Very few studies have examined the efficacy of smoking cessation programmes delivered via the Internet [1, 2]. To our knowledge, no studies have examined smokers' attitudes towards these services. Objectives: The study aimed at examining smokers' and ex-smokers' attitudes towards web-based smoking cessation programmes and resources. The objectives were to determine the influence of age, gender, ethnicity, severity of dependence, and experience with personal computer and the Internet on attitudes toward web-based smoking cessation programmes; and to identify a profile of smokers that could benefit more from this type of intervention. Methods: Participants were students and



staff of St. George's, University of London - UK. They were recruited internally via email messages. Consenting subjects were redirected to a purpose-built website: www.quitsmokingonline.info. The anonymous 30-item dynamic online questionnaire included the Fagerstrom Test for Nicotine Dependence [3] the Computer Attitudes Scale and the Web Attitudes Scale [4]. Wandsworth Local Research Ethics Committee gave approval for the study. Results: 226 people completed the questionnaire. They were: 70% female; 83% White; and 52% students. The average age of the sample was 32 years (SD 10.5). The average time for completing the questionnaire was 344 seconds (SD 377). The majority (61%) of the sample were ex-smokers, 23% were smokers who wanted to give up, 9% were smokers who wanted to cut down and 7% were smokers who did not want to give up. About 20% (n = 44) of the sample reported using the Internet to find out how smoking was affecting their health, with more than 90% of these reporting that they have found the information useful. A larger proportion of current smokers (68%) than ex-smokers (30%) reported that the Internet was a useful stop smoking resource (x2 = 30.4 df = 1, p < .001). Age, gender and experience of using the Internet had no influence on willingness to use the Internet as a tool to stop smoking. Conclusions: Identifying a profile of subjects with positive attitude can prove useful in developing targeted online stop smoking services.

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# Searching the Internet for Drug Related Websites; Analysis of Online Available Information On Ecstasy (MDMA)

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Background: The emergence of the Internet as an unregulated source of controlled substances is an important development that may have significant public health implications [1-4]. Although the Internet is an essential source of information on MDMA [5], no studies have addressed the issue of what is available to the average web user in terms of information on MDMA. Objectives: Our study aimed at identifying, developing and evaluating a reliable methodology for sampling the Internet for relevant information related to MDMA and to provide a description of the type of information available. Methods: This study investigated 280 web pages generated by two search engines in running queries for MDMA (ecstasy). Such queries were carried out in English using a single generic keyword (MDMA) on a week in June 2003 to overcome the problem of the ever changing and expanding nature of the Internet. The Google<sup>TM</sup> and AltaVista<sup>TM</sup> search for MDMA (ecstasy) related websites respectively provided a list of 71400 and 48747 webpages. The first 100 websites identified by both search engines, together with a further random sample of 5% of the remaining sites (101 to 1000) were fully assessed. Since Google™ displayed less than 1000 webpages, the snapshot overall counted 280 web pages. Results: Of the 280 webpages links (ie, 145 from AltaVista  $^{\!\scriptscriptstyle TM}$  and 135 from Google<sup>TM</sup>), 23 (ie, 17 identified by Google<sup>TM</sup> and 6 by AltaVista<sup>TM</sup>) were offline or with restricted access at the time of their assessment, thus reducing the sample to 257. Overall, we identified 49 (19.1%) irrelevant websites (25 with Google<sup>TM</sup> and 24 with AltaVista<sup>TM</sup>). Only Google<sup>TM</sup> showed a statistically significant difference between relevant and irrelevant websites' ranking, having the former an average value of 80.69 and the latter a value of  $142.32\ (t116 = -2.55,\, P < .02).$  In considering the first  $100\ results$  within each search engine, both Google<sup>TM</sup> and AltaVista<sup>TM</sup> produced 18 duplicate links. Moreover, thirty-three out of 164 websites were quoted by each search engine and 49 websites were unique to each search engine. The ranking of these 66 (33 per search engine) websites, in comparison to those 98 (49 per search engine) unique websites was significantly different (t162 = -6.315, P < .001), having the common websites a lower ranking level (37.3) compared to the others (63.3). Regarding websites' position towards drug use, 50.4% were anti drug, 16.2% harm reduction and 24.8% pro drug. The MDMA pro drug websites showed a lower ranking (mean = 40.34; SD = 32.5), hence appearing significantly earlier in the results' list, than both the anti drug (mean = 55.0; SD = 26.6) and the

harm reduction (mean = 54.25; SD = 22.9) websites (F (3; 159) = 3.288; P = .022). Conclusions: This study represents the first systematic analysis of the information available online on ecstasy. Health professionals may need to be aware of the web being a new drug resource for information where pro drug use messages are more likely to be encountered by web users.

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#### **Enhancement of Organ Donation By Internet Education**

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The internet is a powerful tool capable of enhancing both individual and population health. One critical area in population health is the under-supply of volunteer human organ donors. Each day, 18 people die due to a shortage of donated organs. Each donor could potentially save the lives of eight people on wait lists and enhance the lives of up to 50 others. 90,000 individuals are on wait lists for organs. This abstract will present useful medical websites that further the goals of enhancing public awareness of organ donation and the critical shortage of organ donors. www.transweb.org/journey is a web site targeted at teenagers to increase donation knowledge, pro-donation attitudes, and behaviors associated with the choice of being an organ donor. It uses a site that offers information on organ donation and has links to a statewide donor registry. It is a comprehensive, easy to navigate, multi-media enhanced web site offering the choice of dial-up or broadband connectivity. The dial-up option is without audio, but still very effective. www.organtransplants.org is a web site offering education on organ donation in three areas. The first offers nine different vignettes of real life donor families and recipients. It is a very polished and well produced site that weaves potent real life tales with still pictures of the parties and personal audio narration by donors, families and recipients. It includes buttons that allow emailing stories to recipients, or to download a donor card. The second major part of the site allows for interactive body exploration, learning about brain death and how organ and tissue donation restores lives. Effective flash animation allows for well-written explanations of 6 organs and 7 tissues commonly transplanted. In other sections, transplant waiting lists are explained; and brain death is illustrated with useful images of cerebral blood flow in life and brain death. Important explanation of the impartiality of brain death criteria is given. Comprehensive UNOS data reports allow for viewing organ donation data by centers, states, regions or nationally. A section on questions and myths is especially useful. Another area explores the history of organ transplantation. The third major section of the site contains a wealth of educator's resources. It presents an opportunity for young people to explore health literacy, technology, the science of transplantation, quality of life issues, and the rights and responsibilities of citizens. 5 stories of donors and waiting recipients are portrayed. In 'A mother grieves and gives,' personal audio narration by the mother of an accident victim gives an emotional and revealing look at a mother's passage to acceptance of her son's brain death and her ultimate decision to donate. Further interviews show the perspective of nurses, doctors, and the organ transplant coordinator. The vignettes are powerful and professionally produced windows into the world of donors' families and recipients. For educators, this section offers activities and lessons available by age group for download. These sites are but a sample of sites available for better promotion of organ donation and public health using the effective medium of the internet.



### **Comparing Male and Female Cancer Patients Experiences Using the Internet**

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Background: While there are a multitude of cancer-related web sites available, little research has been done to understand the practical knowledge of patients using the Internet for cancer care or to compare male and female patients' experiences. One study of female cancer patients [1] indicated useful components of the Internet. Another study of frequent Internet users described gender differences in Internet use [2]; however, these participants were not currently dealing with a cancer diagnosis. A study of Internet cancer support groups [3] described gender differences in online responses whereby the women sought encouragement and the men focused on information seeking. Additional research into the meaning of Internet use for cancer care will offer additional insight into the specific needs during an illness as well as the gender-specific communication style and preferred content. Objective: The purpose of this study was to gain an understanding of the similarities and differences of male and female oncology patients' experiences of Internet use for cancer care through phenomenological interpretation of their narrative stories. Cancer care is defined as information and support to manage the self care aspects of illness and treatment including symptom management. Methods: Heideggarian hermeneutics was the interpretive approach used to gain understanding of human experience through analysis of narrative stories of 20 female and 15 male cancer patients. Patients were recruited by oncology nurses and had a variety of cancer diagnoses. Participants were individually interviewed and asked to tell stories of Internet use. The interviews were audio taped and transcribed providing data for interpretive analysis. The seven-stage hermeneutical process [4,5] was used for interpretation. Results: Similarities included: 1.) Using Internet for seeking information about disease and treatments. 2.) Gaining self-care information regarding symptom management from a variety of web sources, 3.) Redefining patient/provider relationships. 4.) Reading online patient stories. Differences included: 1.) Men planned information searches and at times accessing their networks for advice, while women use their computer savvy support networks to help filter the information, 2.) Differing views of patient/provider partnership whereby men focused on the politics and women focused on support. 3.) Men focus on problem solving whereas women focused on learning ways to live with cancer as a chronic illness instead of death sentence 4.) Women primarily used online peer support for encouragement and friendship whereas men read online stories to determine possible solutions to problems. 5.) Differing views of complementary and alternative medicine approaches. Conclusions: Gender differences reflect subtle differences in focus and a variety of approaches to the diagnosis including information sought and communication style which informs health care providers of the importance of considering these differences when preparing educational materials and recommending websites.

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### Effectiveness of a Web-based Smoking Prevention and Cessation Intervention for Adolescents

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Background: Although computer tailored smoking cessation and prevention interventions have been proven successful in Dutch adults and young adolescents [1, 2] a web-based tobacco control tool for older adolescents (15-18 years old) has not been developed and evaluated in the Netherlands so far. Objective: The aim of this study it to evaluate the effectiveness of the web-based computer

tailored smoking prevention and cessation intervention 'Smoke Alert' Methods: Participants filled out a questionnaire on the Internet, measuring smoking behavior, attitudes towards (quitting) smoking, social influences, self-efficacy, action plans and intention to smoke or quit smoking. Based on their answers adolescents received a personalized advice about (quitting) smoking. Adolescents were randomly assigned to one of three conditions. One condition received advice through the Internet. The second condition received advice per letter and the third condition served as a control condition, receiving no intervention. Within six moths adolescents in the experimental groups received two tailored boosters. The advices focused on resisting social influences to smoke, enhancing self-efficacy and forming action plans. A follow-up measurement was held six months after baseline. Results: Since the launch of the Smoke Alert website in March 2005, 2,746 adolescents filled out the baseline questionnaire. 26.8% of these adolescents were smokers and 25.8% of these smokers intended to quit within 6 months. The most common action plans were to inform friends about a quit attempt and to remove all smoking materials from the environment. The results of the effectiveness trial will be presented and discussed at the conference. Conclusion: Since computer tailored tobacco control interventions have been proven successful in adults and young adolescents, Smoke Alert is a promising intervention for older adolescents. 1. Ausems M., et al., Short-Term Effects of a Randomized Computer-Based Out-of-School Smoking Prevention Trial Aimed Elementary Schoolchildren. Prev Med. 2002 Jun;34(6):581-9. [tp/www.hihmhgventex.puyfg/tml-Raise&cb-phmellchpt-Abstal&lt\_uit=125007&cpuy\_l1=21&ito1-phmel\_cheam] 2. Dijkstra, A., et al., Tailoring information to enhance quitting in smokers with low motivation to quit: Three basic efficacy questions. Health Psychol. 1998 Nov; 17(6): 513-9

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# Community Approach To Internet-based Early Intervention Systems

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Hamburg as a Federal state of Germany and metropolitan region has decided to implement a internet-based early intervention system as part of an overall addiction prevention and early intervention strategy. Based on data analysis that shows how long it takes before anybody with a addiction related problem enters the help system for the first time a new portal is being introduced to the public together with a regional campaign focusing on moderate consumption patterns and harm reduction. The portal follows two complimentary strategies. At the one hand it takes into account all the possible reasons for not getting in touch with the help systems - and tries to undergo them by following the TTM principles developped by Prochaska and Di Clemente and by offering respective services: Information about help services available without preliminarities, self-help-groups, help services for special target groups or issues (eating disorders, gambling, smoking - children/women/young people), online tests, hotlines, online councelling and self-management programs. All information is made available and searchable in multiple ways but with special focus on location and time search. Special focus was also put on the acessability of information: The portal follows the standards - based on WAI recommondations - for German eGovernment services not obligatory in the state of Hamburg. The next step is the development and implementation of gender-related modules. On the other hand the system is interactive and involves all (over 350) institutions in the field by giving them access to their own data. This is considered to be necessary in order to achieve a high rate of accurate up-to-date data. Date of input/update and name of the person responsible for the data are public. The implemented user-tracking will be used to identify the chosen ways on the portal and can be combined with test results to user profiles. In future this analysis and the research into gender-specific approaches will all be used as stepping stones towards a semantic web approach integrating all webservices in the field for the region.

### Cancer Won't Wait: Implementing EHealth In the New Europe

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In recent years countries of the European Union have grappled with policy and health systems reform towards the goal of building a system of personalized,



high-quality, responsive and citizen-centered care. In particular the use of information and communication technologies (ICT), or eHealth, has been promoted as key to realizing this future. But while governments and the news media publicly hail eHealth and its progress in many settings in Europe, what is the reality once the cameras are gone? How do policies, practice and technology measure up? This case study tells the story of an elderly man in a small town in Lithuania and the efforts by his family and doctors to obtain a qualified second opinion in the treatment of his relentless cancer. Spanning 3 generations, 4 languages and 3 continents, this case highlights the profound impact of ICT in bringing together families, medical traditions and cultures of care across the world and reveals the challenging path ahead to implementing eHealth in the new Europe.

#### **Centers for Disease Control and Prevention (CDC)**

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Standing exhibit of some of CDC's current success stories in eHealth campaigns and the use of interactive technologies for motivating behavior change. Materials from research project in a variety of areas will be provided, including podcasts, RSSS feds, and online applications for health education. An interactive display of possible future applications for communicating health information electronically will also be included. CDC representatives will be on hand to discuss eHealth at the agency.

# EHealth As a Tool for Process Improvement: Research Agenda

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Background: In Finland, as in other western countries, demographic factors such as the aging of the population, and the increase in diabetes-related illnesses have become most challenging issues for the healthcare system. Thus, new system innovations are needed. Previous research supports the use of a care process view in the development of healthcare service provision and eHealth applications in particular [1]. Past research also shows the potential of eHealth solutions in decreasing the work load of caregivers and increasing patient motivation [2-4]. Objective: The goal of our current research is to develop, pilot and measure an eHealth system for supporting the care process of patients with type II diabetes in order to improve the availability of healthcare services, customer satisfaction, and efficiency of the production system. Methods: The research has started with a comprehensive analysis of the entire care process (type II diabetes) in order to understand what are the current workflows, volumes and resources used, and also what kind of an effect new eHealth-based solutions could have on the care process. Based on this analysis, a new care process will be constructed with eHealth applications of those parts of the process to which it is suitable. The required changes in workflows will also be identified. Results: Our research will result in a model on the effects of eHealth on resource use (the changes in volumes and necessary resources in the process change) and on goal achievement in the care process (i.e. the effectiveness of the eHealth solutions used). Conclusion: The research will aid healthcare organizations in the recognition of care process parts suitable for eHealth solutions and in achieving a fit between these solutions and the care processes of which they form a part.

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### Open Peer Review of the Medical Literature

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In medicine there is often a disconnect between clinical practice and the scientific evidence. The scope is far reaching, involving all fields of medicine. The problem is related to the shear volume of medical literature as well as interperating and applying its data. In academic settings, journal clubs are often established to review the current medical literature. There are several shortcomings of traditional journal clubs; First, extensive time must be dedicated from already busy schedules. Second, logistics dictate that most participants will be from one area and similar medical background, thus limiting varying points of view. Finally, important discussion which may impact clinical interpretation of a study is rarely disseminated outside of the "club". Here we review and analyze the scope and efficacy of a working model of an asynchronous international journal club. We expect that this model will lead to improvements in the accurate interpretation of clinical research, and thereby improve patient care. It will stimulate discussion amongst health care teams of the world, and may influence future research. This dialogue also stands to help regulatory agencies and the media to better understand the strengths and weaknesses of specific clinical trials, and thereby shape more educated policies. A demonstration of the model and actual examples of how it might impact health care will be reviewed.

### **Outcomes of Teledermatology Evaluation Studies**

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Background: Dermatology is especially suitable for telemedicine consultations because of its strong visual aspects and relatively low number of urgent cases [1]. In this study, we focus on teledermatology defined as the use of imaging and telecommunication technologies to provide skin services by a dermatologist to another health professional (general practitioner, nurse, other specialist) or directly to a patient. Various evaluation studies have been performed to explore a variety of clinical and non-clinical outcomes related to telemedicine and teledermatology [2;3]. Objective: Aim of this study was to provide an overview of the outcome measures (clinical and non-clinical) used to evaluate teledermatology, their measured results and study characteristics in which they were evaluated. Methods: Published original teledermatology studies were identified by searching in the Medline database (up to April 2005). Literature reviews, comments, abstracts, letters and editorials were excluded. Papers which were not about dermatology and papers where the evaluation of a specific teledermatology service was not a main aim of the study were excluded. Two reviewers selected and read the papers independently and filled in a semi-structured form about study characteristics (number of patients, study design etc.) and clinical (i.e. number of preventable referrals) or non-clinical (i.e. quality of images) outcome measures. Results: The literature search resulted in 345 unique references of which 101 studies were included and 244 excluded. Most of the excluded papers did not report on an evaluation of a specific teledermatology service (n=91). Fifty-two of the excluded papers (21%) were about another specialty (radiology, pathology) or about all kinds of medical conditions including dermatology as a subset but without separate results reported. Finally, 101 studies remained included for further analysis. In 52% of the studies diagnostic accuracy (agreement telediagnosis and gold standard diagnosis) was investigated. Most studies compared telediagnoses to face-to-face diagnoses, but there were also studies using biopsy or histology as gold standard. Mean diagnostic accuracy was 73%, varying between 41% and 98%. An obviously important outcome measure for teledermatology, quality of images, was studied in 19 studies. Patient satisfaction with teledermatology was studied in 20 studies (20%) where doctor satisfaction was explored in 15 studies. In four out of ten randomised controlled trials (RCTs), the number of preventable referrals was explored. The number of preventable referrals varied from 18.5% up to 82% as different methods in different settings have been used to investigate this outcome measure. In the remaining six RCTs, costs were the main evaluation aspect. Two RCTs have shown that teledermatology was not more cost effective than the conventional care. One study showed in an RCT setting that store-and-forward teledermatology was cheaper but less clinically efficient than real-time teledermatology. Conclusions: Our review shows that diagnostic



accuracy is the most popular outcome measure in teledermatology. Possible explanation for repetitive evaluation of this aspect is the changing technology (digital camera) used in teledermatology. It appears that few RCTs performed in teledermatology are mostly interested in cost-benefits aspect. A clinical outcome as number of preventable referrals is scarcely and diversely measured.

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#### Better Evaluation Studies In EHealth and Telemedicine

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Tutorial proposal Better evaluation studies in eHealth and telemedicine J.C. Wyatt, Professor of Health Informatics, Health Informatics Centre, University of Dundee, Dundee, UK j.wyatt@chs.dundee.ac.uk N. Eminovi, research fellow Dept. of Medical Informatics, Academic Medical Centre, Amsterdam, the Netherlands n.eminovic@amc.uva.nl 1 Abstract Many studies have been performed on eHealth and telemedicine systems using a variety of clinical and non-clinical outcome measures and different research designs, to gain scientific evidence for the benefits of these tools. Although there are strong indications that telemedicine and eHealth are useful, and in some countries telemedicine is already implemented in routine care, there is still little valid scientific evidence for its benefits. Systematic reviews have shown that the main reason for this is the low quality of the evaluation studies. Evaluation studies in telemedicine and in health informatics in general - are often difficult to design and perform. Nevertheless, health policy makers, clinicians and patients, let alone lawyers and tax payers, will require evidence from well designed and performed evaluation studies prior to its integration into routine care. Depending on the specialty and goals of the eHealth or telemedicine system, different outcome measures are important. In visually oriented specialties such as dermatology and pathology, the diagnostic accuracy of the digital images is usually first examined, but even here, various approaches and types of analysis have been used. In the first part of this tutorial, existing literature on evaluation in telemedicine will be discussed with an emphasis on teledermatology. The pros and cons of various outcome measures will be explained with examples from the literature. In the second part of the tutorial, the full range of evaluative approaches that can be applied in telemedicine and a wide range of questions that carefully-designed evaluations can address will be presented. This part of the tutorial will be based on a textbook by Wyatt and Friedman (Evaluation Methods in Biomedical Informatics, second edition, 2005) and illustrated with our experiences from designing and performing pilot studies for the English NHS Direct service and a multi-centre cluster randomized controlled trial in teledermatology. 2 Educational goals By the end of the tutorial, participants will be able to: 1. Describe the most useful outcome measures in telemedicine and how to measure them 2. Define the aims, process and role of evaluation within the field of telemedicine and eHealth. 3. Identify and develop specific evaluation questions appropriate to a telemedicine or eHealth project. 4. Critique quantitative and qualitative evaluation studies with attention to measurement issues and demonstration study design. 3 Who should attend The tutorial is appropriate for anyone interested in eHealth and telemedicine, and is essential for anyone designing, carrying out or critically appraising evaluation studies. 4 Level of content (basic, intermediate, and advanced) 80% basic, 20% intermediate 5 Prerequisites There are no formal prerequisites. However, participants should have a general familiarity with the field of biomedical/health informatics, eHealth or telemedicine. Participants might benefit more if they have some familiarity with basic statistical concepts such as standard deviation and correlation. 6 The name of a reference from an organization that has previously sponsored the same or another tutorial of similar duration by the instructor? The first author has presented a generic version of this tutorial at AMIA Fall Symposia; AIME and MedInfo conferences 7 list of audio-visual equipment (incl. Web access needed?) - PC - Projector

### **Healia Health Search Engine**

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Consumers are increasingly responsible for health decisionmaking. Eighty-one percent of online "healthseekers" use a search engine first to find health information (Pew, 2005), but only 16% report being able to find the information they are looking for (Jupiter Research, 2006). People have difficultly finding high quality and personally relevant health information because the major search engines provide many generic hits, which are often of questionable quality. Poor quality information may result in inappropriate health decisions, unhealthy behaviors, wasted clinician time, and reduced worker productivity. Healia (www.healia.com) is a significant advancement in consumer health search technology. The search engine provides high quality and personalized search results and unique health search functionality. Healia's innovative technology is far superior to other search engines for health queries because it: • Provides only high quality results through patent-pending algorithms that access quality. In an independent, blinded trial, physicians at a major university rated Healia significantly higher than other health search engines in the overall quality of health search results. • Employs sophisticated semantic analyses of search queries to suggest alternative search terms allowing users to search more intelligently. Semantic technology is also used to customize the search results so that the most appropriate resources are displayed. • Allows users to quickly filter search results to get individually relevant results. Healia uses unique algorithms to identify Web pages that match specific content types, user preferences, and audience profiles such as by gender, age, and racial/ethnic background. • Expands existing Web applications including electronic health records, decision support tools, and health portals, by seamlessly integrating Healia's search technologies through Web services. Users can search within any Web application. • Provides rapid implementation, ease-of-use and no maintenance through an ASP (hosted) model. Healia is currently seeking partnerships with Web publishers, health organizations, employers, and other organizations that are interested in providing high quality health information to their Website visitors and other constituents. Advertising-supported and advertising-free versions of Healia are available and can be customized to fit the needs of any partner. Healia is a highly customizable and robust health search solution when the quality and relevancy of results counts. Healia was developed under a multiyear Small Business Innovation Research (SBIR) award from the National Cancer Institute, the premier cancer research agency of the United States. Healia, Inc. was founded and is led by business and health professionals with decades of experience in public health, healthcare, health communication, computer science and information technology, and business.

# The Use of Remote, Centralized Raters Via Videoconference In a Multi-site Depression Trial: A Comparison To Site Based Raters

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OBJECTIVE. Rating fidelity may be improved by the use of a pool of centralized, independent raters who are not associated with investigative sites. Several reports have suggested that using different raters at baseline and endpoint in each patient improves signal detection. Two-way videoconferencing has been proposed to make centralized rating practical, in that a rater can be chosen from a pool of available raters without concern for the physical location of rater or patient to be rated. A central rater who has never rated a given patient before can be chosen to rate the patient at the conclusion of the patient's participation in a clinical trial. A central rater can be unaware of whether a patient to be rated is being considered for, continuing, or completing participation in a trial, and can thus be blind to study design (including intake criteria) and current visit, as well as to treatment given, laboratory test results, and adverse events reported by the patient. We report here on a comparison between site and centralized Hamilton Depression Rating Scale (HAMD) ratings in a two-center depression trial. METHOD. Patients were interviewed twice at each of three time points: screening, baseline, and endpoint, once by the site rater, and once remotely via videoconference by a centralized rater, who was blind to study visit and design (site raters were not blind to study visit/design). Raters were blind to each others' scores. A counter-balanced order was used at baseline and endpoint. All raters used a structured interview guide. Patients had to have a HAMD 17-item total score >= 17 at screening, and again at baseline in order to continue in the study. There were 7 raters in the centralized rater cohort, and 4 site raters (2 per site). Centralized assessments used unique raters at each visit, while site ratings generally did not. RESULTS. Site HAMD scores were significantly higher than centralized raters scores at screening and baseline, but not at endpoint. Correlations (ICC) between site and centralized ratings at screen and



baseline were .33 and .40, but improved to .75 at endpoint. Internal consistency reliabilities (coefficient alpha) for centralized ratings were .71, .79, and .84 at screen, baseline and endpoint, and .31, .39, and .83 for site raters respectively. At the screening visit, 43% of patients given a HAMD total score of > 17 by a site rater were given a HAMD total score < 17 by a centralized rater. At the baseline visit, 57% of patients given a HAMD total score > 17 by a site rater were given a HAMD total score < 17 by a centralized rater. CONCLUSION. The use of centralized raters who are blind to study visit would result in significantly different study populations. Blinded centralized raters generally score depression severity lower at screen and baseline. Site and centralized ratings coalesced at endpoint. When information on how patients in the present study were treated become available, we intend to investigate whether central and site raters were comparably capable of discriminating between treatments understood to have different levels of efficacy.

### Going, Going, Still there: Using the WebCite Service To Permanently Archive Cited Web Pages

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Scholars are increasingly citing electronic "web references" which are not preserved in libraries or full text archives. WebCite is a new standard for citing web references. To "webcite" a document involves archiving the cited Web page through www.webcitation.org and citing the WebCite permalink instead of (or in addition to) the unstable live Web page. This journal has amended its "instructions for authors" accordingly, asking authors to archive cited Web pages before submitting a manuscript. Almost 200 other journals are already using the system. We discuss the rationale for WebCite, its technology, and how scholars, editors, and publishers can benefit from the service. Citing scholars initiate an archiving process of all cited Web references, ideally before they submit a manuscript. Authors of online documents and websites which are expected to be cited by others can ensure that their work is permanently available by creating an archived copy using WebCite and providing the citation information including the WebCite link on their Web document(s). Editors should ask their authors to cache all cited Web addresses (Uniform Resource Locators, or URLs) "prospectively" before submitting their manuscripts to their journal. Editors and publishers should also instruct their copyeditors to cache cited Web material if the author has not done so already. Finally, WebCite can process publisher submitted "citing articles" (submitted for example as eXtensible Markup Language [XML] documents) to automatically archive all cited Web pages shortly before or on publication. Finally, WebCite can act as a focussed crawler, caching retrospectively references of already published articles. Copyright issues are addressed by honouring respective Internet standards (robot exclusion files, no-cache and no-archive tags). Long-term preservation is ensured by agreements with libraries and digital preservation organizations. The resulting WebCite Index may also have applications for research assessment exercises, being able to measure the impact of Web services and published Web documents through access and Web citation metrics.

#### The Future of Open Access Publishing

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Matthew Cockerill, Publisher, BioMed Central

Leslie Chan, Bioline International

This panel of well-known publishers and editors of Open Access publications will discuss the future of Open Access publishing with an emphasis on the role of OA journals. In an introductory round, each panellist briefly introduces his journal and/or OA projects, highlights advantages of Open Access publishing from his/her perspective, and provides a vision for the future. In subsequent rounds, each panellist will comment specifically on the question of sustainability of OA journals. Other questions which will be discussed is how the future of academic publishing will look like (will we ever reach 100% open access?), equity issues, and other issues related to Open Access.

# JustInTime: Technology To Deliver Curriculum & Deliver Curriculum & Manage Educational Requirements with Mobile Technology

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Several trends are converging in health professions education, which aim to translate new information and new technologies into safe and effective patient-centered care. Included among these trends are the exponential growth of an information technology (IT) infrastructure and the increasing demand for competency-based education. Given this, technologies that can adapt to changing environmental conditions and successfully deliver curricular objectives, and monitor and record a student's experiences have become key educational needs. The Clerkship Directors of Internal Medicine (CDIM) curriculum is a nationally accepted curriculum that defines the expected learning outcomes for 3rd year medical students on internal medicine. The CDIM curriculum is well accepted by educators, however it requires 61 pages of type written content to cover the requisite objectives. Given this volume of information, knowing "what a student should be able to do" at the point of the patient encounter is difficult. Therefore assessment for attainment of these specific learning objectives is difficult if not impossible and the evaluation burden for medical educators who are forced to rely on paper-based record systems for recording student encounters becomes progressively more likely to be educationally incomplete and logistically unmanageable. The increasing adoption of electronic systems coupled with the wider use of mobile technology (eg PDA s) has the potential to be significant change agents in advancing the cause of improved efficiency, and accountability in health professions education. Given this, we developed a platform technology, JustInTime (JIT), which can be used to support mobile computing in any setting. JIT is a web-based tool that allows easy authoring and downloading of content to a mobile device, and for content to be uploaded back to a central database. As a first application, we used JIT to adapt the Clerkship Directors of Internal Medicine (CDIM) curriculum by integrating a tool that allows students to quickly access the CDIM competencies and to track, document and store a record of their patient interactions. Content that is currently managed by the authoring tool includes - text, images, sound files, calculators and test items. 9 months of pilot test data at Michigan State University has demonstrated our ability to deliver this program successfully to all 3rd year students at our geographically dispersed medical school, with minimal technological problems. Summary data to date includes: the number of patient problems logged by all students was 9579; since September of 2005, the aggregate number of "hits" within the JIT program was 10,000, for an average of 143 per student (average 2.6 times per day conservatively). Anonymous survey data from students who've used JIT (58% of the total) revealed that 42% of students did not have a PDA prior to the IM clerkship; in spite of this, 77% found the program easy to navigate; 51% rated JIT-IM similar or better than other software packages; 91% used it occasionally (72%) or frequently (19%). We believe that mobile technology such as JIT can be a valuable tool as LCME accreditation standards evolve to require more assessment and documentation of trainee competencies and experiences.

# Internet-disseminated PDA Training Versus Paper-based Training

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Background: A literature search indicates that PDA-based programs exist for brief tobacco interventions following the 5A's model, but a comprehensive PDA program for health professionals that integrates tobacco use history, counseling, interventions, and patient data collection is not available. Objective: To create and test a user-friendly, PDA-based training tool (disseminated via the internet) in a medical school that integrates a guide for nicotine dependence interviewing, counseling skills and collects the responses. Methods: Beginning in the summer of 2005, 3rd year students at Loma Linda University School of Medicine (LLUSM)were required to use PDAs for documentation of all clinical encounters. In the summer of 2005, HanDbase software was used to develop a PDA-based program to replace a paper and pencil-based nicotine dependence interview assignment for 3rd year medical students (Class of 2007, n=165) on



the family medicine clerkship. The new PDA program includes a linked database that records all responses and can be transmitted via the internet to integrate into a master database. The first half of the 3rd year students (August to December 2005) were given the traditional paper-based instructions to interview 10 smokers. Beginning in January of 2006, the remainder of 3rd year students were required to use the PDA program for the same task. In August of 2006, these students will be tested with an Objective Structured Clinical Examinations (OSCE) and will take a standardized usability survey about the HanDbase program. The performance of the paper- versus PDA-trained students will be analyzed and compared to the previous year's results, Class of 2006 who only used the paper-based assignment. Results: Preliminary results from January to March 2006 indicate that the majority of 3rd year medical students find the PDA guide easy to follow if they have previous computer and PDA experience. The interview sequence can be completed in two to three minutes. Negative comments involved the barrier of recording answers in a handheld computer while inter-acting with the patient. The OSCE results, PDA usability survey and analysis of the patient response database documented by the students will be presented in this paper. Conclusions: The feasibility of using PDAs to train medical students to master nicotine dependence counseling has been accomplished. This study will be the first to determine the compliance, and usability of PDAs to effectively train tobacco interviewing skills. The PDA presents educators and students with a pocket-sized tool for training students in real time to use effective, evidence-based, interviewing protocols. Advantages include versatility for data storage, dissemination and evaluation as well as increased opportunities for interfacing with electronic medical records, web-assisted tobacco interventions, E- Prescriptions and formatted/tailored reports. Funding: NCI grant #1 R25 CA91958-01 Prevention and Cessation Education (PACE) in US Medical Schools

## Home and Global (bio) Chemical Sensing with Computer Screen Photo-assisted Techniques

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Introduction An unforeseen use of a commonly available consumer platform. a computer and a web camera is described. This combination shows promises for internet based medical diagnostics and global (bio)chemical sensing. The computer screen photo-assisted technique (CSPT) utilizes regular computer screens as controlled light sources, able to produce a stream of colors, and web cameras as imaging detectors for the optical characterization of arrays of (bio) chemical indicators able to trace diverse environmental and sanitary parameters. CSPT is able to examine different optical phenomena such as changes in absorption, emission or polarization of collections of indicators, and since it is an imaging technique it is able to deal with arbitrary layouts using a same experimental arrangement. The versatility and highly disseminated character of the CSPT platforms makes the method an attractive instrumentation for home and primary care based medical testing and for distributed environmental monitoring. In this work, we illustrate the CSPT spectral fingerprinting of an array of fluorescent indicators selectively detecting the presence of carbon monoxide (CO), nitrogen oxides (NOx), triethylamine (TEA) and ammonia (NH3). The example shows a particular environmental application, however, the same principle can be used for odor sensing or medical diagnostics. Methods The sensor is composed by 6 spots of three different porphyrins as chemical indicators, dispersed in a polyvinylchloride matrix and spotted in duplicates on a glass slide (spot size is ~2 mm in diameter). The device is simple, robust, inexpensive and eventually disposable, becoming a natural aid of the CSPT concept. The CSPT measuring procedure is the standard for fingerprinting of fluorescent indicators, and utilizes a 50 colors illuminating sequence provided by the computer screen. The web camera (a Logitech Pro 4000 with a CCD detector operating at a resolution of 320x240 pixels) captures the image of the assay in synchronism with the illumination, obtaining a video stream as result of the measurements. Post processing software extract spectral fingerprints form regions of interests and perform multivariate classification of the results. Results and Discussion The results show the potential of CSPT to capture and evaluate complex and specific response patterns that commonly require dedicated, sophisticated and expensive instrumentation such as e-noses. By contrast, when provided with the right sensing interface, CSPT makes it with

ubiquitous means. It is worth noting that the required source and imaging detectors used in CSPT experiments are also available from modern mobile phones. Finally, given the global dissemination of computer sets potentially acting as CSPT platforms and its natural network integration, randomly performed tests from diverse parameters could be geographically located (within a ~40m resolution and with access to the interior of infrastructures) in a given time window enabling to compose environmental and sanitary maps compatible with modern search interfaces such as Google Earth or Microsoft virtual earth. Thus, CSPT becomes not only an attractive concept to support sophisticated home tests but also a natural input terminal for the global monitoring of diverse parameter of environmental or sanitary importance, using already available resources.

# Controlled Trial of Anti-Stigma Internet-based Education: Preliminary Results

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Background. Professionals working with psychiatric patients very often have negative beliefs and attitudes about their clients [1]. We designed our study to investigate the effectiveness of anti-stigma interventions among university students who are trained to provide special education. Objective. The objective of our study was to compare sustainability of the effect of two anti-stigma education programs. Methods. We enrolled 91 college students form the School of Special Education at the Herzen Russian State Pedagogic University (St. Petersburg, Russia). Of those, 36 read two articles and World Health Organization brochure (reading group, RG) devoted to the problem of psychiatric stigma, and 32 studied an anti-stigma web-based program (program group, PG). Twenty-three students were in a control group (CG) and received no intervention. The second study visit in six months was completed by 65 students. To measure the level of stigma we used the Community Attitudes toward the Mentally Ill (CAMI) questionnaire [2]. The web-based program was based on the Computer-assisted Education system (CO-ED) which we described previously [3-5]. The CO-ED system provides self-paced interactive education driven by adult learning theories. Results. At the time of their first visit the age of the study participants was 19.0±1.2 years; of them, 99% were females. After the intervention in PG, the level of stigma assessed by CAMI decreased from  $24.0 \pm 5.0$  to  $15.8 \pm 4.6$  points (p < .0001). In RG the level of stigma dropped from 24.1  $\pm$  6.1 to 20.3  $\pm$  6.4 points (p < .0001). In six months after the intervention the analysis of CAMI scores showed that the level of stigma in PG was significantly lower than in CG and RG (20.2  $\pm$  6.2 in CG, 21.3  $\pm$  6.5 in RG, and  $18.7 \pm 4.9$  in PG, p < .01). Conclusions. Web-based education or reading anti-stigma materials could be effective in reducing psychiatric stigma among university students. The effect of interactive web-based education based on adult learning theories was more stable as assessed in six months.

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### Internet-Based Decision Aids Embedded In a Patient Health Record: Preliminary Results From a Pilot Before-After Study of the Effects of their Use On Patients and Practitioners In a UK Primary Care Context

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Background: Healthcare provision is facing a rise in chronic patient conditions, and Healthcare organizations are developing the area of Consumer Health Informatics, emphasizing patient choice using IT to assist patients to become more involved in their own health decisions. We focus on the role of decision aids (DAs) [1, 2], investigating their use in the relatively neglected primary care context. Objective: To investigate (1) what types of decisional needs patients have, (2) whether these can be satisfied by Web-based DAs, (3) within which model of clinical care should such access be provided, (4) stage of patient readiness to change to DA use. We also investigate practitioner attitudes to DAs. Methods: Primary care patients and practitioners are given access to a tailored Web-based Patient Health Record with embedded links to Web-based DAs. Before and after qualitative interviews and focus groups investigate patient and practitioner attitudes to, and experiences with, decision-making and the DAs. Results: Preliminary results will indicate patient and practitioner types, stages of readiness, attitudes to and experiences with decision-making and the DAs. Conclusions: Different types of patients/providers have different attitudes to different types of DAs and are also at different stages of readiness to change to integrated DA use in a primary care context.

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# African American Cancer Survivors and E-health Support Group Use

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There are disparities existing between African Americans and Caucasians with regard to cancer. African Americans often have higher mortality rates and poorer health outcomes [1]. Also, although many are using the Internet for health information and support, there is a disparity in this use between African Americans and Caucasians where African Americans are less likely to use the Internet as compared to Caucasians [2]. Our objective is to understand why African Americans cancer survivors are not commonly found using e-health support groups to cope with cancer and to make recommendations for eliminating these disparities. The authors are reviewing the published scientific literature and then presenting our results at a meeting attended by 25 experts in e-health, cancer, and health disparities. Each potential reason will be discussed by these experts and revised based on expert input. Our preliminary explanations for disparities in use include the digital divide and digital inequality which can also include lower levels of computer access and lower access to necessary technology. Also, lower income levels, lower education levels, trust issues with regard to Caucasian culture, preference to receive support from in-person rather than computer-mediated sources, and lack of culturally-specific groups for African American cancer survivors are potentially relevant explanations too. We offer specific suggestions to both the research and practice communities on how to understand this lack of use of e-health groups among African Americans cancer survivors. We offer recommendations on how to create e-health groups that are of greater interest and more accessible to African American cancer survivors.

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- Funding: Robert Wood Johnson # 55815

### An Elderly Information System To Control the Assisted Sanitary Residences

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Abstract For over-65 people, who are no self-sufficient and needs specific rehabilitation or treatments, are recommended the Assisted Sanitary Residences (ASR). An important objective of a public Local Health Authority is to accredit ASRs, both private and public in the district, to guarantee their quality of service. The project aims at creating a central Elderly Information System (EIS) and a web-based framework that allow: to archive all the patients' administrative, social and health information; to assemble all the information, forms and documents needed to reserve a stay in ASRs; to manage the waiting list of all the ASRs; to store all the ASR data: administrative, facility, sanitary, availability, healthcare service; to access and to make available, with different policy, all the data archived into EIS; to analyse and evaluate of all the data archived into EIS. At the end of the on-going validation period, the infrastructure should be considered friendly, easy, accurate, secure, complete and handle EIS and for a global management of the data from all the standpoints: citizens, GPs, ASR providers and welfare operators. Scenario For the over-65 people, who are retired, or who are partially or totally no self-sufficient, or who needs specific rehabilitation after acute symptoms, or who requires treatments for chronic pathologies, are recommended the Assisted Sanitary Residences (ASR). Italy is the Western country with the oldest people (18.5% of over-65 people and 4.3% of over-80 people) and therefore many ASR, both private and public, are under construction during last years. For this reason, an important objective of the public Local Health Authority for territorial health and social services is to accredit the ASRs, in order to guarantee their quality of service and to control the observation by them of the management rules. Within this new situation of healthcare system, for elderly or patients there are also many other problem in choosing: why obtain a subsidy? in which ASR staying? what services looking for? how to submit a request ? which treatment could find? Framework architecture The project aims at creating an unique and central Elderly Information System (EIS) and a web-based framework: · to archive into EIS all the patients' administrative, social and health information; · to inform the citizens and patients about the information of all the ASRs: to assemble for citizens all the information, forms and documents needed to reserve a stay in ASRs; · to manage the waiting list of all the ASRs in the district; · to store into EIS all the ASR data: administrative, facility, sanitary, availability, healthcare service; · to archive into EIS the administrative data of all the ASRs: refunding, in-patients and repayment; · to access and to make available, with different policy for the involved welfare operators, all the data archived into EIS; · to allow the analysis and the evaluation by the LHA of all the data archived into EIS. The web-based framework architecture has been designed in three parts: Extranet: it connects all the ASRs to access only to their in-patients data and to their web-page information; Intranet: it connects the LHA operators, all the involved welfare operators and the General Practitioners to the EIS for administrative and social information about only their patients; Internet: it allows to citizens and patients to find every kind of information about all the ASRs and all the documents needed to reserve a stay in ASRs. Another very important feature of the framework is to generate the P.I.C. (Personal Identification Code) of the privacy of each patient. The P.I.C., delivered by LHA operators at the begin of the new path, is used by the patients in all the following steps to obtain a stay in ASR. The P.I.C. is necessary: to register the specialist visit of surgery or GP; to submit subsidy at welfare office; to present all the forms and documentations at LHA office; to check, in real time and security, the waiting list; to enter in staying at the ASR selected. Main functionality The main functionality offered via web to the citizens by this framework are: · to present a comprehensive view of the whole spectrum of the ASRs available in the district territory; · to show the facilities, healthcare and social services and characteristics of each ASR; · to verify the healthcare service supplied by each ASR for particular patients' pathologies; · to inform about the path and the requirements for patients to enter in the ASRs; · to find all the



information, forms and documents needed to reserve a stay in ASRs; · to find the administrative and sanitary path to present an admission in ASRs; · to offer the possibility to check, simply and secure and in real time, his position in the waiting list of all the selected ASRs; · to insert himself in the waiting list, choosing the best combination of logistics and services; · to inform the elderly about F.A.Q., the "openness" rules of the waiting list, about the privacy, etc. The main functionality to the LHA operators are: · to collect automatically into EIS the up-to-date information about each ASR and its healthcare service; · to acquire automatically into EIS the whole up-to-date information about the ASR in-patients; to verify the required data for the accreditation of the ASRs through the information archived: administrative, facility, healthcare service; · to check, in real time, the ASR availability and the "openness" of the waiting lists' rules; · to manage easily the multiple reservations of the same patient in different ASRs of the district, because there is only on overall waiting list of all the providers; · to supply the elderly, via LHA's website, with all the update information, forms and documents needed to reserve a stay in the ASRs; · to allow the analysis and the evaluation by the LHA. of all the data archived into EIS; · last but not least, to program and to plan the future needs of ASRs and healthcare or social services. The main functionality offered to each ASR by this framework are: · to manage of its general information in LHA website about its facilities, healthcare services, characteristics, costs; · to update, in real time, its availability and its waiting list;  $\cdot$  to upgrade the information about its in-patients; · to provide the required data for the ASR accreditation: administrative, facility, healthcare service. The main functionality to involved welfare operators and General Practitioners are: · to access to the up-to-date administrative and health information archived into EIS about only their patients and the host ASR; · to allow the analysis and the evaluation of all the data of his patients archived into EIS; · to check, in real time, the ASR availability and the "openness" of the waiting lists' rules; · to verify data for the ASR accreditation: administrative, facility, healthcare service. On-going activities Up to now the framework is finishing the testing period focusing on the standardisation of forms and documents and on the activation of procedures. At the end of the validation period, the project goal is that this infrastructure could be considered a friendly, easy, accurate, secure, complete and handle framework for a central submitting and information system for stay requests in ASR, for a global management of the data from all the standpoints: citizens, ASR providers and LHA operators.

# Indicators of Accuracy of Consumer Health Information On the Internet: A Review of One Approach and Its Results

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Background: Some of the consumer health information on the Internet is accurate, but much of it is not. A number of authors and organizations have published guidelines for evaluating the quality of health information on the Internet [1]. These guidelines typically include lists of indicators that are intended to help Internet users to determine the accuracy of web sites. A few years ago there was no empirical data to support assertions that these indicators really are correlated with accuracy (or inaccuracy). Our project has been to develop the empirical methods, and then to test indicators [2,3,4,5]. Objective: The project aims to identify indicators of accuracy for consumer health information on the Internet. Such results will help Internet users to distinguish accurate from inaccurate health information. This paper reviews what we have learned, and identifies future directions. Methods: Typical consumer techniques were used to find consumer oriented web pages on the topics of interest. The accuracy and completeness of these web pages was determined by consulting published guidelines, medical reference texts, and medical experts. The presence on these web pages of a number of proposed indicators of accuracy-most taken from published guidelines for evaluating the quality of health information on the Internet, plus some additional plausible candidates—was noted. Some of these indicators are 'manifest' (ie, open to easy and immediate inspection); others, for example those involving link structures, are not and may require algorithms to determine their presence. The correlation between the presence of the proposed indicators of accuracy on the web pages and the accuracy of the web pages was calculated. The likelihood ratios for the presence and the absence of the proposed indicators of accuracy were calculated. Results: Four studies are referred to: fever in children in the home, Ewing's sarcoma, carpal tunnel syndrome and general reference or 'quick fact' questions [2,4,5]. Some candidate indicators were genuine indicators of accuracy or inaccuracy. Most proposed indicators taken from published guidelines are neither genuine

indicators of accuracy nor inaccuracy. Non-manifest indicators seem to show more promise than manifest ones. Also, contrary to popular belief about the reliability of the Internet, answers to general quick fact questions found on the Internet will very likely be correct. Conclusions: There are genuine indicators of accuracy (and inaccuracy) of health information on the Internet. Determining what these indicators are, and informing the providers and consumers of consumer health information about them, would be valuable for public healthcare. Non-manifest indicators are more promising.

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# Feeding Problems and Gastrotomy In Rett Syndrome: An Internet Study

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Introduction Rett Syndrome is a rare disorder affecting mainly girls and women, with a prevalence of 1 in 10,000 live female births [1]. It is characterised by intellectual handicap and gross motor dysfunction, including hand stereotypies, poor oral motor control and gastrointestinal problems [2]. Swallowing and feeding problems, including chewing and swallowing difficulties, choking and regurgitation are common [3], affecting up to 80% of individuals [4]. The resulting undernourishment can ultimately compromise health and quality of life [2]. Compared with children with other developmental disorders, children with Rett syndrome have lower body weight, a higher number of gastrointestinal problems, poor swallowing abilities, poorer self-feeding abilities and a lower tolerance for thick, textured foods [5]. For some children and their families the problems associated with feeding and gaining adequate nourishment can be great, producing stress and burden on the families. Methods Data were collected about feeding problems and how they affected daily life for the child and family from six months of archived postings to an Internet list-serve called Rettnet and from responses to two questions posted directly to Rettnet. 109 parents or carers of individuals with Rett syndrome contributed postings to Rettnet. A grounded research approach using content analysis was used to identify recurring concerns and issues. Results Over the six-month period, the parents or carers posted, on average, two emails about swallowing and feeding difficulties with a range of 1 to 7 postings. The average age of the child was 11.4 years (SD=8.7 years) with an age range of 2 to 42 years. Common difficulties reported included inability to swallow and chew, aspiration and reflux, often causing dehydration and malnutrition. Many parents commented that they were doing everything they could to help their child but they felt they were failing as many children suffered from reflux, aspiration and air swallowing and were unable to take their medication effectively. Poor weight gain was extremely common in these children and a great concern to parents and carers. Just over a half the children (51.7%) had a gastrostomy inserted. Discussion The use of the Rettnet postings and responses provided a mechanism to investigate feeding problems which had a low respondent burden and focussed on experiences shared with others. The decision and difficulties surrounding the decision to have a gastrostomy inserted for the child was the most common issue raised in postings. Parents often felt they were failing their child in their inability to maintain her weight despite their best efforts. It was very difficult for them to decide to have a gastrostomy and surgery was seen as traumatic for the child and parent. They felt that having a gastrostomy emphasized the child's difference and dependence. However, in retrospect they felt that it had generally positive effects for their child although for some the sense of failure persisted. The burden placed on families from the swallowing problems faced by their daughters is high both in time and worry associated with maintaining their daughter's health. Whilst undergoing gastrotomy is a major and difficult decision it provides relief in knowledge that nutrition, hydration and medication can be managed safely. 1 Leonard H, Bower C, English D. (1997). "The prevalence and incidence of Rett



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## Investigating Scoliosis In Rett Syndrome Using Listserve Postings and Questionnaire.

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Introduction Scoliosis is a common clinical manifestation of Rett syndrome [1], a neurodevelopmental disorder that almost exclusively affects females [2]. Following apparently normal development, girls typically regress and lose cognitive skills, sociability and motor function and severe intellectual and physical disability remain throughout life [3]. Children with compromised early development, those less mobile at ten months, and those who never walked are more likely to have earlier onset of scoliosis [4]. Methods This study used almost 500 postings to a listserve, the Rettnet, to develop an on-line questionnaire to investigate types of scoliosis treatment, parental knowledge about scoliosis and its treatment, factors influencing decisions about treatment and parents' views of treatment outcomes in Rett syndrome. The questionnaire was developed using Dreamweaver MX6 with Lasso for Dreamweaver Plug in and was completed anonymously by respondents. Study promotion was via on-line discussion groups and research foundation newsletters. Results The questionnaire was completed by 165 respondents for whom their child's diagnosis of Rett syndrome could be verified. Three quarters were from the United States with 90% speaking English as their first language and 62% having undertaken tertiary study. Seventy three percent of their children had developed scoliosis with those who had never walked developing scoliosis at a significantly earlier age than those who had walked. S shaped thoracolumbar curves were most common with the curve found predominantly to the right. Most parents were aware that their daughter could develop scoliosis but they generally knew little about it. They were keen to learn and used the internet (53%) and Rettnet (45%) as well as family and friends (33%) as resources. Some accessed medical journals (28%), libraries (26%) and their doctors (7%) for information. The first line of treatment for most was bracing with 63% of those treated having bracing. For some girls there was increased well-being with improved support and better posture. However parents were unsure whether bracing was actually effective in delaying the progression of the curvature. They commented that bracing had merely delayed surgery, seen as inevitable by many. Whilst physiotherapy was used by half of the girls who had developed scoliosis there was a general view that it had not helped delay curve progression. However parents were happy that physiotherapy had improved mobility and flexibility, mood and general wellbeing. The decision to have surgery was often very difficult with concern about the physical and emotional trauma of the operation on their daughter and whether there were any alternatives. Surgery outcomes were mixed: whilst improved posture influencing breathing, quality of life and comfort were positive outcomes, the risk, rigidity and complications resulting from the surgery were viewed as disadvantages. Discussion For parents of children with Rett syndrome scoliosis is a problem they are likely to face. Whilst many felt unprepared for the decisions to be made they often saw surgery as an inevitable treatment which bracing and therapy only delayed. information from the internet and support from other parents through the Rettnet were widely used and valued

### "Diabetic Corner": A Specific Microsite To Help Diabetics To Better Understand and Manage their Disease.

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Background and methods: Diabetes is one of the more prevalent diseases in developed countries[1]. The expected increase in its incidence[2] and the development of new tools in the management of this chronic condition[3] make necessary new educational instruments for diabetics. We show our experience in our health site for patients, www.viatusalud.com. Results: The homepage provide easy access to a wide range of contents. Issues on diabetes types, acute and chronic complications, nutrition, home care, exercise and therapy are presented. Complete information on all types of insulin, oral hypoglycemic drugs and complementary medications is also available. A tool to store and organize the self-controlled glucose values, a test to assess the risk of developing diabetes and an specific body-mass index calculator have been designed. In the personal password-protected area, a formulary has been included to allow users to ask our endocrinologists for information. Four different message boards (treatment, complications, nutrition and living with diabetes) allow users to share experiences and ideas. Next steps will allow patients to introduce their glycemic control values in their own electronic patient record and to receive instructions from their physicians, strategy that probably will contribute to achieve their therapeutic goals[4]. Conclusions: Internet is a powerful communication tool between patients and physicians. 1. The specialization of contents can be a useful way to enhance knowledge in people with chronic conditions. 2. New and prospective studies should be started to address whether this kind of communication may help people with diabetes to achieve their metabolic control goals.

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# Selection and Evaluation of Websites with Patient-Targeted Information In Spanish

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Background: The dissemination of biomedical knowledge over the Internet has meant that citizens now have an unprecedented range of information at their disposal. Although this might encourage greater autonomy on the part of citizens, frequent language barriers and the uncertainty involved in searching for quality information have led professionals working in healthcare to guide patients in this process [1]. Objective: a) To assess the quality of websites providing health-related information for patients in Spanish according to criteria recommended by selected codes of conduct. b) To select websites that could be included as links on the website of the Andalusian Agency for Healthcare Technology Assessment (AETSA). Methods: A group of 24 experts with a range of profiles (National Health Service managers, experts in evidence-based medicine and members of civic or patient associations) were contacted by email and asked to propose a list of 20 Websites selected on their own criteria, 10 providing general health information, and the other 10 targeted at specific patient groups. All recommended sites were assessed independently by three evaluators to evaluate the degree of compliance with the most relevant codes of conduct



for health information on the Internet: i) The American Medical Association Code; ii) The e-Health Code of Ethics from the Internet Health Coalition; iii) The Health Summit Working Group Code; and iv) The e-Europe 2002 Code, as well as initiatives by OECD and e-Confidence for consumer protection on the Internet [2]. The principal factors analysed were: transparency, editorial policy, authorship, updates, personal data protection, website liability cover and accessibility. A measure for popularity according to links, page-rank and the presence of quality seals was also included [3]. Results: The consultation with experts gave rise to two lists of websites providing health information, one for general population listing 25 websites and a second list with 21 sites for specific patient groups. The websites with higher scores on the quality assessment that followed based on compliance with codes of conduct were: 1. Sites targeting general population (www.fisterra.com; medlineplus.gov/spanish; www.lasalud.com: www.pulevasalud.com: www.cdc.gov/spanish/: www.noah-health.org ) 2. Sites targeting specific groups of patients: www.4woman.gov/spanish; www.respirar.org; www.cancer.gov/español; www.todosvacunados.com; www.diabetesjuvenil.com; www.espalda.org; www.aepap.org). The two dimensions of quality in compliance with codes of conduct that showed a positive and statistically significant correlation (p < 0.05) with a larger number of the remaining factors were editorial policy (that correlated with all dimensions except for liability) and accessibility (that correlated with all dimensions except transparency). Discussion: It has been reported that patients tend to search for information on the Internet in their native language [4] [5]. Spanish is the primary language of 400 million people around the world. This study was performed by AETSA as a first step to select sites that will be included as recommended links for patients in its web-page. but also to provide sound basis for evaluating quality of contents of the selected sites during 2006. [www.juntadeandalucia.es/salud/aetsa] Referencias 1. Eysenbach G, Powell, Kuss O, Sa E. Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review. JAMA 2002; 287: 2691-2700. 2. Bernstam EV, Shelton D, Walji M, Meric-Bernstam F. Instruments to asses the quality of health information on the World Wide Web: What can our patients actually use? Int J Med Inform 2005a; 74: 13-19. 3. Bernstam EV, Sagaram S, Walji M, Johnson CW, Meric-Bernstam F. Usability of quality measures for online health information: Can commonly used technical quality criteria be reliably assessed?. Int J Med Inform 2005b; 74: 675-683. 4. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability test, and in-depth interviews. BMJ 2002;324:573-576. 5. Llinás G, Mira JJ, Pérez-Jover V, Tomás O. En qué se fijan los internautas para seleccionar páginas web sanitarias. Rev Calidad Asistencial 2005; 20: 385-90.

### Evaluation of Information On Hormone Replacement therapy After Menopause Available In Spanish On the Internet: Information Or Misinformation?

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Background: Health misinformation on the Internet and its effects on public health are unknown. Misinformation impact could be greater when related to treatments used for situations that are mislabeled as "illnesses" and that affect a large part of the population. One example is Hormone Therapy (HT) after menopause, which affects half of the population at some point in their lives [1]. Objective: To analyze differences in the way that best available scientific evidence is presented in Spanish on the Internet regarding risks and benefits of HT, as well as preventive and palliative measures for post-menopausal symptoms, after the publication of the WHI (Women Health Initiative Study) [2]. Method: A total of 26 web sites were selected following a variety of Internet search strategies attempting to reproduce those that a Spanish-speaking woman would use to find information about HT on the web [3]. Sites were classified according to responsibility into three groups: a) Governmental Organizations (n=8); b) Scientific Institutions (n=5); and c) Miscellaneous Group (n=13). Four categories were used to assess the contents of each web page [4]: a) risks of HT (7 items); b) benefits of HT (5 items); c) false benefits or unproven

potential benefits of HT (6 items); d) preventive and palliative measures for post- menopausal symptoms (9 items). Items were selected based on scientific evidence available. Each Web site was evaluated by two independent evaluators and disagreements were settled by discussion. Results: Governmental institutions presented more information about risks, benefits, and preventive measures, and less false or unproven benefits. These differences were statistically significant in the area of risks (p < .01) and benefits of HT (p < .02). Considering all web sites, the average of informed risks was 53%, 84% in the case of benefits, 34% in false or unproven benefits, and 50% in preventive measures. From 21 sites (81%) that openly recommended HT, only 4 (19%) considered the role of the woman. Of the 5 pages that did not recommend the use of HT, 4 were US governmental institutions, and all of them discussed openly the woman's role in making decisions regarding the treatment The WHI study was only mentioned in 58% of the Web sites (n=15): all the governmental institutions Web sites and approximately 40% of the rest of pages. In 12 sites WHI was the source of HT risks and benefits information, and in 2 sites WHI was included in the context of questioning its validity and results. Discussion: This study shows that in Web sites in Spanish there is more extensive communication of the benefits of HT than of its risks and the possibility of using other measures to alleviate post-menopausal symptoms. Governmental web-sites, especially those of US institutions, provided the most up-to-date information supported by scientific evidence. False or unproven benefits were found more often in Web sites of scientific or professional institutions and in the miscellaneous group. Cultural differences in the concept of patient autonomy, could partly explain differences in emphasis made on women role in decision making process [5].

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## Drug Information On the Internet: Consensus, Popularity and Codes of Conduct.

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Background: Patients are using the World Wide Web to search for health information. Drug related information is one of the most popular search topics. Recent surveys show that 40-54% of patients access medical information via the internet and that this information affects their choice of treatment [1]. Although the quality of medical information on the world wide web has been an area of increasing concern [2], the factors that contribute to popularity of websites have not been systematically studied. Characteristics of popular websites may or may not reflect the information needs of patients [3]. Objective: To compare the relationship between recommendations by experts, website popularity and quality measured by codes of conduct regarding websites on drug information. Methods: 1) The Delphi method (3 rounds) with 25 participating experts was used to select a pool of websites providing drug information. Consensus agreement was assessed by calculating spread of the interquartile range for each website recommended. 2) Link popularity (page rank) was calculated according to the number of links reported by the browser Google (www.google.com) using "link URL" as a strategy of search. 3) A questionnaire based on the main recommendations by different codes of conduct (e-Europe, American Medical Association, Health Summit Working Group and e-Health Code of Ethics) was elaborated to evaluate quality of content. Main variables included: display of authorship; source (attribution or references); date of update; and disclosure of ownership, sponsorship, advertising policies, or conflicts of interest. 4) We used Pearson correlation analysis to explore associations between expert consensus, popularity by page rank and quality by codes of conduct. Results: Our results found no correlation between measures of expert consensus, link popularity and quality of content by codes of conduct. Expert consensus was reached for 42 websites (interquartile range [IQR] 4.0-5.0) divided in six major groups: medical journals, drug data bases, drug agencies, newsletters, patient information sites and miscellaneous. Measures of quality



such as display of authorship, attribution or references, currency of information, and disclosure did not differ between groups. More popular and less popular websites did not differ in any of the quality measures studied. Furthermore, the presence of inaccurate information did not differ between more popular and less popular sites. Conclusions: Although link popularity may identify sites of interest, it does not correlate with expert consensus or quality of content. The growing number of users of the internet searching for health information indicates an unmet need for information [4]. Understanding what patients are looking for on line may help us meet their need for health information [5].

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#### **Web-based Expert System for Nutrition Counseling**

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Background: The Internet is a common medium for lifestyle counseling systems. Most systems provide only general advice in a particular field, others employ forms to categorize the user, in order to give more specific information. They also often contain interactive tools for menu planning, weight control and diet analysis. Objectives: Dietary menu planning is an important part of personalized lifestyle counseling. A number of expert systems for nutrition counseling have been developed recently [1,2,3]. In the menu planning problem several constraints imposed on the quantity of nutrients should be satisfied. There are well defined constraints for the intake of nutrient components such as carbohydrate, fat or protein, which can be computed for everybody, given their age, gender, body mass, type of work and diseases. Plans satisfying nutritional constraints should also be appetizing. There can be conflicting numerical constraints or harmony rules. A study found that menus made by professionals may fail to satisfy all of the nutrient constraints [4]. Methods: Our automated dietary menu generator MenuGene provides personalized advice to prevent and treat obesity and cardiovascular diseases. MenuGene [5] uses Genetic Algorithms to prepare weekly dietary menus for web users. The objectives are derived from personal medical data collected via web-forms, combined with general nutritional guidelines formed as a rule-base built upon a dietary knowledge ontology. The weekly menu is modeled as a multi-level structure on which the evolutionary algorithm based optimization process runs. Results: Results show that the Genetic Algorithm based method succeeds in planning dietary menus that satisfy strict numerical constraints on every nutritional level (meal, daily basis, weekly basis). In particular, we tested the reaction of the algorithm to the gradual diminution of nutritional constraints and measured the variety and mean occurrence of the menu components on which harmony rules where imposed on. The strictness of the harmony rules penalizing a particular component or pair of components in the menu plan where gradually changed. The statistical analysis showed that the harmony rules significantly change the mean occurrences of the components on which they are imposed on, thus driving the evolutionary process in a way that it creates menus with optimal nutritional content and well assorted components while omitting those that are not appetizing. Thus, the rule-based assessment using the nutrition ontology provides a method for adjusting the variety and harmony of the menu plans. Conclusions: By splitting the problem into well determined subproblems and using robust optimization algorithms on each level, weekly menu plans that satisfy nutritional constraints and have well assorted components can be generated with the same method that is for daily and meal plan generation. The method is proved capable of generating menus that satisfy all constraints for non-pathological nutrition.

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### Emerging themes In Disparities Research; the Role of EHealth Solutions

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Over the past decade, a rapidly expanding body of literature has demonstrated the existence of disparities in health and health care. While consensus has not emerged regarding the causes of disparities, they are generally thought to be related to sociocultural, behavioral, economic, environmental, biologic, or societal factors. Despite the implementation of significant policy, legislative and research initiatives designed to address disparities, they have remained surprisingly resistant to improvement and in some cases have worsened over time. To effectively address disparities, several authorities have suggested the need for an enhanced theory driven understanding of the varied and multilevel structural and behavioral determinants of disparities as well as an integrative approach to addressing disparities that involves greater information technology and eHealth investments, eHealth researchers may be able to make significant contributions in this area through research and its applications. This tutorial begins with a brief overview of the history and epidemiology of health disparities in the United States and Europe. It then discusses the role of the Internet and other suggested etiologic determinants in the genesis of healthcare disparities. Attendees will then be led through a discussion of the pros and cons of select current strategies for addressing healthcare disparities. Attendees will then be introduced to a theoretic basis and rationale for the design of disparities interventions. This will be followed by a discussion of emerging theory driven eHealth strategies to address healthcare disparities. The session will end with an open discussion of current knowledge gaps and areas for future research in the field of integrative eHealth approaches to address healthcare disparities

### **Cognitive Assistance In Smart Homes**

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Background: In many cases, people suffering of cognitive impairments (Alzheimer disease, head trauma, schizophrenia...) would be able to stay at home if light assistance was provided. But healthcare resources are scarce. Thus relatives have to take responsibility for care. Too often, this situation then turns to an exhausting burden. Hence relatives and caregivers urge for help. Fortunately, networks, microprocessors, memory chips, smart sensors and actuators are faster, more powerful, cheaper and smaller than ever. They enable to build brand-new communicating objects and pervasive information systems capable to improve the life of elderly and disabled people in their (smart) home and outside [1]. Smart homes are augmented environment with brand-new networked communicating objects, embedded computers, information appliances, and sensors. They can assist cognitively impaired people and foster their autonomy. As well they can help caregivers to grant better care and secure residents and their relatives. Objective: At the DOMUS laboratory, on-going research projects aim at 1) building the theory and praxis of pervasive computing [2] and tangible user interfaces (TUI) [3] compulsory to create smart environments [4] for cognitively impaired people, 2) fostering the autonomy of cognitively impaired people thanks to cognitive assistance, and 3) investigating how pervasive services and TUI can support monitoring, assistance, and communication between cognitively impaired people and their caregivers. Methods: Pervasive computing enables a seamless integration of assistance in residents' everyday life while TUI turns the whole house into a cognitive prosthesis. Prototypes are used to investigate how pervasive services and TUI can support and enhance healthcare and communication between people and caregivers. A fully-equipped experimental apartment can accommodate cognitively impaired people and their caregivers for day and night. This cutting-edge research infrastructure consists of a standard apartment (kitchen, living room, dining hall, bedroom, and bathroom) augmented with sensors, localization systems, micros, speakers, TV, touch screens, lights control, etc.



The middleware provides for spontaneous networking, distributed and mobile computing, and sensor networks. Cognitive assistants use descriptions of activities of daily living to reason upon resident actions. They then rely on context awareness and TUI to interact with people. Finally the assistance systems remotely share information with caregivers. Results: Running proofs of concept show how to monitor activities of daily living of a patient. Assistance is either provided on the assistant initiative or on the patient request. Assistance may result from interactions with the assistance system (cues, messages...), or may involve caregivers synchronously or asynchronously. For instance to supply for memory deficits, the assistant can highlight objects location on a map display [5]. Conclusions: Pervasive cognitive assistants addressing cognitive deficits are deployed into an experimental smart apartment. Their implementation is based on pervasive computing and TUI. Assistance is either provided on the assistant initiative or on the inhabitant request. Assistance may consist in cues and interactions with the assistance system or may involve caregivers. Indeed this approach transforms the whole home into a cognitive prosthesis. Next steps will be to make the cognitive assistant robust enough to enable clinical validations.

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### Successful Participant Recruitment Strategies for An Online Smokeless Tobacco Cessation Program

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Background: An estimated 22% of Americans currently use smokeless tobacco (ST). Most live in small towns and rural areas that offer few ST cessation resources. Approximately 94 million Americans use the Internet for health-related information, and on-line access is growing among lower-income and less-educated groups. Objectives: As part of a randomized clinical trial to assess the reach and effectiveness of Web-based programs for delivering an ST cessation intervention, the authors developed and evaluated several methods for overcoming the recruitment challenges associated with Web-based research [1]. This report describes and evaluates these methods. Methods: Participants were recruited through: 1) thematic promotional "releases" to print and broadcast media, 2) Google™ ads, 3) placement of a link on other Web sites, 4) limited purchase of paid advertising, 5) direct mailings to ST users, and 6) targeted mailings to health care and tobacco control professionals. Results: Combined recruitment activities resulted in more than 23,500 hits on our recruitment website from distinct IP addresses over 15 months, which yielded 2,523 eligible ST users who completed the registration process and enrolled in the study. Self-reports revealed that at least 1,276 (50.6%) of these participants were recruited via mailings, 874 (34.6%) from Google<sup>TM</sup> ads or via search engines or links on another Web site, and 373 (14.8%) from all other methods combined. Discussion: The use of thematic mailings is novel in research settings. Recruitment of study participants went quickly and smoothly. Google  $^{\text{\tiny TM}}$  ads and mailings to media outlets were the methods that recruited the highest number of participants. This project was funded by the National Cancer Institute R01-CA84225.

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# Understanding User Expectations From Web-based Cancer Clinical Trial Search Systems

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As with general health and medical information[1], the Internet is a major source of information on clinical trials[2]. A recent study by Porter Novelli, that reviewed consumer understanding of clinical trials, indicates that 56% of the general population would use the Internet and search online for clinical trials, second only to talking with their physician. But there has been very little user research into how people find and use online information about clinical trials. Clinical trials are a key component of cancer treatment, diagnosis, and prevention. However, research indicates that a very small percentage of eligible cancer patients participate in clinical trials [3]. Given the potential of the Internet in helping patients, find information about cancer clinical trials, a better understanding of the key features that they want in clinical trials search systems is critical to enhancing their chances for clinical trial participation. The National Cancer Institute has a major interest in increasing clinical trial participation and, as the host of a large cancer clinical trials database on its Web site, is keenly interested in continuing to enhance users clinical trial search experience through user research[4]. To help us shape the next generation of clinical trials search on the NCI Web site, we conducted a research project to better understand user expectations from Internet clinical trial search systems. Our paper will review the literature on barriers and motivators to clinical trial participation. In addition, it will present the findings of our research on user expectations from Web-based clinical trial search. The research project involved interviews with cancer patients, their care givers, and family members health professionals, and intermediaries and focused on understanding user goals (why users visit the site) and how to address these goals in the context of use (where and when in the cancer care continuum they visit the site). All aspects of the clinical trial search process from search parameters to search results display were the focus of this user research.. We identify key components of web-based clinical trial search (functionality, design, as well as contextual features) that will enable us to tap the underutilized potential of the Internet in enhancing clinical trial participation. [1] Fox, S. (2005). Health Information Online. Washington, DC: Pew Internet & American Life Project. [2] Ehrenberger, H.E. (2001). Cancer clinical trial patients in the information age. Cancer Practice, 9(4), 191-197 [3] Comis, R.L, Miller, J.D., Aldige, C.R., Krebs, L., & Stoval, E. (2003). Public attitudes toward participation in cancer clinical trials. Journal of Clinical Oncology, 21(5), 830-835. [4] Grama, L.M., Beckwith, M., Bittinger, W., Blais, D., Lollar, C., Middleswarth, A., Noone, M., Price, D., Quint-Kasner, S., Shields, V., Wright, L.W. (2005) The role of user input in shaping online information from the National Cancer Institute. Journal of Medical Internet Research, 7(3), e25

# The Virtual Consultation Project: Enhancing Multidisciplinary Care for Patients with Malignant Spinal Cord Compression (MSCC).

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Background: A virtual consultation (VC) project was designed to facilitate multidisciplinary interaction between diagnostic, surgical and radiation oncologists for the urgent management of acute malignant SCC. This consists on the provision of a predefined set of clinical parameters and electronic diagnostic images by the radiation oncologist to the spine surgeon, where an opinion regarding the need for surgical management is provided. Objective: This study assesses the feasibility and impact of VC on the management of MSCC. Material/Methods: Patients presenting with a clinical or radiological diagnosis o f MSCC were included. Clinical (neurological/ambulatory/performance status, pain score, previous MSCC, life expectancy), spinal parameters (level(s) of MSCC, stability, existing and risk of fracture, deformity, operability), and treatment recommendations were recorded. Results: Between 7/04-2/05, 66 patients were included. Patient characteristics included: 38M/28F, the median age was 59 (range 31-87) yr. Patients presented with multiple levels and repeat MSCC in 62% and 12%



respectively. Quadriplegia or paraplegia and severe pain were present in 32% and 12% of patients respectively. VC was requested for 15/48 (31%) of the eligible patients (17 had surgery prior to referral). Seven were transferred for a definitive surgical opinion and all underwent surgery, the other 8 received a multidisciplinary opinion without a physical transfer. Conclusions: VC is an effective model for providing rapid access to multidisciplinary care for patients with MSCC. A mature database is expected to allow the development of a diagnostic algorithm that would identify surgical candidates (by non surgeons) to further enhance expeditious care for patients with malignant spinal cord compression

#### Survey On the Coronary Risk Among Polish Web Users

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BACKGROUND: Today's most frequently asked question about the Internet is "who is using it?". Relatively little is known about web users' health behavior. AIM: to examine occurrence of ischemic heart disease (IHD) risk factors among polish web users. METHODS: Questionnaire with 19 separate one-choice questions (including: age, gender, IHD risk factors, obesity, life style, frequency of internet usage) in polish available on CARDIOWEBSCREEN web site: http://www.amwaw.edu.pl/cardiowebscreen/. Information about the survey was propagating in the following, only electronic, manner: announcements on electronic journals, postings on Internet newsgroups, announcements made to the mailing lists, links on Web sites. RESULTS: From September 2002 to August 2003, 3268 responses to a questionnaire were posted on the CARDIOWEBSCREEN Web site by web users aged >= 30 years (mean age 42,4±9,8; 2388 males and 880 females). Respondents were in their great majority regular, everyday Web users - 2776 (85%). Occurrence of IHD risk factors were as follows: current smoking 836 (26%), prior smoking 1086 (33%), diabetes 101 (3%), hypertension 171 (21%), hypercholesterolemia 650 (20%), prior myocardial infarction 181 (6%), positive family history 757 (23%), lack of regular exercising 2117 (65%). Prior smokers were older than smokers and (median age, 42 vs. 45, p <0,05) and nonsmokers (median age, 40 vs. 45, p <0,05). Abnormal body mass index (BMI>25) was seen more often in males than females (67% vs. 29%, p <0,05). Mean BMI was 26,7 and was not significantly but lower in high educated web users (65% of total) than in low educated (mean, 26,4 vs. 27,8). High educated participants more often were exercising regularly (30% vs. 20%, p <0,05). CONCLUSIONS: 1) study demonstrates a method for rapidly evaluating interface design alternatives using anonymous web volunteers who have provided informed consent; 2) coronary risk in group of respondents seems to be comparable to statistical population and can not be considered as optimal; 3) web users who smoke are older than nonsmokers 4) they seem to be ill-informed about IHD prevention.

# Telehealth, Digital Medicine and the Concepts for a Virtual Euro-Mediterranean Hospital -VEMH

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Background: Telemedicine aims at equal access to medical expertise irrespective of the geographical location of the person in need; it promises equally good healthcare at any time from any location: best healthcare for everyone, anytime, anywhere [1-2]. New developments in Information and Communication Technologies (ICT) have enabled the transmission of medical images in sufficiently high quality to allow for telediagnosis. At the same time, however,

these innovative developments in ICT over the last decade bear the risk of creating and amplifying a digital divide in the world, creating a disparity in quality of life between the North and the South of the Mediterranean. Objective: In recent years, different institutions have launched several Euro-Mediterranean telemedicine projects [3]. All these projects have demonstrated how the digital divide is only part of a more complex problem, the need for integration. Therefore, provision of the same advanced technologies to the European, to the Mediterranean and to the Adhering Countries should be the final goal for contributing to their better dialogue for integration. Methods: Based on the experience in the exploitation of previous European telemedicine projects an open Euro-Mediterranean consortium would like to propose the Virtual Euro-Mediterranean Hospital (VEMH) initiative. VEMH aims to facilitate the interconnection of the various services being developed through real integration. This integration must take into account the social, human and cultural dimensions and strive towards common approaches but open and respectful of cultural differences: multi-lateral cooperation instead of aid. Results: Pre-operative planning, navigation and robotics offer advantages e.g. in minimally-invasive surgery by increasing the precision of the intervention and shortening the recovery time of the patient. As minimally-invasive surgery is image guided it requires an adequate fully digitized environment for optimized usage in clinical routine. ICT contribute to digital radiology, digital pathology, telemedicine and navigation and simulation. All these areas produce an information flood. To deal with such an amount of information, personalized avatars to represent the user virtually in an online community of medical information systems and multi perception for multi media performance in virtual reality environments are needed. A web-based electronic patient record system can be developed to provide authorized access to integrated patient information irrespective of the location where it has been stored. To integrate these concepts the VEMH will provide a heterogeneous platform integrating satellite links, such as in the EMISPHER project, as well as terrestrial links for the application of various medical services, such as medical e-learning, real-time telemedicine and medical assistance. The methodologies for the VEMH are medical-needs-driven instead of technology-driven. They provide new management tools for virtual medical communities and allow management of clinical outcomes for improved implementation of evidence-based medicine. Conclusions: Due to the distributed character of the VEMH, data, computing resources as well as the need for these are distributed over many sites in the VEMH. Therefore Grid technology becomes important for successful deployment of services like acquisition and processing of medical images, data storage, archiving and retrieval, data mining.

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# Teaching Health Informatics To the Net Generation: A New Baseline for Building Capability?

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Background The current generation of medical students are the Net Generation, said to have developed, informally during their upbringing, distinctive attitudes and practices in the use of Internet-based information and communication technologies (1). However there is a dearth of data on their Internet use to inform universities' approaches to using the Internet, especially Web 2.0, most effectively in medical education (2). In particular, we have little information on students' skills base to use in planning to build greater informatics capacity in the Australian health workforce (3). Objective Collecting evidence of current students' Internet experiences and preferences will help to determine how, or indeed whether, our approach to developing students' informatics capabilities needs reform. This study addresses longstanding issues, by telling us what



Internet capabilities students may have acquired or be likely to acquire "by osmosis" (4). Such evidence is required to help educators to develop students' focus on essential clinical uses of the Internet (5). Methods Data on Internet use by 207 incoming medical students were collected as part of a four-page survey at a major Australian university, on first-year students' experiences with information and communications technologies and preferences about their use in higher education. Findings about Internet use by this cohort were compared with informatics education standards, frameworks and curricula for Australian medical undergraduates, to identify key issues for teaching and learning. Results Students' Internet use is extensive, intensive and competent, but students do not have uniform experiences or preferences and are not major users of some emerging web technologies. In the undergraduate medical curriculum, it is difficult to determine accurately what types and levels of informatics capabilities are specified where, the details of related objectives, activities and assessment, or any picture of student learning outcomes in this area. Conclusions It remains most important that educators identify and address gaps in students' Internet experiences and preferences, in relation to Internet uses that the profession considers most targeted and productive in building students' essential informatics competencies. Educational issues that need to be addressed include: deficits in Internet skill, knowledge and attitude of individuals (including some teaching staff); requirements for customising teaching about informatics to varied student experiences and preferences and within classroom and clinical settings; and considerations of appropriateness and efficiency in Internet use in professional practice.

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#### Internet Interventions for Depression: Panel

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Depression is a major cause of disease burden worldwide and a leading risk factor for suicide. Most people with depression do not receive evidence-based treatment. Many are reluctant to seek professional help due to the stigma associated with mental disorders. The web offers an opportunity for people with depression to access depression information and treatments anonymously. There are currently three publicly accessible depression Internet interventions of demonstrated efficacy on the web: BluePages Depression Information (bluepages.anu.edu.au); MoodGYM (moodgym.anu.edu.au) and the ODIN Internet Intervention (www.feelbetter.org). The panelists, the developers of these websites, will discuss the content of the websites, the results of efficacy and effectiveness studies of these sites and issues related to engagement and retention on websites. BluePages Depression Information is an educational site containing online depression and anxiety quizzes, information about the symptoms and experience of depression and its diagnosis, sources of help, and evidence-based information about medical, psychological and alternative treatments for depressive disorder. It also incorporates a depression specific search engine. Griffiths will describe the content of BluePages and the results of a community-based randomized controlled trial of its efficacy in increasing depression literacy, decreasing depressive symptoms and improving stigmatizing attitudes to depression. MoodGYM is an online self help cognitive behaviour therapy program containing 5 modules that teaches techniques for identifying and modifying dysfunctional thoughts, relaxation and other behavioural change, problems solving and assertiveness. Christensen will present results of randomized controlled trials of MoodGYM's efficacy, effectiveness and cost-effectiveness together with data on attrition. The ODIN Internet Intervention is an online self help cognitive behaviour program meant to be used as a stand-alone therapy or in combination with telephone counseling coaching calls. Clarke will present results of published and in-progress randomized trials, and introduce an updated website for youth with depression. Discussion will focus on effects that may be observed against a background of traditional usual care for depression (pharmacotherapy, psychotherapy). At the conclusion of

the presentations the panel members will discuss future directions for online depression intervention development and research.

### **Oral History and Medicine and the Internet**

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Oral history has been defined as 'the interviewing of eyewitness participants in the events of the past for the purpose of historical reconstruction'. It is a discipline with standards for the acquisition, storage and retrieval of these interviews. There are some analogies with the process of acquiring, storing and retrieving medical information from the Internet. Therefore the two disciplines may provide useful mutual support. Oral history often provides an important addition to the existing record of events and has been shown to make valuable contributions to the study of scientific discovery. Though the use of the Internet in medicine is relatively recent it is not too early to look for possible participants able to fill in the detail left out of conventional scientific papers. Having chosen the theme, the oral history study is planned. Ethical permission is likely to be required if sponsoring bodies are involved and data protection registration is usually necessary. The potential interviewees are contacted. Explanations are made and discussions initiated regarding the purpose and scope of the interviews. Informed consent has to be obtained as the participant's copyright in the material will have to be transferred to an archiving authority given that an agreement has been reached as to how it will be used. It is understood that should any questions during the interview prove unacceptable they will be deleted without comment from the recording. The interviews are held in suitable uninterruptible venues and last normally between one and two hours. The format is best part-structured with a brief chronological survey of background and career leading to the involvement with the Internet and medicine, including outcomes and evaluations and finally any vision of future developments. The recording is made using the best available equipment to minimise errors in the transcript. Digital recording has the advantage of easy transfer to a PC for the purpose of transcription and for making CDROM copies for review and archiving. The use of video recording is increasing. It brings its own problems, but should be considered where a visual element is important. Though computerised voice recognition is not practicable for the interviews, some progress has been made in allowing the interviewer to listen to the recording and to dictate into a voice recognition program. This should make the process of transcription more accurate, quicker and cheaper. Copies of the recording and transcript are returned to the interviewee for review. Editing or amendments may be made, given that they are acceptable to both parties to the interview. The consent and copyright transfers are signed and the paper transcripts and recordings are delivered to the archive, where the material will be made available to researchers within the terms of the copyright. Publication on the Internet is still relatively rare, though prototype markup languages have been developed to assist with this usage. Oral histories of health informatics (USA) and of medical decision support (UK) are under way with some availability on the WWW planned.

### Relationship Between the Use of Internet Information for Health Purposes and Medical Resources Consumption for An English-Speaking Sample

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Background: Many researchers in the fields of Information systems and medical sciences are manifesting a special interest to the area of the Internet use for health-related concerns because the Internet is becoming an important source of information for patients and clinicians (Eysenbach et al., 1999). Indeed, some statistics reveal that more than 93 million American people looked for health information on the Internet in 2002 (Pew Internet & American Life, 2003). Objective: Patients find on the Internet some answers to their health-related questions that make them consult clinicians less frequently, demand fewer complementary medical exams, do less "shopping" for other clinicians, seldom call medical staff for explanations, or spend less time with clinicians (Coile, 2000). However, many people think that the use of Internet information can increase healthcare resources consumption because Web information can make



patients become confused and depressed (Pew Internet & American Life, 2003). The purpose of this research is then to study the relationship between the use of Internet information by English-speaking patients and their consumption of medical resources. Even though the literature dealing with Internet information related to health is abundant, only one study tested this relationship but focused on French-speaking patients (Khechine et al., 2004). Methods: A quantitative study based on a ten-item questionnaire was performed. Questions deal with two variables that are "Habit of using Internet information" (the independent variable) and "Consumption of medical resources" (the dependent variable). The sample is made of 121 patients that suffer from a long-term disease and that are accustomed to the use of the Internet for health-related concerns. Results: Construct validity and reliability were ensured. All items have loadings greater than 0,5. The path coefficient between the two variables is significant and high (0,482). The predictor variable explains 23,3% of the dependant variable. The use of health information by patients has a positive relationship with their healthcare resources consumption. This result can be explained by the fact that patients may misunderstand, be overwhelmed, or confused by the poor quality of the information obtained from the Internet. As concluded by Khechine et al. (2004), this situation can lead patients to make the wrong decisions or to worsen their health state. Conclusion: The results of this research may have theoretical and practical contributions to the fields of management information systems and medical sciences. Indeed, researchers will be concerned with the role that Internet information can play in the management of medical systems and with the design of health-related Websites.

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### Use of An Online Module To Reduce Size Discrimination In the Classroom

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Background: Negatives attitudes of obesity promote size discrimination, social stigma, and body dissatisfaction. Such factors have been associated with inappropriate weight loss efforts and deleterious health effects [1]. Unfortunately, weight-related stigmatization occurs in elementary and junior high school more than any other setting [2]. The recent increase in the prevalence of childhood obesity in the United States [3] emphasizes the need for sensitivity training among professionals who work with children. For this study, principles of the non-diet approach [4] were used to develop an online educational module for schoolteachers. The benefits of conducting online research have been reported previously [5]. Objectives: To test the effectiveness of an online educational intervention to change negative attitudes of obesity; to assess the effect of subject body mass index (BMI=kg/m2) on attitude; and to assess qualitative data about the online module. Methods: Graduate and undergraduate students enrolled in Education degree programs and schoolteachers were recruited via classes and professional organizations, respectively, in the New England area. A secured conferencing software program was used to deliver the educational intervention module and the Antifat Attitudes test (AFAT) at pretest, posttest, and six-week follow-up. Qualitative data, self-reported heights and weights, and demographic information were also obtained via the software. Subjects (n=101) were randomly assigned to a control or treatment group. The intervention promoted normalized eating, acceptance of size diversity, implications of weight loss efforts, and bias-free intervention techniques. The module content was developed using peer-reviewed journals, textbooks, professional reports, Internet, and video clips. Experts in the area of nutrition, obesity, metabolism, nutrition education, and size acceptance reviewed the module for accuracy, ability to meet objectives, and clarity of point. One-way repeated measures analysis of variance was used to compare mean scores between groups at the three assessment periods. Two-way analysis of variance was used to examine the relationship between attitude and BMI. Results: Of the 101 subjects (mean age±SD=26±10 years; BMI±SD=26±5), the majority

were women (80%) and were students majoring in health fitness or elementary education (63%). Attitudes of obesity improved as a result of exposure to the educational module (pre to posttest) (P = 0.000) and the more favorable change in attitude was sustained 6 weeks post intervention (pretest to follow-up) (P = 0.000). No difference between means was noted for the control. These findings indicate that the module was particularly effective in increasing a sense of size acceptance. Subjects' BMIs did not influence attitudes of obesity. Based on qualitative data, subjects appreciated gaining insight into issues of size discrimination and gained skills in appropriate intervention techniques for the classroom. Conclusions: Communicating the size acceptance paradigm online appeared to reduce negative attitudes of obesity regardless of subject BMI. This more favorable change in attitude was sustained six-weeks post intervention. It appears the module would be especially useful for teacher training in size sensitivity. The benefits of the online educational module include a self-paced design and convenient access by participants. The efficacy of conducting online pre and in-service teacher training in health education is encouraging.

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# The Individual and the Information Society: Consumer Access To Own Health Information and Services On the Internet

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Background: Internet and electronic techniques have opened new possibilities in the world's health care settings. Consumer self-management is one assumption for health services' improvement [1]. Previous research show that health consumers believe they have more influence, are better informed and more satisfied when using interactive services [2,3,4]. Electronic evolution in Icelandic health settings is supposed to be in context to the governments' policy of Information Society 2004-2007, including consumer services at the State Social Security Institute of Iceland (SSSI) [5]. Objective: Objectives of this research were to study Icelandic consumers' perceptions, and attitudes regarding access to own health information and SSSI's interactive services on Internet and provide information about their preferences. Further it was to study if beneficiaries' and public consumers' viewpoints differ regarding this. Methods: A descriptive mail survey with comparison design was performed. A random sample of 1400 individuals age 16 to 67 from the Icelandic population were divided into two groups of 700 each: (1) beneficiaries basing their support on compensation according to the laws of social insurance and (2) other public consumers having right to social insurance in Iceland. The questionnaire consisted of 56 questions, descriptive statistics were used and comparison made with 95% as confidence level of significance. Results: Response rate was 34.9%. Participants' (N=434) feedback was in general positive despite scarce experiences of interactive services. Perception of rights to access own health information was 52% and experiences 12%. Beneficiaries were older, they had significantly better perception than public consumers of rights to access (t419=-2.77 p <.006), more assertive preferences and positive attitudes to its impact. Majority believed they should have access (90%) and on its usefulness (81%). Positive attitudes to access impact were most related to decisions, information, perception and communication owing to services. Young participants using the Internet showed more positive attitudes to electronic access than others. Public consumers used and had the Internet much more at home than beneficiaries (p <.001). Conclusions: This research is the first of its kind in Iceland. Results supported previous research findings, consumers think favourably of an electronic health record and expected access will improve communication and understanding of own health. Beneficiaries' and public consumers' viewpoints were significantly different. Results are recommended as a prototype for evolution of interactive services at SSSI and health care settings in Iceland, alongside foreign projects. Further research is recommended on employees' viewpoints. Studying impact of interactive services in Icelandic circumstances would be interesting in the



future, specially related to consumers' well-being and services expenses and rearrangement.

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### Improving Physician Skin Cancer Skills

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N/A I will only be presenting a software demonstration as part of the NCI group

# A Novel Website To Improve Asthma Care: Qualitative Analysis of End-user Experiences

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Background: Research indicates that health practitioners often do not follow asthma guidelines.[1-3] Nevertheless, patients who ask their practitioner for test and treatments are likely to get them. [4, 5] Objective: To explore patients' reactions to and use of an interactive website designed, using current evidence-based guidelines, to provide patients with tailored feedback and help them understand what questions they should ask during doctor visits to improve the quality of care they receive. Methods: We created a website where patients were asked questions about their asthma care and then received evidence-based personalized feedback based on their answers. Feedback consisted of three elements: (1) a list of suggested questions for patients to ask their physician, (e.g. "would I benefit from a daily inhaled corticosteroid?" and "would I benefit from using a long-acting bronchodilator like salmeterol?") (2) a lay explanation of why patients should ask each question, (3) links to other websites for further reading and explanations of the suggested topics. Adults with asthma and access to the Internet were recruited. Semi-structured phone interviews were conducted with 36 subjects that had used the website and subsequently visited a physician. Interview questions addressed issues including 1) use of the website before the visit; 2) utilization of information generated from the website during the subsequent physician's visit; and 3) how use of the website changed communication with their physician, if at all. Interviews were audio-recorded, transcribed, and entered into QSR NVivo® qualitative software. The transcripts were coded based on the grounded theory technique. Results: Analysis revealed two main themes. The first was a shift in attitudes regarding interactions with physicians: "I've been going to this doctor for about 17 years, [but this was] the first time that I've actually gotten anywhere with him as far as changing what he was doing for me [The website gave me] the questions to ask him that seemed to push him in the right direction as far as giving me something on a daily basis instead of the inhaler that I was becoming reliant on." The second theme revealed a change in how patients perceived their role in managing their asthma: "[Asking questions from the feedback sheet] creates a relationship where you're working together to create a plan, and it's not just the doctor creating the plan I have more knowledge now to be able to go to him and have him work on me." "[This time] I was able to speak about the fact that I probably should — or she probably should — look at other means of treatment, and that's different than my usual office visit where I don't make any suggestive

contribution to what part of treatment is. I just take it all in." Conclusions: Overall, the website and its feedback positively influenced patients' experiences, promoted physician-patient communication, and improved perceived quality of care

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### Case Study of PasseportSanté.net: An Overview of Learnings From Website User Data Concerning the Efficacy of the Internet In Informing and Empowering the General Public with Regard To Health Matters

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Background: PasseportSanté.net is a French language website for the general public whose mission is to provide the general public with practical, reliable and accessible information concerning the promotion of good health, the prevention and alleviation of health problems and the judicious use of complementary health care in combination with conventional medical practice. The site is privately funded by a charitable foundation and is free of any commercial influence. The published information is constantly revised and validated by a network of health professionals and scientists. The site has been in operation for eight years. Subject: One clear advantage of the internet over print publications is that user data provides fascinating real-time information on the use of the internet as a health information communication medium. PasseportSanté.net attracts over 450,000 visits per month and has accumulated such data. PasseportSanté.net is unique in that it is the only French language health website which is neutral (thanks to private funding), highly credible (because of its neutrality and the revision of the published material by recognised professionals), which provides health information integrating conventional medicine with evidence-based CAM, and which has extensive information on nutrition. It has a weekly newsletter and has several new interactive features such as a forum, blogs, and other user-generated content, as well as an increasing number of audio and video capsules. The statistics, which will be shared with conference participants, reveal which geographical region users come, what kind of information is viewed on the site, how long users spend on each page, how users find the site, what search terms are commonly used, the level of interest in video clips, the level and type of interaction between users, and the number of repeat visits. In addition, a recent survey asked questions designed to understand the role of such a website in the development of competencies and the increasing autonomy of the population when making decisions about health matters. This survey also provided socio-demographic data on users and insight into the motivation for visiting the site, user expectations, levels of satisfaction, suggestions for improvement and what users do with the information they find.



#### **Development of a Paediatric Diabetes Website for Families**

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We describe the development of a comprehensive, interactive website for families of children with diabetes (www.aboutkidshealth.ca/diabetes). The information architecture of the parents' section of the site follows the natural history of the disease through to adult outcomes. Content was elaborated from the book When a Child has Diabetes, written by the diabetes team at The Hospital for Sick Children, Toronto. Interviews were conducted with parents and clinicians during development to make certain that parent needs were being met and that the material was accessible. The parents' section contains over 67,000 words and includes 20 original medical illustrations and animations of procedures such as testing blood glucose and the administration of insulin. The children's section features three age-tailored, narrated Flash animations focusing on aspects of disease management such as carbohydrate counting and includes downloadable activities. Prototype testing was conducted with children in clinic during development of these materials. Two hour, task-based usability testing sessions were conducted with four parents. Sessions were audiotaped, videotaped, and on-screen mouse travel was recorded. Task-based data were analyzed qualitatively. Participants completed a pre-test questionnaire and a post-test site evaluation questionnaire. The post-test site evaluation included 24 positive statements about the site that were ranked on a 7-point Likert scale (1 - strongly disagree; 7 - strongly agree). Overall mean was 6.3, indicating a very positive reaction to the design, usability, and utility of the site. Usability testing yielded valuable insights. Modifications were made to the site based on the findings.

## Exercise "home Delivery Service" System for Elder People for Preventive Care At Home

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Introduction: Various kinds of measures and businesses have been experimentally introduced to help elder people lead healthy and pleasant lives. Particularly, the exercise which are intended mainly to build up muscle strength are found to be effective because each individual accordingly increases muscle strength regardless of age, which consequently has corroborated reduction of risks such as falling. However, conventional guidance on exercise is mainly provided at fixed facilities, and this fact limits users to "healthy" elder people who can visit such training facilities. Additionally, those elders who lost opportunities to visit those facilities for some reason also lost the support in improving their health conditions due to the lack of the exercise programs which can be carried out at home. This time, a home-visit-type exercise guidance program was developed to support the elders in doing exercise, and a health management system was constructed including personal information manager. The community-based experiment was carried out if such home-visit-type exercise guidance can be viable as the business to support the elders in their leading self-sustained lives and ensuring their QOL. This report is to introduce such home-visit-type exercise guidance program and health management system. Method: The exercise schedule was to provide guidance three times a week at the beginning (until an individual learns and makes correct exercise motions) and once or twice a week when the individual becomes accustomed to exercise (to check if the individual properly continues doing exercise). Electronic fitness chart of database was created for the items which are currently measured in physical fitness measurement (those which are already standardized, those

which are common but yet to be standardized, and items suitable for individual qualities) and the measurement items which have already been reported in papers and newly developed were added as many as possible, so that the items suitable for individuals can be selected. Result: With the system developed this time, visiting schedule management, exercise menus, and exercise records can be collectively handled. Concerning the six exercise machine items, each individual can arbitrarily enter and set up measurement items each time, and freely add and browse data. The main purpose is that the elders appropriately make exercise motions, record them numerically, and compare them with their past records by themselves, therefore, many measurement items were set up. The fitness exercise file is primarily for an individual to record on a daily basis. But, in order to motivate individuals and measure the effects, video recording was also added. Discussion: The experiment was a short trial for three months and fifteen home visits. It might be pointed out the experiment period was too short to find if it would be useful for health promotion and to obtain favorable results of physical strength improvement. However, the purpose of exploring potential demand was achieved and findings about the method to explore prospects were produced.

### **Health Smart Card and Patient Safety**

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In recent years medication error has received considerable attention, as it causes substantial mortality, morbidity and additional healthcare costs. Medication error is a major source of preventable harm to patients in hospitals and is an area in which information technology will have a positive impact. The use of computerized physician order entry (CPOE) and on-line alert to reduce medication error is a common element of medication safety policy. We have implemented an automated alert system for drug-drug interactions (DDIs) in Taipei Municipal Wanfang Hospital (Managed by Taipei Medical University). This system will alert the clinician in real time if DDIs were detected on the same or different prescriptions in our hospital. However, it's quite common for patients in Taiwan to have drugs from different hospitals or clinics at the same time. Now our system could detect DDIs on prescriptions from different hospitals by checking the electronic prescription records on the NHI (National Health Insurance) IC card. The NHI IC cards have been used since 1 July 2003, and they have fully replaced the paper-based cards since 1 January 2004. Hospitals must support the cards in order to provide medical services for insured patients. There are four sections of information stored in NHI IC Card, including the personal information, the NHI-related information, the medical services and the public health administration. The contents of medical services section mainly include the drug allergic history, the long-term care prescriptions, the ambulatory care prescriptions and certain medical treatments. The electronic prescription record on the NHI IC card is a valuable source for detection of DDIs between prescriptions from different hospitals.

### Quality and Effectiveness of Online Learning for Advanced Practice Nurses and Other Allied Health Professionals

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Online learning has become a source for health related academic and continuing education. Busy health professionals are relieved to discover the large number of offerings that exist with few or no restrictions. However, these offerings should be critically evaluated by the user. Well designed offerings provide accurate contextual information, interactivity, navigational ease through the site, instructor and technical support, and evaluation of learning. The purpose of this study addresses the need for quality offerings for advanced practice nurses, physician assistants, and other allied health professionals. Online modules were developed to accommodate a wide variety of learners [1] using the educational principles of Chickering and Ehrmann [2], case study method [3], and recommendations from other authors reporting success with online education [4,5,6]. The modules were designed to be interactive, realistic, competency-based simulations that closely resemble clinical practice. The modules allowed the learners to proceed at their own speed with extensive links for additional information. Online testing and evaluation were incorporated



into the modules. To date, over eighty health professionals have completed one or two of the two modules including pretest and posttest knowledge and attitudinal evaluations. Findings reveal a significant increase in knowledge scores and overall positive attitudes toward this type of online learning consistent with findings from other researchers [7]. The design, implementation, and evaluation of the modules along with recommendations for future online educational programs will be presented.

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# A formal Framework for Deployable Mobile Healthcare Applications

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Ikhu-Omoregbe N.A., Ehikioya S. A., and Ayo C. K. Department of Computer and Information Sciences, Covenant University, Ota, Nigeria ABSTRACT Background: Health care delivery in any typical hospital or health care center across African countries is usually cumbersome with enormous paper work, waste of life, time and resources, long queues, and ineffective treatment procedures [1]. The use of mobile technology devices such as Personal Digital Assistants, Cell phone, Tablet PCs etc for health care delivery promise a revolution in modern health care. Thus, designing and deploying mobile applications with clinical and administrative functionalities at health care centers would reduce medical errors by enabling access to updated patient's information [2,3]. Easy access to information at the point-of-care via handheld devices could bring about substantial life and cost savings and help to address the high mortality rate of more than one in six prevalent in Sub-Sahara Africa [1,4]. Objectives: The objectives of this paper are: (1) to provide a framework for the design of Operations support in e-Health based systems; (2) to provide a robust architecture which ensures easy administration of patient care; (3) to implement a prototype to demonstrate how mobile application can improve health care delivery in a health care setting Methods: We used Object Constraints Language and Unified modeling language to formalize the requirements gathered by interview process. The Client application is developed with Wireless Markup Language. The Server application is developed in java language and provides access to MS Access database. The server receives patient electronic records via an API that returns diagnosis and treatments information in the form of XML document. Results: The application has been tested with openwave v7 simulator, which emulates the Wireless Application Protocol, gateway on a (3-tier) client-server architecture separated by a mobile network The applications shall be eventually deployed at the Covenant University Health Center, Nigeria. Conclusion: The formal framework provided in this paper, could serve as a specification document for mobile health care application development and deployment. Furthermore, since the mobile phone coverage in most part of Africa is developing at appreciable rate [5], the application could be deployed on the National Health Care Networks or existing mobile infrastructures to address the shortage of specialist in rural areas.

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### Evaluation of PHRs and Patient-Physician Messaging Systems In Chronic Care – Studying Healthcare From An Operations Management Point of View

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Background: Patient Health Records (PHR) and patient-physician messaging are increasingly used to improve communication between patients and physicians., The Institute of Medicine, identified email as valuable tool for flexible consulting and speculated that "instead of a \$65 office visit and a half-day of work, a 2 minute email communication could meet many patients' needs more respectively and at a lower cost". Chronic patient care, such as diabetes management, often requires frequent communication. A large part of this communication is routine in nature and can be done asynchronously. Little research exists about the efficiency of these services. This paper presents some core findings from an extensive statistical evaluation of the effects of patient-physician messaging on chronic patient care. Objective: Our objective was to examine how messaging as an intervention changes patient processes. This study looked at two specific research questions: 1) how messaging intervention affects the use of patient care resources and 2) how messaging affects the demand for different care functions. Methods: An extensive study was conducted at a large multispecialty group practice in the California. We analysed the PHRs and messaging with Operations Management (OM) methods, in order to evaluate their efficiency in chronic patient care; namely on type II diabetics. We studied a pre-post cohort for 12 months before and 12 months during the messaging intervention. We examined the resources used and calculated the differences in utilization between pre- and post-periods. This method was designed to control for individual utilization pattern contributed to age, gender and other chronic conditions. We picked a sample group of diabetics that had used the patient-physician messaging system for at least one year and that were using it in March, 2005. The population studied was broken into three groups, each consisting of 127 patients. The messenger population studied was self-selected and the product was commercially available. The two control groups consisted of patients without internet contact and patients who used the internet for information viewing, but not messaging. Results: We found that chronic patients using the messaging service used more resources than the control groups. Statistical analysis suggested that this may be explained by the quantity of health problems they exhibited. Based on an analysis of appointments and telephone calls 12 months pre-and-post the intervention, messaging seems to stop a growing demand on appointments and telephone calls. There was a statistically significant substitution effect of phone calls and visits by the messaging. This will be illustrated by individual case studies of patient care episodes, where changes in patient demand patterns are looked at in detail. Conclusion: This study shows that messaging intervention has a significant effect on chronic patient care productivity. Applying operations management methods to studying the phenomenon provided a valuable insight to changes in care processes, use of resources, and therefore efficiency.

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### Quality Demands of Patients with Regard To E-consult In Primary Care

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Nicol Nijland

Background: Ideally, e-consult systems should satisfy the quality demands and needs of groups most at risk, like the lower educated or elderly patients and those, who frequently use medication or frequently visit their general practitioner [1]. Objective: To examine the quality demands with regard to the use of secure e-consult of various health consumer groups that currently use internet. Methods: Data were collected using an internet based questionnaire. We assessed attitude to e-consult, demanded service quality and those needs that are important in the empowerment of patients by means of five point rating scales. We further assessed age, level of education, chronic use of medication (e.g. for asthma or diabetes) and frequency of GP visits. Results: Of 765 respondents sufficient data were available for statistical analysis, 472 females (62%) and 291 males (38%). In comparison to younger respondents, respondents older than 45 year demanded more service quality from e-consult (P = .01), perceived a higher need of careful use of e-consult (P = .001), a higher need to use e-consult to support direct (P = .001) and indirect control of care (P = .001) and a higher need to use e-consult to support control of information (P = .005). Respondents with a lower level of education (below college level) had a significantly more negative attitude to e-consult (P = .001), demanded a higher level of service quality from e-consult (P = .001), perceived a higher need of careful use of e-consult (P = .001), a higher need to use e-consult to support direct (P = .001) and indirect control of care (P = .001) and a higher need to use e-consult to support control of information (P = .002). Chronic users of medication had a significantly more negative attitude to e-consult (P = .05), demanded a higher level of service quality from e-consult (P = .003), perceived a higher need of careful use of e-consult (P = .004) and a higher need to use e-consult to support direct control of care (P = .001). Patients who frequently visited their GP (at least once every three month), had a significantly more negative attitude to e-consult (P = .05), demanded a higher level of service quality from e-consult (P = .002) and perceived a higher need to use e-consult to support direct control of care (P = .04). Respondents, who did not frequently visit their GP (at least once every three month), perceived a higher need to use e-consult for convenience (P = .002).

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### Evaluation of the Lack of Quality of E-consultation As Perceived By Experienced Patients and Providers In Primary Care

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Background: Despite its potential, the use of patient-provider e-consultation has not yet been widespread in primary care due to concerns about the quality of care [1]. However, there is little empirical research into the lack of quality of e-consultation. Objective: To determine the lack of quality as perceived by patient and providers with experience in e-consultation. Methods: We carried out in-depth structured interviews with 19 patients and 11 providers (GP and other care providers), who currently use secure e-consultation systems, i.e. secure internet based systems with direct consultation by email and indirect e-consultation by means of triage systems. In-depth interviews with patients and providers were conducted to assess the quality of e-consultation, using as

a framework for the discussion the quality criteria as outlined in the Institute of Medicine report [2]. Quality criteria were tailored to specific e-consultation systems and we assessed lack of quality with regard to e-health policy, implementation, usability, quality of interaction between patient and provider, control of care, and control of information. Results: The 19 patients mentioned 125 incidents of lack of quality and the 11 providers mentioned 105 incidents of lack of quality. Mentioned incidents were categorized independently by two observers into the quality categories. Among patients most incidents of lack of quality were related to inadequate implementation (33%), lack of ability to control information (18%), lack of good usability of the system (17%), poor e-health policy (15%) and poor quality of interaction (14%). Lack of control of care was infrequently mentioned by patients (4%). Among care providers most incidents of lack of quality were related to poor implementation (35%), poor usability of the system (28%), poor quality of interaction (15%) and poor control of care (8%). Lack of control of information was infrequently mentioned by providers (1%). Conclusions: It can be concluded that both among patients and providers inadequate implementation causes most incidents of lack of quality. Among patients lack of quality of control of information is frequently mentioned, but not among providers. This problem can be attributed to the use of medical terms and medical thinking in triage systems, which poorly reflect the problem solving strategies of patients. Unexpectedly, it was also found that care providers do have more problems in usability of e-consultation systems than patients. This is caused by incompatibility of e-health systems with available electronic patient record systems.

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### Health Information Seeking On the Internet In Spain: Evolution Or Revolution ?

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Background: The Internet is currently an important source of health-related information [1]. Health information is one of the most commonly searched topics on the Internet [2] but little is known about who accesses this information in Spain and how this Internet usage is evolving. Objective: To describe the characteristics of Spanish people who seek health information on the Internet and determine if there is being any change on these population characteristics. Methods: We analysed Internet users data from the "Survey on the equipment and use of Information and Communication Technologies in Spanish households (ICT-H)", for year 2003 (n=4663) and year 2005 (n=6779). Two multivariate logistic regression models were developed (one for each year) to identify variables associated with online health information seeking. The following socio-demographic characteristics were analysed: sex, age, education level and other relevant household conditions. Results: In 2003, Internet health information seeking was significantly associated with being female (odds ratio [OR] 1.33. 95% confidence interval [CI] 1.15 to 1.54), being 26 to 55 years old (OR 1.77, CI 1.50 to 2.10), having Internet access at home (OR 1.59, CI 1.36 to 1.87), attending computer courses (OR 1.52, 95% CI 1.23 to 1.67) and using Internet frequently (OR 1.52, CI 1.23 to 1.87). However education level, degree of urbanisation, and presence of children in household did not influence the health-related Internet usage. In 2005, there were significant associations with being female (OR 1.46, CI 1.31 to 1.63), 26 to 55 years old (OR 1.65, CI 1.46 to 1.88), having Internet access at home (OR 1.63, CI 1.44 to 1.84), attending computer courses (OR 1.24, CI 1.11 to 1.39), using Internet frequently (2.05, CI 1.76 to 2.39), living with children under 15 (OR 1.13, CI 1.01 to 1.27) and residing in an area with population over 10.000 inhabitants (OR 1.17, CI 1.01 to 1.36). Nevertheless, education level had no significant association with Internet health information seeking. Conclusions: In Spain, adult women are the main online health information seekers similarly to other countries [3], ICT equipment, frequent Internet usage and computer skills are basic characteristics to take advantage of health information available on the Internet. However, education level is a poor predictor of this Internet usage. The rural/urban digital



divide seems to gain importance for online health information seeking. The traditional female role on family health care decisions [4] may explain the evolving significance of presence of children living at home. Despite the short time covered by the analysis, changes are observed on Spanish online health information seekers. Policy may focus on reducing lack of computer skills but further research is necessary to understand long term evolution.

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### Health and the ICT Industry Sectors: Working Together for Success

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Although it is recognized that ICT solutions could fill identified needs within the health care sector, the ICT industry has struggled with defining and executing successful business models within this complex sector. Recognizing this, the e-Health Industry Project was established in January 2005 to act as a catalyst in connecting e-health Industry with health/wellness decision makers. Four services are provided to Industry through the Project: 1) networking-local, provincial/territorial, national and international; 2) workshops, showcases, and demos; 3) impact studies, and 4) industry project space. Impact studies, in simulated and real health settings, are conducted using ICT tools/solutions to determine if such products can be sustained, and assist with bringing best practice, evidence-based information and knowledge to the point of care. Industry Project membership includes small, medium, and large sized companies across Canada. Concrete examples of services that have been provided to Industry by the Project will be outlined and shared, along with testimonials from both industry and the heath sectors, during the presentation. This activity to date has led to the identification of specific and growing ICT business opportunities within health for companies of all sizes, as well as to strategies to assist Industry with defining operational ROI models for success. The Project is jointly funded by Western Economic Diversification and Alberta Innovation and Science, and is built on a self-sustaining cost-recovery business model.

### Improving Communications In Clinical Trials Using a Web-Based Communications Log

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Background: The process of conducting multicenter clinical trials generates significant telephone communications that play an important role in decision making by the research team. Availability of up-to-date information during the conduct of such trials is a useful adjunct to the process of enrolling and treating study patients. Frequently these communications are poorly organized or lost in the process. Objective: To develop a Web-based log system to document and organize telephone communications with a search and reporting function to facilitate decision making; to make the system accessible any where any time; and to include a linked study directory containing the contact information for study personnel. Methods: We devised and implemented a comprehensive communications logging system called CommLog® which contains a study directory and communications database [1]. The system was developed based upon a multi-tier component-based architecture. Security mechanisms were implemented to protect the study information from being seen by unauthorized

users and sniffers. Users with different rights were assigned to different permissions to limit and grant their proper access to the trial information. Results: The CommLog© system has been utilized in a number of industry-sponsored clinical trials. In two completed phase III studies, it recorded 6,278 calls from study personnel at more than 600 international sites, and in one completed phase IV study, it stored 1,064 calls from physicians prescribing the medication. The organization and accessibility of the study communications have been proven key to the success of these studies [2-3]. Study personnel at the coordinating center, the sponsor's research team and monitoring team can retrieve the documented phone conversations in a real time fashion, and generate a variety of reports online. The net result is a dramatic shortening of the turnaround time for the research team to review the phone conversations and relevant reports. In addition, the built-in study directory provides an important tool for coordinating center personnel to locate contact information of study persons and sites from anywhere anytime. Conclusions: The CommLog© system provides an organized approach to document telephone conversations while coordinating clinical trials, thus improving the quality of clinical studies. It has become an invaluable and indispensable tool for coordinating clinical trials at the Vanderbilt Coordinating Center and has enhanced communicating with the industry sponsors and other study team members. The system continues to be used in multi-center, international studies.

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#### Optimizing E-trial Recruitment and Administration

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Background: Use of the Internet to access health information is growing in the United States [1]. Thus, the Internet is increasingly attractive as a mode for conducting health research studies. However, limited information exists about the opportunities and challenges of recruiting for and conducting e-trials. The Center for Health Communications Research at the University of Michigan (UM) has launched novel program projects studying effective health communication. Collaborators include Group Health Cooperative (GHC) and Henry Ford Health System (HFHS). Two research interventions are on the Internet. Project Quit offers tailored smoking cessation advice and nicotine replacement patches. Guide to Decide studies whether and how to customize the presentation of numerical information in order to help people make difficult health decisions, using a breast cancer chemoprevention decision aid. Through these two studies, the researchers learned important lessons about recruiting for and administering Internet-based research studies. Objective: To add to the evidence base regarding the necessary strategies and resources for recruiting participating to e-trials, and managing participation. Methods: Participants for both studies were recruited from GHC and HFHS. Researchers used automated data to prescreen individuals for probable eligibility. Potential subjects then received an invitation letter by U.S. Mail inviting them to visit the UM-hosted study website and enter an access code, and enroll themselves. Using a case study approach, we summarized lessons learned about how to optimize intervention delivery and participant recruitment and enrollment. Results: Conducting an e-trial in an HMO population is fully feasible. However, our experience highlights a series of technical, administrative, and human considerations for recruitment and study implementation over the Internet. Testing such studies for appropriate security, aesthetics, and logic requires substantial time and planning, and collaboration between scientific-, operationaland IT-oriented personnel. Documented consent is not possible over the Internet, raising participant verification challenges. Many people who want to participate



need additional help, so specialized customer service is necessary. Participants appear to regard Internet programs differently -- while some appreciate the convenience, others think it is too anonymous. Additional qualitative and quantitative data will be available to present at the time of the conference. Conclusions: The Internet is an increasingly viable strategy for conducting and recruiting for research in the U.S. However, doing so requires unique technical and customer service planning. IT is increasingly accepted and expected in health care, which in turn creates research opportunities. Researchers should be cognizant of the fact that the inability to verify whether invited participants are truly the users of an e-trial intervention may introduce biases.

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# Lessons From Interprofessional E-learning: Piloting a Care of Elderly Module

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Educating health care professionals is a key issue in the provision of quality health care services. Interprofessional education has been suggested as a means of meeting this challenge. This paper reports on the effects of combining interprofessional education and web-learning for teaching elderly care. Four Finnish universities of applied sciences providing education for nurses, social workers and physiotherapists wished to develop the content and methods of teaching the care of elderly by collaboratively creating and implementing an interprofessional module of 15 European Credit Transfer units, using e-learning. The module was planned and implemented in 2002-2003 and it consisted of five units: - Concepts of elderly, aging and the position of ederly in society -Supporting the memory impaired elderly with coping with everyday life -Elderly customer care systems and case management - Primary nurse as family support in the care of the elderly - Working together on behalf of rehabilitative care for the elderly The participating institutes collaboratively planned the module implementation model, the students' learning process and the plan for assessment. The assessment of the module was based on student feedback, comparative assessment by the teachers, working life expert's assessment of the material produced by students and assessment by e-learning experts that concentrated on the whole pedagogical implementation of the module. The outcome of the experiment was that the web-based environment eminently suited teaching interprofessional care of the elderly. It supported content and methodological development and renewal of the module. It enabled discussion and collaboration between nursing, social work and rehabilitation teachers and students from the universities located in different parts of Finland. However, it became evident during the pilot that the most crucial challenges of the web-based pedagogy were the ability of the teacher to supervise, support and motivate students and the organisation of interprofessional learning offered by collaborating institutions. In conclusion, the pilot study proved the need for further long-term evaluation in interprofessional e-learning. This type of web-based module could be achieved within the fields of art and culture, catering or physical exercise. In addition, an e-learning module that does not rely on place or time, would be a suitable method of complimentary training of people employed in the field.

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### Interactive Web Application for Evidence-Based Medicine Training

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Interactive Web Application for Evidence-Based Medicine Training Introduction: The practice of evidence-based medicine (EBM) imposes utilization of the best available evidence resulted from medical research on

individual decisional process [1]. All over the world, the education on evidence-based medicine concepts represent the first step in EBM implementation [2,3]. In response to the necessity of education on evidence-based medicine in Romania, an interactive web curriculum on deepen EBM concepts was developed and its effectiveness was assessed. Methods: Ninety-six fourth-year medical students decided voluntary to enroll into the study. There was not use any randomization method because enrollment to the study supposes to assign time and attention to a subject that is not included into educational curriculum. Fifty-six students enroll to a mini-course on EBM and an eighteen-item questionnaire was used to measure the acquired knowledge. Forty students enroll to follow the interactive curriculum on EBM and their acquired knowledge were evaluated thought a forty-five tutor-assisted multiple-choice questionnaire at the completion of the self-training period. The results were analyzed according with data distributions by applying of nonparametric tests. The results were summarized and analyzed by the use of Statistica. Results: The assessment of the students' which participated on mini-course on EBM show that the median of the correct answers was 11, with a minimum of correct answer equal with 38.89% and a maximum equal with 88.89%. The assessment of the students' that followed the interactive web curriculum on EBM shows that the median of correct answers was equal with 38, with a minimum of 71.11% and a maximum of 93.33%. The average of the proportions of correct answers in self-directed group (0.844, n = 40) was significantly greater (P = .0174) compared with the average of the proportions of correct answers in directed group (0.617, n = 56). Discussions: The study demonstrates that the interactive web approach on evidence-based medicine education was efficient and effective, obtaining significantly better results comparing with a traditional intervention. The most important advantages offered by the interactive web curriculum on EBM are: allows of chousing the proper time, environment and speed of education, and provide an environment of training, evaluation and access to medical evidence useful in solving the problem-based clinical questions. From the developer point of view, the web approach on EBM training give the possibility of updating educational materials in real time and as many times at it is considered necessary and/or opportune.

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# Information Needs of Patients with Colorectal Disease: The Role of On-line Support

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Background: Quality of life is integral to medical care and prognosis is improved by an efficient coping strategy facilitated by adequate information delivery [1]. The need is acute amongst cancer patients and colorectal disease generates a unique set of concerns related to the possibility or actual presence of a stoma [2]. Objective: The aim of this study was to examine the satisfaction with information provision and to assess the potential use of web-based support. Methods: Forty patients who had undergone colectomy were interviewed using a standard questionnaire. Opinions were sought on the adequacy of information and support provided at the time of diagnosis and during the perioperative period and enthusiasm for web-based methods gauged. Results: Of the 40 patients interviewed. 26 were males and 14 females (mean age of 62 years. range 21-88). The majority 28(68%) had colorectal cancer, 9 (22%) colitis and 3 (5%) other conditions. 20 (50%) had stomas. 38 (95%) felt that the information given at diagnosis was clear and 36 (90%) that it was sufficient. 36 (90%) were satisfied with the level of emotional and social support and 35 (88%) agreed that staff were available to answer any questions. 32 (80%) patients initiated contact with staff prior to surgery and of these 8 (20%) were "nervous" about disturbing healthcare staff. Operations had been clearly explained in 36 (90%) cases, but 5 (12%) described the operation as not being what they expected. A



number of patients (6, 15%) felt they had been insufficiently informed about the details of surgery such as the use of catheters and intravenous lines. 70% of patients said they had immediate access to the internet and one third of the other 30% who did not have access said they would be able to access the net elsewhere if required to. 28 (70%) were interested in using a hospital website as a source of additional information where as 20 (50%) were keen on on-line discussion groups. Conclusion: Despite indicating that they had received an adequate amount of information and support 80% of patients still actively sought further information pre-operatively. This study suggests that there is a need for further information and support among colorectal patients and that many patients are interested in using web-based support which can be used to complement the current information delivery system.

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## Availability and Quality of Websites offering Information On Alternative Medicine In the Treatment of Colorectal Cancers.

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Background: More people are now looking for additional information on the internet than ever before. This has made internet a powerful tool to reach out to the common man to disseminate health information [1]. Many patients, family members and carers are also considering complementary and alternative medicine as one of the options. [2] Objective: We looked at the quality and availability of web based information on alternative medicine in the treatment of colorectal cancers. Methods: A google search was done using the term 'colorectal cancer treatment'. The first 1000 websites were visited and evaluated for information on alternative medicine as a treatment option for colorectal cancers. Of the 1000 sites visited, 68 offered such information. Each of these sites was evaluated using a questionnaire and the 'Discern' instrument for reliability and quality of information. The discern tool was originally developed by a team of experts in the university of oxford. It was devised to enable simple and reliable way of assessing health related information on medical websites [3]. Results: Google identified 3,590,000 sites for the search term colorectal cancer treatment. Of the first 1000 websites that were looked at 68 (7%) had alternative medicine mentioned as a form of treatment for colorectal cancer. The most common alternative therapies listed were herbal medicine (56%), nutritional therapy (50%), acupuncture (37%), homeopathy (21%), mind and body therapy (21%), aroma therapy (15%), naturotherapy (13%). 47 (69%) of these sites were non-commercial. Only 8 (11%) of the sites acknowledged conventional medical treatment as an option where as 15 (22%) provided links to conventional treatment. 2 (3%) of the sites even dismissed conventional treatment. Although 47 (69%) had clear organisation, the information provided was confusing and difficult to understand in 21 (31%). 28 (41%) provided no form of evidence base i.e. quoting a paper, anecdote, testimonial, etc to verify the authenticity of the information. By using the Discern instrument sites were classified in to excellent 8 (11%), very good 8 (11%), good 14 (20%), fair 23 (33%) and poor 15 (22%). Conclusions: There is an extensive amount of information available regarding complementary and alternative therapy for colorectal cancers. Many patients actively seek such information especially after diagnosis [4]. Clinicians should be prepared to discuss these issues with patients and help them seek evidence based information in order to prevent patients from being misled.

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### E-Health and User's Cultural Characteristics – Potential and Limitations

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Introduction: This paper addresses the health information supply and demand characteristics through the lenses of cultural differences and globalization. The Hofstede Cultural Dimensions Model - Uncertainty Avoidance, Power Distance, Masculinity, Individualism and Long Term Orientation - is used to compare countries' dissemination and use of e-Health Information. Of particular interest for this study are Power Distance -Equality between individuals and Uncertainty Avoidance - propensity to avoid uncertainty. Countries high in power distance and uncertainty avoidance have been shown to have patients using more antibiotics in general and seeing their doctors significantly more often while those countries with low uncertainty avoidance have patients with more of a tendency to address their own symptoms using their knowledge. We intend, in this paper, to compare these two types of countries on their health information seeking behaviour in general, and on the Internet in particular. Methods: We explored the published literature and collected data through secondary sources. We compared countries high in uncertainty avoidance and power distance Results: Countries high in uncertainty avoidance and power distance use the Internet significantly less for health information dissemination or access. Those same countries have stronger laws regulating the use of Internet for such purposes. Discussion: Cultural differences seem to have a strong impact on healthcare practices and health information supply and demand. Countries with high power distance characteristics and uncertainty avoidance seem to rely more on the doctors as a source for such information. Conversely, countries with low power distance and uncertainty avoidance have more e-health websites available and individuals use them more. There seems to be more behind the health information seeking behaviour than the mere availability of that information. The lack of trust in that information may be explained, to a large extent, by the cultural characteristics of the patient. Conclusion: e-Health as a discipline should take a stronger consideration of cultural differences to explain the impact of the source of health care information on different countries and adapt the communication to the different targeted cultures. Countries with a higher diversity such as Canada and the U.K. should take cultural differences into consideration even when the health information is being targeted to individuals living within the country. A model aimed at (1) increasing our understanding of the cultural aspects of health information seeking, and (2) stressing the importance of culture of origin in the use of that information needs to be developed since the Internet is becoming a major source of health care information for many individuals around the world.

### Non Gay Identified Men Who Have Sex with Men (NGI-MSM) & the Internet

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Introduction Little is know about NGI-MSM sexual risk behaviors particularly NGI-men who have sex with men and women. Anecdotal evidence suggests that these men are using the Internet to find male sex partners. An online survey was developed to collect behavioral information on MSM including men who have sex with both men and women in order to identify if this latter population: a) would respond to an online survey and b) constitutes a high-risk, bridge population. Methods An online behavioral survey was conducted April through December 2005. The survey collected data from over 851 men and included questions on sexual behaviors and STD/HIV history. Results 162 men (19%) of the total sample did not identify as gay. All had sex with another man within the past 12 months. The majority of respondents identified as White (75%), followed by Latino (8%), mixed race (6%), Black (5%), and Asian (3%). Approximately half of the sample is age 30 years or younger. 23% reported



female "main partners". The majority of respondents are not using condoms with their main sex partner regardless of gender. 31.5% stated that they had ever been tested for a STD; 13% had never been tested for a STD. Only 10.5% of the men reported a STD as reported to them by a health care professional. Genital warts were the most frequently cited STD. 35% had ever been tested for HIV; 9% stated they had never been tested for HIV. 3% have been told that they had HIV by a health care professional. The Internet was the most frequently listed venue for finding married men for sex and for finding partners for unprotected sex. The majority (83%) have at least one online profile containing sexual information for the purpose of finding sex partners. Discussion Our data suggests that members of this population are at high-risk for STD/HIV transmission and acquisition however NGI-MSM continues to be an elusive group of men. Larger samples are needed to collect more data on risk behaviors. Data from this survey can be used to develop future, and much needed, research on NGI-MSM and help guide STD/HIV prevention programs targeted at this population.

# Facilitating the Prototype and Usability Testing of EHealth Programs Using An Internet-Based Tool

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One of the most time intensive activities in eHealth development is testing prototypes with content experts and target audience users. An effective prototype review is extremely important since it is the best and most efficient time to make content, programmatic, or structural changes to ensure that all program elements work together to create the desired impact on the target audience. Often prototypes are not fully functional and require extensive explanations to help reviewers generate effective and helpful feedback. Expert reviewers tend to have limited time and often are geographically distant from the project, making reviews difficult to schedule and complete. To solve some of these issues, Klein Buendel, Inc. developed an electronic prototype review shell. The shell surrounds prototype materials with instructions, background information, and review tools to help experts and target audience users review prototype materials from any geographic location with Internet access, on their own time and without face-to-face guidance. The prototype shell was used in a feasibility study of a web-based nutrition assessment and education tool for middle school aged children. Three main prototype elements were tested using the prototype shell - look and feel examples of the website design, a hard-coded fruit and vegetable consumption assessment, and a sample educational module. Each element required a unique set of instructions and background material to facilitate review, which required the structure of the shell to be adaptable to the various elements, yet uniform enough to avoid user confusion and constant re-learning. The prototype shell also included a downloadable review form that assisted reviewers in navigating the website as well as focusing their review on important aspects of the prototype elements. Content experts, school district administrators and teachers in Dallas, Denver, and smaller cities and towns throughout Texas and Colorado reviewed the prototype elements. Project support staff was available via telephone and email to assist reviewers with technical difficulties and other questions. Very few reviewers requested assistance and all completed the review in a timely manner. Reviewers enjoyed the flexibility the Internet-based review provided and gave constructive feedback through the review form and emails. The prototype shell saved time and effort during the review process. The prototype shell is designed to be generic so it can fit a wide variety of content. The outer areas of the shell contains instructions, background information and navigation elements while content is always presented in the middle area of the shell. The content area is visually separated from the prototype shell to help reviewers easily distinguish content they are reviewing from instructions, background information, and overall navigation. These features allow the shell to present a variety of prototype materials without hindering the usability of the website as a whole. This presentation will highlight the details of the prototype shell, demonstrate the flexibility of the prototype shell and discuss effective use of the shell and it's future plans.

### The Monitoring System Using IC Tag for Application To the Medical and Welfare Fields

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Introduction: The rate of aging has been accelerated in non-Western world in the last decade, and caring for demented elderly is becoming the social issue. Increasing concern for patient safety for demented elderly tends to confine patients in restricted areas. It is a difficult problem about how demented elderly are kept safety and assigned in the safety space. Also a patient after operation will separate from a bed and will take dangerous action. There is also a case which it not only leaves a room, but goes out to town in a dementia patient. If such people's action can grasp at clear and a moment, safe management can be taken in advance. Then, we have made the watching system using the Integrated circuit (IC) tag. The IC tags can be used to improve patient safety by real time monitoring without restricting patient movement. Method: When an active IC tag passes through the trigger field, the tag will send its ID and the trigger field ID, and the receiver will catch the information. PC system stores the information which are time, place and individuals. This information are display on real time as the monitoring system, including the check of the whereabouts on the individual whereabouts of a care scene, a wandering situation, and a bed, use of a toilet, fall detection, the individual amount of movements, etc. Result: Software developed for this system displays the graphical display of the human movement, the distance walked per day, and number of detected by the receiver during 24-hour period by location and by ID number of the IC tag carrier. Discussion: In health care settings, this system could be used to detect falls, to prevent eloping, to conduct needs assessment for rehabilitation, to evaluate rehabilitation program, and to evaluate the quality of dementia care. This IC tag system can be operated through internet and can use for information which can be used for extraction of the stream of a thing or people, control, restriction, the check of safety, and the rescue in an emergency in various situations Although IC tag watching system has the problem of privacy, we think that it is acceptable as necessary for safety.

# Developing Recommendations for "WFME Guidelines and Strategies for Medical E-Learning."

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Aim: The workshop is intended to establish an international TaskForce, which can assist the World Federation of Medical Education (WFME) in 1. Describing a standard?, which can be used - also in developing countries - in planning the use of e-learning in medical education. 2. Collecting and distributing knowledge of learning materials and modules which are freely available to the community of medical educators 3. Collecting examples of how WFME standards? are implemented and supported and how learning management systems are used in this support. 4. Making recommendation to the WFME of to what extent WFME should participate in developing standards? within the ICT areas. Background In 1998 WFME published recommendations regarding the use of Information and Communication Technology (ICT) in Medical Education and a revised version in 2001. During the last five years several changes in technology development and the process of globalization has taken place and the use of ICT is ever expanding within several fields such as internet based learning, knowledge sharing, videobased communication, simulations and telemedicine Today, the international community of medical educators is confronted with several challenges related to these issues. Some are related to infrastructure and planning of ICT in medical education. Others are related to the pedagogic/didactic aspects of using ICT. Method: The workshop will cover the four subjects: (1) a scheme for planning use of e-learning for the first time , (2) how to collect and distribute free learning material, (3) WFME standards and e-learning support and (4) development of global standards in ICT. The subjects will be discussed in small groups and in plenum. Based on the results of the discussions, a Task Force will be formed with representation from all regions of the world and the further work will proceed by e-conferencing methods. Expected outcome: WFME wants the Task Force to end up with



recommendations within all the four areas in 2008 where the results should be published and presented at international meetings.

### A Usability Study To Evaluate the Suitability of a Portable Wireless Solution for Infection Control Practitioners

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Background: In 2003, Ontario faced a serious threat, an unknown infectious agent; Severe Acute Respiratory Syndrome (SARS) spread through health care settings such as hospitals and clinics. 44 people died and thousands became ill or were quarantined. Many lessons were learned from this outbreak highlighting the difficulties in the containment of infectious diseases in both hospital settings and for public health. [1] Campbell, 2004 [2] Walker, 2004. After SARS, a provincial regulation required hospitals to screen for 'Febrile Respiratory Illness' (FRI) for patients entering the hospital. Positive screens must be forwarded to public health units. Business Problem: Hospital staff, like much of the health care system, is stretched thin. Additional requirements such as the FRI surveillance were viewed as time consuming and burdensome. Hospitals also had other public health reporting such as West Nile virus, influenza A and Streptococcus A. These reporting mandates created friction between ICPs and public health, and an easier way to collect information in regional hospitals was sought. Public health was investigating a wireless solution to aid in the collection of this data. Objectives: The purpose of the review was to focus on the FRI Surveillance task flow, processes, and potential for a wireless solution acceptable to both public health and Infection Control Practitioners (ICPs) with consideration of longer-term public health requirements for the ICPs. Methodology: Researcher's job shadowed one hospital ICP and conducted one-on-one, in-depth interviews with three additional ICPs from other hospitals (total population of eight ICPs). Interviews were also conducted with public health management involved in disease surveillance. Workflows were mapped and user profiles were developed [3] (Manning, 2003) [4] Cooper, 2003). Recommendations were presented to public health and hospital staff for review and feedback. Results: Any automated process must allow the ICP to enter data at the source (the ward) and only once. Otherwise ICPs will return to using paper and then have to transcribe the paper copy to the system, thereby doubling their effort. PDAs are appropriate for limited data entry, but are onerous for forms of one or two pages. One page of paper form translates roughly into 2 screens of web pages but requires 8-12 IPAQ size screens. Regardless of the device selected for ICPs to enter data, an internet based connection for distributing forms and communicating them to Public Health will be required. An internet based solution will be strategic, scalable, flexible and adaptable. Conclusion: This poster will demonstrate how the study, using personas, contextual inquiry and task analysis was used to investigate potential reporting solutions. Although a wireless solution was not recommended, there were several design implications for the health care sector to improve its data collection and reporting. For this purpose, PDAs, although portable allowing for data entry near the data sources can have shortcomings in their flexibility, security and cost to develop. Any system implemented must be simple, secure, and scalable, have built-in redundancy, and leverage existing systems.

# Can Internet Interventions Meet Emotional Needs of Managing Chronic Conditions?

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Background: Successful self-management of a long-term medical condition requires patients and their carers to manage both the condition and its emotional consequences [1]. Interventions to support self-management must address patients and carers needs on both levels. Internet Interventions are web-based packages that combine health information with peer support, decision support or behaviour change support. To date research has focused on the potential of

Internet Interventions to meet information needs e.g. [2;3] and the potential of online peer support to meet emotional needs [4]. However the wider potential of Internet Interventions to meet emotional needs is unclear. Objective: To elicit patients and carers' emotional needs and their perceptions of how Internet Interventions could meet them. Methods: Qualitative focus group study. Disease-specific groups of patients and carers managing diabetes, heart disease, hepatitis C or Alzheimer's used three relevant Internet Interventions before discussing their views in a focus group. Focus group transcripts were analysed by a multi-disciplinary group using a qualitative framework approach. Results: We ran 10 disease-specific focus groups in 3 UK areas, involving a total of 40 participants. Participants revealed extensive emotional needs linked to and influencing their information needs, and discussed how certain types of information and different ways of presenting information can meet their emotional needs. Access to extensive information, particularly scientific information (even if users did not need at the time) relieved general anxieties. Information acknowledging the emotional impact of illness was reassuring. Information about new research and treatment options was needed to give hope and optimism. Quizzes, self-assessments, personalised monitoring and feedback tools were thought to provide motivation for their own efforts and light relief from stress and worry. Personal experiences from other patients or carers provided reassurance and motivation and reduced feelings of isolation. Online peer support was considered useful for support when overwhelmed and reducing isolation when depressed. However, many participants preferred to access other people's experiences by reading personal stories or answers to questions asked by other patients and carers rather than using online peer support. Patients and carers felt extensive information, interactive tools, other people's experiences and practical resources (e.g. example questions to ask) would empower them and boost confidence in their own abilities. Conclusions: Our findings argue for the potential of Internet Interventions and suggest they offer additional, indirect ways of meeting emotional needs beyond direct emotional support offered by online support groups.

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# Assessing Consumer Health Vocabulary Familiarity: An Exploratory Study

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Background: Accurate assessment of the difficulty of consumer health texts is a prerequisite for improving readability. General-purpose readability formulas based primarily on word length are not well suited for the health domain, where short technical terms may be unfamiliar. We previously developed a regression model for predicting "average familiarity" with consumer health vocabulary (CHV) terms. Objective: The primary goal was to evaluate the predictive ability of the CHV term familiarity model among actual consumers. Secondary goals were to explore the joint effect of demographic factors and familiarity and 2) surface level familiarity (ie, recognition) and an understanding of the underlying meaning (ie, conceptualization). Methods: Survey instruments for assessing surface level familiarity (45 items) and conceptual familiarity (15 items) were developed. All participants also completed a demographic survey and a standardized health literacy assessment, S-TOFHLA. Results: Based on surveys completed by 52 consumers, linear regression suggests that predicted CHV term familiarity is statistically significantly correlated (P < .001) with participant scores on both the surface-level and conceptual familiarity surveys. Health literacy was a statistically significant predictor of surface-level familiarity scores (P < .001), and a marginally significant predictor of concept familiarity scores (P = 0.06). Educational level was not a significant predictor of either. Participant scores indicated that conceptualization lagged behind recognition, especially



for terms predicted as "likely to be familiar" (P = .006). Conclusions: This exploratory study suggests that the CHV term familiarity model is predictive of consumer recognition and understanding of terms in the health domain. Future validation studies will need to involve greater participant diversity and incorporate a more extensive selection of terms. Potential uses of such a model include readability formulas tailored to the consumer health domain and tools to "translate" professional medical documents into text that is more accessible to consumers.

### Physician office Readiness for Managing Internet Security Threats

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Background: Internet security threats are evolving toward more targeted and focused attacks. Increasingly, organized crime is involved and they are interested in identity theft. A recent report showed an increase of over 140% percent in the number and severity of Internet security threats in the last 6 months of 2005 [1]. These threats include viruses, trojans, spam, spyware, phishing, pharming, intruder and many other ever newer, ever more nefarious threats (malware). Increasing use of the Internet in medical practice is exposing medical clinics to these newer threats. Physicians who use Internet in their practice are at risk for being invaded. Objective: Although many have made recommendations about privacy and security practices for medical clinics [2], there are few studies that actually address physician office readiness to handle Internet threats. We sought to understand physician knowledge, perception, readiness and actual security practices to address various Internet related security risks. Methods: We used questionnaires, site assessments and actual detection of threats using an advanced, monitored Internet security device (ISD), capable of providing real-time detection and management of common Internet threats to study physician practices. 16 physicians in Southern Ontario who use the Internet in their practices were recruited for the 2-month study. They completed pre- and post-study questionnaires. All sites were assessed for presence of firewalls and malware detectors on all workstations. Frequency of updates and scans was also assessed. Results: 90% of physician had heard of 7 common Internet threats. 70% indicated they are aware of Federal and Provincial privacy legislation and 55% said their practices complied with the legislation. Physicians in the study had an elevated sense of their ability to withstand Internet threats -65% felt safe from most Internet threats and 75% felt satisfied with their current Internet protections. However, physicians in the study were poorly equipped to handle newer threats. Although 90% of physicians had a firewall, none actively managed them. 80% of workstations in the practices studied had a virus checker. Tellingly, only 60% had an updated virus checker and only 40% of workstations had had a scan within the past month. Less than 25% of practices had spyware or spam detectors. Conclusion: Passive firewalls and infrequently updated virus checkers are poor defenses against determined attackers who are increasingly less likely to be amateurs and students and more likely to be part of organized crime, determined to steal identities and to utilize vulnerable computer networks for spreading spam and viruses. Organizations wishing to increase utilization of technology in community physician offices need to carefully consider the vulnerability of these locations and provide adequate, monitored and managed protection from Internet security threats and regular preventive workstation and network upgrading.

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# Clinical Decision Support for Vascular Disease In Community Family Practice

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Introduction: Clinical decision support systems have been shown to improve clinical care and patient outcomes in a variety of diseases. Clinical decision

support has generally been provided in institutional settings, yet over 80% of patients with chronic disease are taken care of in community primary care clinics. Problem: The consistency and quality of care provided to patients with chronic disease is quite variable in the primary setting. We sought to develop a scalable and sustainable architecture for providing clinical decision support to primary care physicians in a setting where there is little IT or clinical support. Solutions: We utilize 3 innovations to deliver clinical decision support to 50 community physicians in Southern Ontario. First, a web-based, vascular disease tracker (C3VT) integrated with electronic medical record systems allows physicians to receive up-to-date, evidence-based clinical guideline advice in a simple and easy to digest format at the point of care on 16 vascular disease risk markers. Physicians can also see a population based view of their patients. Patients have access to the same information that their physician sees about them, only in patient-friendly language. Second, we utilize a 'clinical architecture' or workflow that supports team-based care in fee-for-service and capitation-funded family practice clinics. A clinical care coordinator (CCC) travels from practice to practice, assisting physicians to follow-up on their patients and to provide patients with the support and guidance they need to implement the suggestions provided by their physician. An automated telephone reminder system (ATRS) uses a voice-print authentication mechanism to authenticate patients and then reminds them to book an appointment with their physician quarterly and asks them to get their lab tests done 10 days before they see their physician. This ensures that critical data required during the encounter is available at the point of decision-making. Finally, we have developed a scalable and sustainable technical architecture. The clinical practice guideline algorithm service is provided through a web-services connection, allowing physicians to access the latest algorithms using their existing Internet connection. For sites where Internet service is unreliable, we place an inexpensive Linux server on the network which provides the same functionality. The Linux server checks for updates to the algorithms on a daily basis to ensure it is using the latest algorithms. Evaluation and Extent of Implementation: The system is currently implemented at 18 clinics in Southern Ontario. Over 1100 patients and 50 physicians are participating in a randomized-controlled trial to test the safety, effectiveness and cost-effectiveness of the system. The system has been in place for approximately 9 months. We will discuss the key features and benefits of the C3VT.

# Changing Behavioral Stages In Diabetic Children By Adaptive Interactive Applications

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Background: Passive patient empowerment or patient education will not insure the patients' action to change their behavior toward their chronic disease. Therefore the available interventions should be designed to change the behavior of the patients rather transferring abstract knowledge about the disease. Objective: This research will study the effect of 'Adaptive Games' in changing the behavior of diabetic children positively toward their disease and educating them in order to empower the self management process for their disease. Methods: Patient empowerment will be approached through the Stages of Changes Model a modified version of the original Transtheoretical Model. Adaptive or intelligent games will learn from the patients' situation based on their medical records and personal profiles and then the game will adapt itself to the new situation and create new strategies to educate the patient in order to reinforce positive behavior on the part of the patient. The game strategy adaptation will be created by applying a hybrid Ruled Based and Fuzzy System on an available open source game engine. Results: The proposed solution, the game, will be evaluated in a prospective between-subject experiment to measure the effect of the game in changing the behavioral stages of diabetic children while considering the Human Computer Interaction (HCI) factors.

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### Telemedicine Digital Electro-phonocardiography: Costeffective Strategies In Screening for Left Ventricular Dysfunction

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Background: Left ventricular dysfunction (LVD) may be asymptomatic, commonly misdiagnosed in primary health care, but occurs frequently. Screening with the expensive echocardiography is impossible, but with the use of digital phonocardiography a lot of important clinical data could be collected [1-4]. Objective: To develop a community-based program to screen for and treat left ventricular dysfunction (LVD), the role of telemedicine and two non-invasive methods (digital electro- and phonocardiography) were studied with cost analysis. Methods: The study population consists of a general population (GPg; N=192), low-risk group (LRg; N=113), and high-risk group (HRg; N=147). High risk patients were defined as those with any of: IHD, hypertension, diabetes, peripheral/cerebral vascular disease, and heavy alcohol use. The LVEF was calculated using the Simpson method, diastolic heart failure was defined according to the European guidelines. ECG abnormalities were defined: supraventricular tachycardia, atrial fibrillation/flutter, conduction defects, Q-, ST-, T-wave abnormalities, LV hypertrophy. The following DP parameters were determined by the wavelet (continuous; Mexican Hat) analysis of digital phonocardiographs (TriTest device, sampling rate 1kHz, in the range of  $20\mbox{-}12000\ \mbox{kHz}$  ): third, fourth heart sound, systolic murmur at mitral area. The murmur was analyzed by the automated digital subtraction of murmurs in space (local maxima in the mitral area) and in time (optical flow method). The ECG and phono measurements were done in remote sites; the data were stored in an internet server for the analysis. Four screening strategies were compared by sensitivity and cost/effectiveness analysis: Str1.: transthoracic echocardiography (TE) in all subjects, Str2.: ECG + TE if ECG is abnormal, Str3. : DP + TE if DP is abnormal, Str4.: ECG + DP if ECG is abnormal and TE if DP is abnormal. Results: The screening characteristics (sensitivity SE, specificity SP, positive and negative predictive value (PPV, NPV) in detecting LV systolic dysfunction were in the GPg: for ECG abnormal (89, 74, 16, 94,8%); for DP abnormalities (81, 86, 24, 94%); for ECG and DP abnormal (87, 91, 67, 93%), in the HRg for ECG abnormal (84, 62, 19, 93 %); for DP abnormalities (74, 82, 27, 96%); for ECG and DP abnormal (80, 88, 69, 91%). The Hungarian cost per case (in euro) of LV systolic dysfunction in high-risk patients for the four strategies: Str1: 230.1, Str2: 129.1 Str3: 89.4, Str4: 82.4 in low-risk subjects: 8387.5, 2900.2, 3565.1, 1599.4, respectively. This study has found that the telemedicine pre-screening of these patients by ECG and DP could produce great cost-savings compared with the TE screening alone (Str4: mean: 82.4 CI-95%: 69.5-96.4 versus Str1: mean: 230.1 CI-95%: 196.5-254.4; p < .001). Conclusions: Our study showed two special method of internet use in telemedicine application: firstly how to register ECG and phono data far from the cardiologist, secondly how to execute the complex math calculations using the store-and-forward method via internet. This kind of telemedicine application significantly raises the accessibility of general patient population to the adequate management of various heart diseases.

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# Fighting the STI Epidemic with An Innovative Online Tool To Promote STI Screening

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Sheetal Malhotra, The Medical Institute For Sexual Health Katherine Hendricks, The Medical Institute For Sexual Health Background: Early detection of sexually transmitted infections (STIs) through screening can prevent or minimize many STI consequences. About 19 million Americans are infected with an STI annually [1] and many are unaware of their infection. Despite this enormous public health problem, physician utilization of STI screening is poor [2,3]. To help address these problems and take advantage of the public's desire to seek healthcare information on the Internet, we have developed an innovative "STD Wizard" interface for the public. This online tool collects demographic and behavioral risk information and provides screening recommendations based on CDC guidelines [4]. Objective: To evaluate the usability of the STD Wizard and its impact on reported screening uptake in college students. Methodology: The STD Wizard was evaluated in college students using an intervention/nonintervention, pre-test/post-test design. 468 students from 52 undergraduate classes in two universities completed an online pre-test and were randomly assigned to an STD Wizard intervention or a nonintervention group. Post-tests were administered to all students at two weeks and two months. Results: 292 (62%) females and 176 (38%) males participated in the study. 100% of the intervention group found the STD Wizard easy to use; most (81%) also found it useful. 45% (97/216) of the students who went through the STD Wizard received screening recommendations. 57% (55/97) of students who received recommendations had seen (21%) or intended to see (36%) a doctor in the near future. Conclusion: The STD Wizard is an easy-to-use and effective online tool for the promotion of STI screening.

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### Real-Time Collaborative Videoconferencing: Promise for Pandemic Influenza Preparedness

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Background: The avian influenza H5N1 virus has caused considerable damage to the global economic and agricultural sectors, having rapidly spread from Southeast Asia to the rest of Asia, the Middle East, Europe, and to Africa since late 2003. The H5N1 strain has been increasingly threatening the human health sector, and is now considered to be a likely candidate for the next influenza pandemic. Countries in Asia and around the world are thus urgently preparing for pandemic prevention and response plans, and communication has been repeatedly cited as a key factor for preparedness [1, 2]. However, prior global exercises, such as "Global Mercury", have demonstrated that routine communication modes are inadequate to support transnational response to regional or global public health emergencies [3]. New technologies, such as Access Grid, may provide a possible solution. These networks are high through-put and open source, can implement common middleware to enable data sharing across multiple institutions, are dedicated to research and education, and are less congested than the commodity Internet. Methods: Using a well-established electronic network (Asia Pacific Cooperation-Emerging Infections Network [APEC-EINet]), we linked public health officials with the advanced network community (Asia-Pacific Advanced Network [APAN]) in the APEC region. APEC economies were invited to participate in a real-time Access Grid videoconference. Intensive content organization was carried over a six month period prior to the event; technical testing took only one month due to preexisting research and education networks. Vietnam, which lacked the necessary bandwidth and technology, was hosted in neighboring Thailand. Results: On January 19, 2006, a 210-minute real-time videoconference was held. Ten APEC economies, including the U.S. host, presented their epidemiologic situation and pandemic planning status. Few technical difficulties were experienced. Geographic and national tailoring of international guidelines was found. Clinical, veterinary and public health collaborations, molecular surveillance of the virus, scenario exercises, vaccine



and antiviral use, risk communication and business continuity planning were discussed. Among the nine invited economies, five economies responded to the post-videoconference evaluations, and all indicated that the Access Grid videoconference was both effective and efficient in promoting regional information sharing on pandemic preparedness. All responders indicated a keen interest in a future videoconference, with a focus on a timely and important topic to the APEC community. Conclusions: Access Grid videoconferencing was effective and efficient in promoting regional information-sharing and real-time interaction for pandemic influenza preparedness. Public health and advanced networks can partner to better plan pandemic preparedness and response in the APEC region. Deployment and utilization of videoconferencing technology, such as Access Grid, should be considered for pandemic influenza preparedness.

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## Panel On Wireless E-health (WE-health) Technologies for Diet, Nutrition and Quality of Life Monitoring

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We face a major public health time bomb associated with a global increase in obesity prevalence. Management of this complex, multi-factorial problem presents a number of challenges to the health care sector, in particular the need to provide ongoing support to individuals in monitoring their weight over the long term. People often overestimate the healthiness of their diet and the amount of physical activity they do and it has been suggested that greater awareness of eating and activity patterns may be the key to addressing the increasing problem of obesity, since people who have successfully lost weight report doing more physical activity and are more likely to monitor their intake in some way. The potential for new technology to support individuals and health professionals is therefore significant. With global access to the Internet increasing, the potential for the Internet to be used as a consumer healthcare tool in the prevention and treatment of obesity has never been greater. A wide array of web-based weight loss resources exist, although the quality and reliability of this information is variable. Despite the huge presence of such information on the Internet, little is known about their use or effectiveness for weight management, particularly in terms of cost-effectiveness. New wireless technology can support self-monitoring of diet and physical activity patterns by individuals, while also delivering a channel for communication with health professionals. A UK study into the impact of wireless technology in acute clinical environments identified significant potential time and resource savings, suggesting that investment in mobile networks, devices and wireless-enabled applications, throughout a range of health settings, can deliver a sizeable return on investment for healthcare organisations. Such technology could therefore empower people to make better decisions about their health status and result in improved collaboration with health professionals. To start this panel session, Dr Sara Kirk, a registered dietitian and Principal Investigator of an internet based trial will present an overview of the evidence for effectiveness of existing web-based weight management tools, with an emphasis on disentangling the effects of different components, settings and participants. Based on this appraisal of the evidence, common themes will be identified and key issues for the future will be presented for discussion. This will be followed by a presentation by Dr Carl Brandt, a General Practitioner from Denmark, who has set up several successful health websites, and who will share his experience in establishing "Slankedoktoren", a highly successful website for weight management in Denmark. The session will then focus on the potential of wireless technologies through a presentation by Professor Brian Hoyle, from the University of Leeds Institute of Integrated Information Systems, which is developing wireless open platforms that may be used for health status monitoring and self-monitoring. The potential for these to be used for improving the health of the population and their quality of life will be explored. Finally, Dr Alison Marshall, a Teaching and Research Fellow

in the Keyworth Institute, University of Leeds, will discuss the usability issues associated with emerging wireless technologies.

### Weight Loss Online: Results From a Community Trial Evaluating a Weight Control Website In An Obese Sample

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Background: Obesity is a major public health problem and the second most avoidable cause of ill health after smoking [1]. Novel methods for managing obesity are therefore needed. The rapid increase in access to the internet and its use as a health resource make it a viable tool for health care interventions [2], but data are lacking on the effectiveness of internet interventions compared with traditional weight management strategies. Objective: To describe the findings from the first study in the UK to evaluate the effectiveness of a website, based on traditional dietary, physical activity and behavioural features, in promoting weight loss in an obese sample in a community setting [3]. Method: A randomised controlled trial (RCT) was conducted to investigate the ability of the intervention website to produce a weight loss greater than that arising from usual care, defined as obesity management strategies that are typically available within the primary care setting. Participants were randomised to the Intervention (n=111) or usual care group (n=110). Objective measures of weight, height, waist and hip were recorded at baseline, six and 12 months. Data on physical activity, quality of life, dietary practices, self-efficacy and use and views of the website were collected. Repeated measures ANOVAs were used to investigate change over time. Results: Fifty-nine participants (53%) reported using the website at six months with 32 (29%) still using it at 12 months. Based on intention to treat analysis (ITT), a significant weight loss over time was identified in both groups (P = 0.01), but no significant difference in weight loss between the two groups was revealed (difference=0.6 kg; CI=-1.4, 2.7, P = 0.55). No significant between group differences were seen for any measures. Conclusion: This was the first RCT of a weight loss website, conducted in a community setting in the UK. The results suggest that the intervention website provided no additional benefit in terms of weight control in this sample over 12 months. However, the small sample size and high attrition rate seen in this study limited the findings. It may be that web-based interventions are better suited to short term use, alongside other more traditional approaches. Further research is warranted to explore these issues.

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# Internet Strategies for Clinical Services and Prevention Education In Sexually Transmitted Diseases, Including HIV

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The Internet allows men who have sex with men (MSM) to develop new social and sexual networks, resulting in more frequent opportunities to engage in a variety of sexual behaviors, including those that may transmit HIV infection. In fact, outbreaks of sexually transmitted diseases (STDs), including HIV infection, have been traced to users of specific chatrooms. In 1999, seven men, who reported multiple sex partners in the previous two months, contracted syphilis from men they had met in America Online's (AOL) San Francisco chatrooms; four of these men were also HIV-positive (Klausner, Wolf, & Fischer-Ponce, 2000). Community-based organizations (CBOs) and local



departments of public health have begun using the Internet in their HIV and STD prevention programs. In one study (Curotto, Rebchook, & Kegeles, 2003) of 23 CBOs nationwide, the most common online prevention method involved outreach workers announcing their availability to participants in gay chatrooms, with the goal to chat individually with persons online about risk reduction and prevention. That type of intervention accepts the Internet's structure and design as a given, employing a traditional method of health promotion—targeted outreach-to concentrate efforts to reach persons who are at increased risk because they use the Internet to meet new sex partners. Such interventions rely heavily on the continued presence and resources of staff and the funding agency. While potentially very useful at the individual level, these efforts often reach few persons in comparison to the total number using the Internet to seek sex partners. There is a growing recognition within the HIV and STD prevention community of the need for interventions that can alter the Internet environment using structural and political approaches. Some of the more creative, effective, and sustainable program efforts of this type have included online community forums, expert-facilitated chats, online advice columns, online partner notification programs, online testing services, banner ad and billboard advertising, community-level e-coalitions, and placement of warning labels on areas of web sites considered high-risk for behaviors that facilitate STD and HIV transmission. These methods have been more effective than one-on-one online outreach because of the combined support of the community-at-risk and the Internet Service Providers (ISPs). They also reach larger numbers of people at risk for HIV and other STDs, and can be less costly to implement and maintain. The panel members will discuss: 1) The current epidemiology regarding the Internet and STD/HIV transmission 2) Social networking theory as it relates to STD/HIV transmission and the Internet 3) Unique interventions to stem disease transmission 4) Evaluation methods for online STD/HIV prevention interventions

### **Internet Survey Methods: Reliability and Mode Effects**

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Background: Response rates to random digit dial (RDD) surveys have declined in past years, and it is especially difficult to sample adolescents and young adults via these methods. Cell phones, fax numbers, telephone screening devices, and business phone numbers make identification of households for sampling increasingly difficult. Online survey methods are gaining popularity as an increasing proportion of the adolescent population has Internet access. The response biases that occur with each sample vary. Objective: To examine test-retest reliability and mode effects on response biases of Internet vs. telephone survey methods. Methods: We surveyed 15-24 year olds about health behaviors and Internet access at time 1 and again two weeks later at time 2 using: 1) an age and gender quota sample from the Harris Poll Online; 649 respondents were weighted to represent the US population by age, gender, ethnicity and propensity to be online, and 2) a nationally representative random digit dial cluster sample of 198 adolescents, weighted to represent the US population by region, gender, age, and ethnicity. Subjects were asked items including scaled and response options to assess satisficing and other forms of bias. Topics include demographics; emergency contraception; sexual behaviors; condom use: access/utilization of routine and reproductive care, patterns of care, and pelvic exams; and quality of care and confidentiality. Additional items addressed technology and Internet use. Results: There was little difference in reliability (Cohen's kappa) across mode between time 1 and time 2 responses. Both the phone and online sample had kappas that were nearly identical for each question. Kappas for the phone group ranged from 0.32 to 1.00 with an average kappa of 0.75. Kappas for the online group ranged from 0.37-0.99 with an average kappa of 0.77. Most behavioral self-report prevalence rates were similar between online and phone samples. However, in opinion questions, online respondents were almost 3 times more likely to select "neither agree/disagree" than phone respondents. Conclusions: Adolescents are reasonably reliable in test-retest reporting of their health behaviors. Internet-based survey mode did not affect this reliability. For questions offering a no-opinion response option, the online sample was more likely to choose not to express an opinion. This may be due to satisficing, choosing the 'easiest' answer, or to a social desirability bias against 'not' having an opinion about a reproductive health issue, or to both. Future studies to understand mode effects on internet survey item self-report are needed.

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  probability samples with long questionnaires comparisons of respondent satisficing and social
  desirability response bias. Public Opinion Quartely 2003; 67: 79-125.

# Adolescents' and Young Adults' Social Networks In Cyberspace

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Background: There is concern among adults and youth that the Internet may lead to unsafe and predatory contact between children and adults. Adolescents and young adults are developing their identities, but little is known about how cyberspace interactions affect young people's social networks. Objective: To describe cyberspace use and the impact of Internet social networks on adolescents and young adults. Methods: We surveyed 15-24 year olds about Internet access and use using: 1) an age and gender quota sample from the Harris Poll Online; 859 respondents were weighted to represent the US population by age, gender, ethnicity and propensity to be online, and 2) a nationally representative random digit dial cluster sample of 609 adolescents, weighted to represent the US population by region, gender, age, and ethnicity. Results: All adolescents report access to computers and Internet use. The online panel reported access at home (95% vs. 79%; p =0.000), and more Internet use (94% vs.67% use a few times/week or daily; P = 0.000) than the phone sample.All online and 73% of phone respondents had email addresses (P = 0.000). Online respondents spent more time on the Internet (2.8 vs. 1.3 hours/day); 12% of teens and 36% of young adults live in households without landline phones; and 70% have >1 email address. In items asked only online, 45% use Instant Messaging (IM) every day; another 19% use it > twice a week. In contrast, 55% never and 22% rarely use chat rooms; only 12% chat >=once a week. Many (30%) have blogs or web diaries, 45% read each others blog sites, and 27% have secret screen names used when they don't want friends to know they are online. 61% of teens and 67% of young adults knew someone solely from Internet interactions; 26% and 44% had met someone in person whom they had first met online, respectively. Conclusions: Computer and Internet use from home is common for adolescents. Both online and telephone samples may under represent adolescent populations differently, with implications for survey methods. Chat room use is rare, but IM and blog use is common. Adolescents actively manage their online identities, and teens' social networks frequently contain blog Web sites and nodes. Many of these cyberspace relationships have led to real-time interactions. Parents' rules may not reflect the reality of teens' Internet use.

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#### Survey of Internet Use Among Physicians In Croatia

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Survey of Internet Use Among Physicians in Croatia Background: Worldwide, more and more people are using the Internet. In the second half of 2003, 44% of the Croatian population over the age of 18 was reported to be online, but we had no data regarding use by physicians. Objective: To conduct an interview survey to get a better insight into the habits relating to computer and Internet use among physicians in Croatia. Methods: A total of 390 physicians were randomly chosen from a database consisting of 3978 medical doctors. Fifty-four trained interviewers conducted one-on-one interviews with 390 medical doctors. The survey was conducted over a three-week period (October/September 2004). The questionnaire consisted of 32 highly structured questions and lasted 20 minutes. The key areas covered were: demographic characteristics, technical



aspects of the Internet and its contents. Statistical data was provided by the research agency Hendal. Results: A total of 390 physicians (response rate 76.9%) aged between 25 and 65 were randomly chosen from the database: 74% (222/300) were general practitioners (GPs) and 26% (78/300) were specialists (mostly neurologists, infectologists and cardiologists); 69.4% were female (208/300); the majority were employed in urban areas - 95.3% (286/300). Almost all interviewed physicians use computers (87%) and they use them mostly at home (78%). Specialists use computers more frequently, both at home and at work (70.5%), compared to general practitioners (34.7%). The majority of physicians who use computers also use the Internet (90.8%) and most of them use the Internet at home (55.9%). The Internet is used less frequently by physicians over 55 years of age. Almost half of the interviewed physicians have been using the Internet for more than 4 years (46%); 37.1% use the Internet several times a week and they mostly (32.1%) use it between 30 and 60 minutes a day. The majority of them (63.7%) use e-mail for medical and/or business purposes, and general practitioners are mostly non e-mail users (45.7%), compared to specialists (15.1%). Physicians mostly receive medical newsletters by e-mail (51.5%) and use e-mail for communication with their colleagues (43%). Physicians rarely use e-mail for communication with their patients (only 6.3%), even though more than a half of the interviewed physicians know that their patients search for medical information on the Internet (53.7%). The majority of physicians search for medical content (90.7%) and start their global searches with google.com and specialized portals. Conclusion: The majority of physicians in Croatia, both GPs and specialists, use computers and the Internet. Further studies should include a higher number of specialists to get a complete picture of Internet use among physicians in Croatia.

### Health Information Sources for Parents of Young Children: The Role of Internet

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Background: Well-child care includes a variety of health-promoting and disease preventing services [1]. A significant proportion of the well-child care visit should be spend on anticipatory guidance, however studies showed these recommendations are often unmet in practice [2]. One key to an improved provision of anticipatory guidance could be the use of other health information sources [2], like the Internet, to support the anticipatory guidance given during the well-child visit. Objective: The goal of this study was to determine the preferences of parents as well as actual use of various information sources including Internet for information relating to their child's health. Methods: Qualitative and quantitative data were collected among parents of young children. We conducted nine focus group sessions with a total of 50 parents of infants and toddlers to explore parental information needs related to their child's health and their use and preferences for information sources. A survey was conducted among a representative random sample of parents of 1,977 children aged 3 to 48 months, drawn from the patient registries of a regional well-child care provider. Parents received a postal questionnaire that assessed their use of various health information sources and parent and child characteristics (response rate 60%, n=1.190). Results: In the focus groups, parents of infants reported to be receptive to support of the well-child care provider in child health supervision. Parents of toddlers indicated that the role of the well-child care provider was minimal to them. Furthermore, parents said that Internet was an important information source. They also saw a growing role for Internet applications in well-child care, e.g. an online health information help desk accessible 24/7. On the other hand they did not want to exchange their face-to-face contact with the well-child care provider for an online health supervision system for the topics nutrition or child safety. The quantitative data showed that, at this moment, the most important health information source for parents of young children was the well-child care provider. The proportion of parents who reported the well-child care provider was the most important information channel was 40% for parents of infants and 31% for parents of toddlers. Other important health information sources were their environment (family/friends/acquaintances) and books/magazines/leaflets. Internet was of less importance. Only 6% of the parents reported that this was their most important health information channel. Conclusions: The qualitative data showed that there is a wide-use of the Internet for information relating to their child's health among parents of young children. However, the quantitative data showed that Internet was not the most important health information source for these parents. Although the importance of Internet

as health information source will grow in the near future, face-to-face counseling will most likely remain necessary to provide parents with the health information they need.

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### Recent Innovations On the Use of Telemedicine and E-Learning In the Conduct of Clinical Trials

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This session will review research on recent innovations on the use of telemedicine in the conduct of clinical trials in psychiatry. Three areas will be presented: 1) Use of Internet based technologies to calibrate and train raters at diverse sites in multicenter trials: 2) Use of videoconference to centralize ratings conducted in clinical trials; 3) A review of the literature (meta-analysis) on the equivalence of remote psychiatric assessments conducted remotely via videoconference to those conducted in the traditional face to face manner. ABSTRACT #1 Pilot Study of Video Telemedicine in the Ascertainment and Assessment of Primary Care Patients with Generalized Anxiety Disorder, Panic Disorder, and Major Depressive Disorder Janet B. W. Williams, DSW Objective. The results of many clinical trials are disappointing due to high placebo response rates. This could be due to a number of factors, including inappropriate patients being entered into the trial, and problems with the accuracy of the assessment process. Centralized raters could help to accelerate patient recruitment, and improve the quality of patients enrolled in trials by tapping into primary care physicians' practices via telemedicine. The quality and reliability of assessments should also be improved by using a small group of highly trained and calibrated raters. The purpose of this study was to examine the feasibility of identifying and recruiting primary care patients for clinical trials, and to examine patient satisfaction and adherence Method. Patients with Major Depressive Disorder, Generalized Anxiety and Panic Disorder were identified in two primary care practices by waiting room screening with the Patient Health Questionnaire. Once consented, patients were interviewed remotely by a centralized rater using high-quality videoconferencing. The first interview was a diagnostic interview (modified SCID); if qualified, the patient was asked to come back once a week for six weeks for follow-up evaluations (HAM-D, HAM-A, or PDDS), as if they were in a therapeutic clinical trial. Patients received treatment as usual from their primary care physician. Patients completed a satisfaction survey after their last remote assessment Results. 56% (79/135) of eligible patients agreed to participate and were administered the SCID by videoconferencing. Of these, 45 screend positive, and all 45 agreed to enroll in weekly evaluations. Of the 45 patients enrolled, 80% completed the six-week study with no more than 2 missed appointments. Nine patients (20%) dropped out of the study because of personal issues or being lost to contact. Satisfaction and comfort levels of the participating patients using telemedicine were very high, indicating that they would participate again and would not hesitate to recommend to others participation in clinical studies using videoconferencing. More than three quarters (77%) preferred videoconferencing, had no suggestions for improvements, or found no differences from face-to-face contact. Conclusions. Patient acceptance of remote raters is high. Patients in primary care settings will enroll, participate and complete research protocols using 'virtual' interviews (telemedicine). The impact of remote centralized ratings on signal detection in clinical trials must n o w tested.

Abstract #2 Development of a standardized training program for the Hamilton Depression Rating Scale using internet-based technologies: A Comparison To Traditional Rater Training In A Multi-Site Depression Trial Kenneth A. Kobak, Ph.D. Objective: Poor inter-rater reliability is a major concern, contributing to error variance, which decreases power and increases the risk for failed trials. This is particularly problematic with the Hamilton Depression Scale (HAMD), due to lack of standardized questions or explicit scoring procedures. Establishing standardized procedures for administering and scoring the HAMD is typically done at study initiation meetings. However, the format and time allotted is usually insufficient, and evaluation of the trainee's ability to actually conduct a clinical interview is limited. To address this problem, we developed a web-based, interactive rater education program for standardized training to



diverse sites in multi-center trials. The program includes both didactic training on scoring conventions administered on line or via CD-ROM and live, remote observation of trainees applied skills through videoconference and teleconference. The goal of this study was to compare the relative effectiveness of this approach to "traditional" rater training in a multi-center clinical trial. Method: 12 sites from a 22 site multi-center study were randomly selected to participate (6=traditional, 6=enriched). Traditional training consisted of an overview of scoring conventions, watching and scoring videotapes with discussion, and observation of interviews in small groups with feedback. Enriched training consisted of an interactive web tutorial, and live, remote observation of trainees conducting interviews with real or standardized patients, via video- or teleconference. Outcome measures included a didactic exam on conceptual knowledge and blinded ratings of trainee's audiotaped interviews. Results: A significant difference was found between enriched and traditional training on pre-to-post training improvement on didactic knowledge, t(27)=4.2., p <.0001). Enriched trainees clinical skills also improved significantly more than traditional trainees, t(56)=2.1, P = .035. All trainees found the applied training helpful, and wanted similar web tutorials with other scales. Conclusions: Results support the efficacy of enriched rater training in improving both conceptual knowledge and applied skills. Remote technologies enhance training efforts, and make training accessible and cost-effective. Future rater training efforts should be subject to empirical evaluation, and include training on applied

Abstract #3 The use of remote, centralized raters via videoconference in a multi-site depression trial: A comparison to site based raters Nina Engelhardt. Ph.D. OBJECTIVE. Rating fidelity may be improved by the use of a pool of centralized, independent raters who are not associated with investigative sites. Several reports have suggested that using different raters at baseline and endpoint in each patient improves signal detection. Two-way videoconferencing has been proposed to make centralized rating practical, in that a rater can be chosen from a pool of available raters without concern for the physical location of rater or patient to be rated. A central rater who has never rated a given patient before can be chosen to rate the patient at the conclusion of the patient's participation in a clinical trial. A central rater can be unaware of whether a patient to be rated is being considered for, continuing, or completing participation in a trial, and can thus be blind to study design (including intake criteria) and current visit, as well as to treatment given, laboratory test results, and adverse events reported by the patient. We report here on a comparison between site and centralized Hamilton Depression Rating Scale (HAMD) ratings in a two-center depression trial. METHOD. Patients were interviewed twice at each of three time points: screening, baseline, and endpoint, once by the site rater, and once remotely via videoconference by a centralized rater, who was blind to study visit and design (site raters were not blind to study visit/design). Raters were blind to each others' scores. A counter-balanced order was used at baseline and endpoint, All raters used a structured interview guide. Patients had to have a HAMD 17-item total score >= 17 at screening, and again at baseline in order to continue in the study. There were 7 raters in the centralized rater cohort, and 4 site raters (2 per site). Centralized assessments used unique raters at each visit, while site ratings generally did not. RESULTS. Site HAMD scores were significantly higher than centralized raters scores at screening and baseline, but not at endpoint. Correlations (ICC) between site and centralized ratings at screen and baseline were .33 and .40, but improved to .75 at endpoint. Internal consistency reliabilities (coefficient alpha) for centralized ratings were .71, .79, and .84 at screen, baseline and endpoint, and .31, .39, and .83 for site raters respectively. At the screening visit, 43% of patients given a HAMD total score of > 17 by a site rater were given a HAMD total score < 17 by a centralized rater. At the baseline visit, 57% of patients given a HAMD total score > 17 by a site rater were given a HAMD total score < 17 by a centralized rater. CONCLUSION. The use of centralized raters who are blind to study visit would result in significantly different study populations. Blinded centralized raters generally score depression severity lower at screen and baseline. Site and centralized ratings coalesced at endpoint. When information on how patients in the present study were treated become available, we intend to investigate whether central and site raters were comparably capable of discriminating between treatments understood to have different levels of efficacy.

### Internet Facilitating Global Cancer Staging:Expansion of the UICC-TNM Project Global Advisory Group

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Background Through e-communication channels, the UICC-TNM Project Global Advisory Group aims to enhance international collaboration in securing the TNM cancer staging classification as a standard for describing anatomic disease extent. Objective and Goals To demonstrate how the internet can be used as an effective tool to improve the standards of cancer care globally through the implementation of a uniform approach to cancer staging. Its immediate goal is to continue expansion by doubling, and thereafter continuing to increase its existing global membership. Methods A new process was introduced to facilitate open-ended participation in international cancer staging efforts. Communication within members of the Global Advisory Group was conducted electronically, and was integral to the success of this initiative. A strategic goal was to create new national Committees in as many continents as possible with multidisciplinary representation by medical, radiation and surgical oncologists, pathologists, clinical epidemiologists, cancer registries, and statisticians. The goals of these new national Committees include: disseminating information regarding TNM; proactively promoting its use in their country/region; stimulating awareness, building knowledge and facilitating the implementation of universal recording of stage; providing evidence-based expert opinion on the enhancement of staging and prognostic factors; representing the organization on national and international cancer staging committees; and acting as a conduit for proposals for changes to TNM. Results Since May 2003, new national Committees have been created in Australia, Brazil, India, Poland, Singapore, and Spain; bringing the total to 15. Efforts to extend the network to Argentina, The Netherlands, Ireland and Hungary are ongoing. Initial engagement in collaboration is high, in part due to access to and efficiency of the internet in facilitating the TNM Project's goals. Committees are actively developing membership, and terms of reference, and they send an Annual e-Report to the UICC. The internet was key in providing members with continued support, updated information and mentorship throughout this process. Conclusions and Future Directions The internet has served as a key tool in enabling the ongoing expansion of the UICC-TNM Global Advisory Group. Further applications include the rapid dissemination of information regarding cancer staging, translation of TNM into more languages, and the worldwide expansion of local expertise in a manner which is both cost-effective and timely. Plans for future strategies include the twinning of established with new Committees facilitated by internet-based communication, as well as encouraging new Committees to utilize internet-based resources. In conclusion, the experience and work of the UICC-TNM Global Advisory Group demonstrates the central role of the internet as an integral means of communication, and a pathway for efficient and effective dissemination of information amongst international collaborative health networks. It is anticipated that future innovative applications using the internet and other e-health strategies will allow further gains in the coordination and oversight of global cancer control.

### Virtual Clinic As a Support and Tool for Pregnant Parents

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Introduction: The childbearing families of today have experienced the development of information society. Many western countries, such as Finland, has made substantial investments in information and communication technology (ICT) -related education, training, research and development. Furthermore Internet access to information sources, information management and word processing are literacy skills needed by people for personal and professional communication. To be digitally literate, a person must be able to navigate, locate, communicate online and participate both in virtual and in physical, communities. Future definitions of literacy will include informatic abilities - a range of meaning-making/decision making strategies required to assemble knowledge in the virtual world. Effective self-management is very different from telling persons, e.g. pregnant family members, what to do. Individuals have a central role in determining their care, which fosters their sense of responsibility for their own health and wellness. Issues related to child-bearing families and the ways to use ICT as part of modern maternity care are topical. Objective: The purpose of this study was to describe both pregnant families' and professionals' experiences of the new maternity clinic service, virtual clinic, at the introductory phase of the service. A further purpose was to describe the basic safety prerequisites addressed when virtual clinic was developed and implemented by multiprofessionals into maternity care practice. Method: One way to find new solutions today is research and multilevel and multiprofessional development in which also health care customers participate. The development research approach was used to describe the context in which maternity care



was developed by means of new technology. By using versatile research tools, development research can give information on how ordinary pregnant families or multidisciplinary professional team create new ways of communicating or working. Data were collected through conversations (N=21 families), thematic interviews (N=10 maternity care professionals) and questionnaires with both structured and open-ended questions (N=80 project workers). Both qualitative and quantitative analysis methods were used. Results: The families attending virtual clinic developed a virtual sense of community, which gradually evolved into a real-life sense of community, by discovering the similarity of their life situations, by giving parent-to-parent support for life events and by also giving feedback concerning the maternity care service. The maternity care professionals anticipated that young people would be able to use ICT as part of maternity care services naturally due to their computer skills. According to multiprofessionals, a successful development project requires positive commitment, which result in a confidential and open atmosphere during the project. Differences in the working cultures between the participating organizations complicated fluent collaboration. Managerial support was very important during development. Discussion: ICT inevitably changes the role of customers, whose participation in service development and new services will enhance the empowerment of customers. In the long run, should there be follow-up studies to find out whether the available information caused more health and well-being in the pregnant families and even at the societal level? Education is essential to build a bridge between two generations: the generation educated before the ICT revolution and the e-generation, which has gradually learnt the versatile use of modern technology during the past twenty years. Will this increased health informatics literacy affect maternity care professionals' ways of working? How will those families who do not want to use virtual services act? Will they have more traditional services? Will maternity care professional have more time to visit pregnant families who have complicated

### Virtual Clinic As a Support and Tool for Pregnant Parents

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Abstract Introduction: Many western countries, such as Finland, have made substantial investments in information and communication technology (ICT) -related education, training, research and practical development. Today's childbearing families experience the development of information society. To be digitally literate, a person must be able to navigate, locate, communicate online and participate both in virtual and in physical, communities. Future definitions of literacy will include informatic abilities - a range of meaning-making/decision making strategies required to assemble knowledge in the virtual world. Effective self-management is very different from telling persons, e.g. pregnant families, what to do. Pregnant mother has a central role in determining her care, which fosters her sense of responsibility for her own and simultaneously future baby's health and wellness. Issues related to pregnant families' health and wellness and the ways to use ICT as part of modern maternity care are topical because time of pregnancy is very fruitful for enhancing health promotion. Objective: The purpose of this study was to describe both pregnant families' and professionals' experiences of the new maternity clinic service, virtual clinic, at the introductory phase of the service. A further purpose was to describe the basic safety prerequisites addressed when virtual clinic was developed and implemented by multiprofessionals into maternity care practice. Method: The development research approach was used to describe the context in which maternity care was developed by means of new technology. By using versatile research tools, development research gave information on how ordinary pregnant families or multidisciplinary professional team created new ways of communicating or working. Data were collected through conversations (N=21 families), thematic interviews (N=10 maternity care professionals) and questionnaires with both structured and open-ended questions (N= 80 multiprofessional project workers). Both qualitative and quantitative analysis methods were used. Results: The families attending virtual clinic developed a virtual sense of community, which gradually evolved into a real-life sense of community, by discovering the similarity of their life situations, by together describing moments of the pregnancy and delivery again and again, by giving parent-to-parent concrete help or support for life events, and by also giving feedback concerning the maternity care service, such as the timing instructions of departure related to childbirth. Based on ICT experiences the maternity care professionals working in virtual clinic were divided into three groups: 'Doubters', 'Accepters' and 'Future Confidents'. The professionals

assumed that young pregnant families would be able to use ICT as part of maternity care services naturally due to their computer skills learned in school. The professionals preferred that the teaching and training of ICT should be based on individual needs and skills. According to multiprofessional project workers, a successful development project requires positive commitment, which results in a confidential and open atmosphere during the project. Differences in the working cultures between the participating organizations complicated fluent collaboration. Managerial support of each organization was very important during development and implementation of new ICT tool. The data security was considered very important both by pregnant families and professionals. Discussion: ICT inevitably changes the role of customers like pregnant families, whose participation in service development and new services will enhance the empowerment of customers. Virtual clinic served as a forum of mutual support for the pregnant families and a mirrored of the given maternity service. By providing a real-life view of daily family life, virtual clinic gave maternity care professionals a deeper understanding of how to support safe pregnancy and growth of families. To encourage active participation and commitment to development projects, active attention should be paid to internal communication as well as to effective realization of the project tasks. In the long run, there should be follow-up studies to find out whether the available information caused more health and well-being in the pregnant families and even at the societal level? Education is essential to build a bridge between two generations: the generation educated before the ICT revolution and the e-generation, which has gradually learnt the versatile use of modern technology during the past twenty years. Will this increased health informatics literacy affect maternity care professionals' ways of working? How will those families who do not want to use virtual services act? Will they have more traditional services? Will maternity care professional have more time to visit pregnant families who have complicated problems?

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### How Do People with Arthritis, Fibromyalgia and Breast Cancer Feel Empowered By their Participation In Online Support Groups?

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Background: Ever since the rise of online support groups much is expected of the potential empowering effect of participation in online support groups for patients [1]. Although in literature many have pointed at this empowering effect [2, 3], little empirical evidence exists for how patients feel empowered by their participation. Objective: To explore how people with arthritis, fibromyalgia and breast cancer feel empowered by their participation in online support groups. Methods: The participants of nine publicly available online support groups for patients with arthritis, fibromyalgia and breast cancer were approached if they were willing to be interviewed. In total we interviewed 32 participants (11 arthritis, 11 fibromyalgia and 10 breast cancer). Respondents were interviewed in their homes or at another place they preferred, with the exception of three patients who were interviewed by telephone. The interviews were audio taped with prior consent of all participants and transcribed verbatim. Data were analyzed by two coders, using inductive analysis. This method involved that both coders separately read the entire transcript several times, to identify emerging themes. Then the two coders met to discuss their findings in order to resolve differences. Results: The majority of the respondents were women (n=29). The mean age of the participants was 43 years (SD 12.3 years) with a range between 21 and 75. The participants felt empowered by their participation in various ways. First, participants felt better informed. The information they received on the forum was quick, in 'their own language' and tailored to their personal needs. Second, participants felt emotionally supported. Especially the finding that 'they were not alone' helped them to cope with the disease. For some patients, the participation in the online discussion was reassuring, because they could compare themselves with others. Both upward (looking at people who are doing better) and downward (looking at people who are doing worse) comparisons were stated to be helpful. For most participation was also of influence on their process of care. Some for example mentioned that they had discussed specific issues with their doctors, and that their participation had helped them making choices between treatments. Although most were very positive about the support group, some negative remarks were also mentioned. These included concerns about privacy, difficulties in expressing one selves by means of postings, the presence of 'complainers' in the online support groups and 'finding it difficult when a member died'. Conclusions: This study provides us with data suggesting that patients feel empowered by their participation in online support groups. However, this was a qualitative study with a small sample that is not necessarily representative. Therefore, a questionnaire will be developed and posted on several online support groups.

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### Internet-based Global Clinical Trials and Registries. Traditional Paper Data forms Are Soon Completely "out".

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Internet-based global clinical trials and registries. Traditional paper data forms are soon completely "out". Marius Kublickas, MD, PhD. MedSciNet AB, Stockholm, Sweden. Research groups and life science companies are under increasing pressure to lower development costs and academic research organizations are being forced to deliver research results and publications in a shorter time with the limited resources and funding. Recent regulatory and drug

safety concerns, substantial increases in data volume, and rising cost pressures, present these organizations with some very significant challenges. However, fine-tuning existing, paper-based trial processes to lower costs has reached its limits. Changing to electronic data capture (EDC) based studies and trials can help organizations achieve significant cost savings, as well as time, efficiency, and quality gains. Every trial and study starts from design. MedSciNet Specification Tool will dramatically shorten the time required to create electronic clinical research forms (CRF's) and trial workflow. MedSciNet assists researchers in the creation of unique trial structures with predefined validation rules, custom rules, and a repository of standard components. Specification Tool instant preview function will give user the possibility to test forms while creating them. Advanced trial workflow engine will guide user through the process of total trial structure creation. User even may generate trial on his local system and start testing immediately. MedSciNet web-based solutions are known for the best user satisfaction. MedSciNet Clinical Trial Framework (CTF) unique design of the Adverse Event forms leads to very simple and fast registration of these events and instant submission to regulatory organizations, trial mangers and administrators. CTF has very simple yet extremely powerful engine for monitoring and query generation. With just a few clicks investigators, monitors and auditors have access to all aspects of the queries in the trial. MedSciNet can provide you with all necessary experience and tools for single-site Phase I trials to global multi-site Phase IV trials.

### Combining Asynchronous Online Discussions with Traditional Face-to-face Physiology Classes Can Improve Students' Performance On Summative Assessment

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Background: Traditional face-to-face courses are the mainstay of University of Zagreb Medical Faculty (UZMF). Our traditional face-to-face Physiology classes mostly have an instructor-oriented approach which results in "reproduction" of knowledge. Meaningful learning is more likely to occur when we require our students to "talk" physiology with one another and with the faculty [1]. Asynchronous online discussion forum can provide a way for "talking" physiology beyond time and place restrictions of the physical Physiology classroom because it increases time for discussion, gives time for reflection for thoughtful responses, allows for giving feedback, and allows students to seek clarification or help as soon as the need arises. Thus, online discussions can provide a stimulating supplement to usual teaching practices [2]. Objective: The aim was to use online discussions as an additional pedagogical instrument to an existing traditional Physiology class for involving students in wide range of activities that can contribute to meaningful learning resulting in better performance on summative assessment. Methods: Second year medical students enrolled in a regular Physiology class at the UZMF and their physiology teachers were given the opportunity to participate in moderated online discussions. Participation in online discussions was voluntary and the participants were self selected. Because final course grade is the best indicator of student success, the results of the summative Physiology test of students who participated in online discussions and those who did not were compared and the effect size was calculated. Results: Students who voluntarily participated in online discourse during one academic year outperformed their student counterparts with statistical significance (P = 0.0328, t = 2.1526). In terms of an effect size, the mean of the treated group (participants) was at the 66th percentile (d = 0.4) of the untreated (non-participants) group. Conclusion: Most education researchers accept that if it could be shown that making a small and inexpensive change would raise academic achievement by an effect size of even as little as 0.1, then this could be a significant improvement [3]. In this sense we are aloud to conclude that asynchronous online discussions can help students improve their learning outcomes by enabling time/place independent connections among students, teachers and the world of information and ideas.

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### Patient-physician Interaction Over the Internet -a Controlled

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Introduction. Nearly half the Norwegian population claim they would like to use the Internet to communicate with their general practitioner (1). This tendency is about the same in the rest of Europe and in the US. To test the implications of this mode of communication, a web-based system complying with the strict statutory requirements for the processing of personal data was developed. Methods. A randomized controlled design was chosen, where 200 patients were recruited and distributed into intervention and control groups (2, 3). Data was collected through questionnaires, interviews and system logs. The trial period lasted one year, and involved 6 GPs. The patients were given the opportunity to communicate electronically with their GP. Early 2006, after this trial was finished, another study was initiated in order to measure the effectiveness of electronic communication. A program logging the time taken to answer and length of the patient messages was installed at 9 GP offices. The results from this study are expected summer 2006. Results. The patients who used the system sent on average 3.3 messages, the six doctors sent between nine and 65 messages each. Traditional inquiries (visits, telephones) to the doctor averaged 3.2 for the invention group and  $4.5\,\mathrm{for}$  the control group respectively. Forty-one percent of the messages were inquiries about health issues, 22 % were about renewals of prescriptions and sick leave notes, while 13 % were requests for an appointment. Both patients and doctors were positive to this mode of communication. Patients who did not use the service said that they expected to use it in the future. Whether this is a cost-effective way of communicating will be answered in the follow-up study ending this year. Some preliminary results from this study will be presented. Discussion. Electronic communication appears to replace some consultations and inquiries by telephone. This study gives reason to expect that communication between patients and general practitioners over the Internet will be more important in the future. Since the Norwegian primary health system is mainly based on public funding, the relevance for other health care financial systems will be discussed.

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### Self-Efficacy and Intentions To Seek Information About STDs and HIV/AIDS Among Taiwanese College Students

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This study aims to explore the role that self-efficacy plays in determining Taiwanese junior and senior college students' intentions to seek online STD and HIV/AIDS information. This cross-sectional study recruited 482 junior and senior Taiwanese college students enrolled at a university in southern Taiwan to complete a self-report questionnaire. Results show that respondents' self-efficacy to control STD and HIV/AIDS infection directly and negatively predicted their intentions to seek information about STDs and HIV/AIDS on the Internet while Internet self-efficacy directly and positively predicted such intentions. Given that the Internet has become a frequently-used channel for information among young people in Taiwan, this study suggests improving Internet self-efficacy among Taiwanese college students may increase their intentions and ability to use the Internet to seek online STD and HIV/AIDS information.

Web-supported Self-management for Healthy Eating: Development and Validation of Computer-administered Measure of Neuropsychological Performance In Inhibitory Control and Relationships To Everyday Lifestyle.

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Background: Eating behavior in modern society may have addictive qualities due to the wired-in reward responses to food that have evolved over billions of year in an environment of food scarcity. The "decision" to consume High Caloric Food (HCF) may rely on neurobiological processes, which involve the battle between reward/impulse systems and the ability to inhibit such impulses [1]. Developments in clinic and health promotion domains show self-risk assessment, accompanied by supportive educational material, will give people more chance to win the battle [2-4]. Objective: By exploring its relationship to everyday eating behavior, the present study validated a computer-administered measure of neuropsychological performance in inhibitory control, namely Affective Shifting Task (AST), which can help individuals assess their neurobiological vulnerability to HCF temptations. Methods: In an experience sampling study, participants reported their lifestyle behavior six times a day for a ten-day period. The reported lifestyle behavior included whether they had been snacking and craving for food, especially those HCF, in the last two hours. The same individuals also performed computer-administered AST that assess pre-frontal cortex activity in terms of ability to stop motor impulse towards well-learned affective stimuli. Performance on these two tasks has been shown to be impaired in individuals addicted to highly rewarding objects such as drugs, nicotine and alcohol [5]. Results: 132 non-obese (BMI < 30) women enrolled both the experience sampling study and laboratorial testing. Performances on the AST, including correctness and response latency, and parameters reflecting its underlying process, in terms of discriminity and dis/inhibition, were computed for each participant. In a series logistic hierarchical modeles, those performances and parameters served as predictor of everyday eating behaviors reported by participants. Results show that AST performance and process parameters could account for a significant amount of the variance in a person's everyday eating (P-values < .05). Specifically, individuals who had poor inhibitory control at the neurobiological level (as indexed by their performance on AST) were also those who succumbed more easily to temptations. Conclusions: The pattern of response supports the view that to some extent it is possible to help individuals recognize how well-equipped they are at the neuropsychological level. Since AST is well computerized and could be easily implanted into the web environment, it may be useful for individual to face self-control challenges involved in preventing food over-consumption in the modern world of plenty.

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### MEDIAR: An Online Web-Based Repository Site of FMRI Medical Images and Clinical Data for Childhood Epilepsy

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Abstract: Many research efforts have in the past been extended to study the spatio-temporal behavior of brain activation patterns while performing controlled tasks. However, since each institution has a limited subject population to conduct the study, the statistical analysis has been very limited, limiting as a consequence the critical processes of meaningful interpretation and validation. The creation of a multi-site MRI data repository would provide substantial data to convey studies over a widely distributed population. Recent technological advances in functional magnetic resonance imaging (fMRI) has resulted in a much better understanding of brain functions with substantially improved spatial and temporal resolution. As a result, it is possible to observe visually the spatio-temporal behavior of the brain activation during a normal routine. One of the key elements in the functional neuroimaging research (both PET and MRI) is to track and study the spatio-temporal behavior of the activation pattern during the performance of a task. When conducted in an environment with sufficient pediatric population, the functional neuroimaging study has the potential to reveal similarity and differentiation of the activities within the brain at both the micro and macro level within broadly distributed demography. In this paper, we developed an online web based repository site, in which MRI images and subjects' background information, taken from several partners' hospitals in the nation and overseas, can be stored for further processing; such a data will be available to several medical institutions to study the distribution of the spatio-temporal activation patterns. This innovative site allows users to upload and retrieve information in a user-friendly way. A solution based on a Linux platform with My-SQL and Personal Home Page scripts (PHP) has been selected. The designing and implementation of this repository will be detailed in the full paper. What is unique in the approach considered is that all pertinent clinical information about patients is synthesized with input from clinical experts into 4 different forms, which are: Clinical, fMRI scoring, Image information, and Neuropsychological data entry forms. In so doing, data entry, data regards, data retrieval and data mining can all be performed in an optimized fashion both in terms of interfacing creating a user friendly environment and in terms of computational requirements that are set within practical bounds. The results we will report in this article will support this affirmation. Keywords: Online Multi-Site Repository, Medical images, fMRI, DICOM, PACS, PHP, My-SQL, Data-Mining, JAVA.

### Geographic Information Systems and Three-dimensional Modelling of a Disease Infected Building

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An unusual cluster of residents of the Amoy Gardens - a group of high rise residential buildings in Kowloon Bay, Hong Kong - came down with the Severe Acute Respiratory Syndrome (SARS) toward the end of March 2003. The high concentration of infection within a housing estate was a major cause for alarm because densely populated high-rises are common scenes in Hong Kong. Many feared the devastating effect if similar outbreak of SARS were to occur in other communities. As the outbreak unfolded, there was widespread speculation about the means of transmission of the SARS virus, including water sources, air-borne agents, close personal contact, and environmental factors. Our analysis made use of the geographic information system (GIS) to demonstrate significant space-time clustering of infected cases. 3D-modeling was accomplished in a 3-stage process: (1) making of a terrain surface with a photo image as the background, (2) extruding buildings to the required height based upon the number of stories and a standard height of 2.5 metres between floors, and (3) adding number of SARS occurrences by the flat number and coloring the flats accordingly. To improve the speed of processing and optimize tradeoffs between details and navigability, all unnecessary elements and excessive details in the floor plans were excluded. In addition, only building outlines were drawn to enable viewing penetration of the vertical structures. The utility of GIS in suggesting the occurrence of local transmission was made possible by a relatively large number of confirmed cases during a short interval. GIS also serves a vehicle for measuring the success of intervention and control measures.

# Realtime Wireless Data Management and Process Control During Mass Casualty Events, Using a Basis of Internet Communication Protocols.

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Introduction Our group has developed and tested a wireless weather proof wearable computer to register patient data during mass assesment and treatment of casualties in extreme disaster settings. Methods The device and its periferals can be used to register patient data in almost any circumstances. Different methods of data storage, communication and processing are proposed. An associated matrix of communications is conceived to support communication of harvested data towards and between the institutions were the patients are being transported. These mostly use common existing secure internet protocols. Only the access to the net varies according to the resources and possibilities that exist during the disaster. An adaptive protocol is proposed to promote survival of the initially harvested data in several ways. Association of the data with the patient is the prime goal. Alternative pathways for information are formulated in case of failure of communication in the respective stages. The concept comprises an as thorough process control as the disaster permits, using a protocol sequence of available resources. The versatility of the process is both at the front end of the concept for registration and thru-put of the data, as in the post factum round-up of statistics. Results Important is that while patient data is the prime goal, much information can be acquired about the mobility of victims during a emergency relief effort, given the right tools are provided and used correctly. Depending on the on-site communications possibilities (e.g. an emergency deployable and installed WiMax network in a remote area), a transparant process control of the relief effort (including severity of casualties and mobility versus local or distant health care resources) can support the disaster management team to make important decisions concerning the on-going relief effort. Discussion Until now, to our knowledge, no existing effort has facilitated patient registration, tracking and management so much as this in a realively simple way in extreme circumstances. The process is at least multi-facetted in its aim to streamline efforts made during a mass casualty event of unknown proportions.

### Using the Web To Collect Data for Alzheimer's Research

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The Uniform Data Set (UDS) is a new data structure designed to replace the Minimum Data Set (MDS) that has been in used for the past 5 years by the National Alzheimer's Coordinating Center (NACC) to collect clinical research data from various Alzheimer Disease Research Centers (ADRCs) across the US. Unlike the MDS, the UDS was designed to capture data (1) longitudinally, (2) in greater depth (i.e., more data elements), and (3) using standardized data forms and procedures. A task force comprised of clinicians and researchers was created to determine the set of data elements to be collected by the UDS. Then, NACC designed and built standardized case report forms so that data collection procedure can be consistent across independent research sites. Explicit guidelines were also given on how frequently data are to be collected, thus enforcing the requirement for longitudinal data. A database was created using Oracle® as the back-end database engine. The front-end user interface was developed using SAS® (Cary, NC) and HTML. The data submission website, software, and data management system reside on a Sun® Microsystem (Santa Clara, CA) Sunfire 880 server. The system has numerous features and tools that enable participating sites to easily submit data (either by file uploading or direct web data entry), as well as to error-check, modify, and download data. The error-checking component of the system is capable of detecting range violations, missing values, within form AND cross-form discrepancies; it also alerts users to unlikely values in the data submitted. In addition, the system contains an extensive set of quality control reports and graphs, which helps statisticians to detect broad patterns of errors and suspicious values (e.g., are there sites that consistently



fail to submit a particular case report form). Lastly, users can access/download the case report forms, user manuals, data element dictionary, and other special tools from the website https://www.alz.washington.edu. Note that access to the site requires a user ID and a password, and all data are transmitted using 128-bit encryption. In summary, the UDS system has been in operation since September 2005, and data for over 1,000 patient visits have been submitted. The system continues to be enhanced and improved (e.g., tab delimited data files can now be uploaded, a portable electronic version of the case report forms is in development). Our poster will present and discuss the features and implementation of the UDS data system in detail.

### Internet-drugstores In Post USSR-countries (Ukraine and Russia): Problems and Perspectives

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Introduction: Business to Customers (B2C) Internet-pharmacy is well-developed in the USA, Canada and Western Europe. In this work the objective was review of problems and perspectives of this direction of business in the post USSR-countries because in this region Internet-drugstores are only on the level of becoming and it's necessary to make analysis of the opportunities of their activity. Methods: In this work was applied the method of PEST-analysis, which consists of such factors as: Policy, Economy, Society and Technology. PEST-analysis is useful tool for understanding the market, opportunities and problems of some direction of business. Results: PEST-analysis. Political factors: - Absence in Ukraine and Russia a recognition at the legislative level of this form of business activity. So the work of Internet-pharmacies is regulated by general laws of the retail pharmaceutical trade; - In post USSR-countries are conducted the debates about a recognition of this kind of activity that can result either in the prohibition of the Internet-drugstores or to the fully permission of this kind of activity; - Internet-drugstores are allowed in the USA, EU, Canada and Australia, on other side they are forbidden in China; - Ukraine has declared course on euro-integration; - International society proclaims the importance of licensing and government-control of the Internet-pharmacies. Economical factors: - There is a great investment potential, considering the non-saturation of the markets; - There is a good economic example of existence of Internet-pharmacies in many countries of EU (e.g.., in neighbor's Poland, where is Internet-drugstore DomZdrowia.pl, which during first 10 months of the last year has got orders from more, than 10000 customers); - Internet-drugstores are less expensive in comparison with usual drugstores and the taxation of them in Ukraine and Russia falls under the general principles in the retail pharmacy. Social factors: - Internet in post USSR-countries confidently has occupied the role of the quickest and most full source of getting necessary information; -Modern tendency of society are longing for comfort and economy of time; -Accessibility in mode 24\7; - In the Internet exists the problem of fraud, either as in any type of commercial activity. One of the main reason of this phenomena is far from perfect legislative base. Technological factors: - Near to Electronic-commerce develops Mobile-commerce. However, today M-commerce can't form the powerful concurrence to E-commerce, particularly in the field of Internet-pharmacy; - On the Ukrainian and Russian markets are available the most modern program products for the operation of E-commerce; -Organizational-technological non-preparation of some pharmaceutical enterprises complicates integration of the Internet-drugstore with the back-office of the company; - IT require personnel of high qualifications. Discussions and Conclusions: 1. On the base of conducted PEST-analysis can be determined, that retail Internet-pharmacy in Ukraine and Russia actively develops as business-direction. It is a source of money profits and satisfaction of citizen's needs in maintenance with drugs. 2. Post USSR-counties cannot avoid the modern world tendencies, considering the general powerful growth of information technologies the part of which are the Internet-pharmacies.

### Using Web Technologies To Maximise Research and Inform Clinical Practice

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Web technologies can be utilised to assist clinicians and researchers working with rare disorders. This panel showcases the medical decision support software Simulcast that allows clinicians to quickly access clinical and laboratory findings from the peer-reviewed community and two online databases supporting research into the rare disorders Prader-Willi and Rett syndrome. Discussions will touch on a number of issues including funding, promotion, privacy, resulting benefits and future directions. Talk 1 SimulConsult Web technologies provide the opportunity for clinicians to pool evidence-based knowledge to create resources that can be used by all practitioners. One such diagnostic decision support project with 30 contributors and 1000 registered users in 54 countries will be described. Such decision support can be built into the work flow in a variety of ways that use open standards such as HTML and UMLS (Unified Medical Language System) concept codes. Examples include using such protocols in individual communication, blogging, documenting information in EHRs and converting text in an EHR into hyperlinks to access decision support. SimulConsult is an exemplary model of this web based knowledge-building concept. Panel member and SimulConsult founder Michael Segal will provide an overview of this tool and how it is used to: • further our understanding of neurology. • educate new clinicians/therapists and keep existing practitioners up to date. • assist with diagnosis of lesser known disorders. Talk 2 InterRett Improving the understanding of rare childhood disorders is challenged by their inherent scarcity and geographical disparity. The InterRett project has successfully used the Internet to address these challenges bringing together families, clinicians and researchers around the world in a joint effort to explore genotype-phenotype relationships in the rare neurological disorder Rett syndrome. Funded by the International Rett Syndrome Association parent organization and guided by an International reference panel InterRett has collected data on almost 900 cases from 28 different countries. Panel members Helen Leonard and Alison Anderson will explain how their team have used technology to: • recruit cases for epidemiological research. • provide a searchable online database allowing interrogations of clinical phenotype information. • foster data sharing and resource collaboration on a global level. Talk 3 Creating an international database to advance Prader-Willi syndrome research Collecting data for research from multiple countries is advantageous but challenging. Panel member Tony Holland will share his experience on a two-stage project to develop an international database to support Prader-Willi syndrome (PWS). The priorities of the initial stage are obtaining European funding, establishing the database that will store clinical data from many countries and developing standard formats for future data collection protocols to ensure a congruent dataset for research studies. The second stage will involve the development of protocols in different languages and collection of data. Tony will also explain why such a database is needed in PWS research and discuss broader issues such as EU funding for database development and special problems with respect to behavioural and psychiatric research across countries.

### How Can the Internet Help Parents of Children with Rare Neurological Disorders?

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Introduction Rett syndrome is a neurodevelopmental disorder first described in the English-speaking literature in 1983[1]. Predominantly affecting girls, the syndrome is characterised by normal early development followed, between the ages of 6 and 18 months, by a period of regression associated with the loss of fine motor skills and language. By the age of 15 years about 1:8,000 females



will have been diagnosed with Rett syndrome [2]. The recent discovery of the association with the MECP2 gene and thus the confirmation of the X-linked genetic basis of Rett syndrome has prompted substantial interest in this disorder [3]. We have used an internet-based questionnaire to survey parents internationally about their experiences with Rettnet, an email listserv set up for parents and others interested in Rett Syndrome. The aim of this study was to determine the perceived advantages and disadvantages of such an email listsery for parents of children with this severe neurodisability. Methods A web-based survey was conducted using closed and open questions to collect information on the use of and time spent on Rettnet; the information and support Rettnet provides; the topics discussed; and its perceived benefits and disadvantages. Also included was an overall rating of the usefulness of Rettnet, the reasons behind these ratings, and an opportunity for other comments. Results Most (81.5%) participants felt that the Rettnet provided helpful advice concerning their child's management. They also indicated that the Rettnet was useful in dealing with their child's education and as a source of carer support. A high proportion of respondents valued information on symptoms of the disorder. They generally rated the Rettnet highly (mean 8.1 on a scale of 1-10) and the most common reason given for recommending the service to other parents was the emotional support provided. Discussion This study has demonstrated the importance of a listserv for parents of children with a rare neurological condition such as Rett syndrome. The listserv was valued as a means of communication and as a way of connecting those with similar experiences who would otherwise be isolated. It was also valued as a provider of information that empowers carers to make informed decisions regarding management of their children. Clinicians managing children with neurological conditions, both those with or without a defined label should be aware of the needs of their patients' families in terms both of support and information. They should know that email listservs such as we have described can perform an important function in meeting these needs. 1. Hagberg B, Aicardi J, Dias K, Ramos, A. A progressive syndrome of autism, dementia, ataxia, and loss of purposeful hand use in girls: Rett's syndrome: report of 35 cases. Ann Neurol 1983 Oct;14(4):471-479. 2. Laurvick, C, De Klerk, N, Bower, C, Christodoulou, J, Ravine, D, Ellaway, C, et al. Rett syndrome in Australia: A review of the epidemiology. JPediatr (in press). 3. Amir RE, Van den Veyver IB, Wan M, Tran C Q, Francke U, Zoghbi, H Y. Rett syndrome is caused by mutations in X-linked MECP2, encoding methyl-CpG-binding protein 2. Nat Genet 1999 Oct;23(2):185-188.

### Developing a Framework for Comparing Different Videotechniques Used To Assess the Clinical Consultation: A Qualitative Study

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Background: Single-channel video is an established method for assessing the clinical consultation, however, it is hard to infer the body language of the clinician [1] or how information in the consultation is being integrated into the medical record [2]. A three-channel video was developed combining the conventional view of the whole consultation; with a second camera looking at the doctor's facial expression; and a third copying the video output from the computer monitor [3]. However, this was expensive requiring professional grade video to ensure synchronisation of the time sequence. More recently improvements in the quality of budget priced technology have enabled acceptable three-channel video to be set up using domestic grade equipment [4]. However, the choice of three video channels was arbitrary and the camera angles selected has not been critically appraised. Objective: To develop criteria for comparing different multi-channel video methods of recording the clinical consultation. Methods: We adopted a qualitative, hypothesis generating approach. Single channel and three-channel recordings of simulated consultations were shown to twelve health professionals with experience of communications skills training and experience of the assessment of the consultation using (single channel) video. Semi-structured interviews were conducted, and recorded verbatim. The recordings were typed and transferred into NVIVO software for coding and analysis. The transcripts were analysed thematically to identify what factors were important in assessing the quality of the consultation and what views of the consultation were required to inform an assessor whether it were completed satisfactorily. Results: The major elements needed in any tool used to assess the consultation are the ability of the video to pick up quantifiable

non-verbal communication of the doctor and the patient, and the ability to qualitatively and quantitatively reflect the use and impact of the computer on the consultation. The information provided by the current three-channel video used could be further classified to essential, desirable and redundant to guide the future development of the multi-channel video. Essential criteria for multi-channel video assessment were: camera angles which were as close as possible to the view of the other person in the consultation, so that eye-contact could be accurately assessed; detailed view of the patient's body language; what information on the computer was "distracting" the clinician and how the clinician interpreted the consultation in the computerised medical record. Desirable information included: compromises in patient confidentiality; using information on the computer screen to educate the patient; time wasted 'fiddling' with the computer. Many areas of the clinical computer system screen were redundant, especially when the clinician was not looking at or entering data into the computer. Observers would have liked to be able to enlarge the different channels to enable more detail to be seen at different times in the consultation. Conclusions: A multi-channel video tool used to appraise the consultation could be developed to monitor: Body language and facial expression of clinician and patient; as well as how the doctor's knowledge and information collected into the consultation are synthesised into the medical record; and the impact of the computer on the clinical consultation. This study will provide the basis of a rating scale to compare and optimise multi-channel methods of assessment of the consultation.

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### Implementation of Medical E-Curriculum: Use of the Structured Content Development Model

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Introduction In this presentation, we will describe how the Michael G DeGroote School of Medicine at McMaster University developed an innovative XML-based approach to e-curriculum and e-learning development for medical education. This approach, known as the Structured Content Development Model (SCDM), is a flexible and powerful way of approaching the authoring of learning objects that enables such features as SCORM 2004 compliance and single-source publishing. In this presentation, we will explore how the SCDM provided an authoring environment for the School of Medicine that lead to their success, as well as an overview of the issues and challenges in the transition to an electronically accessible curriculum. Background Our Division of e-Learning (fhs.mcmaster.ca/deli) had the challenge of moving large amounts of print-based educational resources to an online format, as well as developing new learning objects for web delivery. Like most organizations engaged in similar e-curriculum and e-learning projects, the medical school needed to rely on their faculty for subject matter expertise and authoring capabilities. In choosing to use the Structured Content Development Model (SCDM) and XML-based technologies, the School of Medicine was able to ensure that their content would be pedagogically consistent regardless of content author, would be reusable across any learning management system and reusable even across media (single sourcing). Methods A robust learning content management system based on XML technologies lies at the core of a scaleable e-curriculum implementation using the SCDM. Analysis of existing curriculum materials and developing a standardized content structure and database for the resources is central. Use of XML facilitated a single-source publishing model whereby curriculum materials can be centrally managed but output to both print and web from the same source documents. This expedites content edits and updates, and also enables versioning control, as well as publishing variations on source content for different audience types (eg tutors and students). All learning objects are indexed or meta-tagged, and compliant with e-learning standards (eg SCORM 2004). Results Some of



the benefits of this implementation model include: 1) the ability to enforce program-wide conventions for the authoring of courseware (eg tutorial problems); 2) an asset repository that enables efficient central management of documents and multimedia on demand; 3) export to any format even if that format is not SCORM compliant (eg print or CD); 4) a searchable library of learning objects that can be shared with other Learning Management Systems (such as WebCT); 5) the ability to link curriculum content with learning paths and activities, for curriculum 'mapping'; and 6) ease of updates and edits to curriculum content. The focus on a standards-based authoring environment also reduces the risk of being 'locked in' to proprietary learning management system solutions. Conclusions The success of McMaster's implementation leads to increased participation from faculty in creating standardized, consistent learning objects and the ability to share content with other programs within the university and other universities who use different Learning Management Systems.

### Internet Technologies for Delivery of Evidence Based Information : Using Web Services and XML Effectively

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Abstract The provision of evidence based information to assist health professionals in delivering care increasingly relies on electronic dissemination mechanisms. There are obvious advantages is distributing information electronically and in utilising clinical systems to facilitate delivery of information at the time and place in which it will be most relevant and useful. Internet technologies have reached a state of maturity such that they can be deployed to achieve these aims. XML is a flexible way of structuring information such that it can be usefully employed within clinical systems. Web services are a means of allowing the systematic consistent distribution of information to a variety of clinical systems via the Internet. The main topics of this tutorial will include: · XML and why it is a useful way of organising and structuring information. o Technologies and techniques for producing, managing and using  $XML. \cdot Web$  services o What they are, why they are useful and how they can be placed within an information provision architecture. This tutorial will step through a number of practical tasks, including: marking up text using XML to structure textual; using tools to manipulate the XML; creating a simple web service that serves XML; creating a simple web service client that uses the web service. Technologies discussed during this tutorial will include: XML, XSLT, HTML, CSS, Javascript, SOAP and HTTP. Specific educational goals that attendees can expect to achieve An understanding of Internet technologies relevant to provision of information for health care, the capabilities of these and how they relate to each other. Who should attend Those wishing to gain an understanding of the ways in which currently available internet technologies can be used to further the provision of information. Level or combination of levels of the content percentage of coverage that is basic, intermediate, and advanced) 50% basic. 25% intermediate, 25% advanced. Prerequisites, if any nil Name of a reference from an organization that has previously sponsored the same or another tutorial of similar duration by the instructor This is a new tutorial. I have delivered content that is related at the Health Informatics Society of Australia's annual conference: Health Informatics Conference 2002.

### **Web Service Delivery of Drug Interaction Information**

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The aim of the NPS Pharmaceutical Decision Support (PDS) Program has been to improve the quality of prescribing and use of medicines by health professionals through provision of reliable information during the decision-making process. Delivery of consistent drug interactions information within clinical systems has been identified as an important part of this process. Drug interaction information from the Australian Medicines Handbook (AMH) is being used as the basis of drug interactions information delivery, provided as a web service. A web service is a software program that is placed on the Internet and can be used by any other program to provide answers to specific questions. The program connecting to the service is called the client. The potential clients of a drug interactions web service are those clinical systems whose users could benefit from drug interaction information provision. A query to the service (formatted using XML) is a list of a number of drugs and can be sent by any client connected to the Internet. A query response is the drug interaction information (also formatted as XML) relevant to the query. The

query response can be processed electronically to provide the user with information on a number of levels, such as: The number of interactions returned (and whether they are drug class or drug interactions) · The distinct drug pairings within the list of drugs sent that have an interaction recorded · A succinct description of each of the interactions · Contextual information around the interactions. The client systems receiving the response can process it in any way that is useful within the context of its user interface. For example, the user may request that interaction queries are sent automatically and that a panel showing the number of interactions is updated. Further detail on the interactions would then be available on user request. Two clients for the web service have been created. The first client is a windows application that calls the web service in response to user input. The second client is a website that uses the web service to dynamically populate its pages. This service is the first example of web service provision of QUM by NPS. Its evaluation will guide the development of further services. NPS is an independent, Australian organisation for Quality Use of Medicines, funded by the Australian Government Department of Health and Ageing.

### The Internet As a Tool In Population-Based Epidemiological Studies.

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Background: The Internet has an excellent potential as a tool in epidemiological research. Apart from being time and cost efficient. Internet offers a multitude of methodologically advantageous qualities[1,2]. More than 80% of the Swedish population has Internet access, making it on of the countries with highest Internet penetration in the world [3]. This and several population based health registers, gives Sweden unassailable advantages for studies of the Internet as a tool in population based epidemiological research. In a first endeavour to investigate the possibilities offered, a study was initiated to examine the potential of collecting health and lifestyle data related to cancer, diabetes, etc using an Internet-based questionnaire. Objective: The aim was to a) compare socio-demographic and health related characteristics of responders and non-responders of different data collection methods and b) to increase our knowledge about how the design of web-questionnaires affects the response rates. Method: In 1991/92 100 000 women were invited to respond to a paper-questionnaire regarding lifestyle and health. In 2003, the 50 000 women that had responded (now 40-60 yrs.) received an invitation to participate in a follow-up study. The invitation letter contained instructions, a personal login, and the web address to the 'Women's Lifestyle and Health Study'-site, that contained a link to the web-questionnaire. Reminder letters including paperquestionnaires were sent to non-responders. The questionnaire contained approximately 100 questions regarding lifestyle and health issues. Information regarding time spent on each web page as well as the operative system used was collected. Results: The total response rate was 72% (web: 41%, paper: 31%). Education was associated with a near twofold-increased risk of responding to the web questionnaire (RR=1.8, 95% CI: 1.6, 1.9). This was the only socio-demographic variable strongly associated with responding to the web[4]. Somewhat surprisingly, age was not associated with an increased risk of choosing the web. Socio-demographic information from the 1991/92 study was accessible for responders as well as non-responders, enabling us to estimate the possible bias caused by the data collection method used. Web questionnaires did not lead to bias greater than that caused by the use of paper questionnaires. This gives us reason to conclude that web is a feasible method for the collection of information in population-based studies among women in Sweden[4]. To study the effect of design on dropout-rate two versions of the same questionnaire were used, the difference only being the ordering of the questions. By comparing the times spent on each page and the dropout rates between the versions, we wish to increase our knowledge about dropout behaviours that in turn could help us prevent dropout and increase response rate. Conclusion: The Internet is not only a cost-effective complement to traditional paper questionnaires, it also offers advantageous possibilities, such as the possibility to reach previously inaccessible populations, interact easily with the study population and investigate phenotyping on demand. Reference: 1. Schleyer TK, Forrest JL. Methods for the design and administration of web-based surveys. J Am Med Inform Assoc 2000 Jul-Aug;7(4):416-25. 2. Wyatt JC. When to use web-based surveys. J Am Med Inform Assoc 2000 Jul-Aug;7(4):426-9. 3. Statistics Sweden. Use of computers and the Internet by private persons in 2005. Unit for Investments,



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# MediUAQ, Bridging the Digital Divide of Internet Based Medical Education In Latin America. Unexpected Outcomes From a Pilot Website Revealing a Growing Need.

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Background: It has been stated that the digital divide between developed and underdeveloped countries is more dramatic than any other inequities in health or income [1]. Although major improvements have been made regarding availability of internet access, educational material developed by local researchers, focused on the regional health care needs and written in the community's native language still needs to be improved [2]. Objectives: To develop a pilot website to provide health care professionals and medical students in Mexico with culturally sensitive medical information focused on the most common pathology of the region and written in Spanish. Methods: Patients with a wide variety of skin diseases were selected for photography of their lesions from the dermatology department of a regional community hospital. A web site incorporating hypermedia features was created to host the images and accompanying text [3]. The site provided the user with an e-mail address for communication with the authors and encouraged them to send questions. Results: From July of 2000 to May of 2005, we selected 480 cases due to their educational value. A total of 1239 digital images were generated and classified into 149 chapters that represented the most common dermatologic diseases seen in the region. Relevant information regarding the clinical aspects of these diseases was also included. Although our site's primary target audience was intended to be health care professionals and medical students, 93% of the e-mail messages (n = 48) originated from patients asking for a second medical opinion. The majority e-mail messages (77%) originated from Mexico and the rest from other countries including Argentina, Peru, Paraguay, Venezuela, Honduras, United States, Germany and Kosovo. Conclusions: MediUAQ Dermatologia is the largest atlas of dermatology on-line developed in Latin-America, written in Spanish and focused on the most relevant diseases of the region. To our surprise, e-mail communication with the authors came basically from patients asking for a second medical opinion from all over Mexico and Latin America. Altogether this information suggests that there is a growing need for patient oriented on-line medical education in Latin America. Further studies will need to be done to determine the specific information needs, internet access capabilities and other characteristics of the potential on-line medical education users in Mexico and Latin-America.

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### MyStudentBody Stress: Benefits of An Interactive, Internetbased Stress Management Intervention for College Students

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Background: Stress can be a significant problem for college students [1], who are in the midst of adapting to new schedules, academic challenges, living situations, and roles [2, 3]. Students who have high stress levels may be more likely to drop out of school, do poorly in classes, develop substance abuse problems, engage in high-risk behaviors, or become depressed. The negative health and social consequences of stress are well documented in college students. For college students, stress and stress management are usually addressed in (1)

college health classes, utilizing traditional textbooks, (2) college health services, including counseling services; and (3) on the websites of some colleges. Except for professional services, these approaches are neither complete nor tailored to the student's needs. While many students are struggling with stress, college health research indicates that they are reluctant to seek professional counseling. Objective: Test the effects of MyStudentBody Stress (MSB Stress) on college students' stress, coping style and adjustment in comparison with a standard, text-based health website and a no-treatment control group. MSB Stress is based on motivational enhancement and brief intervention models. MSB Stress utilizes a Rate Yourself module to help students receive tailored stress reduction information, including a personal stress profile, articles based on personal risks, Shockwave peer stories, an email newsletter, and written and graphical motivational feedback. This website will allow students to receive empirically-based information in a confidential manner, acknowledging their desire for self-help methods. Methods: A randomized, controlled study was conducted at six U.S. colleges (N=240). Students at six colleges and universities were screened for high stress using the Perceived Stress Scale. Two hundred forty students who scored in the above average range of stress were given a battery of online questionnaires (Perceived Stress Scale, College Adjustment Scales, Health-Promoting Lifestyle Profile, COPE Inventory, Inventory of College Students' Recent Life Experiences, Life Experiences Survey, and Hopkins Symptom Checklist) at baseline, and at one, three, and six months after baseline. MSB Stress and control website students were instructed to complete four 20-minute sessions over two weeks. Results: MSB Stress students were significantly more likely to increase their weekly level of light to moderate physical activity, use specific methods to control their stress, and exhibit decreased anxiety. MSB Stress students whose baseline stress level was above average increased their scores on stress-management skills and positive coping styles and also decreased their substance abuse scores to a greater degree than students in either control group. Satisfaction and usability questions posed to the participants who used MSB Stress indicate that students thought the website was interesting, useful, and made them think about their own behaviors. MSB Stress participants spent an average of 75 more minutes on the MSB Stress website than the control website. Conclusions: These findings indicate that MSB Stress has a beneficial effect on college students, especially those with high stress levels. An interactive stress management website like MSB Stress may offer colleges a cost-effective, viable method for addressing student stress.

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### Giving Patients a PEPTalk: Designing a Patient Educational Prescription Process

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Objective: The objectives of this investigation are to evaluate information tailoring processes, cultural sensitivity and the effectiveness of education materials prescribed to patients in personalized online Patient Educational Prescriptions: the PEPTalk project. Our goal was to develop online patient education materials and an "educational prescription" process that was clinically relevant, reliable, and reflective of existing clinical education processes for breast cancer and head and neck cancer patients. We sought to answer the following: Are the PEPTalk process and materials easy to use, useful and culturally relevant from patients' perspectives? Is the PEPTalk prescription process and material easy to use and useful from clinicians' perspectives? Methods: Iterative prototyping and participatory design activities were used to develop materials and the online prescription process with input from a variety of clinical partners, including physicians, nurses, clinical educators, informatics researchers and other healthcare workers. Usability testing was conducted with patients and clinicians who have accessed the online materials. Results: Preliminary evaluation data show that materials and processes were designed effectively using participatory methods. Feedback collected from patients and clinicians has enabled the team to analyze results and make appropriate revisions to the PEPTalk web site, education materials and the online prescription process. Patients and clinicians find tailored, culturally relevant information for managing



cancer useful and usable. Challenges remain regarding full integration in busy clinical processes, and we continue to develop the PEPTalk materials and processes using iterative feedback from key stakeholders. Additional authors: Chien, E.; MacDonald, S.; Wiljer, D.

### Japan-Korea Joint Project On Monitoring People with Dementia

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Background: People with dementia (PWD) display various problem behaviors such as wandering, pica, and violence. Videotaping or personal observation has been used to monitor the wandering patterns of PWD; both methods have limitations with regard to capturing movement patterns over extended periods. Objective: To compare the similarities and dissimilarities in movement patterns of institutionalized elders with dementia between Korea and Japan using new Integrated Circuit tag (IC) monitoring system. Methods: After the approval of the human subject committees in both institutions, proxy written informed consent was obtained for the residents in each country. Antennas were set up on the ceiling of the dementia care units, and tags were sewn into the residents' clothes. A total of 13 residents were monitored for 7 days in the Chubu area, Japan, and 13 residents were monitored for 14 days in Seoul, Korea in 2005. Results: Results showed considerable variation in the distance moved during a 24-hour period by each resident as well as among residents; additionally, varied fluctuations were also observed with regard to the distance moved during a 1-week period. Examination of the graphical depiction of the movement pattern revealed similar patterns of movements for major diagnostic categories across the two study sites. Conclusion: The graphic depiction of movement and various other statistics pertaining to the movement can assist healthcare professionals to improve the care for elderly with dementia. Specifically, this system can be used (1) to examine factors influencing behavioral patterns, (2) to evaluate the need for rehabilitation and the effectiveness of rehabilitation, (3) to improve resident safety by identifying behavioral patterns, and (4) to evaluate the quality of care by observing changes in behavioral patterns.

### International Perspectives On Internet-Based Cancer Information

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No abstract to be submitted; I am a panel chair for a sub-session of MEDNET: Cancer Information on the Internet

# Architecture and Hosting of An AIDS Consumer Oriented Website In the Spanish Language. Evaluation of the First Year of Online Aids Advice By a Medical Expert

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Background: Health-related Internet use is broadening the spectrum of behaviours and relationships between patients, health care professionals and other agents of the medical milieu. Access to Internet resources have shown to have an important impact on HIV/AIDS. For the past seven years we have been running a health website based on a general information newspaper [1]. A specific site for AIDS hosted in the general health website [2] was launched in 2002. Aims and Methods: Besides other educational and news resources, the

AIDS website offers advice and answers to questions and queries about AIDS made anonymously to an infectious disease expert. We described the design and structure of this website and its relationships with the rest of the online newspaper and its classic version in paper. We also performed a descriptive study and a temporal analysis of the questions received in the first 12 months of activity. Results: after four years of running the general health website [2], it was decided to expand its scope by the progressive opening of new online areas covering for specific diseases processes. The AIDS website [3] was launched on November 2002; its structure consisted of a number of sections covering: news about the disease, interactive-graphic educational materials, consumer oriented monographs on different aspects of HIV infection, chats with different leaders of opinion on AIDS and an "ask the expert" section where users could ask any doubts or queries via e-mail. During the first 12 months a total of 899 questions were received with a marked linear growth pattern. Questions originated in Spain in 68% of cases, 32% came from Latin America (Caribbean, Central and South America) and 80% of senders were of the male sex. The highest numbers of questions arose just after the weekend (37% on Mondays and Tuesdays). Risk factors of contracting HIV infection were the most frequent concern (69%) followed by window period (12.6%), tests results (5.9%), symptoms (4.7%), diagnosis (2.7%) and treatment (2.2%). One in three questions (34%) about risk factors concerned oral sex, 26.7% risk related to other routes like saliva or skin contact, 12.3% about unprotected sex whereas 13.5% concerned risk of contracting HIV after sex with protection. Conclusions: Being hosted in a online newspaper [1] has achieved excellent Internet traffic results for our AIDS site with a mean of 4 million accesses and 400.000 single users per month. A general information media online is a perfect vehicle for this type of "asks the expert" services. For a Spanish-based web it is surprising the high number of users from Latin America. In spite of the high level of media exposure of AIDS/HIV, many of the questions addressed were very basic. Aspects like anonymity, free access and immediacy of the answers are key factors for the success of this type of service.

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### Skimming the Cream of Health Information On the Internet

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Techniker Krankenkasse (TK), one of Germany's biggest public health insurers (6 million insured people), is offering its clients a new tool to gather high quality information quickly from the internet. Questions concerning illnesses, symptoms, medicines, care, health promotion and other top-ics can be answered via the TK-Gesundheits(health)browser. The TK-Gesundheitsbrowser does not only search for relevant results, but also lists them according to it's quality and trustworthyness: Information given on Internet sites, accredited to one or more of the major suppliers of quality seals such as Health On the Net (HON), it's German counterpart afgis (Aktionsforum Gesundheitsinformationssysteme), DISCERN and others more, is ranked higher than information related to sites without such seals. One of the biggest databases in German for Internet links regarding health and medicine serves as the backbone of the TK-Gesundheitsbrowser. This database is updated and im-proved daily by a team of experts, employed by Iconmed, inventors and suppliers of the Ge-sundheitsbrowser. At present, about 13,000 hand selected web links (most of them German) represent 1,200 subjects with regard to health topics. Being unable to host the complete range of information itself, TK still wants it's customers to find the most relevant, most helpful and newest information on the Internet. But most of all: it wants them to find the most trustworthy information. Other than common search engines, the TK-Gesundheitsbrowser has already filtered spam, advertisments and other irrelevant con-tent. In a survey conducted on 1,200 users of the TK-Gesundheitsbrowser, more than 82 per cent stated, that the online tool was very helpful for finding the required information. And nearly 94 per cent said, that they will certainly come back to the TK-Gesundheitsbrowser, if they need health related information once more. In Mednet 2006, TK will present detailled information on the Gesundheitsbrowser itself and on the survey cited above.



### Cancer Survivors Information Seeking Behaviors: A Comparison of Survivors Who Do and Do Not Seek **Information About Cancer**

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Objective: When confronted with a potentially life threatening illness such as cancer, information may provide needed knowledge about the disease, treatment, and self-care management. It may also facilitiate coping by mediating uncertainty and anxiety and by providing social support. The purpose of this study was to examine the cancer information seeking preferences and behaviors of cancer survivors. Methods: This cross sectional study used the National Cancer Institute's 2003 Health Information National Trends Survey data to evaluate 619 cancer survivors. Results: Two thirds (67.5%, n=418) of the survivors personally sought cancer information (InfoSeek) and 32.5% (n=201) did not (NoInfoSeek). Regardless of time since diagnosis, all cancer survivors preferred to get their cancer information from their health care provider. Most, however, turned to other sources, primarily the Internet, when seeking cancer information. Significant predictors of cancer information seeking included age (less than 65), gender (female), income (>\$25,000/yr) and having a regular health care provider. NoInfoSeek were more likely to be older (>65), male, with less income, and not having a regular provider than InfoSeek. Conclusions: Not all survivors actively look for cancer information. Although most survivors prefer receiving cancer information from their health care provider, many turn to a variety of other sources, primarily the Internet, Practice Implications: Although cancer information seeking has become the prevailing paradigm for cancer survivors, some survivors may not actively seek cancer information. Health care providers should assess or elicit information seeking preferences and behaviors from cancer survivors. Health care providers might want to better direct the connection between themselves and the Internet and consider its use as an extension and enhancement to their patient interactions. Credible and useful websites could be identified and recommended by health care providers as a means to address some of the barriers identified by survivors.

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### **Conducting Synchronous Online Focus Groups To Assess** the Family Needs of Pediatric Hematopoietic Stem Cell **Transplant Recipients**

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Stefanie Jeruss, Tufts-New England Medical Center Susan K Parsons, Tufts University School Of Medicine Background: About 2,000 pediatric Hematopoietic Stem Cell Transplant (HSCT) are performed at specialized centers in North America annually. Pediatric HSCT families are geographically dispersed making traditional face-to-face focus groups difficult. In addition, since HSCT programs vary in their practices having participants from different programs would provide more generalizable insight into issues families face. This presentation will describe how traditional focus group techniques were adapted in a virtual application. Methods: Parents and health care providers (HCP) were invited to participate in synchronous online focus groups. After obtaining IRB approval, we partnered with a national HSCT advocacy group to advertise in both a print newsletter and through an email listsery to identify and invite a purposive sample of parents and HCP to participate; access to high speed Internet was required. Email invitations were sent to interested respondents; an online survey was completed prior to the focus group to mirror a nominal group process. An online conferencing system provided synchronous chat, use of PowerPoint slides, and transcript features. Instructions were sent prior to the focus group about logging on, how to participate, and group etiquette. Exit surveys were conducted regarding the process. Results: Five web-only focus groups were conducted that included 14 parents and nine HCP. Although there were some technical issues (e.g. logging on or using the chat box, time lag when responding to a comment when the 'conversation' had moved on) for some participants, all were able to respond during their session and felt a part of the group process. Although facilitators were not able to see non-verbal cues, participants may have been more open with the anonymity provided online and were able to express emotions using emoticons and other punctuation. Conclusions: All participants were able to share their experiences and identified issues that families face during pediatric HSCT. This information was used to develop a national needs assessment survey. Costs were comparable to traditional face-to-face focus groups. This process provides an alternative method to reach difficult to access populations. When compared to traditional focus groups, there are many similarities and some advantages and disadvantages which will be discussed.

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### Building a Bilingual French-English Patient-Oriented Terminology for Breast Cancer

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Background: Patients, and more generally citizens, are often faced with the issue of medical vocabulary which they are liable to encounter in the conversations with their healthcare providers, in their medical files or in health information on the web. A Eurobarometer survey published in 2003 [1] showed that nearly one in four Europeans (23%) used the internet to search for health information. In this latter field, there are technical, cultural and linguistic barriers, since most health-related information is available in English and uses a specialized medical vocabulary. Objectives: An ontology coupled with a multilingual terminology reflecting the patients' common language is the first part of an ambitious project aiming at helping patients to better understand and master their health situation. The TIMC laboratory, together with the Grenoble University Hospital, has worked on the patients' terminology in the field of breast cancer. This particular domain has been chosen because of its interest for the citizens and as a testing ground for a methodology which could be extended both to other health domains and to other languages. Methodology: The first part of our work consisted of gathering and structuring the patients' everyday terms into a concept-based terminology in French [2] (we used to call it an ontology, although we are conscious that building a sound ontology in the health domain is a difficult task which would require another kind of competence



and another methodology [3]. The candidate expressions have been automatically extracted from a corpus of patient-oriented texts (mainly web sites and patient forums). The selection processed required the review by a domain expert, and the resulting terminology was completed and validated by patients and health professionals. The second part consisted in establishing links between the French terminology and the CHV vocabulary, which concerns the patients' language over the whole health domain [4]. The connection between the two terminologies was done manually and was much supported by using the UMLS identifiers, which are attached to the concepts in both terminologies. Results. 1312 concepts have been identified and organized using the generic-specific IS-A relationship (e.g., chemotherapy IS-A breast cancer treatment). Other relations have also been proposed (e.g., mastectomy CAN BE FOLLOWED BY radiation). 3245 French expressions have been attached to these concepts. Contrary to the UMLS lexicon, lexical variants were not considered, and only meaningful synonyms have been retained. CHV provided around 4000 English terms for the same set of concepts (some CHV concepts have not yet been assessed). Example: {FR: mastodynie, mastalgie, douleur au sein, EN: mastodynia, mastalgia, pain in breast, breast ache} Conclusions and perspectives: The bilingual terminology which has been built for breast cancer is the basis of future extensions to other health fields and languages. An European consortium is being constituted for that purpose. The first considered application will be concept-based information retrieval, which will enable citizens to ask questions using lay terms and retrieve results in any language.

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# Next Generation Global E-Health Applications – An Integrated Approach To Delivering Prevention, Intervention, and Disease Management Programs

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Next Generation Global e-Health Applications - An Integrated Approach to Delivering Prevention, Intervention, and Disease Management Programs Please join this panel of experts to discuss the application of leading-edge technologies to improve the health and well-being of the world. These panelists are a unique group of experts who are bridging academic research with business in an effort to disseminate best-of-breed health applications globally. Discussions will include current efforts to integrate internet, telephone, and other media communications to positively impact tobacco dependence, diabetes, obesity, cancer and more. In summary, how to best deliver programs with the most bang for your buck. As researchers, practitioners, and decision-makers, understanding how to efficiently assess for and deliver prevention, intervention, and disease management programs so the right message gets to the right person at the right time based on the most up to date information requires empirical insight, creative vision, and technological integration. This panel will address these topics from a broad perspective. Discussions will also include the panelists' experiences pioneering a new way of doing things, navigating the unknown, and commercializing these technologies. In summary, how to take research findings from the classroom to the boardroom. Despite the hardships associated with actually conducting the research, designing the programs, and developing the technological capabilities, an extremely challenging aspect is bringing these capabilities to a wider audience for evaluation, dissemination, and standardization. This panel will share their experiences. Dr. Ricardo Munoz, Professor of Psychology, Department of Psychiatry, School of Medicine at the University of California, San Francisco (UCSF) and founder of the Internet World Health Research Center at UCSF, will discuss how the Internet is being used as a tool for developing, evaluating, and delivering evidence-based Web interventions for the world's most important behavioral health problems. Dr. Victor Strecher, Professor of Health Behavior & Health Education and Director of Cancer Prevention and Control at University of Michigan and Founder of HealthMedia, will discuss the utilization and integration of web-based technologies to deliver tailored interventions and health behavior-oriented

messages to deliver preventive health programs globally and effectively. Dr Tim McAfee is Chief Medical Officer of Free & Clear, a company providing predominately telephone-based tobacco treatment services for 15 states and over 60 healthplans and employers. He will discuss current experiences and future directions integrating telephone, web, medication, and e-communication into an eHealth platform. Initial successes, failures, and future goals of this next step in the evolution of remotely accessed tobacco treatment will be presented and discussed. Dr. Elizabeth Miller, CEO and founder of DatStat, a company providing integrated online data collection and research management solutions. She will discuss the advantages and challenges associated with next generation research paradigms made possible by cutting-edge internet technology. Specific examples of how researchers are leveraging integrated online solutions to improve the assessment, delivery, and follow-up of health-related research programs will be presented.

#### Have You Received Or Sent An E-mail From/to Your Patient?

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Have you received or sent an e-mail from/to your patients? Mira JJ, Pérez-Jover V. Tomás O. Rodríguez-Marín J. Background: There is no doubt that Internet has changed physician-patient relationship[1,2] but its effects in health care is still unclear[3]. There are some studies that show how health information on Internet is affecting the patients' confidence on their physicians. Nevertheless, in Spain there have been no large surveys on the physicians' perceptions about the Net's benefits and harms for patients[4]. In a previous study, we found that Spanish doctors appear not to have a favourable attitude towards patients' chats[5] and a 10% of them send and receive patients' e-mails sometimes. Objective: To analyze the importance given by Spanish physician to Internet for communicating with patients and the use of e-mail as a communication way with patients. Methodology: 529 physicians were surveyed. They belongs to hospitals (58%) or primary care (42%) of three regions of Spain (30% worked in Madrid, 30% in Aragón, and 40% in Valencia). 41% of doctors surveyed were female. Data were analyzed using descriptive statistics and Chi-Square test. Results: A majority of surveyed subjects (64.6%) do not consider useful the e-mail to communicate with patients. Only 8.3% of them receive patient's e-mail on a regular basis. Hospital physicians receive significantly more e-mails (11%) than their colleagues of primary care (4,5%) ( $\chi$ 2 6.82, p < .009). However, the percentage of GPs that receive diary patients' e-mails is higher (10%) than hospitals' physicians (5,7%). There are not gender differences among physician or GP on the frequency of patients' e-mails that they receive. 28,2% of the surveyed physicians recommend specific websites to patients with the objective to promote health education (usually, to patients with a specific disease). A majority of the surveyed physicians (51%) consider that Internet has no influence (negative or positive) on the physician-patient relationship, compared with a 27,9% that consider that it has a negative effect and a 20,0% which assert that it has a positive one. Hospitals' physicians (68,6%) have a tendency towards to considerer that the Net has a negative effect in their relationship with patients meanwhile only 31,4% GP believe the same ( $\chi$ 2 9.81, p < .007). There are no differences due to geographic zone or gender in this data. If the physician considered useful the Net to receive patients' messages, he/she would be more likely to think that the Net made easier the physician-patient relationship (70,4% vs 29,6%,  $\chi$ 2 63.71, p < .0001). Conclusions: Most of the surveyed Spanish physicians do not believe that Internet actually has influence on the physician-patient relation. Less than ¼ of doctors use e-mail as a new channel to communicate with their patients. There are clear differences in the usefulness assessment of the Net between Spanish physicians who are working in hospital and primary care.

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#### Information On the Net and Its Effects On Patient Safety

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Authors: Mira JJ, Rodríguez-Iñesta \*D, Pérez-Jover \*V, Guilabert \*M, Tomás \*O. Title: Information on the Net and its effects on Patient Safety Background: The amount of consultations about health on the Internet has increased during the last years, although not all the information available on the Net is reliable[1][2]. Internet is having a deep impact on the way people use health information[3]. Nowadays it is calculate that more than fifty million people search for health information on the Net and this number is increasing year after year[4]. The same happens with the resources dedicated to provide information through websites about health[5]. Among all these data, information without any scientific basis can be found which can put at risk Internet users' health. Objective: To determine the level of reliability of the information on the Net about arthritis, haemodialysis and leukomalacia. Method: Descriptive analysis of the information found on web sites about health on arthritis, haemodialysis and leukomalacia. Firstly, several web sites about these diseases were found using the search engines Google, Yahoo and Terra. Secondly some extracts are chosen from the four top web sites obtained from the search to be reviewed by the specialists on each disease. Finally, a group of thirteen specialist practitioners on each disease (three rheumatologists, six nephrologists and four paediatrics) assess the information on these web sites, identifying mistakes (including wrong or inconsistent information) in their contents and classifying them as "serious" or "unimportant". Results: 39.1% of the information describing arthritis, haemodialysis or leukomalacia are erroneous, 29.3% are incomplete and 18.8% of them are not currency. 64.1% of all the mistakes identified by the experts were considered as "serious" and 35.9% "unimportant". Among the serious mistakes, 36.6% were about erroneous information, 26.8% about incomplete information and 24.4% about no currency information. Conclusions: Inaccuracies about erroneous information and incomplete information resulted in 68.4% out of the total amount of mistakes found and these ones were also considered the most serious according to the experts. As a conclusion, policies regarding patient safety should include advices about the reliability of the health information on the Net.

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### Using Internet To Train Residents ¿is It a Good Resource?

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Mira JJ, Sancho J\*, Ortiz L\*, Rodríguez-Iñesta D\*, Pérez-Jover V\*. Background: Nowadays, Internet is a practical resource in the work of doctors and residents, and it can be used for the education of health professionals. Objective: To analyze the importance given by Spanish physician to Internet for train residents and the use of e-mail as a way of communication. Methodology: 529 physicians were surveyed. They belong to hospitals (58%) or primary care (42%). 41% of doctors surveyed were female. Data were analyzed using descriptive statistics and Chi-Square test. Results: A majority of surveyed doctors (63,3%) usually use the Internet for train their residents. The main applications of Internet were: bibliographical searches (94,1%), visiting websites related to their specialities (72,2%), preparing update courses (45,6%) and send e-mails to other specialists (12,4%). Hospital physicians (78,1%) advise using the Internet more than their colleagues of primary care (29,1%) with the purpose to train residents (Chi=6,016, P = 0,014). Specifically, 78,0% of the surveyed subjects that recommend to make bibliographical searches are hospital physicians, 77,0% who suggest to visit specific websites are hospital physicians, 76,6% who advise to prepare update courses are hospital physicians and finally, 85,7% who suggest to send e-mails to other specialists are hospital physicians too. There are neither

significantly differences in the variable sex but not in the variable region of the surveyed doctors. Conclusions: Most of the surveyed Spanish physicians consider that Internet is a good resource to train residents. Approximately 95% of surveyed doctors recommend use Internet to bibliographical searches. There are clear differences in the usefulness assessment of the Net between Spanish physicians who are working in hospital and primary care.

# Electronic Transmission and Processing of Prescriptions(ETPP): How the Inflation of Precious Information Is Managed In the Iranian Social Security Organization

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Electronic Transmission and Processing of Prescriptions(ETPP): How the Inflation of Precious Information Is Managed in the Iranian Social Security Organization Ramin Moghaddam , MD , DMI RCSEd Director, Medical Informatics Department, Social Security Organization, Tehran, IRAN Iranian Social Security Organization (ISSO) is responsible for delivering direct and indirect medical services to 30 million insured people through the ISSO's health care network in the country. In the ISSO healthcare network, there are more than 350 owned medical center in addition to 40000 (including 7000 pharmacies ) contracted healthcare institutions . ISSO is going to enable the sharing of health information using a secure electronic environment to improve health of insured people based on scientific approach alongside the facilitation of tracking the financial loads & risks. This electronic environment brings facilities for different stakeholders in the ISSO by means of reducing chances of abuse and redundant inspections, simplification of outpatient procedures, increasing the accuracy of medical expenses report information, holding the reimbursement information, medical records, etc. ISSO has launched the ETPP project since five years ago . A national updated drugs code database , a national XML based prescriptions dataset exchange format, a distributed web based system for transmission of the prescriptions data form all of the 7000 contracted pharmacies to the ISSO 's subsidiaries and then headquarters ,a comprehensive distributed application for processing of the prescriptions data are recent milestones of this project.

### Information Needs: Why Do Colorectal Patients Contact Nurse Specialists?

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Stefan Plusa

Introduction The provision of information and psychosocial support reduces the prevalence of psychological morbidity in patients with serious illness. Despite perceived satisfaction with counselling many colorectal patients have unmet needs and initiate further contact with nurse specialists. This study examined the advice and support sought by patients and their carers on phone. Methods Unsolicited phone calls to nurse specialists were logged and the temporal relation to surgery and the type of enquiry noted. Results Over a three week period sixty people (22 male, 38 female. Mean age 53 years (range 28 -89)) made 101 calls. Mean number of calls per person was 1.7 calls (range 1-5). Thirty-eight (63%) had colorectal cancer, 26 (43%) inflammatory bowel disease, 15 (25%) functional bowel disease and 18 (30%) other conditions or were phoning on behalf of patients. 30% of enquiries were made in the perioperative period (16% pre-operatively and 14% within two weeks of discharge). The majority of telephone enquiries (70%) were not immediately related to surgery. Most concerns were medical in nature (34%), followed by stoma problems (24%), and the rest (42%) included wound, technical and administrative enquiries. Discussion Nurse specialists provide information on many problems the majority of which are not related to stoma care. It is likely that other patients with similar concerns are reluctant to contact nurses and the true information deficit is difficult to quantify. Further information can be obtained via internet sites.



### Differences In Online Health Searches According To their Impact

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Background: The Internet is becoming a major source of health information and is affecting how health seekers take care of themselves and others [1]. However, many health professionals are concerned about the quality of online health information (OHI) [2], especially as health seekers, those seeking OHI, often are not vigilant in finding and evaluating OHI [1,3,4,5]. Objectives: Using national survey data of 521 health seekers from the Pew Internet & American Life Project, this study examines characteristics of 391 (66%) health seekers whose last successful online health search (OHS) according to whether that OHS had a major (16%), minor (52%) or no (32%) impact on their health-related behaviors. It sought to clarify whether there are differences according to the degree of the search's impact in demographics and health status of health seekers, characteristics of successful searches, vigilance in searches, and how health information is used. Results: There are no significant differences by demographic or health status in the impact of the search. Although most OHS are for information for themselves or other family members, only searches for someone other than family members have significant differences in impact, with these being more likely than others to have no impact (Chi-Square = 4.436, P = .002). Most OHS are for information about a specific illness, and these are more likely to have a major or minor rather than no impact (Chi-Square = 7.759, p =0.023). Overall, when OHS have a major impact, health seekers are more vigilant than with minor or no impact OHS. They spend more time searching (F=5.826, P = 0.003), are more likely to look into the site's privacy policies (F=6.626, P=0.002), information sources (F=5.826, P=0.003), timeliness of information (F=4.153, P = 0.017), and are more likely to believe that some online information is wrong or misleading (Chi-Square =8.134, P = 0.017). Health seekers whose OHS had a major impact also are more proactive than others in using OHI. They are more likely to say their last successful search affected a decision about treatment of an illness or condition (Chi-Square = 56.63, p < .001); changed their approach to maintaining their health or that of someone they help care for (Chi-Square = 42.86, p < .001); changed how they cope with a chronic condition or manage pain (Chi-Square =23.544, p <.001); changed how they think about diet, exercise and stress (Chi-Square =40.729, p < .001); affected a decision about whether to see a doctor (Chi-Square =23.544, p <.001); talk to a doctor about the information they found (Chi-Square =21.912, p <.001); and led them to ask a doctor new questions or get a second opinion (Chi-Square =17.713, p < .001). Conclusions: As the importance of the Internet becomes a more important of health and mental health information, we need to understand the impact of a specific search. There are no significant differences by demographic or health status on the impact of the health search. Searches that had a major impact were likely to be for information about a specific illness that was relevant to the searcher. People whose search had a major impact were more vigilant in their search techniques and more proactive than others.

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# Effective and Confident Communications In the Midst of a Major Crisis: How a Pharmaceutical Executive Can Capitalize On Messaging Simulation

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Marketing researchers are being asked to assume increasing involvement in both the quest for corporate profitability on the one hand, and the quest for social responsiveness on the other. No where is this seen more clearly than in the health care arena, as physicians, HMO's, pharmaceutical companies and even governments juggle the twin goals of improved social welfare and private corporate wealth. With this growing importance of marketing researchers as 'knowledge workers' comes the power to understand how the consumer and how the investor will react to different types of corporate news. These roles move market research squarely back into the topic areas that have been originally staked out by Medical Informatics and Consumer Medical Resources. We report the results of a study using experimental design to understand, segment, and optimize messaging about pharmaceutical companies in the hotly discussed and controversial area of pain relief. The study comprised responses to different, actual 'real' messages about brands, companies, FDA statements, corporate planned actions, and general information. Our presentation shows how the market researcher can acquire knowledge of an actionable nature from consumers who are exposed to concepts about companies. The presentation provides the way the researcher can structure these critical interviews, using high-level conjoint measurement, and how modern analytical techniques dig deeply into the mind of the customer to provide this actionable information. The presentation shows how with these analyses the researcher can design communication programs to position the company positively, even in the face of negative news.

### Down Your Drink: A Pragmatic Cohort Study of An On-line Intervention Aimed At Hazardous Drinkers.

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Background. The adverse effects of excessive alcohol consumption include physical and mental health problems, antisocial behaviour, violence, accidents, suicide, injuries, road traffic accidents and unsafe sexual behaviour. In the UK nearly 10% of adults are estimated to be at harm from binge drinking (predominantly those aged under 25), and 15% from regular excessive alcohol intake,1 costing the National Health Service £1.7bn (\$2.9bn) per annum. In the US the costs of alcohol abuse were estimated as \$184.6 billion in 1998, of which \$26.3 billion were direct costs to the health services2. A series of systematic reviews have confirmed the effectiveness of brief interventions in reducing alcohol consumption and the risk of harm3. However, brief interventions are underutilised4. One potential solution may be to deliver a brief intervention aimed at reducing alcohol intake amongst hazardous drinkers over the Internet. Down Your Drink (www.downyourdrink.org.uk) is such an intervention. This paper reports data from the first 10,000 users of the site. Methods Pragmatic cohort study of the first 10,000 registrants of Down Your Drink. Intervention. Down Your Drink, a free six week on-line brief intervention aimed at reducing alcohol consumption amongst hazardous drinkers. It contains motivational enhancement, cognitive behavioural therapy, and relapse prevention with additional interactive features such as an automated drinking diary and consumption calculator, online quizzes, interactive behavioural analysis of drinking situations (the "thinking drinking" log), blood alcohol concentration calculator and an intelligent email service. Visitors to the site completed the Fast Alcohol Screening Test; those whose scores suggested risky drinking were directed to the free course. The primary outcome measure, completed at the end of weeks 1 and 6 was the Short Alcohol Dependency Questionnaire (SADD), secondary outcome measures were the Alcohol Problem Ouestionnaire (HARM) (which assesses harm associated with heavy drinking) and the Clinical Outcomes



in Routine Evaluation - Outcome Measure (CORE-OM) (which assesses mental health). Results 10,000 people scoring above the cut-off for risky drinking registered to use the site between September 2003 and January 2006 (51.9% female, mean age 37y, one-third single, 42% living with children). 16.5% of these (1,654 registrants) completed the six week programme. Mean scores improved on all outcome measures for those who completed the programme. Mean SADD scores for men: week 1 = 11.51, week 6 = 7.65, mean difference (95% confidence intervals) = -3.86 (-4.31 to - 3.40); for women week 1 = 11.58, week 6 = 7.64, men difference (95% CI) -3.93 (-4.32 to -3.54). Mean HARM scores for men: week 1 = 7.18, week 6 = 3.43, mean difference (95% CI) = -3.76 (-4.18 to -3.33); for women week 1 = 6.61, week 6 = 3.05, mean difference (95% CI) = -3.56 (-3.89 to -3.23). CORE-OM scores showed similar improvements. Conclusions This preliminary study suggests that an on-line intervention to reduce hazardous drinking is acceptable to some people, and that those who completed the intervention reduced their risk of harm from alcohol, although this may not have been due to the intervention. This intervention shows promise, and we are proceeding to an on-line randomised controlled trial. (1) Cabinet Office Strategy Unit. Alcohol Harm Reduction Strategy for England. London: Prime Minister's Strategy Unit; 2004. (2) Department of Health and Human Services. 10th Special Report to the US Congress on Alcohol and Health. Washington: Department of Health and Human Services; 2000. (3 ) Heather N. Effectiveness of brief interventions proved beyond reasonable doubt. Addiction 2002 Mar;97(3):293-4. (4) Heather N. The public health and brief interventions for excessive alcohol consumption; the British experience. Addict Behav 1996 Nov;21(6):857-68.

### Down Your Drink: An On-line Randomised Controlled Trial of An Intervention Aimed At Reducing Hazardous Drinking.

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Background. The adverse effects of excessive alcohol consumption include physical and mental health problems, antisocial behaviour, violence, accidents, suicide, injuries, road traffic accidents and unsafe sexual behaviour. In the UK nearly 10% of adults are estimated to be at harm from binge drinking (predominantly those aged under 25), and 15% from regular excessive alcohol intake,1 costing the National Health Service £1.7bn (\$2.9bn) per annum. In the US the costs of alcohol abuse were estimated as \$184.6 billion in 1998, of which \$26.3 billion were direct costs to the health services2. A series of systematic reviews have confirmed the effectiveness of brief interventions in reducing alcohol consumption and the risk of harm3. However, brief interventions are underutilised4. One potential solution may be to deliver an intervention aimed at reducing alcohol intake amongst hazardous drinkers over the Internet. In a pilot study, completion of a 6-week on-line course was associated with a reduction in dependence and risk of harm from alcohol. However, relatively few users (16.5%) completed the course. Objective. To determine the effectiveness of a fully-interactive, theoretically-grounded on-line intervention (Down Your Drink) in reducing alcohol consumption amongst hazardous drinkers, compared with a minimally-interactive intervention providing health information only (How's Your Drink). Subsidiary objectives are to determine whether access to the intervention is associated with less hazardous drinking, lower levels of alcohol dependence, lower levels of alcohol-related harm and social disruption, improved quality of life and cost-benefits exceeding those of face-to-face interventions. The trial will also add to the relatively scant experience to date of conducting trials entirely on-line. Methods. A two-arm on-line randomised controlled trial. The experimental intervention, Down Your Drink, will provide motivational enhancement therapy and computerised cognitive behavioural therapy in addition to health information and self-assessment tools. The comparator intervention will contain health information only. Recruitment, consent and randomisation will all be undertaken on-line. Visitors to the portal site will be offered the Fast Alcohol Screening Test; those scoring above the cut-off for risky drinking will be invited to enter the trial. Those who consent will be randomised to either the intervention or the comparator group. The primary outcome measure will be a seven day quantity-frequency measure; secondary outcome measures will test our

subsidiary objectives and include the: Alcohol Use Disorders Identification Test (hazardous drinking); Alcohol Problems Questionnaire (harm); Leeds Dependence Questionnaire (dependence); Clinical Outcomes in Routine Evaluation Outcome Measure (quality of life); and the EQ-5D (health economic analysis). All data will be collected on-line. Results. We anticipate considerable methodological challenges to do with randomisation (users re-registering to obtain the desired intervention), contamination (use of other on-line interventions), and follow-up of participants. We welcome discussion on these and other methodological issues. Conclusions. Not available. Reference List  $(1) \, Cabinet \, Office \, Strategy \, Unit. \, Alcohol \, Harm \, Reduction \, Strategy \, for \, England.$ 1-92. 2004. London, Prime Minister's Strategy Unit. Ref Type: Report (2) Department of Health and Human Services. 10th Special Report to the US Congress on Alcohol and Health. 1-492. 2000. Washington, Department of Health and Human Services. Ref Type: Report (3) Heather N. Effectiveness of brief interventions proved beyond reasonable doubt. Addiction 2002; 97(3):293-294. (4) Heather N. The public health and brief interventions for excessive alcohol consumption: the British experience. Addict Behav 1996; 21(6):857-868.

### A Systematic Review of Opportunities and Challenges To Utilize the Internet and Central Data Management In Performing Clinical Trials

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Introduction Web based applications and central data repositories have revolutionized resource and data management in different enterprises from mid 1990s. Clinical research, especially multi-central, controlled trials that recruit patients from many locations, present prominent examples of activities that can be managed and coordinated through web based applications. The objectives of this study were to define the areas that the Internet and web-based applications are useful in performing clinical trials, its opportunities and challenges for the investigators, study sponsors and subjects. Methods This study is a systematic literature review of using web-based applications in performing various aspects of clinical trials. Electronic databases such as Medline and Embase were used to locate the literature. Results Forty six articles published from 1996 to 2005 were reviewed. They reported on web based applications use mainly for data collection (30 articles), randomization (5 articles), study communications including protocol writing, adverse reporting, study group communications, and performance reports (8 articles), study drug distribution (2 articles) and web-based pedigree generation (1 article). The technical and operational features of the web-based system are discussed with variable details in the literature. Generally, the earlier reports focus more on the technical and developmental issues of using the Internet for clinical trials, while later reports tend to focus more on performance measures and user satisfaction with this technology. Invariably security of study subjects' information in the open Internet medium is cited as a major concern and different safe guard features are adopted to ensure the security, however no breach of security is reported. The availability of the Internet connection at the point of study, performance problems mostly at client level, and high start up costs are examples of disadvantages of using the Internet for clinical trials. On the other hand numerous opportunities of web based applications are discussed in the papers such as central data management, timely clean data, real time monitoring of study progress, real time adverse event reporting, and cost saving. The majority of the reviewed articles provide descriptive observational or survey data on the efficiencies of using the Internet for clinical trials. Only two articles provide side by side comparison of web based and paper based systems. In one study the attitudes of physicians who had the option to use either web-based, fax-based, or a combination of both in a large clinical trial were compared. The only determinant of opting for the Internet was age and regular computer use. In another study the performance of paper-based and web-based systems were compared. Although the web-based system performed better on some aspects, no definite conclusion could be drawn from that study to demonstrate the overall superiority of the web-based system. The results of this systematic review shows that there is enough evidence in the literature to demonstrate that web based technologies are capable of performing the majority of clinical trials tasks in a secure manner. However, there is little data from rigorous evaluation studies to support the effectiveness of the technology. This does not mean that the technology is ineffective given the numerous successful experiences with the technology, just that it is unproven.



### Individualized Health Information Using SMS – a Smoking Cessation Case

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Introduction: IT development, including the internet and mobile telephony, has opened new and interesting opportunities for communication to promote health.(1) One important change in relation to conventional information campaigns, which feature passive information, is the opportunity for interaction, target group activation and individualized feedback.(2,3) The internet in particular has been the preferred medium for numerous health promotion initiatives, including smoking cessation and optimized drug therapy for asthma, diabetes, cardiovascular diseases, prophylaxis, vaccine programs and exercise. (4-14) Mobile telephony has also been used as a health promotion tool in many contexts, such as vaccine programs, asthma compliance programs and smoking cessation programs. (14-20) SMS technology has shown to be particularly effective, and in one case, more useful than the internet. Decisive factors include the widespread use of SMS, the opportunity for interaction and the independence from time and place. In addition, a mobile phone is a more personal information medium for young people, one that they carry with them everywhere.(16) The following case study describes the results of an advertising campaign that has individual SMS interaction concerning a health promotion message as a central element. The test objective was to provide an individual evaluation of the degree of nicotine dependence and then give suitable recommendations for the administration form of the nicotine replacement. Method: Test yourself to see what kind of a smoker you are and get help to stop smoking. Send an SMS with the text "Nicotinell" to 21 20 01 01 Question 1 How soon after you awake do you smoke your first cigarette? Within 30 minutes = press 1 (code a) After 30 minutes = press 2 (code b) Question 2 What would be the hardest thing about not smoking? I wouldn't be able to function normally if I didn't smoke = press 1 (code a) I would miss the pleasure of smoking = press 2 (code b) Participants then received individualised SMS help based on their responses. Results Ads for the test were placed on buses and on signs in department stores, as well as on postcards at pharmacies. Advertising was concentrated in urban areas. The advertisements were run for four weeks from 1 January 2006 - 1 February 2006. Over a four-week period, 10,565 people participated in the test. Table 1 shows the distribution. Table 1 Status - responses Response 1 Response 2 Number A A 2,396 A B 2,002 B A 994 B B 3,111 Not completed 2,062 Total 10,565 Discussion / Conclusion The case illustrates that it is most certainly possible to activate consumers and provide individual advice and guidance via SMS mobile telephony in connection with health promotion initiatives. The results of the survey do not indicate the extent to which respondents subsequently carried out a smoking cessation intervention by buying a nicotine replacement product. Comparative sales figures for 2005 and 2006 show a 5% increase in total market share for the company's' nicotine replacement products. However, that cannot be attributed to the SMS test, and respondents also had the option of choosing other nicotine replacement products, of course. (1) Street RL Jr. Mediated consumer-provider communication in cancer care: the empowering potential of new technologies. Patient Education and Counseling 2003; 50:99-104. (2) Conlon R. eHealth Tools and eHealth Management -Opportunities and challenges for pharma companies and MCOs. London: Business Insights Ltd; 2001. (3) Mechanic D. Issues in promoting health. Social science and medicine 1999; 48:711-718. (4) Shuter J, Kalkut GE, Pinon MW, Bellin EY, Zingman BS. 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Mobile Phones (SMS -Short Message Service and MMS -Multimedia Messaging Service) Integrated with Internet Applications -the Next Virtual Reality for Optimized Pharmacotherapy and Healthcare Interventions

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Level: Basic Abstract: The use of the internet as a link in optimizing pharmacotherapy and health interventions has proved valuable in some situations and less successful in others.(1-4) One of the problems with the use of the internet as a tool to promote health has been lack of accessibility and concordance between the medium and the user.(3) In practice, the patient must actively seek out the internet, which does not make contact on its own. In contrast, the mobile phone is more widespread and an integral part of many people's information loop to a greater extent, as they have their mobile phone with them much of the time. In addition, the mobile phone is able to activate the patient automatically.(5) This creates opportunities for interaction with the patient independent of time and place, and many interesting examples of this interaction now exist.(6-9) The user interface of the mobile phone is a limitation, naturally, and here the internet has some considerable advantages. Integrating the interactive strengths of the mobile phone with the user interface of the internet generates synergies that can prove decisive for the future optimization of pharmacotherapy and health interventions. Educational goals: The tutorial will review a number of practical examples of using the mobile phone as a tool for optimizing pharmacotherapy and health interventions. Participants can expect to be inspired to incorporate the mobile phone into their projects. Participants will have the opportunity to work on their own cases with regard to incorporating mobile telephony. Focus will be on specific health problems and solutions and not on technological set up. Who should attend? Health professionals who encounter patients that are "difficult to reach" with information tools regarding compliance/interventions. conventional Pharmaceutical companies that want to create a compliance/intervention add-on to their products, which will thereby become more valuable to the patient as well as the health care system. Researchers who want to conduct studies on how mobile phones can contribute to data collection. Max. number of participants: 40 Fee: USD 150 Audio-visual equipment: High-speed internet access, PC projector Instructor Claus Møldrup, PhD (pharm.) Associate professor Deputy head of department The Danish University of Pharmaceutical Sciences Department of Pharmacology and Pharmacotherapy Section of Social Pharmacy Universitetsparken 2 DK-2100 Copenhagen Phone: +45 35 30 64 52 E-mail: cm@dfuni.dk Reference List (1) Conlon R. eHealth Tools and eHealth Management - Opportunities and challenges for pharma companies and MCOs. London: Business Insights Ltd; 2001. (2) Ferrer-Roca O, Franco Burbano K, Cardenas A, Pulido P, Diaz-Cardama A. Web-based diabetes control. J Telemed Telecare 2006; 10(5):227-281. (3) Anhøj J, Nielsen L. Quantitative and Qualitative Usage Data of an Internet-based Asthma Monitoring Tool. J Med Internet Res 2004; 6(3):e23. (4) Etter J. Internet-based smoking cessation programs. International Journal of Medical Informatics 2006;(75):110-116. (5) Anhøj J, Møldrup C. Feasibility of collecting data from patients through SMS (short message service) for an asthma diary: Response rate analysis and focus group evaluation from a pilot study. J Med Internet Res 2004; 6(4):e42. (6) Rodgers A, Corbett T, Bramley D, Riddell T, Wills M, Lin R et al. Do U smoke after TXT? Results of a randomised trial of smoking cessation using mobile phone text messaging. Tob Control 2005;(14):255-261. (7) Bramley D, Riddell T, Whittaker R, Corbett T, Lin R, Wills M et al. Smoking cessation using mobile phone text messaging is as effective in Maori as non-Maori. The New Zealand Medical Journal 2005; 118(1216):1494. (8) Ferrer-Roca O, Cardenas A, Diaz-Cardama A, Pulido P. Mobile phone text messaging in the management of diabetes. J Telemed Telecare 2004; 10(2):282-285. (9) Downer SR, Meara



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### FREE CDC-SPONSORED TUTORIAL (registration Required, See Abstract!): User-Centered Design of Websites

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This tutorial provides in-depth training on planning, implementing, and evaluate the user-centered design process. This tutorial will focus on the research-based method of developing websites to improve user performance and satisfaction. Also included is information on best-practices, usability resources, and examples of how this research-based method can be adapted and used for guidance in the development of any information-based website.

### Research-Based Web Design and Usability Guidelines -Panel Discussion

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Robert Bailey, Computer Psychology, Inc.

Cari Wolfson, Focus On U!

Sanjay Koyani, Department Of Health And Human Services

Panel discussion on the applications for research-based web design and usability and its impact on e-communications. Panelists, including both U.S. Government representatives and nongovernmental speakers, will discuss the application of user testing and design on a variety of websites. Methods for testing-creation, application and evaluation will be discussed, as well as best-practices and lessons-learned.

### Implementing EHealth: Development of a Personal Health Record for Patients (Process, Product, and Principles)

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Abstract Introduction Ehealth, the use of technology and electronic communication to support the delivery and management of healthcare services, offers the rich potential of supplementing traditional delivery of services and channels of communication in ways that extend our ability to meet the needs of our patients. Benefits include enhanced access to information and resources, empowerment of patients to make informed healthcare decisions, streamlined organizational processes and transactions, and improved quality, value, and patient satisfaction. Process The VA Healthcare Network Upstate New York (VISN 2) chartered an eHealth Task Force in November 2000, composed of a multidisciplinary team of subject matter experts in critical areas, to support and strengthen the development and implementation of eHealth initiatives and policies in this integrated Network. A SWOT Analysis was conducted to develop areas of focus for our patient population (Journal of Medical Systems, "Journey to eHealth: VA Healthcare Network Upstate New York", February 2003). In March 2004 the VA Healthcare Network Upstate New York created an Office of eHealth, responsible for strategic planning and project management in leading and coordinating network-wide eHealth Initiatives. The initial task force evolved into a Network Council and local Teams were established at each Medical Center to operationalize initiatives and align implementation with local clinical and business processes. Product One major element of our eHealth program is the My Healthe Vet Initiative, a web-based application that combines electronic health record information with online health resources to empower and inform patients, and to support patient/clinician collaboration. VISN 2 was selected as a pilot site to foster the development of this personal health record. Experience gained from this pilot has been actively integrated into the national My HealtheVet product and strategy. My HealtheVet includes a variety of customized resources and services as well as access to health information libraries. The ability to record and track information (self-entered metrics) as well as grant access to some or all parts of the personal health record offers additional functionality. The personal health record presents a powerful opportunity to utilize technology as a tool to improve patient access to

information, tools and resources, with the core belief that knowledgeable patients are better able to make informed healthcare choices, stay healthy, and seek services when they need them. Principles Adoption of eHealth initiatives requires a cultural transformation. Early in the project the resistance of the clinical community became a barrier to implementation. We responded to these challenges by dialoging with clinicians in a variety of forums, assessing and evaluating the concerns brought forward, and developing implementation and process strategies. The patient has a fundamental right to the medical record. This process currently occurs at VA through Release of Information. The impact of accelerating the process through technology needs to be understood and addressed. Clinicians and patients are partners in the health care process. Our best strategy is to, enhance awareness of the availability of the tool, engage clinical staff, and focus on the utility of the tool features in meeting the needs of both groups. Summary VISN 2 currently supports more than 375 pilot participants across five Medical Centers. Patient feedback has been extraordinarily positive, and additional studies have been proposed to evaluate impact of the personal health record on overall quality of care, patient satisfaction, compliance with treatment plan, and clinical outcomes. This tutorial session will include lessons learned from the pilot and implementation of the personal health record, keys to implementation, and clinical case studies. Educational Goals At the conclusion of the session, participants will be able to 1. Describe the core elements of an eHealth program and organizational processes required to successfully develop and support the program. 2. Describe the importance of planning and analysis in the identification of areas of focus. 3. Identify desired components of a personal health record for patients and how to create a one stop portal for access to services. 4. Identify barriers to implementation and develop strategies for mitigating risk and cultural resistance. 5. Describe case study scenarios which demonstrate the features and benefits of a personal health record. 6. Demonstrate a deeper understanding of eHealth implementation. Who Should Attend Professionals responsible for and/or interested in implementing eHealth Initiatives or programs; Practitioners interested in enhancing their understanding of the benefits of eHealth tools such as the personal health record. Levels of Content 30 % Basic, 70% Intermediate Prerequisites A basic understanding of eHealth and familiarity with health care are beneficial but not required

### **Online Health Communities**

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Online health communities provide a means for patients and their families to learn about an illness, seek and offer support, and connect with others in similar circumstances. They are supported by a variety of technologies and are hosted by patients, advocacy groups, medical organizations, and corporations. Online health communities raise difficult design challenges because of the wide variability of members' expertise and needs. The importance of online health communities is evidenced by the impact they have on the quality of life and health literacy of their members and by their popularity, which is likely to increase due to changes in the health care system coupled with increased infiltration and use of the Internet. This talk will explore current trends in online health communities and the significant issues in designing and evaluating systems that are welcoming, accessible, easy to navigate and use, and able to help members interact with other participants and medical experts in meaningful ways.

#### **Internet Usage Survey In Orthopaedic Outpatients**

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Internet Usage Survey in Orthopaedic Outpatients. Dr. Ikram Nizam, Mr. Max Esser. Department of Orthopaedic Surgery, Alfred and Sandringham Hospitals, Victoria, Australia. ABSTRACT Introduction: An increasing number of patients are accessing the internet for medical information which provides current information on illnesses, prognosis and treatment options. To date there are relatively few studies that have evaluated its use by patients who seek information online. Purpose: The purpose of this study was to 1) determine patient access to the internet 2) determine the proportion of patients seeking medical information online 3) Assess patient attitudes towards the internet.



Methods: Patients in the orthopaedic outpatients were presented with survey forms over a period of 2 months (September to November 2004). Completed survey forms were then assessed for patient demographics, internet access and attitudes towards online medical information. Results: 189 patients attending the orthopaedic outpatients completed the questionnaires. Mean age of outpatients being 47.5yrs (15 to 86yrs). Sixty one percent had access to a computer, Sixty four percent had used the internet at some point, thirty five percent of those attending the outpatients had accessed the internet to obtain medical information for their current medical condition. The largest age group of internet users was 20-39 yrs. Of those who accessed medical information online, seventy seven percent stated the internet was reliable, eighty six percent stated that it improved their understanding of the current medical condition, thirty three percent stated that the information online was more than that provided by the clinician, thirty percent stated the information online improved their health behaviour, three and half percent stated the information online led them to seek a second opinion, seventy fiver percent stated it was a valuable supplement to a doctor and ninety three percent stated it was Not a substitute to a doctor. Conclusions: The internet is a rich source of medical information which is frequently accessed by patients for additional information. The content of the information is variable as it is usually not edited and unregulated and may be used by organizations for profit or non-profit purposes. As clinicians it is important to realize the increasing number of patients accessing medical information online such that patients may be in better informed about their medical conditions.

### Global EHealth Innovation Through Tobacco Control: Lessons Learned From the Web-Assisted Tobacco Interventions (WATI) Initiative

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Background: Tobacco use is the leading cause of preventable morbidity and mortality in the world, with one in ten deaths worldwide attributed to smoking-related causes; a rate that will increase to one in six by 2030 if cigarette use is not curbed on a global level (WHO, 2002). Networked technologies such as the World Wide Web deliver interventions remotely on a population level and connect smokers and health professionals alike for knowledge exchange and have been shown to be effective at promoting both smoking prevention and cessation in multiple contexts. These new interventions build on the lessons learned from work with other intervention formats with smokers (e.g., self-help manuals, telephone quitlines, computerized interventions) and systematic research and evaluation in order to be evidence-based. The Web-assisted tobacco intervention (WATI) initiative brings together a multi-disciplinary group of researchers, practitioners, and policy makers in eHealth, tobacco control, and public health to form a knowledge network designed to promote learning and innovation in developing, delivering and evaluating technology-enabled tobacco control programs. Objectives: An overview of WATI will be presented with reference to the rationale, history, underlying theories, and evidence guiding the initiative with demonstrations of key WATI innovations. The panel will consist of the following five activities: 1. Peter Selby will discuss the rationale for using WATI in clinical work and provide a brief overview of the history of the WATI initiative; 2. Cameron Norman will discuss the theoretical models that underlie WATI and review the evidence for the use of WATI and behavioral eHealth interventions in general; 3. Scott McIntosh will outline some of the lessons learned from WATI and discuss how the lessons from WATI can be transferred to the eHealth community at large; 4. Tim Huerta will present the findings from a two-year project on developing a WATI global community of practice and illustrate this using social network data collected from WATI workshops including the pre-conference event held at MedNet 2006; 5. A discussion among the panelists and attendees will focus on the implications of WATI for eHealth and eHealth for WATI, the challenges of conducting transdisciplinary eHealth research on a global scale, and the exploration of collaborative opportunities between WATI and the eHealth community more broadly through cultivating learning opportunities to improve public eHealth worldwide. Methods: Four interconnected presentations followed by an interactive discussion among panelists and attendees with focus on actionable steps for developing collaboration and knowledge exchange opportunities within and between WATI and the international eHealth community. Conclusions: The WATI initiative has successfully brought together a diverse group to address global tobacco use using information technology. The lessons learned through applying eHealth to tobacco control provide opportunities to translate this knowledge to other health issues. Through creating opportunities for

transdisciplinary collaboration and a community of practice, WATI aims to engage the eHealth community more broadly to help further the science of behavioral eHealth and promote global public health.

### Development and formative Evaluation of a Web-Based Virtual Experience In Radiation Oncology

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Background: Cancer is the second most common disease in developed countries, and many patients receive radiotherapy (RT) at some point during their illness. Radiation Oncology (RO) is the medical specialty that involves the care of cancer patients with an emphasis on the use of RT. It is essential that all graduating physicians have some knowledge of this field, given the significance of cancer as a health problem and the widespread use of RT. Our investigations have revealed that North American medical students receive little or no exposure to RO [1]. Because the introduction of new course content into an already crowded medical curriculum is difficult, we have developed a Virtual Experience in RO (http://www.bluelemonmedia.com/vero) that will allow students to learn about this medical specialty from their computer. Objective: In this presentation, we will review the evidence-informed development and formative evaluation of the web-based Virtual Experience in Radiation Oncology (VERO). In addition, we will showcase the latest iteration of the website. Methods: Five focus groups, with students and other stakeholders, revealed enthusiasm for this project, generated ideas for content and format and produced a list of learning objectives [2]. New user 'think aloud' sessions with students (n=5) and residents (n=4) and feedback from colleagues have been used to construct a VERO prototype, and the target audience has formatively evaluated its proposed content and design [3]. Content for the final website has been developed by experts working with medical students at the University of Toronto, a world-renowned centre of excellence in RO and medical education. Results: In response, we have produced a website covering 17 different domains of RO practice, which will allow students to: 1) explore RO as a possible career choice through such areas as the history of RO, research opportunities, the roles of the Radiation Oncologist and the multidisciplinary team in cancer care; and 2) learn basic principles of RO in preparation for a clinical rotation. The learning section of the website features modules on both pre-clinical topics (e.g., basic radiobiology and physics) and clinical topics, where principles of decision-making and RT treatment management will be illustrated through interactive case scenarios covering common tumour sites. Conclusions: As web-based education is becoming increasingly important in medical education [4,5], the final website will be advertised through medical schools and professional/research/educational organizations. VERO will in turn be evaluated through new-user sessions and an on-line user survey. Benefits to the medical community will include (1) greater knowledge of RO by generalist physicians so that they may better care for their cancer patients and make educated referrals to RO, (2) increased awareness by medical students of RO as a possible career choice, and (3) development of web-based educational skills by RO faculty. This presentation will be of benefit to those in medical education who are developing similar web-based curriculum in other disciplines.

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### Development of a Centralized Information System for Angiograph Images

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Background: Our research group has collaborated with the hemodynamics service of the most renowned hospital on the development of a web-based information system that optimizes the diagnosis process of coronary diseases on the basis of angiograph studies. Objectives: The objectives that we pretended to reach by implanting the medical imaging information system were the following: (1) Provide an efficient storage system for the image sequences associated to each catheterism. (2) Provide a rapid, secure, and flexible access to the information. (3) Allow the medical expert to use different image processing and segmentation tools for the extraction of additional information. (4) Provide the system with a tool for the labeling of the arterial coronary segments and the measurement of the projections of those segments in real dimensions. Methods: The globally followed methodology is called Unified Development Process, which proposes the construction of a complex system by developing subsystems within an iterative and incremental scheme. The development of each increment provides a new operative product. During the first increment, we focused on developing a data model that allowed us to store the medical images in a Relational Database System, taking into account the fact that the images and their complementary information had to comply with the "Digital Imaging and Communications in Medicine" (DICOM) standard. The second increment was focused on automatic data acquisition from any DICOM source. The studies were obtained from digital angiographs and they are stored in the database. The server offers the possibility of establishing the connections through secure channels. In the third increment, the intermediate software defines an interface that allows the fast integration of assistance tools for the diagnostic decision-taking process. This middleware facilitates the incorporation of processing facilities for conventional images and provides various segmentation algorithms that allow comparative studies. During the fourth increment, we have developed and validated a tracking-based algorithm for the identification of arteries and the evaluation of the seriousness of a coronary stenosis [1-3]. Finally, we indicate the location of the stenosis and in a second, optional point we delimit the affected area, receiving an estimation of the percentage of affected tree. Another semi-automatic segmentation tool based on morphological operators and region growing was developed. This tool is based on two approaches that are frequently used: morphological operators [4] and the region growing [5]. Besides the percentage and volume affected by a stenosis is provided. Results: We propose an efficient storage system for medical images that reduces the physical and electronical space required for storage and that optimizes the access time to the information by means of a web interface. Conclusions: Thanks to the assistance of the incorporated segmentation utilities, clinical experts can obtain quantitative measurements over angiographic images stored in the system. These utilities allow them to select the images of the most adequate projection and, with a better defined stenosis shape, perform volumetric calculations and analyses of coronary tree affections.

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### DermNet NZ, Consumer Health Information About the Skin

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The New Zealand Dermatological Society established DermNet NZ in 2006, primarily as a health information site for patients and health professionals. There are now more than 750 illustrated topics on skin diseases and its management. There is a small continuing medical education section and a members' area. We have tried to comply with Health-on-the-Net and other guidelines for health information web sites. There are an average of over 19,000 sessions per day and nearly two million page views per month (May 2006). Visitors are predominantly from North America, the United Kingdom and Australasia, 36% arriving at the site via a search engine. The most popular topics are skin infections, dermatitis, psoriasis and skin cancers. Each month we receive about 80 requests to copy images, mainly to be used for lectures and school reports. The costs of writing and editing high quality material, registration, hosting and managing the site have been mainly funded by sponsorship and advertising by the pharmaceutical industry.

### Short-term Efficacy of a Web-based Computer-tailored Nutrition Intervention; Main Effects and Mediators

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Background: Computer-tailored health education has been identified as a promising technique to motivate and guide people to change health behaviours [1,2]. The efficacy of computer-tailored interventions delivered through interactive media such as CD-ROM or the Internet needs to be established, before large-scale dissemination of these interventions can be recommended. Objective: To evaluate the short-term efficacy of a web-based computer-tailored nutrition intervention, targeting saturated fat, fruit and vegetable intake. Targeting these behaviours is highly relevant, since diets high in saturated fat and low in fruit and vegetables have been associated with an increased risk for chronic diseases [3]. Methods: Respondents were randomly allocated to a tailored intervention group (n = 261), a generic nutrition information group (n = 260) or a no information control group (n = 261). Intake of fat, fruit and vegetables, awareness of personal intake and intention to change were assessed at baseline and three weeks post-intervention. Post-test group differences were studied by means of multiple linear regression analyses. Perceived personal relevance, individualization and interestingness of the tailored information were tested as potential mediators of the intervention effects. Results: Intervention effects were found for awareness (standardized regression coeffficient (B) = .10, p < .05) and intention to change fat intake (B = .09, p < .05), and for awareness (B = -.14, p < .01), intention to change (B = .13, p < .05) and intake (B = .08, p < .05) of vegetables. Perceived personal relevance, individualization and interestingness of the information mediated some of the effects on the determinants of fat and vegetable intake. Conclusions: The tailored intervention was effective in influencing determinants of fat, and vegetable intake, but the effects on behaviour were limited.

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### Development of a Web-Based Open Source Clinical Tool for the Management of Urinary Incontinence

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Background: Urinary incontinence affects from 3% to 55% of the population, depending on the definition of incontinence used and the age range studied [1]. The prevalence is highest among older woman (17%-55%) and incontinence negatively impacts their quality of life [2]. Holroyd-Leduc and Straus (2004) recommend that physicians understand the causes and management options available to their female patients with urinary incontinence [3]. Objective: To



develop a web-based clinical management tool to assist health care providers in the management of urinary incontinence in older female patients. Methods: The health care providers that would be using the tool were consulted for their requirements. Based on the users' requirements the tool provides and maintains a number of validated and un-validated questionnaires. In addition to demographic information, the validated questionnaires included in the tool are the Incontinence Impact Questionnaire-7 and the Urogenital Distress Inventory-6 [4]. A web-based prototype tool using an open-source questionnaire system entitled PHPSurveyor (http://www.phpsurveyor.org) that has administration functions was developed. The usability of the prototype was tested both heuristically and through a pilot study. Results: A challenge to using open-source software is that the software can evolve and change. During the development of the urinary incontinence clinical management tool five releases occurred of PHPSurveyor occurred. In order to cope with these changes, the clinical administration functions were developed to ensure minimum integration with PHPSurveyor. Demographic and validated questionnaires were designed using PHPSurveyor. One of the main integration requirements was scoring of the questionnaires, which was done using PHPSurveyor database only. The administration functions provide for management of users, providing questionnaires to patients/participants, and trending of statistical and graphical questionnaire results. Once the clinical functions were developed, heuristic evaluation was conducted on the questionnaires and administration functions. A number of usability issues were uncovered in both the questionnaires and administration tools. Changes were made before a pilot study was done with older female patients. The tool was modified based on results from the pilot study. Conclusions: The developed urinary incontinence clinical management tool has been implemented in a generic way that allows for the addition of new questionnaires, different scoring methods for questionnaires, limited integration to PHPSurveyor, and a suite of clinical administration functions. The tool could be adapted to other clinical areas where questionnaires are used.

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### Personalised Training Tool for the Promotion of Healthy Lifestyles

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Introduction One of the main difficulties that public health management faces in developed countries is the aging of the population and, consequently, the growing of chronic diseases. Studies conducted show that those diseases "contributed approximately to 59% of the 56.5 million total reported deaths in the world and 46% of the global burden of disease" [1]. Risk factors causing many of those deaths, such as high blood pressure, obesity, high cholesterol levels or sedentarism, could be easily prevented [2]. For this purpose, the elaboration of prevention strategies able to motivate and empower citizens to be responsible for their own health is a key issue in public health policies planning [3]. Thus, systems providing the user with quality and personalized information must be studied and implemented in order to incorporate healthy lifestyles to the users' daily activities. Within these systems, motivational aspects need to be seriously taken into account and the way the information is presented must be carefully analyzed. The latter is of particular importance, since not every user is familiar with new ICT (Information and Communication Technologies). Hence, interfaces must be user-friendly, understandable and transmit information in such a way that motivates the user to perform a change towards a healthy lifestyle. This paper presents a solution developed in this context. The aim of this work is, on the first hand, offer users a training platform that provides personalized information and, on the other hand, motivate them to use an e-health system in order to create healthy routines. This would provide them with means for taking control of their lifestyle and manage their self-care.

Methods The development of such a system is based on the tailoring of information, adapting it to the specific needs and characteristics of the user. The process begins by harvesting statistical data using specific questionnaires. This helps classifying the user regarding several parameters, for example: pathology (obesity, diabetes, etc.), attitude to change healthcare habits, etc. Only the information related to the specific problematic is used, adapting the presentation of the results and recommendations according to their healthcare behaviour state, among others. Results This paper presents a practical example of such platform, implemented using "portlets", a novel Web component based on Java technology that returns dynamic content to user requests [4], allowing the highest possible degree of personalization. The use of new web design technologies, such as Flash [5], increases also the platform's dynamism and interactivity. Information of very diverse sources is provided: in order to personalize it, users are enquired about the content and layout preferences. The application selects, according to a set of algorithms, the specific information to be presented to each user. Discussion The tool has been tested with a number of users and positive preliminary results have been obtained, which show the high potential of this kind of application in an e-learning system. With these results in mind, relevant changes will be implemented. A novel, dynamic and able to personalise tool is presented here. This tool instructs and motivates citizens to improve their lifestyle habits, by presenting high quality and personalised information. This will empower users to be more proactive in the control of their own healthcare and thus, reduce the risks of potential chronic diseases

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### Embracing Collaborative 'D' and 'R' In EHealth.

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Introduction: Much has been written in the health informatics literature about poor end-user engagement in the design of new technologies, the lack of high quality evaluation, and the difficulties that these bring for adoption [1]. Part of the problem lies in the differing language, culture, motives and operational constraints of the 'D' and 'R' communities, which has led to a lack of mutual understanding. Objective: To illustrate the common ground between approaches by mapping the parallel methodologies and concepts adopted in health services research and software design. Method: Review of concepts and methodologies, with reference to examples of successful collaborations. Results: There is considerable overlap in the methods, concepts and objectives of the software engineering and evaluation research communities working in eHealth. However subcultural factors and different ways of working have traditionally restricted the opportunities for and the will towards collaboration. Conclusions: We have more in common that we think. By sharing information about our research approaches and seeking to actively collaborate in the process of design and evaluation, the aim of achieving technologies that are truly user informed, fit for context, of high quality and of demonstrated value is more likely to be realised. This may involve embracing new ways of joint working that are unfamiliar to the stakeholders involved and challenge disciplinary conventions. It also has policy implications for agencies commissioning development and research in this area.

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### Interprofessional Development of Learning Resources for IBD Patient Portal

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Background: This paper summarizes our experiences from a six-month pilot study of a web portal that provided secure communications, education, and support for self-management by Inflammatory Bowel Disease (IBD) patients. An analysis of "don't know" responses revealed room for improvement in site organization and content analysis. Objectives: To address a gap in knowledge, information, access, and peer support for IBD patients and to improve the quality of the website as a knowledge resource. Methods: As part of this pilot study of a web portal for IBD patients, patients' learning outcomes were studied. The portal contents were analyzed for coverage and completeness. Content on the website was written by an interprofessional team of nurses, physicians, pharmacists, dietitians, IBD patients, and health informaticians. It included frequently asked questions, curricula, glossary, Cochrane plain language summaries, and discussion forums. Patients were recruited from the IBD Clinic in Nova Scotia. The study evaluated the impact of this intervention on quality of life using the the SF-36 and the Inflammatory Bowel Disease Questionnaire (IBDQ) pre and post. Patients' learning outcomes were evaluated using the Crohn's and Colitis Knowledge Score (CCKNOW) test instrument pre and post. A survey of primary physicians was done. Portal content was analyzed by concepts using manual indexing and the MetaMap Transfer software for automatically mapping text to Unified Medical Language System. Results: 76 patients (26 male, 50 female) were enrolled from the IBD Clinic in Nova Scotia; 2 withdrew; 57 accessed the site; 49 completed the SF-36 and IBDQ; and 47 completed the CCKNOW pre and post. Patients logged into the portal 893 times. Usage ranged from 96% for FAQs to 28% for private messaging; and 64% reported improved IBD knowledge. The mean scores on the SF-36 were virtually unchanged and on the IBDQ were 151.62 pre and 156.04 post. The mean scores on the 24-item CCKNOW were 12.61 (CI 11.32-13.90) pre and 13.17 (CI 11.85- 14.49) post with median of 13 at both times. The CCKNOW items were categorized as strong improvement (N=6), improvement/nochange (N=10), and worsened (N=8). Nevertheless, there was moderate improvement in CCKNOW scores approaching statistical significance (p <.07>. There were insufficent responses to the primary physicians' survey (N=5) to support a meaningful analysis. The completeness analysis determined that while all items were answerable through inference, there was a coverage mismatch. Text analysis revealed 3,142 unique concepts in 29,373 occurrences. Conclusions: Patients perceived the portal's dual purpose as a communications and learning platform as its strength. Clinicians participating in this study value the importance of patient education and enablement. The pragmatic enrichment method showed promise for improving information retrieval.

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### **Handheld Computers In Medicine**

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A "Hands-On" workshop covering how to use a PDA in a healthcare setting. The workshop begins with an introduction to PDAs, what the different operating systems and specifications required for use in medicine. Continues with introducing medical PDA reference software, including drug references, medical handbooks and evidence based references. Next delegates will learn how to use a PDA database to manage patients, log books and other administrative task. They will learn how to use existing databases and create their own. Finally the

workshop will look at using PDAs in wireless networks and Electronic Medical Records and discuss how handheld computers will become integral in future healthcare delivery. Participants may wish to bring their own PDA to follow along with the presentations. We will have trial versions of the software being demonstrated available for installing on your own PDAs.

#### **Using Flash To Create Interactive E-Learning Animations**

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Presentation on the use of Flash animations in e-learning courses. The presentation will cover how to use Flash to develop instructional animations that can be included in most e-learning material.

### Supporting Primary Care Counseling with Behavioral Informatics

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This presentation will review progress to date of the Patient-centered Assessment and Counseling for Exercise plus Nutrition (PACE) project. PACE research addresses how primary care counseling to promote improved health behaviors can be enhanced through pre-office visit expert system assessment and action-planning and post-visit behavioral intervention support via web, cell phone and other communication channels. The use of behavioral informatics to support key elements of the Planned Care Model for health services delivery will be discussed as well as lessons learned from large randomized controlled trials among healthy adolescents, overweight men and women, and adolescents at risk for type 2 diabetes.

### Custom Web-Based Electronic Data Collection Systems: Making Clinical Trial Data Collection Simple and Reliable

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Despite the fact that Electronic Data Collection (EDC) tools have been available for more than two decades, clinical trials are still mainly conducted using paper data collection as the primary tool. The reason for this can be at least due to the fact that standards for interchange of clinical data among different parties have to be developed, and that these standards should be extended to facilitate data collection at the investigation site. Present technological applications often do not have adequate functionality to meet the current needs. In addition, available commercial applications are usually economically acceptable and the cost is reasonable only for the large-scale trials. And even then they can hardly meet special trial needs, like integration of other data sources. It is inherent to the trial process that it can be modified during the study, and thus EDC system should be flexible to support these changes. With respect to all requirements listed above it is hardly possible to expect a single system which could suit the variety of different trials needs. At the Laboratory of Biocybernetics (Faculty of Electrical Engineering, University of Ljubljana, Slovenia) we developed several customized web-based EDC systems for clinical trials. We used Internet technologies to reach mobility, to simplify system deployment, maintenance and upgrading, to enable multimedia content and to achieve wide user acceptance. This approach allowed us to reduce clinical trial costs and duration in following ways: - Study can be conducted on the existing computer infrastructure - investigators need just a web-browser installed on any PC with access to the Internet. - There is no need for software installation or maintenance on the investigator's site – the system is set on our servers or on the servers at any other institution which offers web-hosting. - Multi-center clinical trials are supported by the system. - Data monitoring time and expenses are reduced due to anytime access to the data from any computer connected to the Internet. -Data cleaning time is reduced due to the integrated data validation routines which do not let investigators to enter meaningless or erroneous data. - Trial can be followed on daily basis through the on-line statistics. - Further data analysis can be done by data export to appropriate form (e.g. Excel table). Until



now we developed four web-based EDC systems for human clinical trials (three of them are multi-center) and one for animal clinical trial. The web-based EDC systems that we developed include features like: - Electronic CRF with automatic data validation and digital signatures - Upload of data from other data sources (i.e. local medical device database) - Image gallery - Interactive human/animal map for making tumor locations - Interactive tumor history map - On-line statistics and data extractions Acknowledgment: Three EDC systems were developed within the ESOPE (QLK3-02002-2003) and ANGIOSKIN (LHSB-CT-2005-512127) projects funded by European Commission and were in part supported by Slovenian Research Agency.

### Persistent Misleading Health Advice About Smokeless Tobacco On the Web.

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Paul Bergen, Public Health, University Of Alberta Ursula Jakabos, Public Health, University Of Alberta Brian Guenzel

Introduction: Compared to smoking, use of Western smokeless tobacco (ST) products causes approximately 1% as much risk of life threatening diseases (1) which creates the potential to promote ST as a substitute for inveterate smokers, a "harm reduction" strategy. In 2003, we conducted a systematic review of websites containing information about ST and health risks to determine the accuracy of the information (2). We found that when information about the health risk from ST was provided, risks were almost always grossly overstated and conflated with the risk from smoking. In 2006, we initiated a follow-up project to determine if there have been any systematic changes in the content of popular websites. Methods: We conducted a systematic review of 53 of the most influential websites as identified using four search engines. Then content was compared to that from previous versions of the websites. Results: Despite a few changes for the better, the dominant message is still that the risks from ST are comparable to that of smoking. Some literally false claims have been replaced by statements that are literally true, but still convey the original false message. It is still the case that most health claims are not referenced to any source, and the limited references are usually to a small number of increasingly dated secondary sources. We still find a collection of specific scientific claims that are contradicted by the scientific literature. Discussion: Consumers get much of their behavioral health advice from websites (3). The predominant popular messages on the web about ST still mislead about health risks and fail to convey the potential benefits of switching from smoking. Changes in the form of some statements suggest a more deliberate effort to mislead readers. It is still very difficult for smokers to learn that ST is a highly-reduced-risk alternative, and ST users are still told, in effect, that they might as well smoke. Misinformation about health risks provided by trusted and popular sources limits consumers' ability to make informed decisions about tobacco products (2,4). (1) Tobacco Advisory Group of the Royal College of Physicians. Protecting smokers, saving [http://www.rcplondon.ac.uk/pubs/books/protsmokers/index.asp] Accessed March 28, 2006. (2) Phillips, CV, Wang, C & Guenzel B. You might as well smoke; the misleading and harmful public message about smokeless tobacco. [http://www.biomedcentral.com/1471-2458/5/31] BMC Public Health 2005, 5:31 Accessed March 28, 2006. (3) Fox S. Health Information Online: Eight in ten internet users have looked for health information online, with increased interest in diet, fitness, drugs, health insurance, experimental treatments, and particular doctors a n d hospitals. [http://www.pewinternet.org/PPF/r/156/report\_display.asp]Pew Internet & American Life Project: 5/17/2005. Accessed March 28, 2006. (4) Kozlowski LT, O'Conner RJ: Apply federal research rules on deception to misleading health information: an example on smokeless tobacco and cigarettes. [http://www.publichealthreports.org/userfiles/118\_3/118187.pdf] Public Health Reports 2003, 118:187-192. Accessed March 28, 2006.

#### Lack of Internet Use By Colorectal Cancer Patients

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Introduction: The Internet has increased the amount of medical information available to patients. This study aimed to determine the prevalence of Internet use by patients with colorectal cancer. Methods: 50 patients (25 male, mean age 69) who had received surgical treatment for colorectal cancer were interviewed using a questionnaire. Satisfaction with information received, access to the Internet, barriers to Internet use and potential use of recommended sites was assessed. Results: All patients were satisfied with the information received, mainly from the consultant surgeon or the colorectal nurse specialist. 26% had access to the Internet, but only a minority of patients (8%) had actually used it for information about their condition. However, 36% said they would consider using a site that was recommended by health professionals. Patients under 60 were significantly more likely to use the Internet to find medical information (Fisher's exact test, P = 0.046) and access recommended sites (P = 0.023). Discussion: The prevalence of Internet use among British colorectal cancer patients is low, especially when compared to similar figures obtained from patients in other specialities in America. Recommending suitable Internet sites could increase usage. Prospective assessment of the potential benefit of this needs to be undertaken.

### Swalis: A Web-based System To Manage and Audit Elective Surgery Waiting Lists

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Background: Waiting lists in elective surgery are dynamical sets affected by complex interaction of many factors: explicit prioritizing algorithms are now considered as an important matter by most of public health care systems [1]. In 2002 Italian government approved 4 urgency related groups (URGs) for admission to elective surgery. Each URG is associated to a maximum time before treatment but a large quota of waiting lists are actually unmanaged and not prioritized (First-In First-Out policy and subjective criteria). Objective: In this paper we present Swalis research project, which lasted from 2003 to 2005 [2]; its aim was to define and measure the main evaluation criteria for waiting lists, to set and test an experimental computer system aimed at prioritizing the management of hospital admissions, to assess impact of waiting and to formulate ameliorating strategies [3]. Methods: A steering committee with economic, medical and technological skills had been set up to receive and implement these policies on a Surgical Unit of the San Martino Hospital in Genoa. A Web-based Informative System had been deployed in order to collect referrals data and produce full reports and synthetic performance and quality indexes [4]. A prioritizing algorithm has been implemented together with every-day waiting list management tools which significantly reduced the personnel overhead caused by the introduction of a new software procedure. This also proved the importance of standardization in waiting list management, naturally developing new business processes and methodology that are nowadays part of every day work. Results: The system is currently in use, and 100% of new referrals are currently input on line; by the end of 2005 the system collected more than 600 referrals since its deployment, on spring 2005. Economic analysis on collected data were conducted, with the aim of comparing the new prioritizing scenario with the traditional one. Major reported problems were related to integration with contemporary ICT programs but the overall satisfaction of users is high. Conclusions: By economical analysis Swalis shows to improve efficiency and equity. The extension of the software to a larger number of Surgical Units had been recently funded by Regional government with a one year grant, confirming the policy makers interests in this topic and the high impact of both tool and methodology.

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### Cross-organizational Healthcare Process Automation Using a Service-oriented Approach

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With the advent of shared and integrated care, in which care processes are designed around patient needs, cooperation, collaboration and data exchange among disparate healthcare organizations have become particularly important and the need to develop process-oriented healthcare information systems that support cross-organizational healthcare processes has received considerable attention. However, when it is required to preserve existing investments on information systems and resources, the real challenge is to create a process-oriented healthcare system architecture that encompasses existing systems while it promotes inter-organizational cooperation through the logistics principle of information that requires the availability of the right information, at the right time, at the right location, in the needed quality and in an appropriately detailed form [2,6]. Process automation with the use of web services has recently started to receive considerable attention in the healthcare field, with regard to both intra- and inter-organizational healthcare processes, especially when heterogeneous systems that have to be retained are involved. Web services can be viewed as a programming paradigm for integrating heterogeneous applications and for extracting and integrating data from heterogeneous information systems. They are self contained and self described modular applications which can be published, found and used on the web. In automating inter-organizational healthcare processes, where at least two organizations are involved, web services and web services compositions can provide an ideal platform that enables easy integration of possibly heterogeneous applications of the participating organizations, that enhances and empowers collaboration and coordination between them and that enables patient information retrieval from possibly heterogeneous information resources of the participating organizations [1,2,4]. As regards patient information integration and exchange among process participants, some important considerations involve the use of appropriate clinical information standards (e.g. CDA) for structuring patient information, the use of standard terminology systems (ICD, LOINC, SNOMED) for coding patient information and the use of appropriate informatics standards (e.g. SOAP messages) for exchanging this integrated patient information [5]. In addition, as concerns security, authorization and authentication services should be considered in order to control process activities executions, web services invocations and accesses to patient information [3]. In this article, two approaches are presented for cross-organizational healthcare processes integration and automation and for facilitating integrated patient information to process participants. The first approach is most applicable in cases where the development of a new integrated healthcare information system is preferable. This approach proposes the development of a service-oriented information system with the use of workflow technology along with web services. The second approach is most applicable in cases where the organizations existing healthcare information systems should be retained, evolved and interconnected. This approach proposes the use of a loosely coupled architecture with the use of web services and their compositions as a means for interconnecting existing information systems. According to these approaches, two healthcare information systems have been implemented in the field of emergency healthcare in order to support and automate inter-organizational emergency healthcare processes executed in two Athens health districts, accordingly.

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### A Service-oriented Architecture for Information Support To Virtual Hospital Structures

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With the advent of shared and integrated care, the healthcare organizations need to inter-connect and to merge into networks of healthcare delivery focusing on the services patients need, thus comprising a virtual hospital structure. Information support to such a virtual hospital structure that may span the boundaries of health districts and even the boundaries of countries may be problematic, since patient information is accumulated in a variety of locations (e.g. hospitals, health centres etc) and is typically structured in heterogeneous formats, using different semantics. Thus, there is a need to use appropriate healthcare standards (e.g. terminology systems, HL7, openEHR) for structurally and semantically homogenizing patient information existing among disparate and heterogeneous systems and to provide the appropriate technological infrastructure to provide access to and exchange of integrated patient information [5]. This need can be addressed by using: standard healthcare terminology systems (e.g. ICD, SNOMED) for coding patient information, healthcare information standards (e.g. HL7/CDA) for structuring patient information in a standard format and a service-oriented approach using web services technology and the Business Process Execution Language for Web Services (BPEL4WS) specification for providing information services [1,2,3]. Web services enable heterogeneous computer applications to communicate and exchange data via the Internet and BPEL4WS specifies the behaviour of business processes (BPEL processes) that make use of web services, thus, enabling web services compositions [1,2]. In addition, XML-based Clinical Document Architecture (CDA) specification in conjunction with SNOMED and LOINC terminology systems can be used to specify a standard structure and semantics of patient information in the form of clinical documents [3.4]. On these grounds, this paper suggests a service-oriented system architecture that aims at supporting the integrated patient information needs of the healthcare organizations participating in a virtual hospital. According to this architecture, BPEL processes are created at each healthcare organization that involve retrieving relevant and authorized patient data from organization's database servers according to requestor's criteria and to organization's local security policy, structuring this data in the form of XML clinical documents according to the CDA release two specification, storing these documents locally and sending these documents to the requestor. These BPEL processes are actually web services that are published in a Universal Description, Discovery and Integration (UDDI) registry. In addition, a BPEL process is created that involves consulting a Master Patient Index (MPI) for specifying the organizations where patient data exist, invoking organizations web services (BPEL processes) for retrieving relevant and authorized patient data in the form of CDA documents and sending these documents to the requestor. This BPEL process can be invoked and executed by any authorized user of the virtual hospital in order to retrieve integrated patient information. With regard to security, access to locally stored data at the database servers of the healthcare organizations, during web services execution, is controlled by the organizations' local security policies. In addition, a role-based authorization model has been designed in order to control web services (BPEL processes) invocations. This model enforces the virtual hospital security policy and is incorporated to a global authorization server existing at a central healthcare organization of the virtual hospital. The authorization model has been implemented in XML Access Control Markup Language (XACML). A prototype system is under development using Oracle BPEL process manager for designing and running the BPEL processes, the Java 2 Platform, Enterprise Edition (J2EE) for implementing web services and the IBM WebSphere Studio Application Developer environment.

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### **Cross-sectional Survey Investigating Public Use of the Internet for Mental Health Information**

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Background: The Internet is being increasingly used to meet information needs, provide social support, and deliver health services such as online therapy.[1] The anonymity of the Internet has the potential to benefit people with mental health problems, who often feel stigmatized when seeking help from more traditional sources.[2] There has been surprisingly little work measuring Internet use to find mental health information, and in particular no previous study investigating the prevalence of mental health-related Internet use among the general population, and among people with mental health problems in the community. Objectives: To identify the population prevalence of Internet use for physical and mental health information-seeking in the UK. To investigate the relationship between health-related Internet use and mental health status. To identify the relative importance of the Internet as a source of mental health information. Methods: Self-completion postal questionnaire survey of a random sample of the UK population (n=1800). Questions included demographic characteristics, psychological health status (12-item General Health Questionnaire, GHQ), past psychiatric history and use of the Internet and other information sources. The questionnaire was developed from a literature review and qualitative interview study. Results: The response rate was 58%. 64% of Internet users had sought health information online (37% of the whole population), and 18% had sought mental health information (11% of the whole population, 20% of those with a history of mental health problems). After controlling for the effects of age, sex and educational level using logistic regression, there was no difference in general Internet use or health-related Internet use by GHQ score or past history of mental health problems. In contrast, mental health-related Internet use was related to current psychological distress (OR=1.82, 95% CI 1.14-2.89, P = 0.012) and past psychiatric history (OR=2.83, 95% CI 1.71-4.68, p < .001). Regarding the relative importance of the Internet as an information source, only 12% of respondents identified the Internet as one of the most accurate sources of mental health information, compared with 24% who identified it as one of the sources they would use. Conclusions: Practitioners and policymakers must take note of the significant role that the Internet is playing in mental health information seeking. As an information source the Internet has advantages of privacy, anonymity and widespread accessibility at low or no cost.[3] However it appears that the public also recognise the frequently expressed concern of professionals regarding the accuracy of online information, as they rank the Internet higher as a source to use, than as a source to trust. Further research should address how individuals actually use the Internet, what they do with the information they find, and how Internet help-seeking relates to other help-seeking behaviour.

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### **Involving Users In Ehealth Research**

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Level of content: basic Abstract: This tutorial addresses an important need for all ehealth researchers: how to effectively involve consumers in our work. It draws both on the experience of the tutor who established the Warwick Ehealth User Group and has worked with users on several projects, and on the work of Involve (www.invo.org.uk), a leading national advisory group on public involvement in research funded by the UK Department of Health. This tutorial will answer these important questions: - What are the benefits of involving consumers in ehealth research? - Who should be involved and where do I find them? - At what stage in the research process should they be involved? - What

methods can I use to involve them? - Should ehealth research use e-methods to involve e-consumers? User involvement in research is not the same as undertaking research on users. It is about understanding and incorporating the user perspective into the project, often from the very initial stages. Effective user involvement can bring many benefits to ehealth research projects - from identifying the most relevant outcome measures, to aiding recruitment of research participants, to assisting the dissemination of findings. The three levels of consumer involvement have been categorised as consultation, collaboration and user controlled, and this tutorial will explain each in the context of ehealth research, together with an assessment of their benefits and disadvantages. The tutorial will also examine the stages of research at which consumer involvement has the potential to bring most benefit. Finally we will consider the various methods to involve consumers in ehealth research with a particular emphasis on the use of e-methods. Throughout the tutorial we will use case examples from the tutor's own experience and from the wider research literature. The tutorial will consist of lectures and small group work. Lecture notes and further reading materials will be provided and participants will be shown where to find further information. Educational goals: By the end of this tutorial participants will have learned: 1. the ten reasons for involving users in ehealth research 2. the three levels of user involvement in research 3. the ten stages at which users can be involved 4. a range of methods to involve users in ehealth research 5. examples of the benefits that user involvement can bring 6. the pitfalls of user involvement 7. where to get further information

### A Bulletin Board and Chatroom forum for Overweight Children and Adolescents – 5 Year History

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Background: Only one study has evaluated an Internet bulletin board and chatroom forum for overweight children and adolescents [1]. That study found such a forum not helpful, however, the study suffered from restricted forum access by a very small group and unavailability on weekends. Objective: Evaluate a bulletin board and chatroom forum for overweight children and adolescents. Methods: Open access bulletin boards and chatrooms for teens and preteens were implemented on a website for overweight children. Users are referred to the site via search engines and via links from other sites. Age, height, and weight are recorded with posts and in chatroom profiles. IP addresses of bulletin board posters and chatroom users are recorded and partially displayed. Results: The site received 10,000-200,000 users per month over a 5 year period. 35,781 bulletin board posts and 78,396 replies were archived. The chatrooms received 10-200 users per day. User ages were 8-21, with a predominant age of 12-16. A critical mass of 20,000 users per month was needed to sustain bulletin boards and 50,000 users per month to sustain chatrooms. If no one is in a chatroom when an overweight child enters, typically the child waits only 20-30 seconds before leaving. On bulletin boards, however, messages may be posted without anyone else using the board at the time, and replies to a message viewed later. Approximately 13% of posts contain essentially the same message, "I am overweight. How do I lose weight?" Many children post their email address, although this is advised against, and they recruit online "weight loss buddies." Once children lose weight, they typically become "helpers" for those struggling or just starting out. The Success Stories board is the most popular forum. Three main groups use the forums: 1) overweight children who want to lose weight and are seeking tips and support (80%), 2) self-proclaimed "gainers", who do not care if they gain more weight and are seeking support (10%), and 3) healthy-weight children, who feel that they are "fat" (10%). 43% of respondents to a survey feel that the chatrooms and bulletin boards are the most useful part of the site. Analysis of key words in 35,781 posts revealed that that "overweight" was used 4926 times, "weight loss buddy" or "diet buddy" - 531 times, "I need help" or "Help me" - 3425 times, "depressed" - 408 times, "support" – 512, "health" - 3282, "tip" – 2536, "exercise" – 2280, "diet" - 5028. In chatroom transcripts over the past year the word "bored" was used an average of 14.6 times per day and the word "weight" 23.6 times per day. The ratio of bulletin board users to chatroom users was 2.12 to 1. Conclusions: Open access Internet bulletin board and chatroom forums are a feasible method of providing peer support for overweight children and adolescents. Bulletin board forums have twice as many users as chatroom forums, which is consistent with a recent report indicating that 57.8% of obese children exhibit characteristics of attention deficit disorder [2].



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### An Internet Intervention Outcomes Study of Overweight School Children – First Year Results

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Background: Childhood obesity is at epidemic levels worldwide, with serious health consequences. One expert has stated, "We have over-medicalized obesity; we don't have the resources or funding to treat all these obese children and adults in a medical setting."[1] A self-care program for overweight in childhood is thus needed. In a study presented at MedNet2002, 1237 children/adolescents participated in an online self-care weight program, without provider/mentor support. Although there was slight weight loss, the dropout rate was 55%, which was felt due to lack of provider/mentor support. A second study was therefore initiated using the same online self-care intervention, but with the addition of school nurses and physical education teachers as online mentors. Preliminary results presented at MedNet2005 consisted primarily of obstacles which had delayed the study: 1) denial of the childhood obesity problem by parents, 2) administrators and mentors, many of whom are overweight, who do not feel schools should intervene for obesity, 3) minimal computer knowledge by mentors, and 4) lack of Internet access by participating students. First year results will be presented. Objective: Evaluate a self-care Internet intervention, with background mentor support, for overweight in childhood. Methods: A website was created for overweight children and adolescents, where users may: 1) find information, 2) interact with other overweight children, and 3) self-monitor, self-manage their weight. A two-year study was launched in October 2005 with 62 overweight (BMI >95th percentile) Alaska school children, using the website self-care system. In addition, twenty-four school nurses and physical education teachers act as online mentors. Participants weigh-in weekly at school on special wireless scales, which transmit their weight to their website chart. Data is reviewed weekly by the mentors, and supportive messages posted in each child's "eRoom." A control group consists of students of matched age, sex, and BMI percentiles, in schools not participating in the study. Primary outcome measures include height, weight, and BMI percentile at 0 and 12 months. Secondary outcome measures (Internet group) include a Happiness Scale [2] at 0, 6, and 12 months, number of weigh-ins, number of mentor/child online messages, and login time of mentors. Results: Initially mean weight of participants increased, then gradually leveled off. Mean goal rate of loss selected by the students was only 0.81 lb./week, thus weight maintenance nearly achieved their goals. Weight control correlated neither with the number of weigh-ins nor with the number of online child/mentor messages, but rather with the quality of the mentor messages and with access by the child to the website support community. Student access to the website was a significant barrier, as most of the students do not have Internet access at home (in spite of statistics to the contrary), and time allotted for students to use computers at school is quite limited. Moreover, kids are embarrassed to use the site in front of peers. Consequently, 46% of eRoom messages from the mentors were unread by the students, and participation by the students in the large support group on the website was minimal. Mentor login time averaged 0.9 minutes per week per child. Conclusions: Background support from a mentor appears to enhance an Internet self-care weight control program for overweight in childhood. Automated management tools greatly leverage mentor time and may allow Internet intervention to become a cost-effective tier in the treatment of overweight children and adolescents, once public Internet access becomes widely available.

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### What Overweight Kids Say In 61 Anonymous Online Surveys Over a 5 Year Period

Background: Overweight/obesity is associated with a significant social stigma. The Internet is anonymous, thus surveys may be conducted without the user having to reveal their identity. The validity and reliability of data obtained online are comparable to those obtained by classical methods.[1] However, in 'open' surveys conducted via the Internet, where website users respond to a questionnaire or poll, selection bias limits the external generalizability of results [2]. Nevertheless, Internet surveys may reveal useful information not possible to elucidate with 'real world' surveys and where further research is warranted. Objective: Evaluate anonymous online surveys for overweight in childhood. Methods: Sixty-one monthly anonymous polls/surveys were conducted on a website for overweight children and adolescents over a 5 year period. Sex, age, height, weight, and comments were logged from each respondent. Topics included "Have you asked a doctor or dietitian for help w/ your weight?"; "Has your doctor mentioned to you that you are overweight?"; "If your parents are overweight, how do they act if you try to lose weight?"; "What motivates kids and teens to obtain a healthy weight?"; "Do you use food to comfort yourself?"; "What is the main reason you want to lose weight?"; "Does junk food removal in schools help kids be a healthy weight?"; "Should overweight be covered in school health classes?"; "Do you worry about obesity shortening your life?"; "Should seats be wider for cars, buses, planes, & theaters, because more people are overweight?"; "Do you keep it a secret that you are trying to lose weight?" Surveys consisted of "clickable" multiple choice or yes/no answers. A cookie was placed on a respondent's computer when a survey was answered. A test cookie was also placed and retrieved to confirm that cookies were allowed. If cookies were not allowed, or a cookie for a survey was detected on the user's computer, the survey was disabled. IP addresses of respondents were logged for each survey, and duplicate results with identical IP addresses were deleted. Results: The site received 20,000 visitors per month in the first year and 170,000 visitors per month in year five. 100-600 children, age 8-20, responded to each of the 61 polls/surveys. Remarkable results will be presented. For example, 70% of overweight children indicate that they are too embarrassed to ask a healthcare provider for help with weight control. 38% say that their doctor did not mention that that they are overweight, and only 36% say that their doctor both mentioned it and suggested ways to lose weight. 28% say that their school has eliminated junk food, but 39% say that kids are selling junk food in their school, on a black market. 25% say that life is not worth living without the foods they love. Conclusions: Even though identities of respondents can not be validated, anonymous online surveys/polls appear to provide useful information about overweight children and adolescents that it is not possible to obtain with "real world" surveys. Further research appears warranted in regard to many of the online survey/poll results.

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### VIP Panel: Barriers To the Internet In Medicine and Possible Solutions

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Bill Crounse, Healthcare Industry Director, Microsoft Corp.

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John Tooker, CEO, American College Of Physicians

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Jonathan Linkous, Executive Director, American Telemedicine Association

Carol Stock, Carol M. Stock & Director, EHealth Legal Services

Utilization of Internet technology in patient/client care (eCare) has progressed little since MedNet first convened 10 years ago. Intel Corporation has stated, "The healthcare industry is behind even the trucking industry in implementation of information technology [1]." A newly published study reveals that only 2.9% of 4203 physicians surveyed use email frequently with patients, even though consumers desire such, and most other professions use email routinely with clients [2]. Moreover, physicians routinely use email for all professional activities except for communication with patients. Use of more advanced Internet technology in medicine, e.g. patient home monitoring, is also negligible. What are the reasons for such low use of Internet technology for patient care? Reimbursement for eCare in the U.S. and most other countries is almost nil. A few Blue Cross / Blue Shield groups are reimbursing in limited amounts for non-urgent online consultations, but only for specific vendor applications. A



survey of 52 Seattle physicians found that 88.4% would use the Internet for patient care, and 75% would use Internet home monitoring, if they were reimbursed [3]. In addition to reimbursement issues, the physicians listed time constraints, data overload, privacy and confidentiality concerns, liability fears, interstate licensure issues, patient Internet access (the "digital divide"), and provider/patient computer knowledge as barriers to eCare. This special panel will explore the impediments to eCare and what solutions are available. Confirmed speakers are: Bill Crounse, MD, Healthcare Industry Director, Microsoft Corp. Mark Blatt MD, MBA, Director of Global Healthcare Strategies, Intel Corp. John Tooker, MD, CEO, American College of Physicians Gail McGrath, President, National Patient Advocate Foundation Jonathan Linkous, Executive Director, American Telemedicine Association Carol M. Stock, JD, MN, RN, Carol M. Stock & Associates, eHealth Legal Services Invited, but unconfirmed speakers, include: Honorable Tony Clement, Minister of Health, Canada There will be 15 minutes of prepared remarks by each speaker, followed by open discussion with the audience. The goal is to make the session as interactive with the audience as possible, with point-counter point responses. A list of action items will be compiled to address the current obstacles to use of the Internet in medicine. Speaker abstracts/outlines: Bill Crounse, MD, Healthcare Industry Director, Microsoft Corporation Advanced communication and collaboration technologies hold great promise for delivering healthcare information and certain kinds of medical services, improving access to care, lowering the cost of healthcare, and increasing the satisfaction of those who provide as well as receive care. Communication modalities that used to necessitate expensive hardware and network infrastructure have now become commoditized. What once required a multimillion dollar broadcasting facility can now be done with an inexpensive web camera, high-speed Internet connection, and notebook computer. Anything that can be done on a laptop or desktop computer can be shared out to one person or thousands of people at the same time. So why aren't we taking greater advantage of these powerful communication and collaboration technologies in healthcare? During this panel discussion, Dr. Bill Crounse, Microsoft Healthcare Industry Director, will share his perspectives on the opportunities and challenges for analog healthcare providers in an increasingly digital world, including an open discussion of such myths as: Doctors are techno-phobic Physicians aren't interested in doing e-mail with patients Patients aren't ready for digital healthcare There can be no doctor-patient relationship in front of a computer screen There is no return on investment for Internet medicine No one is going to pay for medical services d e l i v e r e d electronically

--- John Tooker, MD, CEO, American College of Physicians E-Communication: A Strategy to Increase Patient-Physician Communication and Improve Care. The American College of Physicians (ACP) recognizes the need provide enhanced and convenient access to care not only through face-to-face visits, but also via telephone, email, and other modes of electronic communication or e-communication, including Web portals. In the world of patient-physician interactions, time is precious—but generally, not reimbursable if the doctor and patient are not in the same room. Rapid advances in computer communications technology have made it possible for physicians to provide care to and monitor their patients without the inconvenience and cost of an office visit. Some experts believe that online patient consultations could produce a 20% decrease in office visits, saving consumers an estimated \$7 billion per year. Surveys of both patients and physicians show a rapidly expanding interest and use of e-communication technology for medical research, education, and treatment purposes. In this climate, patient demand for online contact with their physicians has soared and has led several health insurers to pay physicians for such "e-visits." This revolution in medical care and communication is powered by dramatic growth in use of the Internet, and will ultimately change, support, and improve the physician-patient relationship. However, the ACP recognizes there are several barriers to the expansion of e-communication including (but not limited to): • the current episodic patient care model that does not support patient-centered, physician-guided, cost-efficient, longitudinal care that encompasses and values both the art and science of medicine; • concerns about the ability to comply with the patient privacy, confidentiality, and security requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the consequence for breaches; • concerns about medical liability risk exposure resulting from online communication with patients; and finally, • concerns about the potential for patients to abuse or over-utilize electronic communication with physicians. Dr Tooker's presentation will focus on the current climate and barriers to e-communication. In addition, his talk will outline potential solutions to help promote e-communication based on the

Mark Blatt, MD, MBA, Director, Global Healthcare Strategies, Digital Health Group, Intel Corporation • The current scenario for patient care: the patient

makes an appointment, travels to the physician's office, waits for an hour in the 'waiting room", sees the physician for a few minutes, travels to a pharmacy, waits again, travels back home. Hasn't changed in 300 years. • The Internet will replace, not merely supplement the doctor-patient relationship. • The patient care paradigm needs to switch from treatment, intervention, and crisis management to prevention and wellness. • In 20 years, with baby boomers all retired, we will need 20 times more doctors and 20 times more hospitals. Otherwise physicians will have to see 600-900 patients per day to keep up with the load. • Self care, telemedicine, and home care are key - a three minute home care video will be shown • Artificial intelligence will be used to process patient physiologic data via the net, with physicians supervising • Bank analogy - would a customer choose a bank without an ATM or online banking? • Bring medicine back into the home • Reason organized medicine and state medical boards are currently resistant to the Internet in medicine is guild mentality and turf protection • Healthcare will become a commodity, and overseas care via the Internet w i 11 become prevalent

President, National Patient Advocate Foundation Consumer Concerns surrounding HIT • Privacy and security • Safety • Accessibility • Portability

--- Gail McGrath.

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#### Home Support of Elderly Via Website Algorithms

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Background: The step-by-step algorithms have been verified as improving patients home health care problem solving. Purpose: To describe the design and implementation of home support intervention via web site algorithms in a randomized clinical trial study of elderly (mean age 63.7 years) living at home (n = 208) with continuous positive airway pressure (CPAP). Method: The website included illustrations, information, and guides problem solving through the use of care steps models of common and recurrent problems that can be managed at home. The site used geragogy education principles such as large font, simple graphics and straight-forward navigation [1,2]. It was accredited by Health on the Net and reviewed by the experts to ensure educative quality and clinical accuracy [3]. Results: Hierarchical regression analysis indicated the previous use of computers and the Internet explained 34.2 % of the variance in home health care problem-solving confidence (F = 4.04, p = .033). When controlled for preparedness scores the subjects in the intervention group were significantly more confident in their ability to manage at home than the placebo group (F = 6.43, p = .015). Those younger were more willing to use the Internet than the older (age >60), ( $\chi 2 = 8.48$ , p = .004) [4]. In both groups 50-70% of subjects rated the site as encouraging, positive, informative and enjoyable. Only a few subjects rated the website as a chore and not useful. Conclusion: The web site or telehealth nursing improved subjects' confidence for solving common health management problems. Research on potential health services costs reduction is continuing.

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### Feasibility, Acceptability, and Quality of Internetadministered Adolescent Health Promotion In a Public Health Setting

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Introduction. Community and preventive health services can contribute to preventing diseases among adolescents, especially by promoting good health and a healthy lifestyle. The approach in doing so varies by country. The current Dutch public health care system monitors adolescents' self-reported health and health-behavior via printed questionnaires administered at schools. Based on the self-reported health (from physical to psychosocial health and sometimes also health-behaviors), some public health services refer adolescents with a risky health profile. During such a consultation, adolescents may receive preprinted generic information on health and health-behavior topics. Monitoring data are not only used for individual care, but also for generating health profiles at the group level. Based on these health profiles, schools may decide to adopt specific preventive programs/interventions. We developed an Internet tool to enhance monitoring, personalized feedback, and referral to support routine adolescent public health care. The aim of this study was to evaluate indicators of feasibility (i.e. actual use), adolescents' and physicians/nurses' acceptability (i.e. satisfaction), and quality of the Internet-administered adolescent public health care procedure by comparing it to the current procedure, which uses printed questionnaires and no tailored online feedback. Methods. Internet tool: The health and health-behavior questionnaire and feedback via Internet were developed using PHP (4.0.1 and higher), MySQL (3.22 and higher), and JavaScript (1.3). Access to the questionnaire was password protected, with the student's name not being recorded and only identifiable by the researcher and physician/nurse. Data were sent to the server in a scrambled format. The screen displaying the questionnaire used two separate frames, the left one displaying a list of topics, the right one displaying the questions per topic. Questions not relevant to the student were not displayed. Logging out after completing the questionnaire was only permitted after answering all items. Each physician/nurse received a personal login code from the researcher to access the Internet tool. 1071 Students (average age 15 years) from seven secondary schools were randomly assigned to the Internet-procedure-group or paper-and-pencil (P&P) group. The Internet group received a health and health-behavior assessment, tailored feedback on health and health-behavior (specifically fruit consumption), and an on-line referral to see a physician/nurse if necessary. The P&P group received the same assessment, but included preprinted generic advice on fruit consumption and a mailed referral (where applicable). Students and physicians/nurses completed evaluation forms to assess indicators of feasibility, acceptability (i.e. satisfaction), and quality of each administration mode. Results. Student participation rate was 87%. The electronic health feedback was positively evaluated. Students perceived the Internet-tailored fruit advice as more pleasant, more personally targeted, and more enjoyable, but less credible than the generic preprinted advice (p < .01). No differences in indicators of acceptability and quality of consultation were found (P≥0.05). Discussion. This study was very much interweaved with the existing practice of adolescent public health. We conclude that the Internet can be a valuable tool to support physicians/nurses in this field of preventive care. We recommended further optimizing and evaluating the Internet as a tool to be applied in the setting of public health.

### American Cancer Society's QUITLINK: A Randomized Trial of Internet Assistance for Smoking Cessation

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Introduction: Telephone counseling has been shown to be cost-effective and capable of reaching large numbers of smokers seeking to quit. But internet communication provides an even greater potential for cost-efficiency in health communication. With scalability providing the ability to increase volume without

significantly increasing costs, the internet has the capacity to assistance to the millions of smokers at a reasonable cost. This study examined the effectiveness of internet cessation assistance in a large-scale randomized clinical trial. Methods: Smokers (n=6,451) visiting the American Cancer Society's internet site offering cessation assistance were, after providing consent and determining eligibility, randomized to receive access to a static internet site with quitting advice or to one of five interactive sites provided by cooperating research partners. Three-month follow-up surveys were conducted either online or by telephone to assess quitting success and 54% provided follow-up data. Results: Three-month results showed no significant overall difference in cessation rates among participants assigned to the interactive or static sites. There were large differences in the utilization of the five interactive sites. When sites were grouped by level of use there was a significantly higher reported three-month cessation rate among participants assigned to the more highly utilized sites than among those assigned to the less utilized sites (12.2% vs. 10.2% of all randomized participants, Pearson Chi Square test, p < 0.05; 26.0% vs. 22.1% of followed participants, Pearson Chi Square test, p < 0.05). Six-month results will also be discussed in this session. Discussion: These findings show that interactive internet sites yielding high levels of utilization can increase quitting success among smokers seeking assistance via the internet.

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### **Internet Survey Data Management Using SAS**

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In this workshop we will take a data file in a format commonly provided by online survey providers, into SAS and work through the steps to prepare it for statistical analyses. This workshop will be most valuable to researchers and program evaluators who would like a brief refresher in using SAS and exposure to several potentially useful data management techniques. Project managers and researchers who supervise SAS users may also find this workshop beneficial. Advanced SAS users should refer to the workshop outline below to see if any of the techniques are unfamiliar to determine if the workshop will be beneficial. Those who have never been exposed to SAS may find the pace too fast. In the first hour will focus on getting a data file into SAS, examining the contents, and creating a permanent SAS data file. Outline of the first hour Brief overview of SAS Option statements Libname statement Importing data files Import wizard Creating and saving an import macro Excel Dbf Using Proc Contents SAS data step Temporary vs. Permanent SAS data files In the second hour we will focus on creating variables and working with dates in SAS. Internet-base surveys often contain questions that allow multiple responses. Summarizing that data is often problematic. Data files from Internet-based surveys routinely provide those multiple responses in single response value as a string separated by commas. We will be using the substring function to separate data of that type and creating dummy variables to facilitate summarization. Outline of the second  $hour\ Creating\ variables\ Dummy\ variables\ Substring\ function-Uniform\ response$ length Plan ahead and specify response values of uniform length. Variable response length Dates Using the MDY function to create dates Formatting dates in SAS Using D-base to strip time stamps In the third hour we will use three techniques to combining datasets and discuss the appropriate conditions for the use of each. There are a variety of instances in which it is necessary to combine data from various sources. Intake and evaluation data are usually collected in separately and must be combined. On-line surveys are often supplemented by telephone surveys to boost response rates. This also produces Outline of the third hour Using the Merge statement to combine data files Using the Set statement to combine data files Using the Update statement to combine data files Run; Stop;



### Free Professional Medical Online-consultation: Helping Agent for Adolescents with Limited Informal Resources?

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Introduction: In cooperation with the University Children's Hospital the University Hospital Zurich is providing a free and anonymous medical online for children and service (www.medizinmann.unispital.ch) in order to gain insight into medical concerns of adolescents. Using an online-consultancy service is a specific form of help-seeking behavior [1,2] and help-seeking behavior of adolescents is associated with psychosocial factors as older age [3,4], absence of depression [5], active coping behavior [6] female gender [4,7] and use of informal resources [3,7-9]. We were no only interested in topics and types of questions asked but also in demographical and psychosocial characteristics of adolescent users. Methods: During one year the incoming questions were collected and users were asked to complete an unsolicited online-questionnaire about psychological variables related to help-seeking behavior. 240 adolescent users aged from 14 to 20 years asked 314 different medical questions and 37% provided a valid questionnaire. Results: Online-consultancy was mainly used by young males for very intimate and personal questions. The perception of users that it may be possible to discuss their questions with at least one parent was associated with lower psychosocial resources but not with the questions' degree of intimacy. Conclusion: A medical online-consultancy service is suited for adolescents with poor psychosocial support who have no parents to turn to and can provide help in the case of problems where adolescents would be too embarrassed to seek help for. This is especially true for male adolescents.

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### @neWorld: A Virtual Community for Kids with Cancer

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@neWorld® is an award winning educational and social support intervention that uses the Internet as a community-building tool for hospitals and schools. It provides educational continuity for children and adolescents undergoing treatment for cancer and is designed to operate on a small, lightweight laptop featuring a built-in Webcam to facilitate use for both inpatients and outpatients, although it is accessible from any computer. Animated interactive Agents provide online help to the patient, and a proprietary Web-based "mood engine" tailors the look and feel of the site design based on the patient's health status and mood. Teacher and healthcare provider interfaces enable interaction with the patient and make it possible to download curricula and class content. Usability testing was completed at the Communications Technology Branch of the National Cancer Institute. Efficacy testing in a clinical trial with 38 pediatric cancer patients was completed in 2004 and demonstrated that @neWorld has a positive effect on school achievement and self esteem, and reduces behavioral problems. Hospitals participating in the study include Ronald

McDonald Children's Hospital, Children's Memorial Hospital, Hope Children's Hospital, and the University of Wisconsin-Madison Children's Hospital.

### Internet Uses for Health Information Seeking: An International Literature Review

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Background: With the widespread of the Internet, it would be relevant to report on current knowledge about health information seeking on the Internet from the consumers' standpoint. Objective: To conduct an international literature review on the Internet uses for health information seeking. Methods: In early 2005, a bibliographical research over the past five years was conducted at Medline® and other search engines or health catalogues, using the following health words: Internet. information. consumer information/informatics. Sixty of the most relevant articles or reports were selected out of more than 200 papers when they dealt with the informational facet of ehealth and were written in French or English (or at least with an English abstract). Results: A large proportion of papers came from the United States. Most of the studies were merely descriptive and highlighted that the factors associated with health searches on the Internet were similar to those underlying the digital divide. Consumer searches are deemed efficient although search skills remain below standard. Attempts are underway to ensure better quality information on the Internet. However, comprehension and literacy are still issues in some social groups. Regarding the impact on consumer health per se, a positive effect of the Internet seems more assumed than effectively evaluated. Conclusion: This review highlights the heterogeneity of the amount of research studies by contry. Many of the behaviors, uses or limits addressed in this review not only pertain to the specific area of health but also occur in any information seeking on the Internet [1]. However, longitudinal investigations are needed, while rolling out a comprehensive approach to the temporal evolution of user practices and experiences. Both could determine how (and for whom) the Internet alters information seeking behaviors and, in fine, to what extent this affects health behaviors and healthcare utilization.

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# Internet Uses for Health Information Seeking: A New Digital Divide? a Study On a Representative Sample of Paris Metropolitan Area, France, 2005

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Background: In France, as in other industrialized countries, the digital divide is decreasing as Internet penetration is increasing [1]. Though, in the specific field of health information seeking, remaining or "new" obstacles may lead to the exclusion of people the most in need of health information [2]. Objectives: To assess social factors associated with Internet access and uses for health information seeking. Methods: In the late 2005, a cross sectional study was performed among a random sample of households (representative of the population of Paris metropolitan area and over sampling poor neighborhoods). A face-to-face questionnaire was administered at home. Results: About 23% of contacted person have refused to take part in the study. A total of 3023 subjects have undertaken the questionnaire. Among them, almost 64% had an



access to Internet (whatever the place of connection: at home, at work, by friends or in public place). This study confirmed the known factors associated with the digital divide (level of education and income, age but not gender). It also showed that after adjustment for these characteristics, people "the most in need" of health information (the sickest, most socially isolated, oldest, most excluded from health care, and/or migrants) were also the ones who were less interested in health or had low access to Internet. For example, French people are more connected to Internet than foreign people (OR=3.62, 95%IC: 2.75-4.75) and isolated people are less interested in health (OR=0.39, 95%IC: 0.24-0.63). Among people connected to the Internet, over 58% have already searched for health-related information on the Internet. The effect of some social factors persist, and even if health information searches are not linked to any medical consultation (in 80% of cases), health seekers are often directly concerned by a personal health problem or by a relative's one (OR=1.70, 95%IC: 1.33-2.16, OR=1.25, 95%IC: 1.03-1.52 respectively). Conclusion: The utilization of Internet as a source of health information is still growing in France, as it does in other industrialized countries. The digital divide is still present and other social factors (like social isolation or exclusion from health care) seem to be related to inequalities in health information seeking on the Internet. Research must continue in order to better understand how French people deal with this information in a specific health system. Further investigations should also be done to know whether other health information sources are sufficient (for non Internet health seekers), or whether health information seeking on the Internet can increase social health disparities.

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### Rationale and Design of a Telemedicine-Delivered Smoking Cessation Intervention for Rural Smokers

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Background: Rural Americans experience high rates of smoking and tobacco-related mortality. Rural physicians lack the resources to effectively address smoking. Objective: We describe the rationale and design of a cluster-randomized trial to examine the effectiveness of integrated telecounseling versus usual care. This proposal is under review at the U.S. National Institutes of Health. We will encourage discussion of strengths, weaknesses, and recommendations for improvement. Methods: Sites will be recruited from a rural primary care research network and assigned to either: 1) Usual care (UC), whose patients will receive free nicotine replacement therapy or bupropion, and whose physicians will receive practical tools for helping smokers quit; 2) Integrated telemedicine-delivered counseling (ITM), whose patients will receive the same intervention as UC plus 4 sessions of real time interactive video telecounseling for smoking cessation and whose physicians will receive faxed feedback on patients' progress. Counseling sessions will occur during scheduled office visits, in examining rooms equipped with 2-way webcams mounted on desktop computers. Counselors will deliver sessions from an urban medical center. Participants still smoking or who relapsed by 6 months will be offered another course of treatment. Fourteen smokers from 40 practices (N=560 patients) are required to detect the proposed treatment effect. Results: Outcomes will be assessed at 12 months and include smoking cessation, smoking reduction, and cost-effectiveness. Conclusions: This is a novel approach that employs a disease management model and capitalizes on new Medicare reimbursement for telemedicine and tobacco treatment. Medicare reimbursement creates a strong potential for widespread adoption. 1) Center for Medicare and Medicaid Services. Medlearn Matters: Smoking and Tobacco Use Cessation Counseling, MM3834. Center for Medicare and Medicaid Services. Available at: http://www.cms.hhs.gov/medlearn/matters/mmarticles/2005/MM3834.pdf. Accessed November 21, 2005. 2) Cronk CE, Sarvela PD. Alcohol, tobacco, and other drug use among rural/small town and urban youth: a secondary analysis of the monitoring the future data set. Am J Public Health. May 1997;87(5):760-764. 3) MMWR. Physician and other health-care professional

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### Mobile Computing Instead of Paperbased Documentation In German Rheumatology Using DocuMed.rh

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Objective: Our software DocuMed.rh was developed for the documentation of patients with inflammatory rheumatic diseases in Germany, it is used by over 30 outpatient clinics and practitioners in routine patient care. Our objective was the integration of mobile computing into routine patient care for improvement of acceptance, process optimisation and quality. We focused on self-administered standardized patient questionnaires that are important in assessing the benefits of therapy for rheumatic patients. Validity of online obtained data and the capability of patients with disabilities to handle a modern medium as Tablet PC was assigned. Methods: A Compaq Tablet PC TC 1000 was connected to a web server that runs DocuMed.rh. On a regularly scheduled visit after short instructions by a study coordinator 117 patients (51 rheumatoid arthritis (RA), 53 systemic Lupus erythematosus (SLE), 13 spondyloarthropathies (SpA)) completed prearranged sets of self-administered questionnaires (containing 3 of the following: Funktionsfragebogen Hannover FFbH/calculated HAQ, SF 36, BASDAI, German SLAQ version) as a paper-pencil and an electronic version before respectively after the rheumatologists contact in a cross-over design. An additional paper based questionnaire assessed patients sociodemographics, experiences with the Tablet PC and history of computer/internet use. Positive ethics approval and signed patients consents were obtained. Results: Patients were predominantly female (74.0 %), mean age 46.7±14.6 years (yrs), mean disease duration 6.2±7.0 yrs (median 3.0). 11.1% had a high education level. 27.4 % had retired, 41.9% worked fully or part time. 66.7% reported regular PC use for a period of 9.7±5.6 yrs, 65.0% regular internet use since 4.8±2.5 yrs. Confidence into the internet was rated as  $3.3 \pm 1.3$  on a 1-6 Likert scale. Professional users were 2.5%, common users 44.9%, layperson 17.8% and beginners 27.1% of the patients. No major problems with the Tablet PC occurred during the data input, only 4 (=3.4%) patients felt uncomfortable with the Tablet PC due to their illness. 65.0% preferred data entry on the Tablet PC in the future. Scores obtained by patients direct data entry on the Tablet PC did not differ significantly from the scores obtained by the paper-pencil questionnaires in the complete group and in subgroups, see Table. Score Tablet PC Paper-pencil based Spearman Rho# P\* FFbH 87.5 (14.7-100.0) 86.1 (13.9-100.0) 0.988 0.725 HAQ 0.71 (0.37-2.8) 0.75 (0.36-2.8) 0.985 0.829 SF-36 physical health 38.5 (19.6-50.2) 39.2 (21.2-52.9) 0.821 0.943 SF-36 mental health 44.7 (27.4-57.2) 44.8 (28.9-57.8) 0.733 0.600 BASDAI (SpA patients) 5.0 (0.7-7.2) 4.8 (0.7-7.3) 0.991 0.642 SLAQ (SLE patients) 33 (22-40) 32 (21-40) 0.835 0.111 Table Median scores and ranges; #bivariate correlation; \* Wilcoxon Rank test Conclusion: Compared to paper-pencil based documentation online application of self-administered questionnaires on the new medium Tablet PC is efficient and capable in patients with RA, SLE and SpA using DocuMed.rh. Patients answers are valid and reproducible. Data acquisition on a Tablet PC is not influenced by the underlying disease. Mobile obtained data are rapidly available just within the patient visit and can easily be merged with clinical data, thereby contributing intensly to patients empowerment and improved patient care.



### Web-based Self Help Interventions for Problem Drinkers and their offsping

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WEB-BASED SELF HELP INTERVENTIONS FOR PROBLEM DRINKERS AND THEIR OFFSPRING In this panel session we would like to present the results of our research projects into web based self help interventions one for problem drinkers and one for children and adult children of problem drinkers with a focus on the effectiveness, cost-effectiveness and large scale implementation of these interventions. Problem drinking is highly prevalent (estimated to be 10,3 % of the population of 16 years and older in the Netherlands) and entails a formidable disease burden and substantial economic costs to society. These costs largely arise through lesser productivity when problem drinkers are absent from work (work loss days) or not feeling perfectly fit while at work (work cutback days). Although problem drinking has many adverse consequences, problem drinkers rarely present themselves at specialised health services. In the Netherlands health service uptake is limited to only 5% of the population of problem drinkers. Not surprisingly also there exists a high prevalence of children of problem drinkers who are at higher risk of developing physical mental or social when compared to children of non-problem drinkers. And parallel to their parents this group is highly invisible for health services but also services on offer are very limited. Against this background it is imperative to provide easy-to-access, low-cost, acceptable and effective interventions for problem drinkers and their offspring. Web-based interventions may fulfil the current gap in services on offer. We start our presentation with a brief introduction to the web based self help intervention for problem drinkers (Drinking Less, Do it Yourself). We will then report on the effectiveness and cost-effectiveness of this highly structured, cognitive-behavioural, self-help intervention. We tested the hypothesis of superior effectiveness of this web based self-help intervention vis-à-vis an online psycho-educational information leaflet for problem drinkers. Method: The intervention was evaluated in a pragmatic randomised cost-effectiveness trial with two parallel groups and follow-up at 6 months and 12 months. Participants were adult problem drinkers (N=268) with a weekly alcohol consumption in excess of 210 g methanol for men and 140 g for women, or consuming at least 60 g in men or 40 g in women in any one day in the past six months which were randomly assigned to either the web based self help intervention (n=134) or a web based information leaflet (n=134). MAIN OUTCOME MEASURES: (1) Reduction in mean weekly alcohol consumption. (2) Number of participants who reduced their drinking habits to under the normative limit of the Dutch guideline for sensible drinking. Alternative outcomes such as hazardous drinking and problem drinking are also discussed the and cost/utility ratio (\$/DALY). RESULTS show that participants in the intervention condition reduced their alcohol consumption significantly more than participants in the information only condition 6 and 12 months after the start of the intervention and . the DL intervention showed to be a cost effective intervention in terms of \$/DALY's. Web-based self help treatment for problem drinking without guidance is (cost) effective in reducing problem drinking. In the discussion we will focus on the generalizebility of these result into daily practice and in relation to the constraints our study. We will present the first results of our current research project which entails the implementation of this intervention including issues on effective recruitment strategies, attrition of participants, the place of the intervention in an online stepped care model for problem drinking and rolling out the intervention and implementing it on a larger scale. Part two of our presentation concerns the results of our process evaluation of a web based self help intervention for children and adult children of problem drinkers (Drinking, thank you so much!). This intervention has at the moment the status of 'best practice intervention'. We will present to the following results of our pilot implementation: 1) characteristics and number of the target group reached in relation to the intended target group, 2) quantity and quality of the e-mail service used in practice, 3) in what way content analysis of the peer to peer moderated forum of this website. We end this part of our presentation by discussing some of the problems encountered to perform a clear cut RCT of an intervention of this kind at this moment in time. Finally, we discuss on how these interventions can be placed in an online stepped care model for problem drinking for different target groups.

### ISRII Panel: Examining Issues of Adherence In Internet Interventions

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Adherence is a significant issue for most health interventions, and particularly with respect to Internet interventions. Poor adherence results in less than optimal disease management and causes suboptimal clinical benefit. In fact, The World Health Report of 2002 declared that adherence was the primary determinant to the effectiveness of all treatment. In general, poor adherence causes medical and psychosocial complications of disease, reduces patient's quality of life, and wastes health care resources. Non-adherence across Internet interventions varies greatly with researchers reporting anywhere from 0% to 99% non-adherence. With such a range, it is difficult to determine the obstacles, strategies, and potential solutions for non-adherence. In fact, the notion of adherence, and specifically "drop-out," may need to be considered differently in Internet intervention research given the different ways people may use this form of treatment. This panel, made up of researchers from the International Society of Research on Internet Interventions, will focus on the myriad of related issues involved in adherence, attrition, penetration rates, attainment, and treatment 'dosage' to web-based programs. New data examining adherence within several recent Internet intervention trials, including applications for weight loss and diet, diabetes, encopresis, stress, physical activity, and substance use will be presented.

### How Do Text Features Affect Readability? Expert Evaluations On Consumer Health Web Site Text.

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Background: Previous research suggests that consumers frequently have difficulty understanding written health information. Objectives: This exploratory study investigated the influence of linguistic and stylistic features on the readability of consumer health texts. Specifically, the research goals were (1) to examine the importance of previously identified predictors of general readability in the consumer health domain, based on expert judgment, and (2) to characterize patterns associated with expert ratings of readability across the various predictors. Methods: Health communication experts (N = 4) reviewed a sample of 22 consumer health texts on two common health topics, asthma and weight management. Each expert independently rated the contribution of 15 specific features on the readability of all documents in the sample. Results: Simultaneous multiple regression found that a 15-variable model significantly predicted readability for a general audience (F (15, 72) = 11.802; P < .001). However, only two variables, "Vocabulary" and "Main Point" significantly predicted general audience readability. A factor analysis of all ratings for the 15 features across the 22 documents revealed three clusters of features representing expert perceptual orientations: (1) discourse-level features, (2) sentential-level features, and (3) semantic features ("Vocabulary" and "Main Point"). Conclusions: The preliminary results suggest that developing consumer health-specific readability tools may require both modifying existing general measures, such as including health-related vocabulary, as well as adding new predictive features, such as ability to detect the "take-home" message. Future work includes verification of this expert evaluation by consumers.

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### **Evaluating Structural Change In a Reference Terminology**

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Introduction: Clinical terminologies are domain-specific collections of terms and concepts that represent entities or events related to healthcare. Existing terminologies can change to meet new intended uses related to knowledge representation, data storage, data mining and knowledge discovery, among others. Formal approaches for revealing and quantifying terminology evolution can help developers and users assess the potential impact of changes before integrating them into their local systems. Existing methods for identifying and characterizing terminology change, such as that by Oliver et al., primarily address individual concepts and their interrelationships rather than overall terminology structure. Elkin and others have developed a tool called Ontologic hierarchical Distance Identification Network (ODIN), which displays the gross structure of an ontology in terms of the relationships and conceptual distances among concepts. ODIN presents terminologies as inverted ontological trees with concepts represented as nodes, and interrelationships as branches. Using ODIN, it may be possible to visualize overall terminology structure and calculate various structural attributes. The current investigation extends ODIN to quantify a terminology's structural attributes from successive versions occurring as it changed over time. Methods: We measured novel structural attributes of four successive versions of the National Drug File Reference Terminology (NDF RT) Physiologic Effects hierarchy. The NDF RT models medications with definitional roles for the physiologic effects (PE), mechanisms of action (MoA), and therapeutic intents (TI). Attributes included measures for overall size, dimension (i.e., width, height, mass, depth), complexity (i.e., node recurrence, leafiness, branchiness) and balance (i.e., skew, variation, smoothness). Results: Four versions of the NDF RT physiologic effects reference hierarchy from December 3, 2002; December 11, 2002; December 19, 2002; and January 7, 2003 were available for display in ODIN. Of these, the first version included 711 nodes representing 690 unique concepts, with numbers of terminal nodes under each branch ranging from 5 to 86. The second contained 926 nodes representing 901 unique concepts, the third contained 1701 nodes representing 914 unique concepts, and the fourth included a total of 1638 nodes representing 916 unique concepts. In this final version, nodes were distributed into 2 major branches, with one having 151 terminal nodes and the other having 885. In the ODIN graphic output, the relative mass, density, and balance can be easily visualized, and areas having relatively increased density can be seen. The branch "Neuromuscular Transmitter Activity" in particular grew out of proportion with other branches. In the first version, this branch contained 2 terminal nodes; by the fourth version, it contained 558. Discussion: We have applied novel metrics for quantifying gross terminological structure using a hierarchy visualization tool. Using this tool and the proposed metrics, it was possible to characterize changes that occurred as modelers created the NDF RT physiologic effects reference hierarchy. Visualizing and characterizing the structure of successive terminology versions revealed how the terminology changed at a high level, and where it may have been relatively over specified to meet modeling- or use-based needs. Exposing high level terminology structure may improve developers' and users' ability to identify changes occurring over time.

### Collaboration Across National Borders Using E-health Technology, a Technical, Organisational and Legal Review

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Background The use of obstetric ultrasound imaging are now widely accepted as a service for pregnant women in developed countries. In Norway and Sweden all pregnant women are offered an ultrasound examination during the first 18 weeks of the pregnancy. In order to establish the best possible diagnostic quality the facilities offering these services have access to specialized centres for the diagnosis of difficult cases. There is further need for communication between the different levels of service providers. Telemedicine has been a recognized and accepted technology for at least ten years. During the early phase the bandwidth limited the possibilities to send real time motion frames. Now, new developments with telemedicine make it possible to send real time motion pictures for preliminary diagnosis or second opinion. In this project we have connected two diagnostic centres; Umeå (Sweden) and The National Centre for Fetal Medicine (NCFM, Norway) using Telemedicine. This pilot project is a part of the Interreg financed EU project called Baltic e-health. Baltic eHealth will promote the use of eHealth in rural areas of the Baltic Sea Region by creating a large trans-national infrastructure for eHealth, the Baltic Sea Healthcare Network. Objective The project goals for the eUltrasound clinical pilot. • The project aims for better clinical quality of care using telemedical techniques regarding: o Faster treatment and diagnosis • Competence gain at both hospitals as a result of better peer-to-peer communication. • Treatment of 50 patients using second opiniong • Test a new technical solution for this approach across national borders [1][2] • Conduct evaluations in order to ensure ethics [3][4] • Assess legal and organisational barriers across national borders [5] Results • We have tested and established two technical solutions for peer-to-peer communication of ultrasound video, using both synchronous and asynchronous communication. • We have tested the work processes for different communication methods and how the medical staff regard the different technical solutions. • The staff is positive toward the technical solution and the quality of data transmitted using the Baltic healthcare network. • We are using the equipment and procedures for transmitting live cases from peer-to-peer. • We have evaluated and solved the legal, technical and organisational matters.

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### An ECG Data Management and Processing System for Teaching and Research

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Introduction: There is a need for integrating Information Technology into the realm of medical care. As noted by Ball [1], "Building a new health system for the 21st century ... requires that we use Information Technology". The American Institute Of Medicine is the quoted as saying [1,2] "that the Internet will likely be the platform of choice for many, if not most health applications." The use of health informatics with patient care is an area that is well explored with healthcare Information Technology systems researched and deployed in a number of countries [3-5]. These systems address the need for the patient care but Information Technology can also form an useful and integral part of research and training for healthcare professionals. Objective: This paper describes the database design of a medical information system for ECG signals for teaching and research. Methods: This system has been created using a modular design to allow extended functionally to be added easily. The extended functionally is added to the system through "plug ins". This means that the system can be



more versatile where required and that new algorithms and visualisation techniques can be easily added. Results: The database comes pre-loaded with a number of common pathologies as well as 'normals'. A variety of display and processing algorithms are also included. It is envisaged that biomedical students and researchers will use this system both as a trainer as well as a testing ground for new data processing algorithms. The database can be accessed through a web-based front end or with conventional database tools. Conclusions: This paper presents the design of the database together with illustrations of the system in use and some simple plug in tools.

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### Salutogenic Paradigm and Web Assisted Tobacco Intervention: The Case of Www.parar.net

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Background: Portugal is a country with 1.6 million estimated smokers [1] that has ratified the WHO Framework Convention on Tobacco Control. Although tobacco consumption has been decreasing, with the prevalence of smokers within the population age group over 15, situated at 19.5%, critical issues still remain.[1] Smoking increase that is verified in women as well as in the 35-44 age men group, deserves a special concern. Salutogenesis [2] is considered a needed paradigm for intervention.[3] A communication protocol based on the Internet to address these issues is considered. Objective: being recognised as an intervention of high cost-effective ratio, services of tobacco-habit breaking do not register the needed development. Only 102 services are available at the National Health Service system. Waiting lists with a mean of 132 days (range from 8 days to 2 years) suggest that the support smokers need, is difficult to receive.[4] The preparation of a Web-Assisted Tobacco Intervention tool that could be effective to assist health professionals in their interventions and keep track of stop smoking candidates' progress over time, is proposed. Also, as a tool for capacity building, it should be a citizen's empowering instrument. Methods: A portal in the Internet www.parar.net was developed with a progressive step by step approach based on the Portuguese acronym "Renasceres".[5] A community of practise of 34 health professionals evaluated it. It was launched with no advertising, but based on a person-to-person information process dissemination. A first period of evaluation allowed the presentation of preliminary results. Structured interviews as well as quantitative analysis were used. Results: a group of 312 persons are active in the data base and 96% followed a personal stop smoking approach deciding the "D" day, registered in the web platform with other measures such as the Sense of Coherence, Prochaska and DiClemente's Stages of Change, Fagerstrom tolerance scale score, with 24 other constructs measurements considered relevant for improving the path to a life without smoking. After 3 months, 57% of these are still not smoking and a special relapse prevention program is proposed until one year will be passed (due by November 2006 for the first users). In proportion, more women than men use the platform. [5] Conclusions: www.parar.net seems to answer two objectives: assist health professionals in their task, and help women and adult males to reinforce their decision to stop smoking. The fact that Internet use is common for the young adults and adults may be considered as a positive issue for interventions based on the www. The high percentage of women using this platform with its technological processes, reveals, thus far, that Internet is not an obstacle for the capacity building this intervention was intended to achieve. Time and resources are needed to understand more fully the real implications of a web assisted tobacco intervention in the Portuguese context, particularly when the issue of its use by people from other parts of the "global village" speaking the same language (e.g. emigrants, Brazil and Portuguese speaking African countries) is to be considered.

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### Evaluation of a Web-based Smoking Cessation Information System By Malaysian Pharmacists Trained for a Smoking Cessation Program

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Background: In Malaysia, a government initiated project related to tobacco control was launched in February 2004 by the Malaysian Prime Minister, Datuk Seri Abdullah Ahmad Badawi through an anti-smoking campaign - with a "Tak Nak" (ie, Say No) slogan [1]. Although this campaign might encourage smokers to quit smoking, Malaysia requires more professionals to help them to quit. For that purpose, the Malaysian Pharmaceutical Society [2] in collaboration with the Clearinghouse for Tobacco Control of National Poison Centre of Universiti Sains Malaysia [3] have initiated Certified Smoking Cessation Service Provider workshop to train pharmacists as advisors for a smoking cessation program. Presently, there are 440 pharmacists certified for such service in 53 pharmaceutical related institutions. In order to facilitate the smoking cessation program, we have developed a prototype web-based smoking cessation program information system which is called the "Smokefree-Online System". The system consists of: (a)Guidance for health providers on the smoking cessation program (eg, facts about tobacco, relapse prevention, advantages of quitting from smoking etc) (b)A personalized patient record system including history of smoking, level of nicotine dependence, progress record etc Objective: To evaluate the acceptability, usability and applicability of the prototype SOS by pharmacists. Methods: A quantitative study was conducted by collecting data from a self-administered questionnaire given during the CSCSP workshop. The questionnaire was pre-tested by 23 participants at the 5th Asian Conference on Clinical Pharmacy. Subsequently, 181 pharmacists of the CSCSP workshop in the 3rd quarter 2005 [6] were recruited by convenience sampling. The SOS was demonstrated during the workshop. The pharmacists were asked to respond on the self-administered questionnaire after the presentation. Results: The number of respondents was 132 (72.9%) out of 181 participants. On the acceptability of the SOS, 93.2% thought it was user-friendly. On the usability, 96.2% thought it was practically effective for facilitating the smoking cessation program. On the applicability, 31.8% said that they would choose "advice patients according to your own knowledge" as their first choice to implement the smoking cessation program, while 27.3% would choose "refer patient to quit smoking clinic" and 15.2% would choose "utilize SOS". Conclusions: The responses were positive on the acceptability and usability of the SOS. The responses on the applicability should be revised by conducting a further structured study. Furthermore, the pharmacists should experience hands-on training to explore the SOS.

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 CSCSP Training Program – 3rd Quarter 2005. Home page: http://202.144.202.76/new\_mps/ cfm/announcement\_view.cfm?id=1078 Webcite: http://www.webcitation.org/ query?id=1141967123102606 [cached 10.3.2006] weaknesses of this approach and implications of this kind of education for improving international relations as well as medical education sciences.

### **On-line Social Networking Supports Weight Loss**

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Weight loss is notoriously difficult to achieve and maintain. Weight Watchers, one of the only programs to have been documented scientifically to work, utilizes in-person peer groups to support weight loss efforts. PEERtrainer is an online company that utilizes proprietary software to form weight loss peer groups based on participants stated preferences (e.g., middle-aged with 10-15 pounds to lose). Participants log their diet and exercise daily in whatever format they find easiest and most helpful for them. They also post comments to other members of their group about their own efforts or the efforts of their group-mates. Logs are only viewed by members of the group unless the logger chooses to make his/her log public for additional accountability. Members of the PEERtrainer community also post comments on topics of their choice in the PEERtrainer online lounge. Anecdotal evidence from postings in the public logs and community lounge (changes in diet, improved exercise, weight loss) suggest that PEERtrainer is a useful adjunct to an individual's weight loss efforts. Data presented will include the number of current and former participants, duration of participation, self-reported weight loss, and comments on perceived importance of PT in participants weight loss efforts.

Expanding International Relations Through Videoconferencing: Evaluating the Strengths and Weaknesses of Scientific Teaching Through Videoconferencing

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11 World Congress Internets in Medicine (Poster Presentation) Expanding international relations through videoconferencing: Evaluating the strengths and weaknesses of scientific teaching through videoconferencing Mahvash Salsali, BSc, MSc, PhD, Associate professor and director of International Affairs Office, Tehran University of Medical Sciences Javad Maleki, MD, Tehran University of Medical Sciences Majid Salsali, MD, Milad Hospital, Tehran, Iran Background: Video conferencing is a medium where individuals or groups can meet face-to-face in real time to interact. Bringing the world into the classroom through the use of this technology is becoming increasingly more popular. Better planning, interaction with experts, learn about cultural differences, addresses different learning styles, increases motivation, better retention, and improving skills are advantages of videoconferencing. Methods: To pilot and assess the role of internet and videoconferencing in medical education and expanding international relations strengths and weaknesses of this approach were evaluated through this study. An abstract of this research examining the efficacy of using videoconferencing to provide medical education with low cost and high quality as well as expanding international relations. This research had quasi-experimental design with three phases. In the first phase of this study main leader of different faculties introduced the most important topics for videoconferencing and all of the groups prepared appropriate packages for participants. In the second phase of this study after arranging the program teaching through videoconferencing was organized and finally in the third phase of this study evaluation by participants and main leaders have been done. Objectives: 1. Implementing conference and scientific teaching through videoconferencing; 2. Evaluating the strengths and weaknesses of scientific teaching through videoconferencing; 3. Introducing the appropriate approach for improving the quality of education through videoconferencing Results and Conclusion: Results suggest that videoconferencing equipment and protocols have been used successfully among different universities around the world and Tehran University of Medical Sciences. Additionally these data suggest that videoconferencing can be effective tool for providing medical education with high quality in our country. Meanwhile we could improve our international relationship through internet and videoconferencing with other countries. In this presentation, the researchers describe the implementation and use of two way interactive videoconferencing for expanding international relations among different countries. Researchers also discuss the identified strengths and

#### **Open Access Publishing Workshop**

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This multiple paper session is designed to address a number of aspects of open access publishing and provide assistance to both prospective authors and researchers intending to start up open access journals. Open access is defined in three parts: firstly, the articles are freely and universally accessible online; secondly, authors retain copyright to their work; and thirdly, all articles are archived in an open access repository. This session will contain both didactic and interactive components. The first short paper will address the technical aspects of medical e-writing, in particular for open-access journals, for example artwork and reference software, archiving and writing style. This didactic presentation will be followed by an interactive session designed to assist participants to understand how to prepare a paper for submission to an open-access journal. The second short paper will outline the process of starting a new online open access journal. Topics covered will include: rationale for a new journal; how to develop a proposal; and, how to best work with the open access electronic publishing process. This presentation will be followed by a Q&A session for potential editors of new journals.

# User Satisfaction Survey and Usage of An Electronic Desktop Document Delivery Service At An Academic Medical Library.

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Background: The Baugh Biomedical Library at the University of South Alabama is a Resource Library in the National Network of Libraries of Medicine. The Library has an extensive journal collection, serving local, regional as well as some national and international information needs. The Library also provides all information needs for the colleges of Medicine, Nursing, and Allied Health Professions, including all document delivery services. Objective: To improve the speed of document delivery to our patrons, the Biomedical Library Interlibrary Loan Department introduced Prospero, an open-source electronic desktop document delivery software, in June 2000. This paper discusses the results of a user satisfaction survey of Prospero. Methods: To assess user satisfaction with Prospero, a questionnaire approved by the Institutional Review Board, was sent via e-mail to all 400 Prospero users listed in the Prospero user log. Results: Forty nine responses were received, a response rate of 12.25%. Seven responses were incomplete and were excluded from the survey. Of the forty two remaining responses, fifteen were from affiliated users, twenty seven from unaffiliated users. Of the fifteen responses from affiliated users, five were from students, six from staff members, and four from faculty members. Of the twenty seven responses from unaffiliated users, fourteen responses came from medical libraries, ten from individual users, and three from business-related entities. All respondents said they would use the service again, because the service was easy, convenient, efficient, fast, and very responsive. Two students had problems viewing or downloading the documents. No staff or faculty members had any problems. None of our unaffiliated users had any problems viewing or printing their documents; they all agreed they would use the service again. Three respondents would not recommend the service to someone else. Everyone said they received their articles on time. Conclusion: From June 2000 till November 2002, 3,084 articles were delivered via Prospero, representing 11% of the interlibrary loan requests, and 19% of the in-house requests. Survey results indicated that users both on and off campus were generally pleased with the service. Fewer problems were noted in the work place than the home setting. Based on the survey results, instructions on how to use the service and how the service works were updated on the Library's webpage.



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### Integrating Library Instruction In Online Graduate Nursing Research Courses.

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Background: Using eCollege, the College of Nursing has enrolled a growing number of graduate students in online courses, who do not attend on-site library orientation. To meet evidence-based practice competencies expected of students in the nursing graduate program, nursing faculty recruited two librarians from the Baugh Biomedical Library to assist with research related questions from the students, and to provide library instruction in three online courses. Objective: To enhance nursing students' research and evidence-based practice skill-sets to prepare them for best practices that are based on the most current evidence. A vital component of this process was accomplished by introducing library resources, instruction, reference and document delivery services into online nursing research courses. Methods: For two semesters, two librarians responded to students' questions in threaded and group discussions in two online graduate nursing research courses. Studies have shown that on-site student orientations are ineffective for library purposes. Therefore, the following semester, based on ACRL and SACS guidelines, the librarians provided web links to library policies, online resources, Live Chat virtual reference service, electronic desk top document delivery, and tutorials within the e-college web page, which the students can access at their convenience. To enhance online interaction with the students, the librarians also established their own group space, "The Reference Desk", where the students directed their library related questions. A Mediasite presentation on "how to find the evidence" was prepared. This model was implemented in three online nursing courses, consisting of eleven sections. Results: Students expressed gratitude for assistance with their research needs in the threaded discussions and class evaluations, which encouraged the instructor to continue and expand the librarians' involvement. Most questions had to do with which search terms to use or which databases to search. Based on the questions received from the students, the librarians and the instructor were able to identify areas requiring clarification, such as how to formulate the research question (PICO), how to evaluate research results, and expert searching using controlled vocabulary vs. key words. Conclusion: As online courses over the Internet are continuing to proliferate, librarians must build relationships with teaching faculty and collaborate in this virtual environment. This collaboration demonstrated successful use of multiple software applications. Using students' questions as feedback also improved teaching strategies and positive student project outcomes.

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### Integrating Virtual Reference with Electronic Library Resources and Electronic Document Delivery Services.

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Justin Robertson

Background: The College of Nursing is offering courses over the Internet, enrolling a growing number of online students, who do not attend on-site library orientations. Reference librarians needed a more effective way than the telephone to assist these students with their information needs. A virtual reference service using LivePerson was introduced in mid-2003. This virtual reference service allows librarian to "push" links to database searches, full-text articles, and other library services, to the virtual "caller". Objective: Virtual reference service, using the Internet, was implemented to provide a more technically relevant information service to students attending online courses. This paper discusses the integration and delivery of electronic web based library resources to remote library users at their point of need. Methods: Statistics and satisfaction surveys from chat transcripts were gathered to determine level of use and satisfaction with the service. Document delivery statistics were collected to determine the level of use of electronic document delivery service. Results: A total of 461 chats were initiated between July 2003 and February 2005. The reference shift from 8 am-1 pm received the most questions (n=168). Mondays had the most questions (95) and Sundays the least (29). Most questions were extended or ready reference type questions, followed by instructional questions, all of which peaked in February and September. Questions about CINAHL, the premier nursing database, far outnumbered questions about all other resources, including Medline and electronic journals. Users were generally satisfied with the service. The electronic desktop document delivery service experienced peaks in March and December, following the timeline for research assistance. 445 documents were delivered electronically March-September 2005. Ten percent of the service was devoted to nursing students. Problems identified were: Dial-up Internet connections slow down database searching sufficiently to significantly slow down virtual chat as well, links to library databases on the university's online course page did not work, pdf files pose problems for outdated computer equipment, long distance database instruction is still difficult. Conclusions: The virtual reference service using the Internet has proven to be a useful tool for integrating the Library's electronic resources and services to meet the information needs of remote users. Distance education students expressed satisfaction with the virtual reference service. Statistics gathered are helpful in assessing staffing needs at the reference desk, and identifying focus areas for instruction, such as CINAHL. Statistics also showed the flow of service from research assistance to document delivery. Problems identified in the live chat sessions were addressed with nursing faculty.

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  and resource usage. Poster presented at: Medical Library Association Annual Meeting, San
  Antonio, TX, May 14-19, 2005.

### ChewFree.com: Results of a Web-delivered Smokeless Tobacco Cessation Program

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Background: An estimated 12 million Americans currently use smokeless tobacco (ST). Most are in small towns and rural areas with few cessation resources for ST users. Approximately 94 million Americans use the Internet for health-related information, and online access is growing among lower-income and less-educated groups. Objectives: This RCT compared a linear, text-based website presenting ST cessation information (Basic Condition) vs. an interactive, tailored Web-based ST cessation program (Enhanced Condition). Methods: Participants were recruited primarily through thematic promotional mailings to media outlets in 31 states with high ST prevalence of ST users.[1] Other recruitment tools included paid online advertising and targeted mailings to state tobacco control organizations and professionals. Participants completed consent and enrollment online, and were randomized to one of the two conditions. Follow up was collected at 6 weeks, 3 months, and 6 months post enrollment via online surveys or by phone for non-respondents. Results: More than 2,400 participants were enrolled over a 15-month period. Point prevalence of self-reported tobacco use among participants in the Enhanced Condition was significantly higher than for those in the Basic Condition at all time points (intent to treat: 22% vs. 15% at 6 weeks, p < .001; 22% vs. 17% at 3 months,



 $p<.05,\,$  and  $20\%\,$  vs.  $16\%\,$  at 6 months, n.s.). Repeated-point-prevalence outcomes will also be presented, and alternative methods for dealing with missing data will be explored. Predictors of cessation and measures of website use and participant engagement will also be presented.[2] Implications for broadening access to cessation assistance via the Web, and the unique properties of web data collection systems will be discussed. Discussion: Results of this study indicate that our Web-delivered cessation programs for smokeless tobacco users are effective, and that the Enhanced site was significantly more effective than the Basic site. This project was funded by The National Cancer Institute R01-CA84225.

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### Predictors of Online Information Seeking Behaviors: Comparing Patters of Urban African American and Rural Caucasian Breast Cancer Patients

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Background: A large and growing percentage of breast cancer patients are turning to the Internet for health education and support [1] and research indicates that among women who have had breast cancer, the Internet is second only to their healthcare providers in terms of where they would go first if they had a strong need to get information about their disease[2]. However, while studies suggest demographics affect channels of communication and help-seeking for health issues [3,4], little is known about the antecedent characteristics of cancer patients that predict online health information seeking. Objective: This paper examined and compared the psychosocial characteristics that predicted online health information seeking behaviors for two diverse breast cancer populations - urban African Americans and rural Caucasians. Methods: Online service use was examined in terms of service type (Experiential or Informational) and by topic (Practical, Medical, or Psychosocial). Statistical tests examined group differences in online service use and correlated breast cancer patients' pre-test survey scores with subsequent, specific types of online cancer information seeking behaviors within a particular Interactive cancer Communication System called the Comprehensive Health Enhancement Support System (CHESS). Results: 144 Caucasian and 83 African American breast cancer patients participated. African Americans spent more total time using the services than Caucasians, t = -1.94, p < .05, but no significant difference was found within service types. African Americans sought more information on psychosocial topics than Caucasians, t = -2.94, p < .01. Predictors with significant correlations (p <.05) with service and topic use differed between African American and Caucasian patients. Few significant correlations emerged for African Americans, and included social support, negative emotion and religious coping. For Caucasians, many correlations were significant, with participation in health care, information competence, health self-efficacy, and functional well-being as the most frequent predictors. Specific correlations will be presented. Conclusions: The two diverse populations of urban African American and rural Caucasian breast cancer patients differ in their pattern of online cancer information seeking and the predictors of their information service use. These findings have practical implications for information resource development and practice.

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### Effects of Prayer and Religious Expression within Computer Support Groups On Women with Breast Cancer

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Background: Previous research indicates that two ways women with breast cancer often cope with their diagnosis and subsequent treatments are participating in computer support groups [1] and turning to religion [2]. This current study is the first that we are aware of to examine how prayer and religious expression within computer support groups can contribute to improved psychosocial outcomes for this population. There are a variety of psychological mechanisms that may explain why religious coping may be related to improved emotional, psychological, social and attitudinal outcomes among breast cancer patients outlined in our paper [3][4]. Objective: This study examines the effects of prayer and religious expression within computer support groups. The basic hypotheses are that prayer and religious expression in a computer-mediated environment will improve psychosocial outcomes for breast cancer patients. Methods: Surveys were administered before providing access to the online support group and then four months later. Message transcripts were also analyzed using a word counting program that noted the percentage of words related to prayer and religious expression. Finally, messages were qualitatively reviewed to better understand results generated from the word counting program. Results: Of the 231 women who joined the study and were provided access to the Interactive Cancer Communication System (ICCS) intervention, 97 women became active participants in the support groups and their transcripts were analyzed. As hypothesized, writing a higher percentage of religion words was associated with lower levels of negative emotions (b = -.226, p < .01), higher levels of perceived health self-efficacy (b = .278, p < .01), functional well-being (b = .196, p < .05) and positive reframing (b = .166, p < .05). Conclusions: Given the proposed mechanisms for how these benefits occurred and a review of the support group transcripts, it appeared that several different religious coping methods were used such as putting trust in God about the course of their illness, believing in an afterlife and therefore being less afraid of death, finding blessings in their lives and appraising their cancer experience in a more constructive religious light.

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### Use of Time-based Visual Metaphors In Pregnancy PHR Interface Design

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Background: To date, personal health record (PHR) systems that address the needs of pregnant women and the development of visual metaphors for organization, presentation, and access to personal health data and information have received relatively little attention [1,2]. We explore use of two time-based visual metaphors-calendar and timeline-for the presentation and organization of personal health information and data. The interface designs incorporate calendar and timeline metaphors across five topical facets for information



presentation and organization. Objective: This project was intended to (1) understand information needs and uses of pregnant women and their families, (2) explore use of visual time-based metaphors and faceted organization and classification systems for the presentation of personal health information and (3) develop time-based interfaces for PHR systems in support of the information needs and uses of pregnant women and their families. Methods: Review and analysis of temporal organization of (1) popular pregnancy guides and (2) interfaces of PHR systems currently available on the market directed at families and general audiences was performed. Review of a paper-based pregnancy record form set, a pregnancy organizer, and literature examining information-seeking and health record use as related to maternal care and pregnancy was taken into consideration when designing the interfaces. Temporal visual metaphors were reviewed with respect to time-based factors of pregnancy and pregnancy records. Information derived from these resources was applied to the development of three experimental PHR pregnancy system interface design prototypes. Results: Based on our research, we designed three pregnancy PHR system interfaces using two time-based visual metaphors-calendars and timelines. Information contained within the system is organized by these metaphors and according to a five-faceted classification scheme: (1) Appointment, (2) Diary, (3) Health Data, (4) Finance, and (5) Resources. Conclusions: Visual metaphors, based on time or other factors, are a potentially rich design resource for the development of PHR system interfaces. Exploration and application of visual metaphors in information design has the potential to develop more 'individual' PHRs that appeal to potential user groups. Interface design specifications for PregHeR, the hypothetical PHR system presented here, were developed by the application of the Agile Views interface design framework [3] and the application of Piccolo Fisheye viewing techniques [4] to enhance user access to information. Our research could be supplemented by experimental assessment of user needs and uses of PHR systems.

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### HIPAA Compliant and Secured Content-Based Support Environment for Temporal Lobe Epilepsy

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Inter-institutionally accessible medical databases are crucial in collaborative research work. They raise three important issues: 1) security, 2) transaction logging, and 3) privacy. In this paper we briefly introduce our multi-modality image database for temporal lobe epilepsy and its security and transaction logging models. One issue that necessitates the inter-institution collaborative research work concerns the limited number of patients admitted to each medical institution. In many cases, the institutions must share sensitive patient data for research purposes. While complying with HIPAA regulations, they need to maintain the usability of the shared data. We use a "Safe Harbor" strategy with maximum data suppression. However, the usability of the proposed privacy model is maintained by providing all the operators (averaging, time difference, etc.) with the unsuppressed data and removing the sensitive part just before having them displayed to user.

### **Trial Bank Publishing of Randomized Trials**

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Background: Publishing randomized clinical trials (RCTs) machine-understandable "trial banks" in addition to journal articles may allow computers to better help clinicians practice evidence-based practice. We have defined an ontology of clinical trials [1] and have used this ontology to build RCT Bank, a trial bank that can capture over 160 aspects of trial design, execution, and results. Trials can be deposited into RCT Bank through a secure web-based interface that automatically parses eligibility rules into coded, computable representations. RCT Bank entries are available under open access at RCT Presenter [2]. Avenues for accruing trial bank entries include trial registration, data curation by funding agencies, and co-publishing with medical journals. This paper presents our preliminary results of trial-bank publishing. Objective: To co-publish RCTs into RCT Bank. Methods: We invited authors of RCTs published by JAMA or Annals of Internal Medicine between January 2002 and July 2003 to co-publish their trial in RCT Bank. We entered all information from participating manuscripts and from authors themselves where necessary into RCT Bank using a secure web-based tool. Completed entries were released at RCT Presenter [2] and were linked reciprocally to the journal's website. We conducted an online survey comparing RCT Presenter reports to the corresponding journal articles. Results: During the project period, 54/108 RCTs met inclusion criteria. The author participation rate rose from 38% to 76% after an example of a co-published trial was available. 14 diverse RCTs were co-published, covering a variety of clinical domains, intervention types (e.g., drugs, procedures), outcome types (e.g., categorical, survival), and result types (e.g., efficacy analysis). We also captured methodological information such as blinding and follow-up. Data entry time averaged 1-2 hours while extracting information from the manuscript averaged 6-8 hours. 30 survey respondents rated RCT Presenter better than journal articles on speed (85%), ease of use (81%), information organization (85%), and clarity (65%), and better or comparable to journal articles on trustworthiness (80%), trial under-standing (73%), and use in clinical care (85%). 50% preferred using RCT Presenter over journal articles. Overall, 70% of respondents rated RCT Presenter as good as or better than journal articles for all surveyed attributes. Conclusion: We have demonstrated proof of concept and user satisfaction with trial bank publishing. Current work includes integrating trial bank reporting with trial registration and clinical trial execution systems, building visualization and analytic routines for trial banks, and partnering with journals to have authors submit trial-bank entries directly for peer review [3]. Trial banks offer an important link between the clinical trial execution informatics infrastructure and knowledge management systems for evidence-based practice.

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### Multilingual Ontology Enrichment for Semantic Annotation and Retrieval of Medical Information

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Context: Knowledge management is one of the areas of interest of the European project Noesis [1], through concept-based annotation of documents and Information Retrieval (IR). The chosen area of experimentation is that of Cardio-Vascular (CV) diseases. Objectives: The initial objective to build a multilingual ontology of the CV domain had to be restricted to that of enriching an ontological structure based on the MeSH thesaurus, given the means and duration of the Noesis project. Therefore, we concentrated on the multilingual



aspects of the terminology and vocabulary enrichment. The concept structure - improperly called an ontology [2] - which supports the terminology, is an OWL representation of the MeSH subset related to the CV field. In order to support the automatic conceptual indexing of CV texts for IR, the vocabulary must match as much as possible the terms that can be actually found in the texts to be indexed. As texts can be in different languages, multilingual vocabulary enrichment is a major objective. Methodology: The concept structure taken from the MeSH thesaurus has been represented by using the OWL (Ontology Web Language) which is the W3C standard language to represent ontologies. We decided to stick to the MeSH concepts and structure, i.e., add no new concept. The intial vocabulary consisted of the sole English terms associated with the MeSH concepts. A first enrichment phase automatically added the UMLS terms associated with these concepts, in five out of the six languages considered in the project (Greek is not in UMLS). Some automatic cleaning of the obtained terms was necessary because UMLS contains lexical variants which are not useful for our purpose (the Noesis approach relies on stemming, thus eliminating lexical differences) and other pieces of information are often inserted for semantic purposes. A second enrichment phase was done manually, relying on a corpus of CV scientific texts taken from the biomedcentral repository [3], from which terms have been automatically extracted and then manually selected by a medical expert. The terms in the other languages, including Greek, were obtained by translation from the English vocabulary. Results: The first version of the ontology contained 680 concepts corresponding to a strict subset of CV concepts [4] but was later extended to 2500 by adding other CV-related concepts. After enrichment, it contains 15000 English terms and around 10000 terms for each other language. It is used in the Annotation tool for manual semantic annotation [5] and supports automatic concept-based indexing and retrieval. Conclusions and perspectives: This is the most detailed terminology known today in the CV field for any of the six considered languages, including English. It has been used within the Noesis project for the (manual) semantic annotation of scientific texts. Its use for multilingual IR is still to be evaluated in depth. The methodology for vocabulary enrichment, both automatically from UMLS and manually form a corpus of texts of the domain, can be applied to other domains. It can also be used to extend a medical ontology with a richer terminology.

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# Adolescents Searching for Health Information On the Internet In Thailand

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Adolescents Searching for Health Information on the Internet in Thailand Nantawarn Kitikannakorn, Chanthonrat Sitthiworanan Introduction It is well-documented primary care unit is the most visiting place for general community illness [1-4]. However, it remains unclear where adolescents obtain general health information. Many at-risk youth seemed not awared of health information resources either when they received the information or they perceived that they did not need [4]. Searching on the internet has become an important and rapidly-expanding tool for youths with health concerns. Although, many studies stated the increasing number of youths online to look up health information, there is no relevant study about youth searching for internet-based health information in Thailand. Then, it is crucial to characterize how Thai youth navigate through the web for health information [5]. Objective The aims of this study were to identify frequently used sources of health care information on the Internet by adolescents based on age and sex differences. Methods Random sample of undergraduate students in Phitsanulok, a large educational center in lower Northern part of Thailand, were recruited. Questionnaire was

used to survey health information searching via internet. The questionnaire was comprised of personal data and internet-based health information accessibility. Data was analysed by inspection of percentages and bivariate associations. Results 3,720 questionnaires were completed; about sixty-six percents of respondents were female. Mean age (SD) was 20.59 (1.89) years old with 17-30 years old in range. Ten percents of these participants were health sciences-related students; thirty-five percents were sciences-related students. Almost sixty percents of respondents lived in dormitory. Eighty-five percents of respondents used to access the internet, however, about eighty percents had access to the internet at school and majority of these students reported using a computer about 1-3 times per week, with a range 1-3 hours per time. Approximately forty percents of these internet users had accessed to health information. The most of searching health information are general health (81.7%), disease and its treatment (47.7%), and herbal medications (39.4%). The health-related on Internet users stated the most reasons of internet-based information using were easy access (81.0%) and update information (73.8%). The most of problems for uses which respondents faced with internet-based information searching were unidentified webmasters (58.9%), English language (56.4%) and medical technical terms (53.6%). Most adolescents indicated that internet-based information providers should address self-care; sexually transmitted diseases and sexually literacy; and recent widespread diseases topics on. Female (P = 0.003), age range 20-25 years old (P = 0.050), dormitory resident (P = 0.001), non-sciences-related students (p < .005) and experienced self-medication (p < .005) were significantly differences in internet-based health information searching. Conclusions This study showed a high tendency on searching Internet-based information of youth in Thailand. Quality evaluation and language were significant barriers of information searching. The results have implications for constructing realistic simulations of searching behavior and improving value of websites on health information, in Thai, relevant to youth.

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### Efficacy of An Online Tutorial About Cancer-related Fatigue

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Background: Approximately 39% of those diagnosed with cancer use the internet directly, with another 15% using it indirectly through relatives or friends.[1] Many cancer patients report receiving insufficient information about the disease, although information can help with decision-making, reduce anxiety, increase treatment compliance, and provide realistic expectations, [1] To help meet these informational needs, the American Cancer Society is developing a set of interactive tutorials. The information architecture of the tutorials uses a hybrid design [2] with a suggested order of viewing, a menu enabling users to skip sections, and links to outside resources for more in-depth information. Interactive elements include videos, audio files of topical, facilitated conversations with survivors, and quizzes with feedback. Fatigue is one of the most commonly experienced symptoms associated with cancer, can persist long after treatment, and is treatable, yet many patients fail to address it.[3] The fatigue tutorial is intended to empower participants to take action about fatigue by increasing their knowledge and changing their beliefs. Research has shown that use of Internet health information is related to self-efficacy and proactive patient behavior.[4] This paper explores whether an online tutorial can increase knowledge and affect patient beliefs. The Health Belief Model (HBM) [5] was modified for this study to delineate relevant beliefs about fatigue and provide a theory to understand how beliefs might influence behaviors (e.g., discussing fatigue with a doctor, exercising). Objective: This study was designed to evaluate



the usability of the fatigue tutorial and its impact on fatigue knowledge and fatigue beliefs. Methods: The sample consisted of 26 survivors and 8 caregivers divided into 12 focus groups. Participants took a survey, completed the tutorial, took a second survey, and then participated in a facilitated discussion about the tutorial. The surveys included a 19-item fatigue knowledge quiz and 20 fatigue beliefs questions based on a modified version of HBM that included seven components: susceptibility, symptom severity, benefits, barriers, communication with health provider, fatigue management efficacy, and intent to act. Results: Participants evaluated the tutorial quite favorably, as reflected by comments such as "I wish this had been available when I was diagnosed. My doctor told me I'd be tired but didn't tell me what to do." The mean score of participants on the fatigue knowledge quiz rose from 67.3% before the tutorial to 87.8% afterwards. A matched pairs analysis showed this difference to be significant (p < 0.001). All but one of the 20 fatigue beliefs questions changed in a direction consistent with taking steps to ameliorate fatigue. For example, the average level of agreement with the statement "I know the difference between persistent fatigue & feeling tired" went from neutral to moderate agreement. An item analysis will be conducted to determine which changes were statistically significant. Conclusion: Comments from focus groups indicated that the content was useful and readily accessible. This was confirmed by improved scores on the fatigue knowledge quiz. Patterns of response to fatigue knowledge and beliefs items suggest areas where the tutorial and questions may be improved.

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# Using Interactive Web-Based Technology To Help Consumers Interpret and Understand Concepts of Cancer Risk

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Background: The National Cancer Institute's (NCI) Office of Education and Special Initiatives (OESI) has developed a Web (http://understandingrisk.cancer.gov) to help users understand concepts of risk and put this information into perspective in order to make decisions about risk-reducing behaviors. Objective: The NCI risk Web site was developed with the specific intent to provide an informative, yet interactive experience to visitors. Rather than relying on static information on a single page, the NCI risk Web site allows each user to navigate the site based on the specific information they seek; for example, much of the information is organized according to cancer type so visitors can find information specific to their needs. At the same time, information on important risk concepts is integrated throughout the site. Methods: The site is based on extensive formative research conducted by NCI, including reviewing the risk communication literature, examining other cancer risk education materials, consulting with risk communication experts, and working with partners across NCI divisions. Additionally, a series of focus groups were conducted with 66 information-seekers on conceptual issues of risk prior to development (including groups with English-speaking Latinos), telephone focus groups with 20 cancer information-seekers on storyboard concepts, and usability testing with 8 information-seekers prior to launch. Results: Based on feedback from experts and consumers, NCI developed a Web site composed of three main areas to address information needs in an interactive manner: 1) A primer on the concept of cancer risk, including risk-related terms that consumers may encounter and an explanation of the four main categories of risk factors; 2) Discussion about the known risk factors for six common cancers in the U.S. (breast cancer, skin cancer, colon cancer, prostate cancer, lung cancer, and cervical cancer), allowing users to explore their own risk factors, and think about ways that they can lower their risk; 3) A section focusing on media literacy, using real-world examples

to provide tips that users can apply in analyzing the newspaper, broadcast, or Internet-based cancer information they encounter. Conclusion: This site was newly launched in June 2006. It features many interactive features including audio information, quizzes and other areas for visitors to test their knowledge, and many opportunities for users to delve further into issues they wish to know more about. In the future, the site will be evaluated to assess user impact.

### **Practicing Hematology and Oncology Via Telemedicine**

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The University of Kansas Medical Center (KUMC) has offered hematology and oncology services via interactive tele-video systems to patients in rural Kansas for over a decade. A tele-oncology practice, consisting of telemedicine clinics as well as on-site clinics, was established in 1995 between KUMC and a rural medical center. A university-based oncologist - who is located at KUMC in Kansas City, Kansas in the northeast corner of the state - connects with patients at Hays Medical Center (HMC), which is located approximately 265 miles west of KUMC in central Kansas, using telemedicine technology. The technology enables the KUMC oncologist to conduct a complete patient visit without being in close physical proximity to the patient. The patient's history is obtained in the same manner as it would be during a face-to-face visit, and a physical is performed with an HMC nurse serving as a proxy examiner for the oncologist. Patient heart and lung sounds can be heard by the oncologist through an electronic stethoscope, and x-rays may be reviewed using a document stand that accompanies the telemedicine system. The oncologist is able to utilize telemedicine to care for patients with a variety of hematologic and oncologic disorders, just as a physician is able to do in a traditional, face-to-face clinic setting. The Kansas tele-oncology practice was initially established in response to a lack of specialty healthcare services available to individuals living in rural locations. While cancer remains a significant public health issue for all population groups, it is an issue of paramount importance for people living in rural communities, as they are more at risk than others. In addition to addressing the issue of how to adequately provide specialty healthcare to rural patients, telemedicine has proven itself to be a cost-effective alternative to providing frequent, regular outreach clinics. To date, three cost analyses have been conducted with the tele-oncology practice, and each analysis has revealed that the costs associated with providing hematology and oncology care via telemedicine in Kansas continue to decrease. Data from the analyses suggest that the Kansas tele-oncology project is successfully sustaining itself.

### **EHealth Nursing: A University Pilot Course**

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Background: Despite widespread availability, increased consumer demand, and improved patient outcome studies involving Internet disease management, provider eHealth technology adoption continues to lag. Few medical and nursing schools offer eHealth course work in their curriculums. [1] [2]. Consequently, students are ill prepared to meet the eHealth challenges and opportunities they will face in 21st century practice. We hypothesized that if graduate nurse practitioner students with limited computer skills were introduced to the concept of eHealth in supervised mock practices before real world application that they could learn the technology, fear could be displaced, and they would be more likely to utilize eHealth tools in future practice. Lack of eHealth coursework in medical and nursing curriculum coupled with increased industry and patient demand for Internet use in healthcare delivery justifies further inquiry. Objectives: The pilot study objectives were threefold: determine perceived and actual barriers and benefits of Internet patient care in a simulated healthcare practice; evaluate provider's ability to perform patient monitoring and management of common chronic conditions via the web; and, describe the dynamics of provider/patient interaction utilizing online patient eCare. Methods: A five-week graduate nurse practitioner course on eHealth practice was developed. The course included an introduction to eHealth, a hands-on mock patient eCare monitoring project and a healthcare website design project. Seven nurse practitioner students actively practicing in clinical positions, acted concurrently as a fictitious patient and provider in a double-blind study, monitoring and managing each other via the Internet. A Pre and Post course questionnaire was utilized to ascertain perceived barriers, benefits and concerns



of eHealth regarding provider and patient utilization, as well as how each student rated their own computer skills. Instrument registration, log-on and data entry were taught as well as outlined in a detailed written instruction manual. Both groups were also instructed to keep a log of their feelings regarding interaction, complaints and problems regarding the monitoring project. Results: Provider and patient groups were able to install the software, send instrument data and post results, write comments and view data utilizing the written instruction manual or by emailing the instructor. Most problems encountered were technology related. Only one problem, registering with a provider's wrong identification number, was operator error related. All students performed the eCare monitoring and management successfully. Post-course questionnaire results indicate that the students learned the technology easily and felt the technology afforded them better tools to care for their patients. Other trends suggest that the group felt eCare monitoring would save time and money and that they would be more likely to use eCare technology in future practice. Conclusion: This pilot study indicates that fear of eHealth can be eliminated by simulated hands-on patient/provider eMonitoring and eCare interaction to those with limited computer skill in a brief period of time. The study also illustrates a method by which eHealth technology can be introduced to healthcare providers, learned quickly and applied to practice. Further research regarding simulated eHealth pilots in an academic setting transposed to actual clinical practice with larger sample size is warranted.

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# Redefining Informed Consent In the Era of E-Health

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Abstract: In the context of e-health, patients or health care consumers are faced with several potential risks, that include: • the level of accuracy, completeness and timeliness of medical information available online • security and privacy of medical data • safety of medical devices operated by patients at home for the purposes of transmission of vital and other clinical signs • level of identity disclosure of online providers of health information and services. A further challenge arises from the fact that in the context of e-health, even if information on the parameters listed above is made available, it is uncertain whether health care consumers accesses and consequently comprehends it. Consumers frequently access and brows online resources to make a decision and complete a health care related transaction such as signing up for a health plan, purchasing drugs or participating in a live chat with a health care professional. While most online resources make the term of conditions or privacy statement of the online application available, as required by federal laws, it remains uncertain to what extent users access, and most importantly, fully understand these disclosures and their rights pertaining to the online use. The question that arises from these observations is whether an e-health consumer can be truly informed. Knowledge in this context refers to both the clinical risks as well as the implications of the technology use and the online communication. Disclosure is hindered due to the fact that risks associated with e-health are not known to a great extent. In addition, patients' possible lacking of technical expertise can hinder this process further, as the presentation of technical risks (e.g., explanations of security and privacy threats) can have varying levels of success based on the user's profile. In this tutorial, we are going to explore and analyze the various forms of informed consents in the context of e-health, the legal and philosophical implications, and the impacts on health care consumers. The argument that we present is that informed consent needs to be redefined in the new era of e-health. Goals: The tutorial will cover the following four sections: Section 1. The Evolution Informed Consents o The Historical Origin of Informed Consents o Purposes of the informed consents o Fundament Differences in Informed Consents Before and After the Advent of E-Health Section 2. Laws and Regulatory Requirements o International o USA o Institutional Review Boards o E-health Environment Section 3. Basic Elements of any Informed Consent o Threshold Elements (Preconditions) o Information Elements o Consent Elements Section 4. Need for redefining informed consent /Challenges o Is informed Consent a Process or an Event? o Effects of E-health Technology on Informed Consents The tutorial aims to provide not only an overview of the evolution of informed consents and allow participants to comprehend the historical origins

of informed consent, but also the current and future challenges in the context of e-health. The tutorial will cover a global overview focusing on the legislature in different countries. Finally, after an overview of the basic elements of any informed consent the focus will be on the need for redefining the concept of an informed consent in the context of e-health. Case studies and examples will be presented to demonstrate the need for new definitions and legal initiatives to protect health consumers and patients. The exit competencies of this tutorial include: • a deep understanding of the process of informed consent • the challenges in protecting users and consumers in the context of e-health and providing a truly informed consent of end-users • an analysis of implications for e-health system designers and evaluators • comprehension of the need to redefine the concept of informed consent and to redefine the legal and regulatory environment for e-health Audience: The audience of this tutorial includes system designers, health policy makers, informatics researchers and educators, health law professionals and the general public. Levels: The content coverage is basic to intermediate. Prerequisites: There is no perquisite for this tutorial. Previous Presentation: This tutorial has not been previously presented anywhere. Audio-visual: A projector for a laptop PowerPoint presentation will be needed.

# Differences In the Effects of Filters On Health Information Retrieval From the Internet In Three Languages From Three Countries: A Comparative Study

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Background: Although information filters can get rid of some objectionable materials, they are not perfect. Just as they block objectionable materials, they also block relevant information. There are differences in types of filters and filtering mechanisms; in addition, the geographical location, that is, where the information is originated, seems to influence information retrieval as well. Objective: The purpose of this study was to compare the differences in the effects of information filters on health information retrieval from the internet in three countries using three languages. In particular, we would examine (i) what was blocked that consumers could not see; (ii) if what was blocked that consumers could not see was relevant health information; and (iii) what was the difference across different languages at different geographical locations where the web sites originated. Methods: We selected twenty search terms on woman's health from various sources and tested them on Google, once with strict filter on and once with filter off. Searches were specified to three countries (Mainland China, Germany, USA), in three languages (Simplified Chinese, German, US English). Results: We found that the proportion of relevant women's health web sites that were blocked was quite high. For the Chinese language web sites originated in China, 72.6% of the blocked web sites were relevant. For the German language web sites originated in Germany, nearly half (49.4%) were relevant. For the US English web sites originated in the US, 95% were relevant. Conclusion: We concluded that people might unknowingly miss potentially important health information due to information filtering. Keywords: Consumer Health, Health Information, Internet, Women's Health, China, Germany, USA, Comparative Study.

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# Open Access Publishing with Open Source Tools: Towards Sustainable Non-Commercial Journals

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An important part of making Open Access publishing sustainable requires substantially decreasing the cost of online journal production. Similarly, Open Source software has been shown to lower the cost of deployment and maintenance for online applications. In particular, the freely-distributed Open Journal Systems (OJS) software, combined with a "lean" publishing approach and a variety of other Open Source tools, has enabled the possibility of low-cost Open Access publishing. The Journal of Medical Internet Research (JMIR), a peer-reviewed trans-disciplinary eHealth journal, has developed a hybrid business model based on this system. In doing so, it well may be one of the first examples of high-quality, sustainable Open Access publishing. This presentation aims to showcase the Open Source tools and lean publishing methods used by JMIR to establish it as one of the most efficient, and technically advanced, online journals currently produced.

# Designing Universal Access To Health Care : The Role of Virtual Infrastructures In India

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Designing Universal Access to Health Care: The Role of Virtual Infrastructures in India Background: As the world's largest democracy, India faces the vast challenge of developing a national health care system to offer equitable and effective services to a culturally and economically diverse population of more than one billion citizens. [1] While international trade in the Indian health care sector is growing, the Indian State strives to reduce the disparities in health status between the country's richest and poorest populations. [2] Health care services in India are delivered through a complex institutional system integrating a donor-supported social medicine model as well as a large number of private organizations, both for-profit and not-for-profit, under Indian as well as foreign ownership and control. Objective: The objective of this paper is to describe the changing institutional configuration of the Indian national health care system with a particular focus on the problem of underserved populations and the role of virtual health care infrastructures to promote participation and service delivery through local data collection, accountability and evidence-based management. Methods: The research methodology selected for this study is qualitative case analysis. According to Yin (1994), case methods offer a flexible approach to the understanding of large and complex health service delivery systems embedded in their social context. [3, 4] The Indian health care system is a unique inter-organizational network valuable to the process of scientific study as a critical case, particularly for in-depth analysis of the co-evolution and integration of diverse subsystems under a democratic ideology. [5] Results: The Indian Ministry of Health and Family Welfare online encompasses administrative and control functions over the systems of both modern and Indian medicine including research, education, and service activities. The Indian Council of Medical Research presided by the Minister of Health and Family Welfare manages research programs aligned with national health priorities conducted by the 21 permanent specialized institutes. Several of the permanent institutes associated with the Council are WHO collaborating centers. It is important to note the roles of the ministries of Health and Family Welfare, Local Government and Rural Development as well as private enterprise in supporting Internet infrastructures to promote participation and access to health care services for the Indian population at state, district and local block levels. These infrastructures are important tools for health information and services, but they also require active participation at local levels to input required information and generate interaction among local citizens and authorities Conclusions: Results suggest the critical importance of both centralized and local virtual infrastructures for health care services and the need for integration of public and private sector initiatives to improve the performance and accessibility of the Indian health care system. Indeed, success at the local level - including participation, governance, research, and service delivery- is an essential foundation for sustainable development as well as the Indian leadership role among the South Asian nations.

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# The Efficacy of Digital Computer-tailored Smoking Cessation Feedback: Do Action Plans Work As Strategies for Smoking Cessation?

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Background In 2004, 74% of the Dutch population had access to the internet. In 2007, this is expected to be 82%. The internet therefore is an important and influential medium that can be used to communicate with a target population. e.g. smokers. Smoking is a major preventable cause of premature death and disability throughout the world. In the Netherlands, 28% smokes and 25% of smokers want to quit within the next year. Computer tailored feedback to promote smoking cessation is an effective tool for successful smoking cessation [1,2]. Computer tailoring can be applied through the internet, which makes it possible to reach a large audience. Although this is a way of mass communication, it has the benefit of being applicable to a particular individual's situation [3]. Objective We are currently testing a revised computer tailored feedback program that not only provides feedback about attitudes and self-efficacy, but also provides additional feedback on forming action plans as a goal-setting technique. Action plans are strategies that can be used to convert an intention into the intended behavior [4]. These action plans need active self-regulation [5]. Methods Respondents (N = 400) are randomly allocated to either a control group (standard non-tailored feedback) or an experimental group (tailored feedback). The intervention consists of a tailored letter that provides feedback on the pros and cons of smoking cessation and self-efficacy enhancing information extended with feedback on strategies useful in the process of smoking cessation (action plans). Respondents are asked which of 17 strategies they would plan to help them quit smoking, e.g. using smoking cessation aids, planning a quit date or rewarding oneself after a period of not smoking. Respondents complete a questionnaire based on the I-Change model [6], of which the most important measures in light of tailoring are demographics, attitude, self-efficacy, action plans, intention and behavioral measures. Follow-up will take place six and twelve months after the intervention. Results Preliminary results show that at baseline, the following action plans were chosen most of the time: never smoke again, not even a puff; change smoking habits; do something else when craving for a cigarette; think of how to prevent weight gain. Furthermore, women made, compared to men, more plans to: 1. think about how to prevent weight gain before actual smoking cessation; 2. do something else when craving for a cigarette; 3. reward themselves after a period of smoking cessation. Men, compared to women, made more plans to quit at once without cutting down first. Respondents intending to quit within one month made more plans to set a quit date, compared to respondents intending to quit within six months or one year. They also made more plans to tell others about their quit attempt than respondents intending to quit within one year and more plans to reward themselves than respondents intending to quit within six months. Discussion Results and discussion (stage transition, point prevalence, role of action plans) of the baseline measurement and one month follow-up will be presented at the conference.

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### A New Tool for Creating Online Clinical Case Simulations

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The experience medical students receive in practicing their diagnostic skills is restricted to what they encounter in their clinical rotations. A new software tool called Problem Based Learning Interactive (PBLi) makes it feasible to create online clinical case simulations which can enhance the breadth and depth of experience to which medical students are exposed. These simulations allow students to explore and collect the information about the patient that is required to arrive at a differential diagnosis. This exercises their skills in clinical reasoning, as they must make the decisions on what information is required in order to rule in or rule out options on the differential diagnosis. Learning to make these decisions is a critical part of clinical reasoning and the decision making process. Clinical case simulations developed with PBLi have the following features: - Students can select the appropriate questions in taking a patient history, conducting a physical examination, or ordering diagnostic tests, as they would in an actual patient encounter. - Images, sound, animations and video can be used for conveying information about the patient. - Feedback is provided through responses to multiple choice questions and by "debriefing' at the end of the case, including time and dollars expended. - The program can track the path taken by the student, making it a powerful research tool for investigating the cognitive processes involved in clinical reasoning. The presentation will demonstrate how the PBLi tool may be used to quickly create a large variety of clinical case simulations.

# Development of a Numeric Data Extracting and Analysis System Using Dependency Analysis On Nosocomial Outbreak Investigation Database

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Background: Sharing infectious information is very effective to correspond and prevent infection outbreak[1]. For instance, we can know what infection disease is outbreak now around them, and how they corresponded the infection disease in past. Therefore we can settle this outbreak fast and adequately. Therefore, to inform this kind of infection disease, nosocomial infection anecdotal research paper summaries database was developed [2]. This database has more than 350 summarized records of outbreak case reports and anyone uses the database on World Wide Web. This database has few categories and main body. These are specific categories which show each nosocomial infection anecdote, for instance, author, journal, pathogen, case definition and so on. These categories are very useful to retrieve his target document efficiently, but are only listing paper list with abstract. Therefore, If we wanted to survey the a focused infection, we must read all retrieved documents and choose target data like patient or isolate numbers. On this time, we developed that numeric information extracting system using modification structure[3] in order to treat web data based on free text as database[4], and survey system based on result of choosing infectious information. Method: We used 362 nosocomial infection anecdotal research papers, which were collected to develop the database system mentioned above. These infection papers did dependency analysis by which numeric information revealed relation of other words. Next, we developed information retrieval system which targeted these papers using query in order to narrow the search to user's wants and could do crossover survey based on numeric information. Result: number of numeric data in these reports was 2987. Some examples of numeric data are about patient, health care worker (HCW), things of infection

and so on. For example, Some Specific data are "patients: 366 occurrences", "days: 174 occurrences", "cases: 119 occurrences", "isolates: 50 occurrences", "infants: 30 occurrences", "HCWs: 28 occurrences" in all 362 papers. So, this result leaded to calculate crossover statistic. For instance, it was possible to calculate basic statistics of "patients" in these papers (mean = 33, Standard Deviation = 79.44, median = 10). When a user narrowed the search using the retrieval system, it was able to calculate these statistical indexes depending on the search results. Conclusion: In this paper, we tried to extract relation between numeric data and dependency words with dependency analysis. We became possible the calculation of basic statistic in each retrieval result. Consequently, we were able to survey using the numeric data and do diversified analysis in nosocomial infection anecdotal research papers.

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# Improving Medication Safety Through the Use of Electronic Stop/Change Drug Treatment Orders within An Electronic Prescribing and Integrated Drug Management System

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Robyn Tamblyn, Tewodros Equale, Allen Huang, Robert Perreault, Gillian Bartlett, Laurel Taylor, Nancy Winslade, Yuko Kawasumi, Robert Perreault and the MOXXI Research Team Purpose There is consensus that electronic prescribing and integrated drug management systems can reduce avoidable adverse drug-related events by providing physicians with complete information on current drug therapy, alerts and reminders for potential prescribing errors, and typed prescriptions to reduce dispensing errors. One additional source of error that has not been addressed is communication of drug treatment changes. To address this problem, we developed a stop and change order function within an electronic prescribing and integrated drug management system and assessed the rate of use and reasons for changing therapy. Methods 28 primary care physicians and 15,046 of their primary care patients were enrolled in an electronic prescribing and integrated drug management project in 2003. The stop and change orders function that required documentation of the reason for the request using an automated menu list was instituted in October, 2005, and its use assessed between November, 2005 and January, 2006. Results 857 stop and change orders were written for 13,611 drugs prescribed for 3,889 patients who made a visit in the 3 month study period, providing a stop/change rate of 6.3 per 100 prescriptions. The most common reasons for stopping/changing medications were ineffective treatment (48.3%), adverse drug effect (21.6%), and adjustment of dose to optimize treatment (8.1%). Conclusion & Recommendations Electronic medication stop/change orders are feasible, accepted by physicians, and may contribute to a reduction in the rate avoidable adverse events. As many stop/change orders arose because of ineffective treatment or adverse effects, future research should assess the utility of using stop/change orders as part of a pharmacosurveillance system.

# Anticipating Failure: A Task Model Design Approach for Safer EHealth Applications

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Background: The advances of healthcare technology bring the field of medicine to a new level of scientific and social sophistication. There is exponential growth in the number of successful diagnoses, treatments and lives saved each year.



Technology transforms the dynamics of the healthcare process in ways that increase the distribution of tasks among individuals, locations and automated systems. Thus, technology represents the backbone of the healthcare process. However, it is healthcare professionals who usually assume responsibility for the failures of technology [1]. While medical technology continues to advance scientifically, safety and reliability thresholds lag behind in comparison with other safety-critical industries [2]. The discussion of human factors in medicine centers on accreditation, licensure [2], a posteriori analysis of accidents [2, 3], and human decision-making [4]. Objective: The goal is to motivate the design of safer and error-tolerant eHealth systems, and to leverage knowledge from other safety-critical fields like Air-Traffic Control. We propose an approach for the design of eHealth applications that considers the error-prone nature of the distributed computer-supported medical work process. We draw attention on the modeling of potential breakdowns in communication as afforded by the medium, the task, and the workflow. Methods: We expand the existing task analysis modeling techniques for interaction design of computer-supported cooperative activities to tailor them to the requirements of the medical domain. We identify three levels of potential failures that produce an adverse outcome in eHealth applications: communication, coordination and cooperation [5]. Each is seen as a parameter to a subtask in the hierarchical cooperative task-model, and is associated with an outcome. Such an adverse event driven task model contributes to the development of safer and error-tolerant eHealth systems. Results: We demonstrate the applicability of this approach - how it could have predicted and prevented adverse events associated with a telemetry patient monitoring system made by a major manufacturer and currently used in a number of hospitals in North America. Over the last thirty months, 19 out of 21 reports about this system submitted to the U.S. Food and Drug Administration (FDA) Manufacturer and User Facility Device Experience database (MAUDE) are associated with communication breakdowns in one of the levels we propose; 89% of the breakdowns resulted in a life-threatening situation or in the patient's death. Conclusions: Despite advances in medical technology, there is a strong call for design methods that would reduce development of technologies and applications in the medical field that induce adverse incidents. An a priori focus on medical error is more cost-effective and desirable than a post-mortem analysis. Medical technology needs to draw on the knowledge and experience of more mature fields in tackling safety and human factors in the design stage. In the Air Traffic Control domain the International Civil Aviation Organization (ICAO) developed a communications protocol to deal with potential errors in communication between pilots and air traffic controllers. We propose a model-based approach tailored to the needs of the medical domain and discuss its advantages, limitations, and cost-benefit potential.

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# A Framework To Support Design of a Consumer-driven Element Set To Tailor Online Consumer Health Resources (HINFOMED)

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Background: In the last five years there have been more and more attempts to use the recent information technologies based on Semantic Web architecture to make online health-information-tailoring services more user-friendly. Included are variety of attempts to catalog online health resources using various metadata vocabularies (element sets) that are partially to completely based on the Dublin Core element set—the most universally accepted vocabulary standard in the Web domain. However, we identified low consumer-centeredness as a common shortcoming that may impede the usability of these vocabularies in the consumer health-informatics domain. Objectives: In this study, we propose an XML-based framework to develop a new concise element set that is shaped through iterative interaction cycles with representatives of consumers and professionals to allow consumer-based information tailoring. Methods: A hybrid (user-focused + user-centered) approach was proposed in three phases. Phase I encompasses a series of professional design tasks performed by developer/s with a user-focused

vision. In this phase, a preliminary set of elements was built to annotate a collection of health resources on several major on-campus health topics, such as alcohol abuse and sexually transmitted diseases (STDs), followed by building the related metadata registry and web-based interface. In phase II, during a series of interview sessions, consumer and professional subjects (undergraduate university students ages 18-20 and the local health professional) will be given frequent opportunities to comment on the suggested element set, add new elements, and challenge the preliminary annotations made to the resources. In phase III, the improved usability of the information services provided will be compared to a control web site through a qualitative-quantitative analysis of the results from successive usability-testing sessions. Results: Eighty-four online health resources were collected and added to an XML-based primary database. A suggested list of 12 elements in three categories — document-related, annotator-related, and target-related — was composed and further incorporated into our Resource Entry Forms (REFs) to annotate the resources collected. And finally, REF forms are used to assign values and create the primary Resource Description Frameworks (RDFs). Our preliminary findings up to this stage (phase I) have revealed the following: 1- For the annotator-related category, we found that a differentiation was required between horizontal (professional-to-consumer) and vertical (consumer-to-consumer) tailoring. 2-Temporary elements were found necessary to allow one-time case-based annotation. This capability would permit individual tailoring by enhancing the generic annotations included in the initial resource-entry process. 3- The main challenge so far has been the issue of possible variation in the initial assignment of values in creating the RDFs. This would impede the reliability of annotations made by various annotators. Conclusion: We found the primary-user-focused design useful in identifying the areas of element sets that needed particular improvements in our research's succeeding participatory design. Further investigation in phase II is expected to reveal the degree of usability for the suggested elements and example annotations by analyzing the feedback from selected users' representatives (consumers and professionals).

### **Narrative Medicine and Rare Diseases**

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Background: In November 2005, the Centro Nazionale Malattie Rare (National Center for Rare Diseases), CNMR, of the Istituto Superiore di Sanità (Italian Health Institute), ISS, launched a collaboration project on rare diseases and narrative-based medicine, which will be promoted through the CNMR website. In 2003, the National Library of Medicine officially introduced in the Medical Subject Headings (MeSH) Thesaurus the new entries Rare diseases and Narrative medicine. Illness stories may be illuminating and help to illustrate some of the patients and families problems and experience in their lives. Patients and/or families who turn illness into story transform problems into experience and experience in resource. In our project, we stress the importance to collect illness stories as a participatory and inclusive method to better understand unmet needs and to develop public health activities. Objective: Narratives will complement data already collected by the CNMR-ISS on accessibility and quality of socio-medical services for patients with rare diseases (RD), activity performed in the frame of the EU project NEPHIRD. The narrative project aims at paving the way towards the extension of any form of participation in issues on rare diseases, for the benefit of patients, their families, patient associations, health services, physicians and other professionals in the field. Methods: A pilot phase has started within a focus group which included a selection of patient associations representing different rare diseases. Objectives have been discussed during the first meeting. Patient associations are already spreading information through their website or newsletter. A pilot database of individual patient stories. to become narrative section on the website, is under way; it will be first for internal use for pilot patient associations and, once tested, opened to all categories of users. Results/Conclusions: During the above mentioned meeting participants in the project underlined that 1) it is high time to meet the needs of rare disease patients and their families in terms of health-related services; 2)



narrative plays a focal role in physician-patient relations; 3) narrative focuses on needs, assistance, obstacles to accessibility and quality of socio-medical services; 4) telling illness stories is a specific method of patient/family participation. Acknowledgements This work has been supported by the European Commission (DG-Sanco). Project Network of Public Health Institutions on Rare Diseases (NEPHIRD), Contract N.: SI2.307538 (2000CVG4-810).

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# Online Focus Group Methodology As Data Gathering Strategy In Pediatric Oncology

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Background: Although guidelines in pediatric oncology support the principle of open communication with both patients and parents, in daily practice difficulties are encountered in managing communication with young patients and their parents [1]. To bridge this gap, focus groups were used to investigate the information needs and participation preferences of children diagnosed with cancer, their parents, and survivors of pediatric cancer. Focus groups have been shown an appropriate research tool in eliciting children's views on health-related matters [2]. We opted for a moderated, asynchronous form of online focus group discussions instead of the traditional face-to-face version. Following the literature on online focus groups [3] our arguments were fourfold: 1) This methodology allows spatiotemporally separated participants to join the discussion at home and at a convenient time; 2) The anonymity allows participants to speak more freely; 3) Youngsters' familiarity with the Internet pleads in favor of the use of this new methodology; 4) Since the written contributions of the participants yield immediately available and analyzable data, data entry and analysis are quicker and less expensive. Objective: Separate online focus group discussions with patients, parents, and survivors of childhood cancer were conducted, with the objective of determining what constitutes good quality of communication in terms of participation and role delineation from their point of view. This led to the construction of a questionnaire evaluating the quality of communication and role delineation. Methods: Participants were sampled from the population by consecutive inclusion in two University Child Oncological Wards. Seven 8-17 year-old children in active treatment for childhood cancer, eleven parents, and eighteen children who had completed treatment participated in separate online focus groups. During one week, the participants logged in and reacted to statements and questions introduced by the researchers, who acted as moderators. Data from the focus groups were coded using deductive and inductive coding schemes and content was analyzed for the existence of themes. A questionnaire measuring attitudes and experiences was developed based on the focus groups data. All participants were asked to evaluate the pilot version of this questionnaire. Results: The online focus groups generated rich and detailed data, and highlighted issues that were not yet evident in the literature. The results show that both children and parents have explicit and elaborate communication and role preferences. Participants were unanimous in their appreciation of joining the online focus groups. In discussing the results, we will highlight methodological and practical considerations regarding design, sampling, planning and conducting online focus groups. Conclusion: The study reveals that online focus group methodology is a useful and feasible tool for collecting data in the field of communication in healthcare from respondents who probably would not otherwise join a study.

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# Understanding Predictors of Electronic Decision Support Utilization By Physicians

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Background: More effective management of patient care processes can be obtained by well-designed decision support tools to assist physicians in their practices. General practitioners provide front-line primary care, act as gatekeepers for specialist care, and generate the majority of therapeutic prescriptions [1]. Therefore a focus on providing effective decision support tools to this group offers promise to substantially improve health management decisions that will, in turn, improve system safety and the quality of patient care and outcomes. However, the mere availability of such tools is inadequate to improve processes and quality of patient care, Past work indicates that the majority of the target population do not use such tools or fail to implement the recommendations provided by decision support tools that are available [2,3]. There appear to be physician characteristics that influence the utilization of such systems, specifically physician response to new information regarding effective clinical strategies, but this has not been assessed. Physicians can be characterized into one of four types of information seeking behaviour: seeker, receptive, traditionalist, and pragmatist. Objective: To determine differences in utilization patterns of an integrated electronic drug management system designed improve the prescribing patterns of community physicians by physician response to new clinical information (physician typology). Methods: The Medical Office of the Twenty First Century (MOXXI) project tests the potential benefits of implementing an electronic prescription, drug and disease management system for primary care physicians, community-based pharmacists and their patients. The project currently has 64 participating general practitioners. Physician information seeking typology was assessed using a 17-item questionnaire on a five point Likert scale at the time of recruitment [2]. System utilization was evaluated using two measures: (1) the number of patient consents per physicians, and (2) the number of electronic prescriptions per physician. An electronic prescription included all medications prescribed during a patient visit. Results: Analysis of the preliminary data show that in this population of physicians 3.2% were classified as seekers, 16.1% as receptives, 77.4% as pragmatists, and 3.2% as traditionalists. Participating physicians wrote 7951 electronic prescriptions and consented 8988 patients in the first three months of the study. Preliminary results for the first 64 physicians are suggestive, but not statistically significant, of differences in the level of utilization by physician typology. Seekers, receptives and pragmatists had similar rates of patient consent (17.6, 18.5 and 17.7, respectively) and electronic prescriptions (10.5, 11.6 and 14.7, respectively), while traditionalists varied significantly in their utilization rates (5.6 patient consents per week and 1.8 electronic prescriptions per week). Conclusions: These early results demonstrate the need for further work to more fully identify the predictors of successful integration and utilization of electronic drug management systems designed improve the prescribing patterns of community physicians. The ability to make a more accurate prediction of utilization patterns will allow for appropriate customization of decision support tools and the associated training and follow-up support.

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# ECANCERCare BRIDGES THE GAP BETWEEN RESEARCH AND CLINICAL CARE

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PURPOSE: Many institutional clinical care systems collect a generic set of data for a broad spectrum of patients, consequently not meeting the needs of disease-focused care and research which require a more comprehensive disease-specific data set. Better methods and techniques to collect and integrate this vital information are required. METHODS: eCANCERcare comprises three components: ePOC (electronic Point-Of-Care), DePICT (Disease-specific electronic Patient Illustrated Clinical Timeline), and ePROTOCOL (electronic PROTOCOL), in a browser based software application that interfaces with Oracle relational database management system. RESULTS: eCANCERcare is a suite of software applications that are integrated with an institution's electronic health record to provide a complete set of data for research, patient care and disease management. For example, eCANCERrb includes retinoblastoma clinical point-of-care data with electronic fundus drawings and an integrated visual clinical summary, linked with ePROTOCOL to facilitate the management of clinical trials and guidelines. eCANCERbladder includes an electronic note automation system that has reduced the transcription of cystoscopy clinic notes by 600 over the past year. CONCLUSIONS: The complete eCANCERcare package allows for the collection of more accurate and timely data for research, eliminates the cost required for transcription of dictations, and provides both patient and caregiver a better understanding of the patient's clinical history

# E-Therapeutics – Evidence-based, Clinical Decision Support Tools for Practitioners To Improve Safety and Outcomes From Drug therapy

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Drugs are the second largest expenditure in the Canadian health care system with an estimated \$24.8 billion dollars spent in 2005 [1]. The challenge for practitioners is to ensure that drugs are prescribed and managed to achieve the best possible outcomes for patients. e-Therapeutics addresses this challenge by providing a set of electronic tools to inform and support clinical decision making at the point of care. e-Therapeutics gives health care professionals – in particular, physicians, pharmacists and nurse practitioners - access to current, credible, unbiased drug and therapeutic information. The easy-to-use web and mobile applications make it possible for practitioners to compare various treatment options and choose appropriate therapy for their patients. e-Therapeutics was developed by the Canadian Pharmacists Association in conjunction with a broad network of partners and with support from a contribution from Health Canada's Primary Health Care Transition Fund. e-Therapeutics offers evidence-based therapeutic information written by Canadian experts (physicians and pharmacists) and rigorously reviewed by leading authorities in each clinical subject area. Drug information is supplied by e-CPS CPhA's electronic Compendium of Pharmaceuticals and Specialties Health-Canada-approved drug monographs. These comprehensive resources are supplemented by a wide range of external references including links to new drug safety information, a drug interaction analyzer, and access to public drug plan formularies. e-Therapeutics also provides additional links to external references including PubMed, the Cochrane Collaboration, clinical practice guidelines, systematic reviews and original research. Recently recognized in the Health Council of Canada's 2006 Annual Report, e-Therapeutics is designed to integrate with other e-health applications, including clinical office systems, pharmacy software systems and provincial health information networks. The Health Council urges prescribers to adopt this new tool to increase the efficiency and accuracy of prescribing while preventing adverse drug events and encourages provincial linkage with other patient health information systems to ensure a fully integrated record of patient care [2]. Some Canadian provinces currently at work in developing pharmacy information networks have already recognized e-Therapeutics as an essential component [3]. e-Therapeutics provides functionality that is key to the development of a pan-Canadian electronic health record. In the increasingly complex health care environment practitioners are moving away from remembering towards the look-up of therapeutic information. Canada Health Infoway has identified e-Therapeutics as supporting this shift from paper-based information resources to electronic information for health care practitioners [4]. Throughout development e-Therapeutics was tested by professionals from across the country to ensure the features and functions best meet day-to-day practice needs. This presentation will give an overview of the initiative, demonstrate these e-tools, describe user experiences and outline the change management strategies used to support adoption.

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# Primary Care Physicians Experiences of Carrying Out Consultations On the Internet [1]

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Background: The Internet is increasingly used for health matters [2-3], including consulting a doctor [4]. Primary care physicians (GPs) will probably be involved in performing text-based consultations on the internet as a complement to physical meetings. Methods: A questionnaire was given to 21 GPs performing consultations on the internet for a public, non-commercial 'Ask the doctor' service. The questionnaire was carried out at a meeting or sent by mail. The doctors answered a total of 39 questions, 21 of which included graded alternatives. Objective: To explore the experiences of GPs already performing consultations on the internet: the challenges, worries and educational demands of the task. Results: The participating GPs were stimulated and challenged by performing consultations on the internet with previously unknown enquirers, in spite of limitations caused by the lack of personal meetings and physical examinations. The participants experienced a high educational value as a result of the problem-based learning situation induced by unfamiliar questions. The asynchronous feature was appreciated as it allowed time to reflect and perform relevant information searches before replying. Prior training and long-term experience as a family doctor were recommended before embarking on this method of consultation. Conclusions: We conclude that the GPs studied experienced their new role as internet doctors mainly in a positive way, with some limitations. With the increase in consultations on the internet, training in this technique should be integrated into the curricula of medical schools and of continuous professional development (CPD).

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# MEDNET – a New Healthcare Platform In Germany To Manage Patient Health Files Safely

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The flow of information between hospitals, general practitioners, pharmacists, patients and others has always been a challenge. Computers and network structures offer the opportunity of improving information management. The new MEDNET Server provides the possibility of a safe storage of medical files in a "safe deposit box" on the server with maximum flexibility and easy access for those involved in the patient's medical treatment. The MEDNET Server solution is divided into four different units: The User server, the Register server and a number of file and index servers. The User server administers all user information, their public keys, serves as a gateway to the trust center and itself is a key certification service for enabling access to a File server. The Register server has access to a reference list of all published files and of the respective File servers on which they are stored. In addition, the Register server is also its own key certification service. The patient can exclude any and all medical users from access to his/her data at any time and several times without any loss of data. The server technology of the MEDNET Server file and document servers offers a patient-oriented health care platform that is built upon a strong and dynamic security and authentication concept. The concept of the file and document server gives patients the possibility of storing medical documents safely and in a trustworthy manner in a "safe deposit box" on the server.

## Platform for Intelligent Agent Subscription In ICU

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Background: The Intensive Care Unit (ICU) is an extremely data-intensive environment. This large amount of data exceeds however human intellectual capabilities [1]. Not only the amount of data, but also the heterogeneity makes data processing in the ICU problematic. Information technology can facilitate the abstraction of relevant information and support the physician through software agents for medical decision support. Typical examples of medical decision support agents for the ICU are a sepsis detection agent and multi-agent systems for prescribing antibiotics in the ICU. The authors already designed a multi-layer architecture providing inherent support for flexible plug-in of medical decision support agents [2]. Objective: It is however expected that in future ICU information systems, tens of agents will be active simultaneously in order to optimize the care of critical ill patients. Therefore the authors present a management platform for agent subscription, data handling, the notification and presentation of results from the agents, as well as load balancing of the agents over multiple workstations to execute them simultaneously. This was not addressed in [2] and has been the subject of recent research. Methods: The platform, referred to as the Intensive Care Agent Platform (ICAP), has been implemented based on the principles of service-oriented architectures, using the Web service technology. The total framework is composed out of multiple services as independent building blocks. These services are autonomous, independent of other services and only responsible for their own functionality. ICAP allows for the intelligent subscription of medical decision support data and the load distribution of agents and offers advanced features such as transparent data migration; user-friendly patient/agent subscription and profile based filtering of support messages. The platform supports both push and pull message models. Laboratories can send new medical data results by triggers using the push model. On the other hand retrieving medical data from databases is supported by the pull system. Processing these data from both models, agents

can generate a result set or medical suggestion and send it to the appropriate users over the platform. Security is also an important issue for the platform since ICAP operates on logical endpoints that abstract the physical components and application infrastructure, incorporating multi-hop technology with intermediate actors. Therefore a combination of transport and message level security is used to secure the communication between users and the platform. Results: A platform prototype has been implemented and is currently being evaluated by the Department of Intensive Care of the Ghent University Hospital. ICAP allows for the intelligent subscription and handling of medical decision data and supports as well push as pull models. The overhead of both channel security and message security has been analyzed in order to secure the subscription platform. Conclusions: A platform for intelligent agent subscription in ICU has been motivated and will be discussed in detail. By using the Web service technology, generic interfaces and exchanged messages, the platform is largely generic, independent from the agent implementation language, operating system and hardware of the workstations and the particular type of the agents.

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# Speech Recognition - Better Care and Lower Cost

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It's a familiar story throughout radiology departments in the United States essential reports delayed for hours, days and in some cases weeks awaiting transcription by an overwhelmed transcription service. Documentation is the life blood of radiology and instant access is no longer "nice to have" it is a "must have" feature for delivering high quality service to radiology department customers. Without documentation there is no communication between the various members of the healthcare team and no payment for services rendered by healthcare providers to patients by government or insurance payors. But documentation has increasingly become quagmired in almost every radiology department. With healthcare becoming increasingly complex and specialized rapid communication of results and procedures between specialists and various members of the patient care team is essential to the delivery of high quality safe clinical care. Speech Recognition has reached the Plateau of Productivity (a term defined by the Gartner group which highlights the relative maturity of technologies in different domains and the point at which the technology demonstrates real world benefit and becomes more routinely accepted). Put another way - Speech Recognition has reached the Tipping Point for healthcare. This session will explore the value of speech recognition in radiology documentation and tight integration into radiology systems to provide easier interaction for time challenged physicians and the value this brings to the quality and speed of clinical data capture.

# Systematic Review of the Contribution of E-health To Diabetes Care Management

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Background: Currently there is a lack of knowledge about the contribution of e-health to diabetes care management. Previous review studies about e-health were predominantly focussed on the acceptance with the used technology. Few studies have examined the specific contribution to control of care of different e-health tools that provide an interactive component. Objective: To review research into the use of video conferencing and teleconsultation for patients with diabetes, focusing [1] on the quality of control of care, e.g. metabolic control, quality of life, control of care, online patient-provider cooperation, usability, cost effectiveness and health policy. Methods: We searched electronic databases on patient-provider electronic consultations (Medline, Picarta, Psychinfo, ScienceDirect, Telemedicine Information Exchange, ISI Web of Science databases). The reference lists of papers identified were hand searched of other relevant references, also indexes of international journals on



telemedicine or diabetes. Results: 40 studies were included (from 852 potentially relevant studies) that met the following criteria: trials related to evaluation of consultation for diabetes type 1 and 2 or gestational diabetes whereby communication takes place between care providers and patient(groups) irrespective of the stage in the diabetes disease continuum; communication includes both synchronous or asynchronous communication. Studies evaluating electronic consultation not aimed at diabetes particularly and solely discussing technological aspects or medical registrations were excluded. Study methods used were half structured interviews (11), focus groups (5), logfiles (12) and questionnaires non standardized (14), validated (14). Study designs were randomised controlled trials (13), well designed trials without randomization (3), well designed not-experimental studies (8) and weak designs (16). Sample sizes were  $\leq 20$  (9),  $\leq 100$  (18), > 100 (12), not specified (1). The heterogeneous nature of the identified studies did not permit a formal meta-analysis. Used consultation modalities were video conferencing (n=23), teleconsultation (n=23) and videoconferencing combined with teleconsultation (n=6). In particularly, video consultation and the combined modalities were used to enhance patient's self-control of care and cost savings (in service utilization and triage of personnel). Teleconsultation was directed in particularly to prevent medical complications through metabolic control by means of internet or e-mail and to disease management by means of cooperation between patient and care providers and coordination of information exchange between local clinicians and specialists. Video consultation has been proven as a potential tool to empower patient's self-management care and to encourage life-style management, and education. The combined studies were specialized in home care and supplement teleconsultation. Teleconsultation developed from a stand-alone system for registration of data to an integrated care system that empowered patients as well as providers. Besides, recent teleconsultation and videoconferencing studies were more aimed at well being (quality of life), behaviour (control of care) and social-political aspects as equity and transparency. However, threats of teleconsultation and videoconferencing are the uncertainty about the continuity of care; only 3 of the examined studies expected a follow-up after the pilot period. The lack of a clear vision about the potential of a certain technology to support self-care, the lack of education to handle health care problems at home by means of technology and the lack of knowledge of professionals to measure social and behavioural aspects of e-health. Conclusions: To enhance the contribution of technology to diabetes care, competent research designs are needed focussed on the combination of clinical, organizational, economical and behavioural outcomes to offer a complete picture of the effects of technoloy 1 Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001. URL:http://www.nap.edu.books/039072808/html/

# Medical Algorithms, Knowledge Representation, Domain Ontologies and Web Services

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Background: Large volumes of computerized medical data are generated by daily medical routine and stored in information systems of various healthcare institutions. Mere availability of this data to health professionals does not ensure that all information contained in this data is understood. Computer support to data interpretation is one of the central topics of health informatics, addressed by all systems for automatic processing of health-related data. New developments in both computer science (collaboration and resource sharing in GRIDs) and health information science (representation of knowledge in machine-readable ontologies) open new perspectives and ways of computerized processing of health data. Objective: To explore the potential of GRID computing for processing of health data in several domains (and possibly also across domain boundaries), project MediGrid (funded by the Czech National Research Programme) has brought together experts from health informatics and computer science. In the second year of the project, methods of semantic matching of data and procedures are being explored. Methods: Existing semantic

bases are being explored for their potential for clear and unambiguous description of data that can enter computational algorithms. UMLS is the most representative one, IUPAC / IFCC databases are another example. Where necessary, further reference is sought and evaluated in order to support decisions whether specific data can or can not be processed by specific algorithms. Results: Structure of information relevant to applicability of various algorithms to various types of medical data has been drafted. A web service has been designed and implemented in a small scale to handle and present this information. Conclusions: Where vocabularies are tightly bound to routine medical practice (as is the case of IUPAC / IFCC databases), their granularity is usually sufficient to support decisions whether specific data can or can not be processed by specific algorithms. General medical vocabularies (like those included in the UMLS Metathesaurus), however, are often too coarse-grained and have to be specifically extended. For further documentation of concepts, it is also useful to add further information (as e.g. list of representative citations). These bits of information can be handled by web services.

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# **EPROTOCOL- RB : Web-Based Clinical Trial Management Tool.**

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Objective: The challenge to study the rare pediatric cancer of the eye, retinoblastoma, led to the partnership of two organizations to design, develop and implement a unique clinical trials management tool. ePROTOCOL-RB is web-based tool for protocol and patient management in clinical trials. ePROTOCOL-RB contains clinical trial protocols and automatically monitors the patient electronic record to notify the clinicians when a patient is eligible. After a patient is registered, ePROTOCOL-RB recommends the details of protocol-specific therapy including doses through the patient's electronic record. Methods: ePROTOCOL-RB is a PHP/ Oracle/Apache Windows web-based solution. ePROTOCOL-RB defines study plan/guidelines with Treatment Cycles, Procedures, Labs, Medication and Adverse Events. Adverse event standards underlie automated toxicity grading in the context of each institution's lab value ranges with automatic flagging and notification of relevant events. ePROTOCOL-RB can specify events, timing of encounters and audit and report on compliance, toxicity and endpoints to designated authorities. Results: ePROTOCOL-RB provides comprehensive role-based management for different user groups. An authenticated user will create treatment plans, automatically track changes of protocol status, manage eligibility criteria, and download adverse event standards from regulatory agencies. ePROTOCOL-RB automatically calculates toxicity grading in the context of an institution's lab value ranges and flags relevant events. The audit feature automatically keeps log of different operations on the database including addition, deletion or modification of any treatment plans, medications, and lab tests. Conclusion: ePROTOCOL-RB provides an innovative tool to create, maintain, track and view graphically all stages of a clinical trial in a web based electronic format. ePROTOCOL-RB will enhance patient care and clinical research for rare, and also frequent and complex cancers.

Digital Triage To Discriminate Medical Complaints for Which a General Practitioner (GP) Should Be Consulted From Complaints for Which a Self-care Advice Can Be Given.

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Marek Turnovec

Introduction: On average every Dutch visits their GP 1,4 times a year for a new medical complaint. Among the most frequently presented complaints are cough, nasal congestion, throat complaints, low back pain, headache, neck/shoulder complaints and diarrhea. In more than 80% a self-care advice is given. To support the GP's the Dutch College of General Practitioners (NHG) has developed professional standards for telephone triage. Doctor assistants use these standards to determine whether a patient can come to visit the GP. Objective: To examine whether digital triage based on NHG standards can empower patients and promote self-management of self-limiting diseases. Methods: A symptom driven expert system was developed. Twenty-five 'entry' complaints were selected based on the following criteria: high frequency, no physical contact required to assess medical situation and the possibility to rule out emergency situations. The system was certified based on ISO 9000:2000 standards by an independent certification institute (TNO-OMIC). Through a secure website the patient can enter the expert system by selecting the main complaint. Each complaint leads to a specific triage module. Information required to asses the specific situation is gathered through a dynamic questionnaire which is can vary on gender, age and the answer on the previous question. On top of that patients were asked to answer an additional 4-8 question about the service. Upon completion the expert system assesses the urgency of the current situation and provides an advice. Those advices vary from 'contact a doctor immediately' to a self-care advice. Results: In a pilot study almost 2000 individuals used digital triage to assess their everyday medical complaints. 65.1% of the patients who started a digital consult completed it. Of them 52% answered the additional questions. Asked about their reason, 75,9% answered that they wanted to find out what to do with the complaint they had. Of those 81,5% originally planned to visit their GP for that complaint. In 17,4% a self-care advice was provided. 79% of the patients who received a self-care advice indicated that they would follow the self-care advice first and postpone the planned visit to the GP. 89,1% rated the advice and information they received as good or better, 62,3% rated it as great or outstanding. A follow up study in which the long term effects are studied is on its way. Discussion: The system developed was able to perform automated digital triage for a specific group of everyday medical complaints. The high ratings suggest that patients are empowered by digital triage. The fact that a vast majority of the patients who received a self-care advice postponed their planned visit to their GP seems to support the idea that digital triage can be used to promote self-management of self-limiting diseases. Further studies have to be conducted to value the potential role of digital triage in the primary health care process.

# **Quality Assessment of Statins Obtained From the Internet**

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Introduction: Using "statin" drugs to treat patients with coronary artery disease (CAD) and hypercholesterolemia reduces the risk of cardiovascular mortality, coronary events, coronary revascularization, stroke, intermittent claudication, and congestive heart failure. Statins are among the most widely prescribed class of drugs, with two products, Zocor® and Lipitor® in the top 20 most widely prescribed drugs in the U.S. Unfortunately, statins are very expensive drugs that are unaffordable for many who need them. Consumers have turned to Internet pharmacies for prescription drug purchases for discounted prices and greater convenience. Internet pharmacies are defined as Web sites that sell prescription drugs and other health and beauty products. With the lower drug price on the Internet may come health risks associated with a lower quality drug product. It is reported that a large number of Internet pharmacies conduct unsafe and illegal dispensing practices that may endanger the health of the patients being served. Objective: 1) Evaluate the equivalency of generic simvastatin obtained from the Internet to the innovator product Zocor® manufactured and sold to U.S. consumers through rigorous quality assurance testing, 2) Identify the international Internet pharmacy Web sites and foreign countries that bypass U.S. regulations and sell statins to U.S. consumers. Given the difficulty of the FDA and U.S. Customs to deter importation of non-FDA approved drugs, the results of this study may provide benefit and assist consumers to: 1) Identify potential risks to the public health posed by unscrupulous Internet pharmacy operations and 2) Provide information so that consumers and health care professionals can make educated and well-informed decisions regarding Internet drug purchases. The rationale for this study is based upon recent reports asserting that drugs from foreign sources are not equivalent to FDA-approved counterparts, and often consumers are unable to make this distinction. Patients who take poor-quality statin drug products may place themselves at risk for

ineffective—even potentially harmful treatment. Patients may not receive the protection for heart attack or stroke due to substandard delivery of active drug from the poorly-made dosage form imported from non-FDA approved sources. Methods: Internet pharmacy Web sites selling simvastatin were identified with the search engine Google using the search terms "generic simvastatin" and "generic Zocor." The perspective was that of a consumer seeking prescription medications or comparison price shopping. Twelve simvastatin-containing tablets were purchased from international Internet pharmacy Web sites that sell prescription drugs to US consumers. Tablets were analyzed using near-infrared spectroscopic chemical imaging, HPLC, disintegration, dissolution, weight variation, and friability. Results: Depending on the sample tested and country of origin, differences exist in API blend uniformity, weight variation, and dissolution among tablet samples, with no significant differences in potency, disintegration, and friability compared with the innovator product. Conclusions: These findings have clinical, legal and economic implications that should be addressed in order to protect Internet consumers from potential risks of poor quality pharmaceuticals. LaRosa JC, He J, Vupputuri S. Effect of statins on risk of coronary disease: a meta-analysis of randomized controlled trials. JAMA. 1999 Dec 22/29; 282 (24): 2340-2346. Elsevier, Inc. Mosby's Drug Consult<sup>TM</sup> Top 200 Drugs. http://www.mosbysdrugconsult.com/DrugConsult/Top\_200/. Accessed December 14, 2005. Walker JB and Hunter TS. Internet pharmacies: The good, the bad, and the unsure. (In: Hunter TS, editor. E-Pharmacy: A Guide to the Internet CareZone. American Pharmaceutical Association: Washington, D.C. 2002; 191-226.) U.S. Food and Drug Administration. FDA/U.S. Customs import blitz exams reveal hundreds of potentially dangerous imported drug P03-73. shipments. Document September http://www.fda.gov/bbs/topics/NEWS/2003/NEW00948.html. Accessed November 10, 2005. Veronin MA and Youan BB. Medicine. Magic bullet gone astray: medications and the Internet. Science. 2004 Jul 23;305(5683):481.

### **Online Pharmacies Panel**

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Internet pharmacies are defined as Web sites that sell prescription drugs and health-related products. Legitimate Internet pharmacies can provide numerous benefits. For example, patients who have difficulty traveling or are confined to the home, such as the disabled, have access to prescription drugs and pharmaceutical products. Although the Internet may be an accommodating way to meet patients' pharmaceutical care needs, it also fosters questionable-and often illegal-healthcare practices. Internet pharmacies have become major access points for illegitimate sales and distribution of prescription drugs from sources around the world. Sales of unapproved new drugs, prescription drugs sold without a valid prescription, and products marketed with fraudulent health claims are well documented and may present risks to the public health. It may not be apparent to the average consumer to distinguish legitimate from fraudulent Internet operations due to the relative ease of creating a Web site that looks like it represents an actual business. In the U.S., drug importation from foreign markets has reached record levels. National and international policymakers have identified key issues with buying medications through the Internet that potentially threaten optimal drug use. Problems associated with drug quality, counterfeiting, equitable pricing, and regulatory policies will be described with discussion of potential solutions. Large-scale cooperative relationships among international healthcare organizations and governments are needed to protect medication supply chains to assure the welfare of patients.

# Breast Cancer Information Quality In Commercial Vs. Nonprofit Websites

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Background: Eighty five million Americans access the Internet for health information, while a generic Google search for the term "breast cancer" (also



the leading cancer site among women in the U.S) yields about 122 million results. It is becoming increasingly difficult for audiences to differentiate between credible and misleading health information, including propaganda by websites with commercial interests. It is therefore important to examine health information online, specifically the absence or presence of quality characteristics to develop resources and support creative approaches to educate Internet users who search for and use health information online in an effort to increase individuals' health literacy. Objective: The objective of this study is to conduct a content analysis of the quality of information in commercial versus nonprofit breast cancer websites and to determine whether there are differences in the quality of features or characteristics available on those websites. Methods: The top ten most popular commercial and nonprofit websites were identified using Google's Advanced Search facility. All first level links and home pages on each of the sites were downloaded and subsequently content analyzed (N=627). The content categories included European Union's quality criterion for online health information, and select constructs from the Health Belief Model (HBM). Results: Both nonprofit and commercial websites were found to have low scores of breast cancer information quality. Significant differences were found between nonprofit websites and commercial websites in overall quality scores, as well as whether they cited sources of information and identified content as being "commercial". Neither commercial nor nonprofit websites made the first level web pages handicap accessible. Conclusions: The findings have important implications for e-health specialists, health communication scholars, and online health information-seeking audiences. The lack of quality characteristics found here, especially in commercial websites, suggests the need to develop health literacy resources to educate Internet users about judging the quality of information online. Health blogs and web-based ICT (Information Communication Technologies) projects in developing and underdeveloped countries deserve examinations of a similar nature in the future.

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# Development of An Internet Search Strategy for Use By Urologists To Identify New Technologies In Diagnosis and Treatment of Localised Prostate Cancer

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Background and objectives: Technological change has brought remarkable improvement in medicine over the past decades. There is however widespread variation in how new health technologies are used across countries, indicating that the most effective and efficient technologies are not always the ones employed. Scanning the horizon for new, potentially significant health technologies is therefore important [1]. The Internet provides an enormous possibility to keep abreast of technological change but clinical experts are needed to separate the wheat from the chaff. To utilize the potential of both sources, we explored the development of an Internet search strategy to find new health technologies for use by clinicians. In urology, diagnosis and treatment of localised prostate cancer is among the indications characterised by rapid technological change [2]. The objective was to end up with a list of prioritised web sites that would be easy to search, and provide appropriate information. Methods: Health on the NET, OMNI and Google were used to find web sites. A checklist with in- and exclusion criteria was developed including criteria related to the specific indication, user-friendliness and efficiency of searching web sites, and quality/reliability related criteria. Selected web sites were

evaluated on the basis of overlap in hits, and by the urologists in the team on the relevance of the technologies found. Finally, a sample of six general urologists who were not involved in the project tested the strategy for user-friendliness, and efficiency. Results: Of 376 URLs considered, ten were included in the final search strategy, including detailed guidelines how and where to search on the sites. The strategy includes e.g. YahooHealth [3], DoctorsGuide [4], and The National Electronic Library for Medicines [5]. The full list will be presented at the conference. Conclusions: It is possible to create an Internet search strategy to identify new medical technologies for a well-defined indication. The strategy should be updated regularly because of rapid changes of the Internet. The methods used may be generalisable to develop similar strategies in other clinical areas in urology and perhaps in other specialties as well. The systematic approach of secures users of the Internet search strategy access to trustworthy, accurate and valuable information on new health technologies

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# Health Information therapy: Advanced Online Consumer Tools and Content

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With the ever-increasing challenge of rising healthcare costs, healthcare providers are turning to new means to empower consumers with taking charge of their health and wellness. Health information therapy is a wellness and prevention information and knowledge therapy for empowered individuals who want to understand more about a particular condition and are proactive in treating or preventing a condition or striving for optimal health. It contains detailed self-service information integrated with tools and services for optimizing individual health. A person who needs reliable information about general health or a medical condition is highly likely to research it on the Internet – 31% will go online first to get answers to their question(s). This jumps to 46% if they are regular Internet users. (Fox, S, Pew Charitable Trust Internet & American Life Project, July, 2003). In Ontario, Telehealth averages 1 million calls a year. HealthyOntario.com, winner of the 2004 Webby as the best government website in the world, receives about 2.5 million visitors per year (and growing). 87% of users were highly satisfied with HealthyOntario and 86% of users approved of Telehealth. Of the 52% of callers to Telehealth who felt they would need to visit a hospital, 14% were able to self-manage. Of the 20% who felt they would need to go to a clinic, 17% solved their problem. Of the 55% of the visitors to HealthyOntario.com who planned to or were considering visiting a doctor or a hospital prior to visiting the website, 10% were able to self-manage. The bulk of care still happens in-person, but in-person care is changing. The person (i.e. doctor) is becoming a team, and with primary care renewal, this team will be better able to understand how it can improve services more seamlessly with tertiary care. Hospitals are re-thinking the best pathways to support people moving in and out of their institutions. Chronic disease management has had a paradigm switch that recognizes its multiple facets and the limitations of responsibility lying solely with a primary caregiver. At the same time, people want high quality balance sheets (i.e. decision trees) to empower their health decisions and provide an opportunity to get advice from a wide variety of resources and health care providers. HealthyOntario.com has been a leading consumer health portal for 3.5 years. Winner of the 2004 Webby award for Best Government + Law Website on the Internet, HealthyOntario.com is the flagship promotion program of the Ontario Government's commitment to public wellness and health empowerment. Early this year, HealthyOntario.com launched the first in-depth chronic disease self-management center of its kind in Canada. The HealthyOntario.com Diabetes Self-Management Center is the first step in offering comprehensive health information therapy for Ontarians. This in-depth case study presentation by Dr. Mike Evans, University of Toronto and Chief Medical Editor, HealthyOntario.com, and Toby Ward, Publisher of HealthyOntario.com and President of Prescient eHealth, will demonstrate how HealthyOntario.com uses health information therapy while showcasing the health portal's innovative tools and award-winning content.



# Web-based Protocol Standards Development, Patient Recruitment, and Research Data Collection: A Discussion Panel On the Cutting-edge Research and Practice of E-Trials

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Valerie Monaco, University Of Pittsburgh Scott Corley, Cancer Research And Biostatistics

Traditional paper-based clinical trials research is expensive, time-consuming, and error-prone. Paper-based practice also makes it difficult to scale multi-site trials and reviews. Recent advancement in the Internet and the World-Wide-Web has brought great opportunities to improve the efficiency of clinical trials research through eTrials. This discussion panel brings together three field experts on web-based clinical trials research and practice: Dr. Valerie Monaco and Dr. Douglas Fridsma from the University of Pittsburgh Cancer Center and Mr. Scott Corley from the Southwest Oncology Group, one of the Cooperative Cancer Research Groups. The goals of this panel are for the field experts to present the current web-based approaches for various activities throughout the life cycle of clinical trials and to brainstorm with the audience about the major issues in eTrials research and practice, such as system integration, change management, usability, and multidisciplinary collaboration. The panel consists of two parts as follows: In part one (30 - 35 minutes in total), each panelist will use about 10 minutes to present their research. The panelists will address issues such as patient needs, implementation challenges, observed system benefits and impact, and remaining research questions. They will share their expertise around some common issues for eTrials, such as (1) change management strategies (2) iterative and incremental system design (3) tradeoff between system usability and system efficiency. Dr. Valerie Monaco will provide an overview for the current web-based systems and services for clinical trial recruitment. She will also present some qualitative research results from several ongoing research projects. Dr. Douglas Fridsma will review the current research progress on protocol standards development related to the caBIG initiatives and the BRIDG project. Mr. Scott Corley will present the real-world implementation experiences of a web-based clinical trial data submission system in a cooperative group setting, the Southwest Oncology Group. He will address issues including change management, business process re-design, and iterative and incremental system design. In part two (10 - 15 minutes in total), all three panelists will interact with the audience and discuss the topics or questions raised by the audience or provided by the panel's chair in advance. Some example prepared topics include: 1. Potential barriers for patients in web-based recruitment technology 2. How early and easy can patients find trial information online? 3. Change management in business processes: from paper-based to web-based data submission 4. Coordination or Collaboration: which works better for interdisciplinary protocol writers? 5. Integration challenges for a coherent solution to various web-based trial activities Panelists and Presentation Titles 1. Douglas Fridsma: Community-based Protocol Standards Development Progress Report 2. Valerie Monaco, Recruiting Clinical Trial Participants via the Internet: Is There Room for Improvement? 3. Scott Corley, Implementing Web-Based Data Submission at a Cooperative Cancer Research Group

# A Methodological and Technical Approach To Web-based Multi-method Evaluation

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Background: Potential patients, health care providers, health economics and other stakeholders in health care use the Internet in order to support their decision-making on health related questions [1]. This leads to the call for comprehensive, ubiquitous available and up-to-date data on health care services. Hospitals represent the largest medical service in health care. Flexible and easy-to-use applications are necessary for granting access to hospital data in the continuously changing setting of health care. Objective: The CERES Project implemented a prototype of a Web-based information system on hospital data [2]. The data refer to the structure (i.e. departments and staff), the services, and the results. Users can compare information on different hospitals. Requirements

analysis and formative evaluation of the modules were based on qualitative research methods such as focus group and single interviews. Summative evaluation included cognitive walkthroughs and quantitative tests. The multi-method evaluation of the prototype starts with the specification of an adequate study design and the implementation of a data acquisition tool. Method: The approach respects privacy and fulfils acknowledged standards of scientific research in the Internet [3]. Evaluation is based upon three parts: Firstly, the scope of the study and the type of data to be included are specified. Acquisition and analysis of both quantitative and qualitative data (known as multi-method research) improves the quality of the study and grants insights on users' needs and requests [4]. Secondly, web-based acquisition of the evaluation data from the users is designed and implemented. Thirdly, programming interfaces are specified and implemented to enable the data transfer from the acquisition environment to modules for quantitative and qualitative data analysis. Result: We have implemented a Web-based infrastructure for an evaluation study of a Web-based information system on hospital data, according to the multi-method approach: Logfiles record the number of user visits and actions. An XML based questionnaire acquires data on the user profiles and their experiences, further wishes, and ideas. Users may enter a comprehensive, natural language feedback via free text forms. Textual data form the basis of the qualitative research. Data of the questionnaire and texts are stored in a MySQL database. Quantitative data are transferred to tools, which support a statistical analysis, for example SPSS. Texts representing the qualitative data are automatically exported to computer tools for qualitative text analysis (here: MAXqda). Conclusion and Outlook: Websites on health care related data are a central resource, used by health care professionals and potential patients during their decision making. The data and information help to achieve transparency in health care and to support the informed consent. Concise evaluation approaches and procedures are needed to assess the quality of such information systems and to identify necessary adaptations [5]. With the described methodological and technical approach, we want to contribute to Web-based multi-method evaluations. By evaluation of the described Web-based information system on hospitals, we expect insights about how far we meet users' needs on up-to-date, location-independent and easily accessible data, which is suitable for supporting their own decision making - and necessary improvements.

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# BostonBreathes: Improving Pediatric Asthma Care with a Home-based Interactive Website for Patient Education, Monitoring, and Clinical Teamwork

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To achieve modern and effective management of patients with chronic disease in the primary care setting requires a reengineering of health care systems and relationships to create interdisciplinary teams of professionals providing evidence-based patient-centered care. Asthma has long been recognized as the most common chronic disease of childhood. It has become increasingly prevalent and severe in recent decades despite effective medical therapy. In urban areas and among the disadvantaged, these trends are particularly marked. Research data illustrate that proper use of effective medications, environmental control interventions, teamwork among health care professionals, and patient education



for self-management each independently, and even more powerfully when employed in combination, can reduce asthma morbidity and associated health care costs. The BostonBreathes (BB) system is an interactive website enabling physician-physician and physician-patient communication, monitoring (peak-flow, medication use, symptoms) of asthma patients in the home, and patient and family asthma education. The system helps primary care physicians to function in team relationships with asthma specialists and nurses. Patients and families can interact with their health professionals online as members of the care team. BB uniquely combines patient education, monitoring, and clinical teamwork functions into one integrated web environment. This presentation will describe a new method of promoting each of these factors to achieve improved outcomes. The system is currently functional with 20 patient and 6 physician users, with an enrollment goal of 150 patient users. This project is being evaluated to determine if the BB website will improve patient knowledge and medication adherence, and teamwork among individuals caring for pediatric asthma patients, resulting in improved quality in the process and outcomes of asthma care. This team approach will be adaptable to many other chronic diseases managed in diverse primary care delivery systems. This presentation will describe the barriers to improving quality of care of pediatric asthma, and the design of the patient and health care providers websites that are BB, the educational content and processes, the clinical teamwork processes, and preliminary evaluation outcomes including utilization, patient and provider feedback, and impact on asthma outcomes including adherence to medication, symptoms, and quality of life. This research and development is supported by The Commonwealth Fund, NYC.

#### Patient Access To the EHR Panel: What Is the Problem?

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Joanne Hohenadel, Centre For Global EHealth Innovations/University Health Network

Howard Pai, Radiationn Oncology/BC Cancer Agency James Walker, Chief Medical Information Officer/Geisinger Health System Pamela Catton, Oncology Education/Princess Margaret Hospital/University Health Network

Over the last several years, there has been a movement to transform the exchange of information with patients and their families by harnessing the potential of the electronic health record (EHR). Research studies have demonstrated that it is feasibile and may have several potential benefits. In addition, empowering patients through acces to the EHR is a viable strategy for improving continuity of care and managing chronic disease. Nevertheless, the adoption of this approach has been slow. Institutional barriers also seem insurmountable and include a range of issues that include technology, infrastructure, workflow, existing and new policies, and confidentiality and privacy. This panel will focus on a range of solutions and examine a number of key issues including maintaining confidentiality, developing institutional strategies for change, managing policy implications and encouraging patient involvement. Hohenadel: Virtual Clinics This presentation describes the development and evaluation of a Virtual Clinic (VC) - an Internet and telephone-based application designed to support patients across the continuum of care. The presentation will focus on three major components of the application. The first component helps patients prepare for clinical appointments by encouraging them to list and prioritize their questions, and to be prepared in advance to answer questions the clinician is likely to ask. The second component supports a virtual consultation. The third is a tool to help patients access support services in their home communities. The results from two site evaluations demonstrate patients and providers' support for such systems and the potential for significant savings in time and resources for the health system. Case Studies Pai: BC Cancer Agency Despite increasing awareness and interest in providing patients in the Canadian Healthcare system access to their electronic health records, modest research and progress has been achieved. By sharing the experience of a grassroots-type initiative undertaken at the BC Cancer Agency - Vancouver Island Centre in Victoria, BC to enhance cancer patient access to their medical records through electronic means, this presentation will attempt to elucidate and discuss the current limitations, barriers and gaps that hinder the provision of EHR to patients. This will form the basis for the main purpose of the workshop to develop strategies and action plan to overcome these challenges. Walker: Geisinger Health System Amid the

growing—and justified—enthusiasm for EHRs, there is an echoing drumbeat of warnings about the potential for EHRs to introduce new and serious types of errors, with negative effects on patient safety. This presentation will address the following questions: What do we know about EHR safety? What sorts of errors have been documented? What have the effects on patient safety been? What is the way forward toward EHRs whose benefits and adverse effects are better characterized? How can my organization prevent EHR-related errors? How can we predict where and when they are likely to occur? How shall we monitor for them? How shall we minimize the harm they cause when they do occur? How should we organize our industry to increase our understanding of EHR-related error and how to manage it?

Socio-technical and Institutional Challenges To Building Information and Communication Technologies for Patients Living with Chronic Illness: A Case Study-based Tutorial On Qualitative Research In Medical and Health Informatics

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Informational preferences and needs for chronically ill patients are quite different than for patients who intermittently seek medical care for acute, short-term, or self-limited problems: given the long-term incurable nature of many such illnesses, informational requirements continually evolve over time and place. Patients experience varied and numerous illness patterns and disease trends over time; they develop a certain expertise in the experiential aspects of living with their illness, as well as acquire tacit and explicit knowledge of disease symptoms and sequela, disease patterns, and the long-term effects of medications and other therapies. They also acquire pragmatic insights into the adaptation of realities of chronic illness to everyday life, and become keenly aware of limitations within the healthcare system and care delivery processes regarding chronic illness management. This presentation reviews findings from two recently completed qualitative studies that extend and enrich a previously published grounded theory study on patient-perceived usefulness of patient-accessible electronic medical records (EMR) systems. The first employs meta-ethnography to explore the importance of trust in patient acceptance and use of personal health information in chronic illness self-care. The second uses institutional ethnography and complexity theory to uncover patterns of power and control in chronic illness care that serve to undermine so-called patient empowering technologies. These findings will then be employed to critically analyze a proposal for an on-line virtual community access portal to support the knowledge work of a population of patients living with chronic skin disease. This exercise will help illustrate how organizational cultural relations and techno-centric and bio-medical biases, if left unchecked in the design and development process, can significantly undermine the success of seemingly useful information and communication technologies for chronic patients.

# **Usability Metrics In Practice**

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Discover how to use usability metrics to shape your usability tests and inform your design improvements! This presentation discusses the effective use of usability testing to improve site design, function and appeal to users. Learn how usability testing can not only capture qualitative metrics like users' frustrations, but also capture quantitative metrics like successful completion rates, time on task, number of pages viewed, error rates, and satisfaction rates. Before and after results from a variety of US Government and commercial sites will be discussed, including: how one site improved user success on its website by 93%, while helping users find information 45% faster than the original website; how another organization conducted usability testing on low-fidelity prototypes and used a quantitative clickstream analysis to inform the development of its taxonomy; and how a commercial site conducted a comparative usability study of its competitors' websites and discovered that users' satisfaction was actually tied to the number of words on the home page.



#### International Use of the Online Medical Literature

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International use of the online medical literature has increased dramatically in recent years. This paper will discuss the overall trends in US versus global use of online health information, and the key driving factors behind these trends.

### **Subjective Computer Training and Management Support**

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Subjective computer training and management support: factors in using computers Farideh Yaghmaie, Shadeed Behesthi University of Medical Science and Health Services, School of Nursing and Midwifery, Tehran, Iran Abstract Background: There have been many changes made to information systems. Changes in information systems require users constantly to update their computer knowledge and skills. Computer training is a critical issue for any user because it offers them considerable new skills. Studies have identified computer training as one of the factors that influence the success of users of computer systems (1, 2). Davis and Bostrom state that user training is a key factor for organizational success in computer use (3). Objectives: The purpose in this study was to measure the effect of 'subjective computer training' and 'management support' on attitudes to computers, computer anxiety and subjective norms to use computers. Methods: For measuring subjective computer training the Subjective Computer Training Scale (SCTS), developed by Yaghmaie, was used (4, 5). The Cronbach alpha coefficient was 0.85. Regarding measuring of management support, Igbaria developed a scale that contains two broad categories of support: (i) the presence of an information and (ii) general support (6). The scale contains eight items, and the internal consistency of the scale in this study was 0.81. For measuring computer attitude, Nurses' Computer Attitudes Inventory (NCATT), with 22 items with three factors: (i) Patient care, (ii) computer anxiety, and (iii) patient confidentiality (7) was used. The internal consistency of the scale was 0.90. To measure subjective norms, a five-point Likert scale was used. The internal consistency reliability of the scale was 0.82 (8). The data were collected by mailing questionnaires to 430 health workers employed in community health centers in a local area; we asked that they be completed by every staff member (nurses and health workers). The response rate for completed questionnaires was 302, 70% of the total number mailed out. Results: Of 302 respondents, only 111 (37.1%) had computer training, and the remaining 190 (62.9%) had not attended any computer training courses. There was a significant difference in level of computer training on computer attitude, F(1, 109) = 9.15, P = 0.003. The users with higher levels of computer training had more positive attitudes towards computers (M = 3.721) than those with lower levels of computer training (M = 3.450). Moreover, there was a significant difference between levels of computer training and computer anxiety, F (1, 110) = 15.64, P = 0.000. The participants with higher levels of computer training had lower levels of computer anxiety (M = 1.904). On the other hand, the participants with less computer training showed higher levels of anxiety (M = 2.378). The results also indicated that there was a significant difference between computer training and subjective norms, F (1, 109) = 11.08, P = 0.001. The participants with higher levels of computer training paid more attention to others' expectations (M = 3.594) than the participants with lower levels of computer training (M = 3.242). However, there were no significant differences in management support on computer attitude, computer anxiety, and subjective norms to use computers. Conclusions: This study suggests that computer training can reduce computer anxiety. Therefore additional research is needed to find how training can reduce the duration or intensity of computer anxiety. Also, specifying the exact nature of computer anxiety should be made high priority for determining whether and how it can be alleviated by computer training. Acknowledgement: The author would like to acknowledge the assistance of Dr Rohan Jayasuria, Patrick Rawstone in the data analysis.

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## **Subjective Computer Training: Development a Scale**

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Subjective Computer Training: Development a Scale Dr Farideh Yaghmaie School of Nursing and Midwifery, Shaheed Behesthi University of Medical Science and Health Services, Tehran, Iran E-mail: Farideh\_y2002@yahoo.com Abstract Bakground: Studies have shown that computer training has been identified as one of the factors that influence the success of users and computerized systems (1). Thus computer training is an important factor because it can provide opportunities for users to participate in the process of information system development and successful performance (2,3) special in those areas such as health. The current study would assist resaercher to measure computer training. Therefore, computer training could be more efficient for better service to patients/clients. Objective: The purpose of this study was to develop valid and reliable scale to measure computer training. Methods: There is no explicit definition in the literature of computer training. By reviewing the literature and examining the different perspective, subjective computer training are define by the researcher as; 1. "Sensations and judgement of users regarding the process and product of a particular computer training activity". 2. "The internal feelings of users that is reflected from computer teaching and practice". To generate a representative sample of items of computer training, the researcher implemented a variety of procedures such as, a literature review, focus groups and interviews. Participants of focus group and interview were nurses and health workers from hospitals and community health centers. From above approaches, Subjective Computer Training Scale (SCTS) was developed with a 5-point Likert type scale ranging from 'strongly agree' to 'strongly disagree'. The items measure subjective perspective of users in four dimension; quantity, knowledge, skills and satisfaction. Psychometric evaluation of the SCTS: To test the content validity of the SCTS, the researcher selected ten nurses and health workers as computer experts from the community health centers and hospitals. The experts were asked to rate each item based on relevance, clarity, simplicity and ambiguity on a four-point scale. Based on the suggestions of the experts, the items were modified. To assess discriminant validity in this study, the SCTS and Nurse's Computer Attitude Inventory (NCATT) (4), were mailed to all nurses and health workers who employed in community health centers in a local area in NSW of Australia and was requested that the questionnaire should be completed by every staff member. The response rate for completed questionnaires was 302 (70%) of the total numbers. Results: Table 1 presents the intercorrelations among the study variables. Adequate discriminant validity was demonstrated that the internal consistency reliabilities were much higher in all factors and the subscales. As expected, SCTS and NCATT had positive correlation with the most of the subscales, except with computer anxiety that had negative correlation. Of interest, the score of the total SCTS correlated positively with the computer attitude (r = 0.34) while having a high negative correlation (r = -0.78) with the computer anxiety. These results suggest that the SCTS is measuring predominantly positive perspective. Part of this, may be attributed to the fact that the items in the SCTS are positive. This suggestion is further supported by a large negative correlation between anxiety and the subjective computer training (r = -.40). These results confirm that the SCTS has the power to measure the assumed construct and also demonstrated satisfactory discriminant validity. In this study, internal consistency reliability of Subjective Computer Training Scale (SCTS) was measured. The analysis of data showed that the Cronbach coefficient alpha was 0.85 that was exceeded the recommended values in Nunnally's (5) guidelines. Conclusions: Based on the finding, this study shows that SCTS as a valid and reliable scale can help researchers to measure the value of computer training course. Results of the study clearly indicated that 'computer training' is multi-dimensional concept that the nature is complex. The SCTS can serve as a diagnostic tool for measuring computer training within organizations as a guide for course development.



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# International Communication Via the Internet: Turkish Nursing Students' Experiences

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Background: Computers have not only changed how information is communicated worldwide, but they have also become key tools in many professions. This study consisted in having students obtain nursing and healthcare information about a foreign country via the Internet. Objective: The purpose was to heighten students' global awareness while improving computer skills. Methods: This project involved 31 first-year baccalaureate nursing students. Data were collected using a questionnaire developed by the author. The results were analyzed using descriptive statistics. Data obtained were analyzed using SPSS for Windows. Results: The average number of days it took for replies to arrive from the selected schools was 28.41 days. The average number of e-mails sent by the students was 6.48. Difficulties reported by students during the e-mailing stage were language problems and late replies or wrong addresses. The contacts represented 12 different nationalities. As a result of this work assignment, at least 31 contacts were established and information was exchanged between first-year nursing students at 20 different universities in five countries. Conclusions: Despite some process problems, all students found the assignment challenging and exciting. They reacted positively to the assignment; were enthusiastic about their improved computer and Internet skills, the knowledge they gained about different cultures and healthcare practices, and having nursing students in other countries as e-mail contacts.

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# Computer Courses In the Undergraduate Nursing Curriculum In Turkey

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Background: Educators agree that computers have an important role to play in modern education. Most literature on the subject focuses on the Internet as a tool used by educators. This study surveys computer courses in undergraduate nursing schools in republic of Turkiye. The assignment consisted of having students using their computer skills and doing research on the Internet to obtain information about computer classes at other Turkish nursing schools. The objective of this assignment was to correspond by e-mail with first-year students at these institutions. Objective: The purpose of this study was to survey how Turkish nursing schools have integrated computers and computer courses into their undergraduate programs. Methods: The study used a descriptive design. Data were collected using a questionnaire developed by the researcher. The results were analyzed using descriptive statistics. Data obtained were analyzed using the Statistical Package for the SPSS 11.0. Results: As a result of this assignment, at least 70 contacts were established and information has been exchanged between nursing students at 45 different universities in Turkey. This study shows that one method used by undergraduate nursing schools in republic of Turkiye to educate their students in modern nursing practices is to integrate computer courses in their curricula, thereby providing students important practical technology skills. Conclusions: The results of this study that undergraduate nursing schools in Turkey are serving a crucial function by integrating computer courses and technical skills into their curricula.

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# Integration of Telehealth Into the Delivery of Rural Palliative Care Consultations

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Background: Palliative care is a philosophy of care that aims to: Reduce suffering and improve the quality of living and dying for any individual and/or family living with a life-threatening illness, regardless of diagnosis, prognosis, age, setting of care, or extent of concurrent disease-modifying therapy; and Help individuals and families address physical, psychological, social, spiritual



and practical issues at any time during the illness and bereavement experiences [1]. The Calgary Health Region has a well-resourced interdisciplinary palliative team model that provides consultation support to inpatients and community patients with the goal of supporting primary care service provision to palliative patients within the city of Calgary. Since the expansion of the Calgary Health Region, the challenges of providing palliative consultant services to the large rural area surrounding Calgary have become apparent. A secondary level consultation model that provides interdisciplinary team support to primary care service providers was employed as the model of care. The Rural Palliative Care Consultation Team is a team of physician and nurse palliative care specialists who support front line care providers in the delivery of palliative care to any individual or family in any rural setting within the Calgary Health Region. By integrating telehealth technology as one of the methods of care delivery, the challenges of a widely dispersed rural population can be overcome [2, 3]. Objective: To increase access to consultation services by palliative patients within the rural borders of the Calgary Health Region. Methods: The feasibility of using telehealth technology for the provision of rural palliative care is being examined via an 18-month clinical project. The Calgary Rural Palliative Telehealth Project targets adults with a palliative diagnosis who live within the Calgary Health Region, but outside the boundaries of urban Calgary. Consultation and case coordination services using telehealth technology are provided to augment traditional face-to-face consultations. Video-consultations, via video-conferences or videophones, are available to appropriate patients when referred for assistance with pain and symptom management, emotional distress, psychosocial issues and to assist with coordination of services. Telehealth connects the Rural Palliative Care Consultation Team to patients/families via video-conference in facilities and via videophone to housebound patients and care providers via scheduled video-conference case reviews. Results: Measured outcomes will include: improved access to secondary-level palliative care consulting services in rural CHR communities, with 100 patients benefiting from initial or follow-up telehealth consultations; improved case coordination; improved home support; reduced need for travel by both patients and consultants; improved symptom management for rural and home-bound patients; and improved participation of local acute-care/home-care nursing staff and primary care physicians in the consultation process, resulting in improved communication, increased local skills, and autonomy. Conclusions: Telehealth technology, when integrated into a Rural Palliative Care Consultation Team service model, offers an innovative solution to the provision of palliative care consultation services to a widely dispersed rural population by helping to overcome barriers of time, distance, and weather that could impede the efficient and comprehensive delivery of these services.

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## **Semantic Classification of Consumer Health Content**

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Although the Semantic Web concept holds considerable promise, it does require the Web pages/sites to explicitly mark up the "machine-readable meaning" of their content. For consumer health content, to manually annotate content accurately and consistently would be time-consuming and labor-intensive and require significant knowledge of the domain ontology. Thus, we set out to develop computerized methods for the task. First, we created a partial taxonomy of consumer HIR needs taxonomy. Text-based content are processed to extract words, phrases and concepts, which served as features for classification algorithms. Classification was performed on 3 levels of the taxonomy with accuracy of 92% to 95%.

# Www.dipex.org: An 'innovative and Humanistic' Internet Resource Featuring Video and Audio Clips From Qualitative Studies of Health and Illness

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The DIPEx research group, based in Oxford University in the UK, conduct qualitative interview studies of experiences of health and illness. As well as publishing the results of our studies via the usual channels (social science and medical journals 2-4) we also disseminate the studies via an award winning, multi-media website which is widely used by the UK public (we have over a million hits a month). The site is intended for patients the public and family members as well as health professionals in training and policy makers (1,2). www.dipex.org was launched in 2001 and is supported by a charity with an ethical funding policy. Five years later we have launched 30 collections including several cancers, heart diseases, depression, epilepsy, experiences of pregnancy, screening and immunisation, sexual health and a new area www.youthhealthtalk.org which focuses on young people's health issues. We have also published over 35 peer reviewed papers based on DIPEx studies, including analyses of how people with serious illness talk about using the internet for health reasons (3-4). We collaborate with researchers in other Universities who want to publish their studies on the DIPEx site and are in discussions with groups in several other countries and cultures about collecting compatible studies for publication on an international DIPEx. Each site is founded on a stand alone, qualitative study based on narrative interviews with a maximum variation sample of people gathered from all over the UK. We identify around 25 issues that emerge as important to the people we have studied and write brief thematic analyses that appear on the site as 'Talking About' summaries illustrated with video, audio and written extracts from the interviews. These include topics such as decisions to seek medical help, getting the diagnosis, communication, work life and finances, complementary approaches, family, living with the condition, recovery etc. This presentation will introduce the DIPEx project, demonstrate some of the thousands of video and audio clips from interviews that are shown on the site, and discuss how we plan to develop the project in other countries. We will show how the collections are being used to inform and support people facing health issues and to help health professionals, policy makers and researchers learn about the 'patients' perspective'. 1 Herxheimer A. Ziebland S. DIPEx: Collecting personal experiences to help other patients and educate professionals in Hurwitz B, Greenhalgh T and Skultans V. (eds) Narrative Research in Health and Illness BMJ Books 2004 2 A Herxheimer et al A database of Patients' Experiences (DIPEx): new ways of sharing experiences and information using a multi-media approach. Lancet 2000 355 1540-43 3 Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the Internet affects patients' experience of cancer. A qualitative study. BMJ 2004; 328:564 - 567 4 Ziebland S The importance of being expert: how men and women with cancer use the Internet Social Science and Medicine 2004; 59:1783-1793

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