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Thursday, September 17, 2009

09:30 AM - 10:30 AM - Auditorium

Topic: Consumer empowerment, patient-physician relationship, and sociotechnical issues

Chair: Gunther Eysenbach

E-patient Dave DeBronkart, Society for Participatory Medicine, Nashua, NH, United States*

Keynote: "Gimme My Damn Data!"

Business

One of the most fundamental rights is the right to be fully engaged in one's well-being, especially in moments of crisis when a life is at stake. My experience with moving my data from my hospital's PHR to Google Health gives us all good reason to be deeply concerned about how well the healthcare industry manages data quality. (And I mean YOUR data not "patients'" in the abstract. This is personal.) I want to be able to audit my medical records, annotate them, export them easily for sharing with other providers, and any other innovation we can dream up that will help fulfill the promise of Participatory Medicine, in which doctors and patients engage in a thriving collaboration, each supporting the other. This talk will cover real-world examples of how inability to do this has cause harm and how ability to do it has improved outcomes. I'm serious about this. "Patient" is not a third-person word. We're talking about policy issues that will affect you, your parents, your spouse, you children. Let's work together. Patients can help.

Medicine 2.0’09 on twitter

Please Use Hashtag #med2

11:00 AM - 11:45 AM - Auditorium

Topic: Blogs

Chair: Adalsteinn Brown

Jen S McCabe, Chief Patient Advocate - OrganizedWisdom (USA), Cofounder - NextHealth (NL), CEO/Founder - Contagion Health (USA), Leonardtown, MD, United States; Saad Alaam*, Eli Lilly, Indianapolis, IN, United States; Chia Hwu, 23andMe, Mountain View, CA, United States*

Eviscerating Pride and Profit? Young, Interconnected, Innovators Examine Strategies for Multi-Generational Success in the Era of Social Media

Practice

Tomorrow's global health innovators aren't sitting around waiting for you to retire; we started tweeting about generational gaps in HIT when you still thought "Twitter" was a sound made by birds. Our activities disrupt traditional views in academia, push patient-centric design, motivate others to use mHealth, and redefine today's microstartup world. We're social entrepreneurs gathering on Twitter, Facebook, and LinkedIn, Skyping to create interdisciplinary peer groups. Personal productivity is measured via papers hosted on Scribd and presentations on Slideshare. We meet online in the blogosphere (most of us are Medblogger and HONCode certified), but take conversations offline, gathering in coffee shops all over the world. We call this "business as usual." We spend 'spare' time designing projects using cloud-based wikis and shared Google Docs. We consider presenting at HealthCamps or organizing BarCamps a Friday night well spent. What else do you need to know about us? We work fast, we work hard, and we're not asking permission to excel. Panelists have built SMS services for hospitals in Malawi, organized international unconferences, been "twitterviewed" by European medical journals, and worked behind-the-scenes spreading (and critiquing) the Health 2.0 movement. Aside from a passion for innovation and caffeination, we share a sense of impatience. We're not content to wait passively for future opportunities. You'll find us co-creating value using P2P networking tactics that destroy preconceived notions of the way Gen-Yers do business, all while finishing degrees, volunteering and working on our own startups and consulting gigs. But our choices are not without cost; personal and professional. We're hyper-committed, at least as long as we can make a living in healthcare innovation. Personal business model evaluation is a constant challenge. You'll hear from each of us how we manage to make it work (or not). Some of the tough choices we've made to excel in our field may surprise you. We are fierce collaborators who navigate around traditional hierarchies. We are soon-to-be doctors, public health researchers, tech/events experts, and experienced e-patients working in tandem to make healthcare a more efficient, participatory experience. This panel consists of 4 under-30 innovators who have lived and worked in over 10 countries to date; 2 soon-to-be physicians, 1 e-patient, and 1 mobile health/tech events guru. Special Guest: A policy-maker with an international track record will serve as a moderator. Don't expect all talk and no action. The panel offers 12 key points (3 per panelist) for productive engagement from the perspective of today's wireless innovators. In first-person, narrative style we explore how healthcare can bridge the gap between young, workaholic idealists and experienced babyboomers in charge. Our mission? To push the boundaries of traditional organizations and redefine contemporary healthcare delivery - now! Your healthcare will be in our hands in less than a decade. Can we make it work? And will we stay in the healthcare field long enough to find out? We want to work with you, not against you. Come hear the next generation of healthcare innovators speak clearly about challenges we're all facing and offer a 12 point prescription for success.

11:45 AM - 12:30 PM - Auditorium

Topic: Web 2.0 approaches for clinical practice, clinical research, quality monitoring

Chair: Peter Selby

Peter Selby, Centre for Addiction and Mental Health, University of Toronto, OTRU, Toronto, Canada; Cameron Norman*, University of Toronto, Toronto, Canada; Tupper Bean*, Centre for Effective Practice, Toronto, Canada*

Tobacco Control 2.0 Panel

Practice

Tobacco Control in the 21st century has adopted powerful new web-based tools and technologies that are providing a new vehicle for sharing and promoting up-to-date information on evidence based practices, and promoting tobacco control, cessation, prevention and interventions for health promotion. Tobacco Control 2.0 involves the use of networked technologies, wikis, websites, platforms for knowledge exchange and dissemination, web-assisted tobacco interventions and practice-based research networks. Objectives: The panel will examine existing Web 2.0 tools and technologies that have been applied to Tobacco Control including: platforms for integrating knowledge exchange and translation of “best practices” in tobacco control, the use of practice-informed research networks to promote collaborative knowledge translation between smoking cessation researchers and front-line practitioners, interactive tools like discussion boards and the use of wikis for developing and promoting up-to-date clinical practice guidelines. The panel will consist of the following activities: 1. Cameron Norman will discuss the theoretical models that underlie Tobacco Control 2.0 and will talk about the role of Web 2.0 technologies in tobacco control research. 2. Tupper Bean will discuss collaborative knowledge translation and the applicability of a wiki model for primary care practitioners to a tobacco control context. 3. Peter Selby will discuss CAN-ADAPTT, an innovative practice-informed research network that facilitates research and knowledge exchange among practitioners and health care/service providers and tobacco control researchers to inform the development of a dynamic set of cessation guidelines for use in clinical practice and population-based strategies within Canada. 4. Together the panel and the audience will explore the use and potential impacts of Web 2.0 technologies related to tobacco control and smoking cessation on practitioners, researchers, policy makers and population health overall. Tobacco Control 2.0 uses innovative tools and technologies to create important opportunities for collaboration, dissemination and engagement with a multi-disciplinary group of researchers, practitioners and policy makers to help further tobacco control research, innovation and practice.

11:00 AM - 12:30 PM - CR2

Topic: Personal health records and Patient portals

Chair: Trevor Van Mierlo

Mark Fam, Deloitte, Toronto, Canada; Michael Matthews*, Deloitte, Toronto, Canada*

Personal Health Records: Helping Consumers Take the Driver’s Seat

Business

Although health technology focus has recently been on EHRs, EMRs and patient portals, there is an unprecedented opportunity to shift the traditional provider-centric paradigm to a collaborative patient/consumer-focused model. Around the world, leading nations and private companies are stepping beyond the EMR/EHR to provide health consumers with access and control over their own personal health records (PHRs) – aimed at enabling the consumer to manage and control the health of their self and family. Through a PHR, the consumer is able to maintain a holistic and transferable record which encourages them to further build relationships with care providers through alternative means outside of the hospital walls. This session will focus on the gaining momentum of PHRs in Canada, providing an overview of PHRs as a disruptive innovation in health care, PHR interoperability and emerging vendors, and exploring what is required for hospitals, other health providers and government to prepare for the renewed focus of health care technology on the patient. The PHR has evolved though the years into a more robust and attractive platform – with vendors such as Microsoft and Google pushing the PHR market to new levels, and Canada Health Infoway focus on PHR standards and interoperability. As the PHR matures, the shift of the paradigm from the provider to the consumer is starting to occur in parallel. The consumer is becoming the ‘de facto’ center for all health transactions; the PHR allows the consumer to have a more structured, holistic way to collect, manage & share information. A recent Deloitte study of health care consumers found over 65% are ready for and interested in PHRs. As PHRs are starting to make waves, health providers and government partners will need to consider several areas to be revisited: healthcare services reimbursement model, privacy and security legislation, breadth of scope, and funding. And as organizations prepare for the PHR, and consider related investments, they need to consider their overall readiness across several dimensions including their organization, stakeholders, broader environment, and the optimal approach to implementation. The following are examples of the key questions facing organizations today across these dimensions, which will be explored in this session: • How ready is your organization in terms of culture and infrastructure? • How willing are your stakeholders, consumers and healthcare providers, in participating in this innovation? • What is the state of PHR readiness for stakeholders external to your organization? • What is your method of implementing PHRs: technology platform, funding source, change management philosophy, and consumer engagement process? • What would be the appropriate funding model for PHRs? The market for personal health records is vibrant and large within Canada – it is one that requires partnership and collaboration across hospitals, care providers, consumers, and governmental bodies at a local, provincial, and national level. This session will explore the many aspects of PHRs to help foster this collaboration and dialogue among audience members on how to prepare for this disruptive innovation, and how to ultimately re-focus health care information technology efforts on the patient.

Yunan Chen, University of California Irvine, Irvine, United States*

The Impact of Accessing Medical Records on Care Coordination and Disease Management

Research

Background: Although Personal Health Record (PHR) systems allow individuals to access to their medical records, only a small number of patients currently manage their entire medical records themselves. The benefits of individuals accessing to medical records include: empowering patients to actively manage diseases, improving patient-provider relationships, and facilitating care coordination process. Understanding how individuals manage their lifelong records would increase the functionality and usability of the future PHR system design. Objective: The goal of this study is to examine the long-term impact of accessing and managing medical records on care and disease management behaviors among physicians and patients. Method: This study examines medical record management practices in urban China, where patients maintain ambulatory medical records themselves. Consequently, patients have to keep their complete medical records from multiple providers at home. This study deployed field observations and semi-structured interviews methods to investigate patients’ records keeping and usage behaviors. 4 physicians and 76 patients visits were shadowed for totally 60 hours. In addition, 18 semi-structured interviews were conducted to patients or family members. Results: Overall, patients displayed a strong sense of ownership over their medical records and enjoyed being able to manage their own medical records. Most patients prefer to keep their records at home because if the convenience of accessing medical information at anytime, anywhere, especially for those who have chronic or serious diseases. Patients have engaged in multiple personal health information management activities associated with medical records usages. They initiate active learning strategies to comprehend the medical information on their own and build their lifelong information repositories for disease management proposes. Medical records serve as a key information source for care coordination during clinical practice. Patients always bring in their entire medical history to the consulting room. Instead of inquiring about symptoms and medical histories, the first step of medical consultation is to check the records brought in by patients, no matter it is from the same provider or not. The records are brought in by patients and contain information received from multiple providers including diagnoses, prescriptions, lab results and even radiologist images. Physicians are able to view and consider diagnoses, prescriptions and test results from other providers. Accordingly, they can make prompt and informed decisions to avoid possible drug interactions, repetitive checks and prolonged waiting times. Conclusion: The patterns of medical records usages examined in this study suggest that individual access to medical records enables effective care coordination and empowers patients to engage in more active health information organization, management and learning process. These usage patterns can be used to inform future PHR system design to accommodate the needs of records management behaviors among individuals. Future studies will be carried out to examine issues of trust, privacy, and patient-provider relationships in the context of individual accessing to medical records and to apply survey methods to quantitatively validate these findings.

Sam Nordfeldt, MD PhD, Linkoping, Sweden; Lena Hanberger*, MSc, RN, Linkoping, Sweden; Carina Berterö, RNT, MSc, PhD, Linkoping, Sweden*

Patient and Parents' Views on the Web 2.0 Diabetes Portal - the Management Tool, the Generator and the Gatekeeper: Qualitative Study

Research

Background The Internet has undergone rapid development, with significant impact on social life and on modes of communication. Modern management of childhood Type 1 diabetes requires continuous support and problem-based learning, but few pediatric clinics offer Web 2.0 resources to patients as part of routine diabetes care. We previously reported practitioners' attitudes (J Med Internet Res 2009;11(2):e12), but little is known about the views of young patients and their parents. Objectives We aimed to explore patients' and parents' attitudes toward a local Web 2.0 portal tailored to young type 1 diabetes patients and their parents, belonging to a geographic population of two hospitals. The portal offered a range of targeted services: social networking tools (such as message boards for young patients, message boards for parents, simple blog tools), interactive pedagogic devices and locally produced self-care and treatment information (such as extensive text and video materials from local practitioners, simple e-mail question and answer services, local news from practitioners, diabetes research updates with practitioners comments, and much more). Opportunities and obstacles were sought. Methods Sixteen mothers, 3 fathers and 5 young patients (ages 11-18 years, median 14 years) each wrote an essay on their experience from using the portal, irrespective of frequency and/or success in using it. Two main guiding questions were asked."Tell me about a situation when you succeeded in using Diabit. Has Diabit made managing the disease easier in any way? Are there any advantages in using Diabit? Tell me about a situation when you did not succeed in using Diabit. Has Diabit become an obstacle in some way? Are there any disadvantages in using Diabit?" We analyzed the essays within the context of self-care, using qualitative content analysis. Data were collected in 2008, when login was still required for access to the portal. Results Three main categories were found: the Management Tool, the Generator, and the Gatekeeper. The Management Tool: a set of positive attitudes and a wide range of concrete examples were found regarding useful facts and updates. Being enabled to search when necessary and find reliable information provided by local clinicians was regarded as a great advantage, facilitating a feeling of security and being in control. Finding answers to difficult-to-ask questions, questions they did not know they had before, and questions focusing on sensitive areas such as anxiety and fear, was also an important feature. The Generator: visiting the portal could generate more information than expected, which could lead to increased use. Active message boards and chat rooms were thought to have great potential value for enhancing mediation of third party peer-to-peer information. A certain level of active users from peer families and visible signs of their activity were considered necessary to attract returning users. The Gatekeeper: a gatekeeper effect from login procedures was created from human mismatch with the login system. This and other unsuccessful experiences caused users to drop the portal. A largely open portal was suggested to enhance use by those associated with the child with diabetes, such as school personnel, relatives, friends and others, and also by young users somewhat unwilling to identify with the disease. Conclusions Web 2.0 services have great potential for supporting parents and patients with type 1 diabetes by enhancing their information retrieval and disease management. Well developed services may generate continued use and should therefore be carefully maintained by health care professionals who are "on their toes." Login procedures should be simple and minimized to necessary levels. The education of clinical practitioners regarding their use of Web 2.0 resources needs more attention.

Louis Cornacchia, Doctations, Inc., Garden City, United States*

The Role of MultiTenancy Architectures in Healthcare IT

Business

Client/Server EMR systems silo information within each medical practice. Exchanging information between client/server systems requires synchronization with a shared central system. In a world without universal patient identifiers, sychronization algorithms cannot achieve the level of accuracy required for mission-critical clinical data. Furthermore, unless the synchronization is real-time, the potential for medical errors induced by failure to upload local client-server information to the shared central system in a timely fashion is inevitable and with dire consequences. Furthermore, real-time synchronization between hundreds of thousands of private practice client/server EMR systems is not practical and the cost of the centralized system is prohibitive. Peer-to-Peer networking systems cannot solve these problems and introduce other difficulties. The ultimate answer lies in multi-tenancy architectures which use cloud computing technologies to allow millions of users to interact with a common database through a common interface in real time. Facebook, Salesforce.com, Google and others have validated this approach in other industries and with millions of users. Multi-tenancy architecture systems like Doctations.com scale to provide a secure, private, world-wide network for doctors and patients to share internet space to transact healthcare with greater accessibility, more efficiency and increased quality.

11:00 AM - 12:30 PM - CR3

Topic: Web2.0-based medical education and learning

Chair: Christophe Laurent

Lawrence Sherman, Physicians Academy for Clinical and Management Excellence, New York, United States*

CME/CPD 2.0 Are We Close?

Practice

Continuing Medical Education and Continuing Professional Development (CME and CPD) represent the longest portion of physician life-long learning, yet have the least structure of all medical education components. Whilst CME has certainly evolved over the last 10 years, it lags behind other physician-oriented information delivery when it comes to technological innovation and use. An ongoing review of electronic CME (eCME) and other technology-based CME platforms continues to reveal a paucity of activities that take advantage of the benefits of strengths of the media in which they are presented, as well as a lack of understanding of how to best use the media in many instances. Best practices have been developed, but more examples of worst practices can be found. A strategic plan for the incorporation of new media and technologies into CME and CPD activities is necessary, and innovation in educational strategies is always required. This presentation will review the very brief history of technology-based CME and CPD and provide a strategic plan for incorporating open and closed social networks, wikis/blogs, point of care technology, smartphones, and other platforms into CME and CPD. The roles of these technologies will be explored from the perspectives of assessing educational needs and professional practice gaps through educational methodology selection and ultimately demonstrating their use in measuring educational impact as improving physician competence, physician performance, and patient outcomes. The session will be interactive, with the audience serving as an additional collective presenter by sharing observations of best and worst practices and sharing their thoughts about the future.

Patricia Francis Anderson, Health Sciences Libraries, University of Michigan, Ann Arbor, United States; Theodore Alexander Hanss, Office of Enabling Technologies, UMMS, University of Michigan, Ann Arbor, United States; Lynn A Johnson, School of Dentistry, University of Michigan, Ann Arbor, United States; Jane L Blumenthal, Health Sciences Libraries, University of Michigan, Ann Arbor, United States*

Skin, Flesh and Bones: An Anatomy of Health Education 2.0

Practice

As social media and technologies are widely adopted by the general public and patient care communities, academic healthcare environments face challenges of assessment, adoption, implementation, integration and dissemination of these tools. Driving this process is a balance between evolved efficiencies in current workflows, resistance to change, perceived inutility of new tools, and risks of institutional self-marginalization and loss of new workflow efficiencies through delayed adoption. At the University of Michigan, this dynamic has been addressed through collaborations across schools, creation and promotion of new content through social media channels, integration of healthcare students into the content production workflows, and planning of curricula to provide context and support for faculty, staff, and students. To support the University of Michigan Medical School's exploration into outcomes-based education, we're creating a fluid ecosystem of dynamic, innovative tools integrated into and coordinated by the Sakai learning management system using IMS Learning Tools Interoperability. Tools are conceived, designed, developed, deployed, and used in learning activities in a 10-15 week cycle. A key development platform is Google App Engine, facilitating development and delivery of services through cloud computing. The system allows users to view, comment, and interact with learning objects outside of traditional LMS constructs. This reinforces open education concepts as, instead of importing learning objects into the LMS, we link to the shared, open learning object. Our future plans include adding these learning tools to our OER publishing platform at to facilitate open learning communities beyond our enrolled students. The Medical School, with the support of the Hewlett Foundation, recently launched the Health Open Educational Resources (OER) initiative. OERs are learning materials offered freely and openly for faculty, students, and self learners around the world to use, improve, and redistribute. Also participating in Health OER are Dentistry, Public Health, Nursing, Information, Public Policy, Engineering, LSA, and the University Library. In 2009, the project's objectives are to maximize the impact and visibility of our faculty-created educational content by converting our pre-clinical curricular materials into OER and collaborating with universities in Ghana and South Africa to co-create new learning materials. Central to Health OER is using students as dScribes, "digital and distributed scribes," working with participating faculty to publish materials online, a student-driven model prototyped in the earlier iTunesU project in the School of Dentistry. To facilitate the student and faculty interaction around OER, we developed OERca, a web application for collaboratively clearing and annotating OER. Synchronously with content creation activities, the Health Sciences Libraries collaboratively developed and implemented curricular interventions ranging from baseline social technology competencies for medical students through Science 2.0 gateway, bridge, and mastery tools for faculty and research scientists, focusing on utility of social technologies for productivity and bench-to-bedside applications. Use of virtual worlds and other collaboration technologies are included to enrich connections for distance learning and our remote partners. The overall goal is to promote awareness and acceptance of tools to facilitate new media competencies, supporting the aforementioned projects and the campus focus on open access and open educational resources.

John Moore Wiecha, Boston University Medical Center, Boston, United States; Robin Heyden, Boston U. School of Medicine, Boston, United States*

Learning In a Virtual World: Experience With Using Second Life for Medical Education

Practice

So called "Web 2.0" technologies hold great potential for medical education. Second Life is the best known of a group of new web-based social networking virtual reality environments. Although these environments are being increasingly explored for use in education, we are aware of almost no use or evaluation of these environments for formal medical education, either at the undergraduate, residency, or post graduate levels. Most applications of these environments in medical education have been limited to patient-centered sites for disease or condition specific education and support, or for supporting larger professional meetings via providing a virtual environment in which to participate in the meeting. We designed and delivered a post-graduate continuing medical education (CME) program in the virtual world social networking program Second Life. Our objectives of this pilot project were to: 1)Explore the potential of the virtual world social networking web environment Second Life (SL) for CME activities 2)Determine possible instructional design models for using SL for CME 3)Understand the limitations of SL for CME activities. 4)Understand the barriers, solutions, and costs to using SL, including need for training of participants, and presenters. 5)Learn about the types of environments within SL environment that promote learning. 6) Measure user feedback. We trained and enrolled 16 primary care physicians in an hour-long highly interactive event in Second Life on the topic of Type 2 Diabetes, given by an endocrinologist. Participants completed a pre and post survey, with case-based questions assessing acquisition of learning objectives of the program, and the post survey assessed their attitudes towards the virtual reality learning environment. We also tracked time and costs associated with developing a program of this type, including costs of training participants. Preliminary analysis of our results shows high levels of participant satisfaction, with rates of agreement to the following evaluation statements: 1) “Overall, I found this experience in Second Life to be an effective method of CME”: 100% agreeing, (including 64% “strongly”agreeing). 2) “The Second Life approach to CME was superior to other methods of online CME in which I have participated.”: 100% agreeing (including 55% “strongly” agreeing). 3) “This Second Life CME method is superior to face-to-face methods of CME”: 36% neutral, 9% disagree, 55% agree (including 18% “strongly” agreeing. 4) 100% agreed they would take another CME course in Second Life, including 82% who “strongly” agreed. Virtual world environments will become a significant component of medical education programs in the future. Little is known about how to use this technology for medical education. This project will provide some useful information to help move this understanding forward. It is likely, however, that until the state of art in both technology, access to high speed internet, and user competence all improve, this method of education will be slowly adopted.

Larry F Chu, Stanford University, Stanford, United States*

What Do Residents Really Want? Building an Anesthesia E-learning Portal from the Ground Up: The Stanford Ether Project

Practice

The Stanford ETHER project is an anesthesia e-learning portal website for faculty, residents, medical students and staff of the Stanford University School of Medicine Department of Anesthesia. The website provides a wide variety of medical information created or curated by our medical faculty including “Top Ten” lists of recent articles from the scientific literature, course syllabi, clinical algorithms, and access to medical databases through the Stanford LANE portal. In addition to static content, the ETHER project has incorporated “Web 2.0” technologies wherever practical to facilitate active engagement of our users and to promote an end-user content model whereby our own end-users create educational content for the website. Some interactive Web 2.0 features we have implemented include embedded RSS feeds from major anesthesia journals as well as a Blog written by our faculty members addressing educational issues in anesthesia. We have utilized the blog format to create interactive quizzes and contests which residents receive each month and compete for recognition and prizes. We have also created a web-based database collection of educational content (MAJIC) that allows Stanford faculty and residents to upload their own articles and content using a web browser (e.g. PDF files, powerpoint lectures, etc.) to be shared with others. These entries can be actively searched by end-users or accessed by an RSS feed that is automatically updated when new content is added to the database. We also created a series of podcast video lectures available in RSS feeds and the Apple iTunes store. To enhance use of ETHER at the point of care, we have also recently created ETHER LITE, a version of the website that is compatible with mobile computing platforms, specifically the Apple iPhone. Our objectives in the Stanford ETHER project are to assess benefits and limitations of different Web 2.0 services in providing online educational content to our users. We found several benefits of Web 2.0

services include the ability to dynamically integrate content into our portal without the use of specialized content management software (CMS), ability to keep our users aware of the most current content available on ETHER, and to engage our users to create their own content for the website. Some disadvantages we have encountered include occasional platform incompatibilities with various third-party Web 2.0 services we are using, and occasional problems retrieving content using these technologies. We have taken a faculty-moderated approach to content contribution to ETHER to insure the quality and validity of contributions created by our end-users. Web server logs show the mean visit duration for ETHER since its launch on 7/1/2008 is about 7 minutes with page visits as follows: homepage (55%), paging services (24%), CA-1 tutorial (2.2%), social activity photos (2.06%), telephone directory (1.66%), and resident call schedule (1.37%) Interestingly, content domains of Ether that were the most labor-intensive to produce, including podcasts, and MAJIC, accounted for less than 1% of total web site traffic. Future research will explore possible reasons for this observation as well as strategies to optimize use of Web 2.0 technologies on Ether.

12:30 PM - 01:30 PM Lunch with "unconference" (open microphone)

Munch your lunch and network with your peers. Open stage microphone for anybody to speak out, to make a short presentation, to talk about whatever they like - e.g. what they are working on (or what they would like to work on), what others are doing, what partners and collaborators they are looking for, what they deem important issues, etc. http://medicine20.crowdvine.com/posts/4815231

01:30 PM - 03:00 PM - Auditorium

Topic: Web 2.0 approaches for behaviour change, public health and biosurveillance

Chair: Peter Murray

Marcelo D'Agostino, Pan American Health Organization, Washington DC, United States; Theresa Bernardo, Pan American Health Organization, Washington DC, United States*

Coordinating the International Emergency Response to Influenza A(h1n1) by Combining Social Networking and Traditional Media

Practice

On April 24th 2009 the World Health Organization (WHO) announced an outbreak of Influenza A (H1N1) in both the United States and Mexico. Laboratory confirmation of a virus that had not been previously detected in either humans or pigs immediately raised questions as to its severity, potential for spread and the availability of vaccines or treatment. Mounting a rapid and effective response required collaboration among countries and input from a wide range of disciplinary experts. As the regional office for WHO in the Americas, the Pan American Health Organization (PAHO/WHO) used web conferencing to facilitate real-time communication among the key players, combined with interpretation to overcome language barriers and phone lines for those without ready internet access. One of the challenges was to facilitate virtual meetings among the Ministers of Health throughout the Americas region (the Caribbean, North, Central and South America) so the Ministers could hear first-hand from their counterparts in affected countries in order to formulate their national response. PAHO/WHO already had an installed base for web conferencing at its headquarters in Washington DC and in all of the 35 Member Countries which was used by most of the Ministers, however, some of them asked to participate by phone. Three virtual meeting rooms and three phone lines (one for each of English, French and Spanish) were set up in a physical meeting room. Each phone line was connected to the virtual meeting room of the same language through an internal bridge. All participants could speak in and listen to the language of their choice. Just as in a traditional multi-lingual meeting, the sound was piped into small booths for the interpreters to hear. The interpreters spoke into a microphone that was connected to the appropriate virtual meeting room (and phone line). A similar configuration was used for meetings of technical experts (eg. epidemiologists, emergency operations centers) and to hold press conferences with the media in both English and Spanish. Issues raised and frequently asked questions from all forums formed basis for future action and development of educational materials, including an online course on Influenza A (H1N1). The web became the central repository for daily updates of official data (countries affected, number of cases and deaths, etc.), technical documents and video-recordings of press conferences and interviews. Web traffic increased by a factor of over 600%. Daily reports, epidemiologic reports and press releases were fed into RSS feeds and Twitter. Press conferences were available on YouTube. This was an unprecedented use of social networking to link the global community (governments, press, academia, NGOs, health workers, laboratories, the general population, UN and other international agencies) in multiple ways and languages to respond to an emergency. The use of social networking should be an integral part of emergency preparedness planning.

Cynthia Mei Chew, University of Toronto, Toronto, Canada; Gunther Eysenbach*, University of Toronto, Toronto, Canada*

Pandemics in the Age of Twitter: Content Analysis of “Tweets” During the H1N1 Outbreak

Research

Background: Twitter is an instant micro-blogging service that allows users to post, read, and exchange information and thoughts easily with masses across the globe. In response to the 2009 Influenza A virus subtype H1N1 outbreak (aka "swine flu"), users produced thousands of posts on the subject. Media outlets have claimed that Twitter and other forms of social media have led to the viral distribution of mass misinformation and may be a threat to public health and government initiatives. However, quantifiable evidence of these claims has not been substantiated. Objective: This exploratory project aims to analyze the content of Twitter posts or “tweets” shared during the H1N1 outbreak to determine the types and quality of information that social media users are exchanging in pandemics. Methods: Using the Infovigil system, an emerging infoveillance system, we are continuously identifying and archiving health-related tweets. Between April 28 and May 11, 2009, we archived over 300,000 tweets containing the keywords or hashtags “swine flu”, “swineflu”, or “H1N1”. A random selection of tweets from each hour of each day were coded for content by two raters. A multi-axial coding scheme was created using an iterative process to reflect the range of data. Data analysis consisted of descriptive statistics and univariate analysis of content between days. Non-English posts and reposts (“retweets”) were excluded from the analysis. Results: Preliminary analysis of 400 tweets indicates that news posts were the most common type of information shared (46%) followed by public health education (19.18%) and H1N1-related humour (18.25%). 36.75% of all posts quoted news articles verbatim and provided URLs to the source. Only 7 cases could be identified as possible sources of misinformation. Conclusions: Contrary to anecdotal evidence, misinformation is not rampantly spread via Twitter. Instead, the service is being utilized to distribute news and information from credible sources and almost one of five tweets are of humorous nature. Contrary to some media reports of Twitter fueling an epidemic of misinformation, Twitter can and is already used to quickly disseminate pandemic information to the public. Further analysis of tweets collected during an epidemic will allow us to refine the Infovigil system for twitter-based syndromic surveillance

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Gayatri Singh, All india Institute of Medical Sciences, New Delhi, India; Ambarish Pandey*, All India Institute of Medical Sciences, New Delhi, India; Mansher Singh, All India Institute of Medical Sciences, New Delhi, India; Nivedita Patni, All India Institute of Medical Sciences, New Delhi, India et al.*

Effective Use of Popular Internet Video Broadcast Site Youtube for Dissemination of Information about the Potential Pandemic of H1N1 Influenza

Research

Background: The outbreak of H1N1 influenza in April-May 2009 across different regions of North America has created a significant concern for a pandemic causing panic amongst people. Adequate dissemination of correct information about H1N1 influenza could help in decreasing the disease spread and associated panic in the population. In this study we look into the effective use of popular internet streaming video site YouTube by health organizations (CDC, UN and WHO) as a source of information dissemination for the general population during the peak time of H1NI outbreak in April-May 2009 . Method : Youtube was searched using key words “swine flu “ or “H1N1 influenza” or “influenza “ for videos that have been uploaded in past one month containing pertinent information on prevention, symptoms, treatment or recent update of the disease. The search and screening was done by 2 independent observers and inclusion was done on the basis of mutual agreement. Total viewership, no of days since upload and total duration of the videos that were uploaded by CDC , United nations and WHO and independent users were noted. A qualitative assessment scoring of the videos was done using the scorecard as follows. Each of the following aspect of the video was scored with 1 point and then a total aggregate score was obtained by summation of individual scores . A: Information on symptoms of the disease [Y(1)/N(0)] B. Information on disease prevention [(Y(1)/N(0)] C. Information on treatment of the disease [Y(1)/N(0)] D. Current status update of the disease [(Y(1)/N(0)] E. Counseling to prevent panic because of the disease threat [(Y(1)/N(0)] Total Score : A+B+C+D+E Results: Total no of videos included in the study were 26 (CDC:7 , UN/WHO:10 , independent users : 9). Total duration of CDC, UN/WHO and independent user videos was 34.75 , 43 and 39mins respectively. Total viewership per day for CDC, UN/WHO and independent user videos was 24863 , 26931 and 77770 respectively while the total viewership per video for the same was 248007, 22777 and 31840 respectively. Thus, CDC broadcasted videos had a significantly higher no. of viewership per day and per video as compared to UN/WHO broadcasted (p value<0.05) and independently uploaded video (pvalue<0.05). 30% (n= 6) of the top 20 most viewed videos had relevant information of different aspects of H1N1 influenza that could be considered useful with CDC contributing to majority(n= 4) of it. Mean qualitative assessment scores of CDC videos was significantly higher than that of independent videos (4.42 + 0.53 , 2.3 +1.2 : p value <0.05).Mean Qualitative assessment scores of CDC videos was higher than UN/WHO videos but the difference was not statistically significant (4.42 + 0.53 , 3.67 + 1.2 : p value= 0.06). Thus CDC videos have more comprehensive coverage on different aspects of current H1N1 influenza outbreak and are being used in increasing proportion by the viewers as a source of useful information.

Chen Luo, National Institute of Health Innovation, School of Population Health, University of Auckland, Auckland, New Zealand; Chris Paton*, National Institute of Health Innovation, School of Population Health, University of Auckland, Auckland, New Zealand; Robyn Whittaker*, Clinical Trials Research Unit, School of Population Health, University of Auckland, Auckland, New Zealand*

Facebook: An Innovative Influenza Pandemic Early Warning System

Research

Background: The common influenza virus imposes global monetary and productivity costs and cause mortality among the vulnerable. Novel influenza viruses like H5N1 can spread rapidly in an increasingly globalized world. Surveillance is crucial to identify and effectively contain outbreaks. In most developed countries traditional sentinel monitoring with virological sampling has a 1-2 week reporting lag. Developing countries are less well co-ordinated. Facebook an online social networking site with 175 million users worldwide has great potential as a global real-time pandemic early warning system. Objective: To conduct a pilot study on the effectiveness of Facebook as an influenza pandemic early warning system. Methods: A comprehensive literature search was performed using MEDLINE, ISI Web of Knowledge, INSPEC, SCOPUS and other relevant databases. Non-published works were searched using Google and Google Blog Search. Separate literature searches were performed for a suitable influenza case definition. No published literature has assessed the use of online social networks in disease outbreaks. However our search identified Gripenet, a European-wide initiative assessing real-time influenza surveillance of volunteers though a website using email notifications. Weaknesses of this type of system include: low participation, participation reliant on traditional media and a complicated case definition for influenza. A participant is defined as having influenza-like-illness (ILI) if they have had fever, cough and fatigue in the past week. This case definition by Thursky was chosen of its simplicity, fair sensitivity (43.5-75.1%), specificity (46.6-80.3%) and positive predictive value (23.3-59.7%). The Influenza Tracking Project (ITP), a Facebook application was built using PHP and MYSQL. Enrolment requires an initial demographic questionnaire and informed consent. Subsequently, participants receive weekly email reminders to complete a short 15 seconds questionnaire asking: in the past week have you had fever, cough, fatigue or none of the symptoms. On submission of the questionnaire, participant IP addresses are automatically collected and are translated by geolocation software identifying the city where the participant assessed Facebook. The ratio of the number of participants with ILI divided by the number of participants without ILI symptoms will be used to compare cities and countries. The resulting data will be displayed on a colour coded geographical map showing the severity of outbreaks of ILI. This ratio will be compared across time and against different cities or countries. External recruitment of participants are from traditional (newspaper, radio and TV) and non-traditional (blogs, website) sources. Internal growth will be maintained using Facebook features of "newsfeeds", "invitations" and "profile badges". These are Facebook equivalent of real world methods of social persuasion or "word of mouth", driving an organic participation growth. Results: The ITP has completed beta testing with 97 total users with a median of 8 days between filled weekly questionnaires. We expect 300-500 total users by the time of the Medicine 2.0 conference with full results and analysis.

01:30 PM - 03:00 PM - CR2

Topic: Consumer empowerment, patient-physician relationship, and sociotechnical issues

Chair: Donald Juzwishin

Paula Hucko, HSAGlobal, Mississauga, Canada; Mark Smith*, HSAGlobal, Auckland, New Zealand*

Social Healthcare Networks - Leveraging Social Networking Technologies and Approaches to Connect Patients and Clinicians

Business

A number of key market trends create a “perfect storm” for a ground shift in the way that healthcare is delivered to the global population. These include global growth in the 65+ age group; increased prevalence of chronic disease; growth of the middle class; severe healthcare workforce shortages; decrease in family support networks; and the increasing financial burden of healthcare for governments. As well, an increasing number of countries now have more mobile phones than people. At a global level, around 80% of the world's population enjoyed mobile phone coverage as of 2006. This is projected to increase to 90% by the year 2010. International health studies show people with long-term conditions who have direct, self-managed interactions with their own care plan are more likely to sustain their adherence to interventions. There is a huge potential in utilizing social networking, mobile phones and other social networking technologies to facilitate better self-management. This confluence of a growing patient base with increasingly sophisticated and ubiquitous social networking provides the healthcare industry with an opportunity to deliver those improved outcomes on a global scale. This presentation will cover three major areas: 1. Text messaging as a clinical intervention – HME-STOMP as an example. The use of text messaging in the healthcare industry has become increasingly commonplace. SMS messages are now a well-accepted means of communication between patients and care organizations. For example, the National Health Service in the United Kingdom has piloted the use of SMS for sending outpatient appointment reminders to patients' mobile phones and to inform bank nurses of shift availability. HME - STOMP (Healthphone Messaging Engine - Stop Smoking Over Mobile Phone), is an SMS text message-based smoking cessation service based on published clinical research conducted by the Clinical Trials Research Unit at the University Of Auckland, New Zealand. This research showed that an SMS-based intervention can double the success rate of smokers trying to quit. 2. The need for a Software-as-a-Service business model for healthcare that incorporates social networks, mobility and wireless services at the grass roots, removing the barriers to entry for smaller organizations and individuals. This model allows applications to be delivered to healthcare providers with less upfront investment and cycle time to implement than traditional IT. There are numerous examples of this in the prevalence of free hosted blog services such as Wordpress.com, MySpace etc and also examples in healthcare such as Microsoft's Healthvault. Mobile phones are the ideal health improvement tool: portable, accessible, and personal. Targeted personal information and support can be delivered directly to a person's mobile. 3. Joining the dots - Public Health Impact = Efficacy x Reach In healthcare there is often a tradeoff between the frequency of interaction and the cost of delivery. We believe that leveraging social networking technologies and approaches in connecting patients and clinicians represents a viable and effective way to achieve significant positive health impact. Using social networking technologies, appropriate clinical interventions can be delivered at relatively low costs to huge populations and social segments.

Aditya Damle, CEO, MEDgle Inc., Sunnyvale, United States; Francisco Jose Grajales Iii, Medical Informatician, MEDgle Inc., Sunnyvale, United States*

Enabling Semantic Health Apps: The MEDgle Clinical Decision Support Service Api

Business

Semantic Web (Web 3.0) evaluates informational relationships to understand user queries. In a medical context, patients can browse for symptoms, diagnostic tests, procedures, or drugs to understand their medical options and risk for disease. This is MEDgle; a series of semantic algorithms with over fifty million medical-concept relationships aimed at increasing access to quality medical information in eight languages. On January 14th, 2009, MEDgle released its clinical decision support service application-programming interface (API). With applications in m-health, personal health records, electronic medical records, patient empowerment, education, and public e-health, it allows programmers and users to leverage semantic health apps for an almost unlimited number of purposes. This presentation will host a series of applications for the MEDgle semantic decision support API, including: 1. Healthiermee – a facebook compatible health social application that helps users understand the relationship between activity levels and risk for chronic disease; 2. eNurse Kim – a bot nurse that helps patients through a process where they can understand their medical options; 3. HelloHealth EMR – the Myca electronic medical record, featuring decision support that compliments physician's medical knowledge though an interactive, participatory patient dialog; 4. Public eHealth Triage – a demo of a call centre implementation of clinician mediated patient decision support; 5. Futuristic implementations – A demonstration by the New Media Medicine Department of the MIT Media Lab will reveal the teaching and research applications of our semantic algorithms.

Trevor D Van Mierlo, Evolution Health (formerly V-CC Systems), Toronto/ San Francisco, Canada; Rachel Fournier, Evolution Health, Toronto/ San Francisco, Canada; Breanne John, Evolution Health, Toronto, Canada*

Good Intentions and Bad Investments: EHealth and the Reality of Market Forces

Business

Introduction: Eysenbach's well-cited Law of Attrition was the first peer-reviewed journal article that effectively captured the phenomenon of users dropping out of controlled trials. Moreover, attrition permeates all areas of Web 2.0 technology and is not exclusive to controlled trials. Other ongoing challenges include sustaining search engine rankings, competitive IP and software platforms, program conversion rates, and investor confidence. For eHealth programs to be successful, overcoming diminishing returns requires a consistent refueling of reinvention, reinvestment and capitalization. Objective: This presentation is designed to assist researchers, inventors, entrepreneurs and investors by illustrating real-world examples of potential roadblocks and strategies for overcoming them when working in the field of eHealth. Background: For over nine years Evolution Health (formerly V-CC Systems Inc.) has built, maintained, and promoted Internet-based brief interventions, CBT programs and social networks for governments, pharmaceutical companies, non-profit organizations, universities, insurance companies and health plans. While the majority of experience has been in Canada, the United States and the United Kingdom, the company has recently expanded its reach to Japan, Brazil and Argentina. Through real-world examples, this presentation will underscore the need for projects and enterprises to embrace technical design principles, expandable software platforms and effective promotion. Discussion: The vast majority of failed projects are the result of misallocation of budgets and lack of realistic planning, or what the company refers to as Internet Math. Conversely, successful long-term projects begin with a realistic understanding of ongoing investment. eHealth programs, while never perfect, are only effective if they are current, maintained, upgraded and promoted. Programs that are statistically effective at time of publication are often rendered ineffective when converted to a non-academic environment due to their inability to compete in the marketplace. Conclusions: While there are financial barriers to entering the field of eHealth, there is still much promise for patient researchers, inventors, entrepreneurs and investors. However, these stakeholders should be prepared to navigate time-consuming costs surrounding development, launch, ongoing upgrades, maintenance and legal fees. Sales cycles for business-to-business models are long and the vast majority of business-to-consumer models have failed. If eHealth programs are to reach their potential and augment the traditional delivery of health care services, an increase in government funding and ongoing partnerships between vendors and research institutions is required.

Mark Fam, Deloitte, Toronto, Canada*

Health Care Consumerism – Understanding the Behaviours That Will Impact Health System Design

Business

Consumer-driven services in business and the need for efficiency are accelerating changes in the way organizations operate. Many consumers today are taking greater control of their purchasing power and healthcare decisions and are demanding excellence in service. The challenge is how to give them the best service in a meaningful and economic way. First, however, we must understand consumer attitudes, motivations and behaviours. The session will explore how consumerism is emerging as a trend globally and across Canada, with specific insights into consumer perspectives on Ontario's hospitals and health system, their own self-care and wellness management, traditional medical treatments, use of alternative therapies, and positions on health policy reform. A survey of Canadians was conducted to better understand the perspectives of public and patients as healthcare consumers. This research provides an important and timely perspective on the Canadian public and patients as healthcare 'consumers'. Through a comprehensive assessment of consumers' behaviours, attitudes and unmet needs related to health and healthcare, the study identifies implications for health providers and policymakers as they face the growth of health consumerism. A conceptual framework was used, reflecting the six major domains of healthcare consumer activity: use of traditional health services from medical professionals and hospitals, use of alternative and non-conventional approaches to care, self-directed care, information seeking, financing and health policy reform. Using statistical analysis, an examination of the choices made or anticipated by health consumers is compared for their impact on health providers and policymakers. Consumers' experiences with doctors, hospitals, prescription drugs and other healthcare services form the basis for their attitudes and beliefs about how the system performs and which areas might need to be improved. Preliminary research indicates consumers' attitudes are derived from personal experiences rather than a "studied" view of the system, and vary widely as a result. Given the variation in consumers' behaviours and attitudes, findings suggest a tailored approach to key segments of Canadian health consumers is needed. Findings suggest healthcare consumers want improved service, personalized programs and demonstrated results. This transition from a patient-orientation to a consumer-orientation has far-reaching implications for all stakeholders in the Canadian healthcare system, pointing to a needed focus on delivering the convergence of quality, service delivery and cost. Health consumerism is emerging as an important trend in Canada, and this is expected to grow. The demands that consumerism will place on the healthcare system are only starting to be understood, but clearly present a new set of challenges and opportunities for Canadian health providers, governments and policymakers.

01:30 PM - 03:00 PM - CR3

Topic: Building virtual communities and social networking applications for patients and consumers

Chair: Lisette van Gemert-Pijnen

Inmaculada Grau, Hospital Clinic de Barcelona, Barcelona, Spain; Francisco J Grajales Iii, eHealth Strategy Office, University of British Columbia Faculty of Medicine, Vancouver, Canada; Joan Gene, Consorci d'Atenció Primària de Salut de l'Eixample, Barcelona, Spain; Miquel Bernardo, Hospital Clinic de Barcelona, Barcelona, Spain et al.

Success in Virtual Clinics for Hispanics: Lessons Learned from Forumclinic Users

Practice

Forumclinc (www.forumclinic.org) is an interactive e-public health program in Spanish and Catalan for patients living with chronic diseases. Conceived and developed in 2007, Forumclinic provides high quality; evidence-based, unbiased information transcribed in lay language through a set of audiovisual materials and moderated forums for schizophrenia, diabetes, COPD, cardiac ischemia, breast cancer, depression, metabolic syndrome, bipolar disorder, arthritis, and obesity. Chronic disease audiovisual materials are culturally sensitive to Hispanic and Catalan audiences separately, and available both via web or DVD. During 2008, forumclinic received over 459 000 unique web visits and distributed 195 000+ DVDs. Presently, its web audience is doubling each trimester, with half of web visitors from the Americas. We believe that there are a number of unique properties that have allowed forumclinc's success and user engagement. These include: 1) disease-specific board-certified moderators; 2) clinician continuity of care from the bedside to e-home care; and 3) multi-stakeholders forum openness (i.e. patients, family members and friends). This presentation will provide an overview of the lessons learned in the engagement of Hispanic and Catalan audiences, from inauguration to present developments. Forumclinic's user-set, as a public health program, e-learning clinic, and virtual community will also be discussed. Particular attention will be placed on moderator engagement, sociodemographics and user geographical location.

Robert David Murray, Centre for Addiction and Mental Health, Toronto, Canada*

Betting on the Net: The Development of Www.ProblemGambling.ca

Practice

[Note: This presentation (poster) is a companion presentation to the one being delivered by Chris Tysiaczny entitled “Professional Portal to Client Portal – The Evolution of ProblemGambling.ca”] Ontario has experienced an unprecedented expansion of gambling opportunities over the past period of time. Since Ontario’s first permanent casino was opened in Windsor in 1994, 28 permanent casino operations have opened throughout the province and approximately 83% of Ontarians gamble in some form or another. According to the Canadian Gaming Association, during the past 14 years gambling has grown by 235% in Canada to more than $15 billion annually. This figure does not include informal and illegal forms of gambling, as well as the huge amount of gambling done via the internet. Gambling is also a major public health problem. Research has shown that the prevalence rate of moderate and severe problem gambling in Ontario adults is estimated to be 3.4%. Translated into real numbers, that means that 253,857 people in Ontario experience moderate problems with gambling and 78,110 experience severe problems with gambling. And people with moderate to severe problems with gambling produce 35% of the revenue that Ontario generates from gambling. Problem gambling is also linked to a host of public health and social issues, including financial debt/bankruptcy, crime, suicide, intimate partner violence, child abandonment/neglect and various psychiatric comorbidities. Unfortunately only a small minority of people affected by problem gambling seek treatment. ProblemGambling.ca is an online resource designed to support Ontario’s specialized problem gambling treatment system, to build awareness and helping capacity within a broad range of helping professionals and to educate the general public. It is home to a comprehensive range of resources, including online training, guides for helping professionals such as physicians and financial counselors, as well as information and self-help tools for people affected by problem gambling. It also hosts a wealth of resources developed by community partners committed to reducing the harm caused by problem gambling that focuses on a number of specific populations including women, youth, older adults, and aboriginal people. In a relatively short time ProblemGambling.ca has become an international destination for information about problem gambling and is now one of the most popular sites of its kind in the world. This presentation will discuss the goals and objectives of the website, the online resources and services that have been developed, our measures of success and future directions. Robert Murray, MSW, I.C.A.D.C. Robert is Manager of the “Problem Gambling Project” at the Centre for Addiction and Mental Health in Ontario, Canada. This program is an important component of Ontario’s problem gambling strategy and is devoted to providing specialized problem gambling training and resources to the province’s specialized treatment providers, allied professionals and the general public.

Chris Tysiaczny, CAMH, Toronto, Canada*

Professional Portal to Client Portal – The Evolution of ProblemGambling.ca

Practice

ProblemGambling.ca is Ontario’s foremost online resource for the province’s specialized treatment providers and allied professionals working with problem gamblers. The site is an initiative of the “Problem Gambling Project” at the Centre for Addiction and Mental Health in Ontario, Canada, which is an important component of Ontario’s problem gambling strategy. The web site was first launched in 2006 offering information and tools for professionals and the public. In March of 2008 the site was relaunched as a portal site based on the Microsoft SharePoint Enterprise Portal platform. The site included a restricted electronic community of practice for the Problem Gambling Treatment System (PGTS) of Ontario. In anticipation of expansion, the site was recently redesigned to support additional communities of practice, and better serve multiple audiences including researchers, clients and the general public. This included the addition of new Web 2.0 capacity including the potential use of blogs, wikis, surveys, quizzes, polls, and enhanced calendar and discussion board capabilities. The site has also launched a successful series of webinars and plans to introduce podcasts and other streaming media. However, the biggest challenges lie ahead. The next step in the evolution of the site is the addition of new online services for those with concerns about their own gambling, or who are actively seeking help. Initially, this would likely take the form of an anonymous peer support site where individuals can confidentially reach out to each other with their stories, questions, and advice. This might also include the involvement of a problem gambling therapist offering general advice and answering general questions. Subsequently, the intent is to move from anonymous peer support, to more direct provision of online therapeutic services. This presentation will focus on the challenges of evolving the site from primarily an informational site, through the development of communities of practice, and ultimately to the provision of support and services for clients. This will include: • The technological issues and challenges including the use of the SharePoint Enterprise Portal platform. • Our experiences and plans in the use of Web 2.0 strategies and technologies. • The unique policy, legal, privacy and process issues surrounding the provision of client facing services. Chris Tysiaczny, M.B.A., CMC Chris is the Manager, Web and Portal Technology at the Centre for Addiction and Mental Health in Ontario, Canada. Chris is a certified management consultant with over 15 years experience in the strategic use of the Internet, usability, user experience and user centred design.

03:30 PM - 04:30 PM - Auditorium

Topic: Health information on the web: Supply and Demand

Chair: Gary Schwitzer

Gary Schwitzer, Publisher, HealthNewsReview.org, St. Paul, MN, United States; David Henry*, Institute for Clinical Evaluative Sciences, Toronto, Canada; Alan Cassels*, Media Doctor Canada, Victoria, Canada*

Panel: Online Grading of Health News Reporting: >2,500 Stories in 3 Countries

Practice

Australian, Canadian and U.S. teams have been using the Web to post evaluations and grades on health news coverage for the past several years. This is an attempt not only to improve health journalism itself, but to improve the accuracy, balance and completeness of information that flows to news consumers and health care consumers. This panel will reflect on what's been observed and what's been learned after the combined review of more than 2,500 stories in the three countries. The founding publishers of HealthNewsReview.org (US), Media Doctor Australia and Media Doctor Canada will present.

04:30 PM - 05:00 PM - Auditorium

Topic: Building virtual communities and social networking applications for health professionals

Pat Rich, Canadian Medical Association, Ottawa, Canada*

Asklepios and Mydoctor.ca: Innovations for Canadian Doctors and Patients

Practice

An overview on how the CMA is using new social networking and online tools to enhance both patient care and physician interaction. A year ago, the CMA launched Asklepios, a social networking site for Canadian physicians, medical students and residents. The site now has 3000 members and this presentation provides an update on experiences with the site to-date. An update will also be provided on the CMA's mydoctor.ca portal aimed at helping physicians and patients work together to manage chronic diseases online, with specific focus on a new diabetes management tool.

03:30 PM - 05:00 PM - CR2

Topic: Consumer empowerment, patient-physician relationship, and sociotechnical issues

Chair: Kevin Clauson

Alex Savic, ALENSA AG, Zurich, Switzerland*

Transformational Internet Technologies for Pharmacies

Business

The Internet has had a positive transformational effect across many industries including banking, travel and consumer goods retail. It is now also finding its way into the healthcare system, with many 'eHealth' services gaining traction in recent years. However there is an important node in the eHealth network, the pharmacy, that is only just starting to undergo the necessary technological and business model changes that are required for it to become an effective contributor to the eHealth network. Whilst most pharmacies limit their use of PCs to electronic stock keeping and registering sales, the potential of new internet technologies to improve the way pharmacies operate is tremendous. What is lacking seems not to be a lack of motivation on the part of pharmacies, but instead a lack of awareness of the possibilities. In exploring the main avenues for improvement, the following approaches appear most relevant : - Adopting electronic medical records and electronic prescriptions - Providing web access for patients to manage their prescriptions online - Conducting online patient consultation/support (telemepharmacy) - Increasing use of e-commerce - Communicating with customers through social media This presentation examines some of the best-practice suggestions in each of these five areas and seeks out the solutions which are both cost-effective, easy to implement and deliver the best patient outcomes.

David Hale, National Library of Medicine, Bethesda, United States; Mike Kirkwood, Polka, Berkley, United States*

Pillbox: Enhancing Patient Safety through a Mashup of Government Data, High-Resolution Imaging and Analysis, and Community-Developed Tools

Business

Medication identification is a key component in mitigating the 1.5 million adverse drug events which occur annually in the United States. Poison control centers receive over 500,000 medication identification calls annually. An IOM study reported that doctors and pharmacists can correctly identify pills no more than one-third of the time. While a variety of electronic databases exist to assist in the identification of unknown medications, quality standards for images of solid-dosage medications do not exist. Further complications arise from the lack of interoperability between pharmaceutical information systems at various federal agencies. The National Library of Medicine (NLM), at the National Institutes of Health, is leading an inter-agency patient safety initiative involving the development of a public domain library of high-resolution macro images of solid-dosage pharmaceuticals. Advanced image processing and analysis using open source software developed at the NLM creates a unique physical characteristic profiles for every pharmaceutical imaged. The focal point of this initiative is Pillbox, an application which mashes pharmaceutical data from the FDA, NLM, and image analysis, enabling rapid identification of unknowns and creating connections across various federal pharmaceutical information databases. Pillbox's UI is built on Adobe Flex, which allows a platform-independent rich user experience, based on user profiles generated through ethnographic field study in a variety of modalities. A long-term goal of the project is automated identification of unknowns, based on an image taken with a mobile device. All data generated from Pillbox (including high-resolution macro images and image analysis/search UI code) will be placed in the public domain. NLM will present the project and schema, and demonstrate the identification system. Through dialogue with the health information technology community, NLM seeks to facilitate development of applications based on the data, images, and software. Areas of innovation currently being explored include emergency response, disaster relief, clinical practice, anti-counterfeiting, and citizen use. Polka, a mobile health company, while participating in a community workshop where Pillbox was presented, saw the opportunity to build upon this data. After the workshop, Polka set about describing a consumer application for the NLM data and a lightweight framework to leverage high resolution images and profiles for next generation mobile and web pill search and quality information delivery. In this demonstration, Polka will show examples of how visual recognition of a medication can have profound impact on the experience for the user in tracking their regimen accurately and easily. Mobile devices, in the hands of patients and providers, can assist in real-time identification during emergencies, as these applications become adopted in consumer and clinical environments simultaneously. Personal health observations have increased utility when they have a backbone of data quality and precision. Polka is exploring submitting this application as a component of a project for Project Health Design to further explore leverage points and opportunities to allow others to fund commercialization where appropriate.

Grazia Orizio, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia , Brescia, Italy; Sara Rubinelli, Institute of Communication and Health – University of Lugano, Lugano, Switzerland; Peter Schulz, Institute of Communication and Health – University of Lugano, Lugano, Switzerland; Serena Domenighini, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia, Brescia, Italy et al.*

Persuasion Strategies of Online Pharmacies: How the Web Transforms Patients into Consumers

Research

Introduction: Online Pharmacies (OPs) are recognized as a threat to public health by FDA and WHO, as they pose a risk to consumers. Indeed, it is difficult to determine whether drugs purchased online might be counterfeit, unapproved or illegal. Moreover, OPs often provide drugs without a prescription. Despite the efforts by health authorities to regulate the selling of drugs over the internet, the global dimension of the web makes it difficult to control the phenomenon of drug selling. Objectives: Drawing from the field of argumentation theory and persuasion research, this paper investigates the strategies of communication that OPs adopt to market their drugs. Method: The sample frame of OPs analyzed comprises 175 OPs selected using the Google search engine and coded using an ad hoc Codebook according to the Content Analysis method. Results: Regarding prescription requirements, 39 (22.3%) OPs asked for a medical prescription (prescription OPs, POPs) and the remaining 136 Ops (77.7%) did not ask for a medical prescription (non-prescription OPs, nPOPs). 87.2% of POPs declared their physical location, compared with 23.5% of nPOPs (p= .000). Regarding sales promotion strategies almost all pharmacies provided privacy reassurances, about safe use of personal data, and delivery in a plain package. Concerning prices, 96 (54.9%) stressed the lower prices in comparison with “bricks and mortar” pharmacies, 84 (48.0%) offered the chance to become a member of the web pharmacy in order to gain a bonus, 78 OPs (44.6%) used sales arguments encouraging customers to buy more to pay less, 72 (41.1%) offered free delivery. Among the reassurances regarding the quality of service we found the opportunity to check the orders in 77 OPs (44.0%), and testimonials by people who had already bought online in 61 cases (34.9%). Statements about drug quality existed in 124 OPs (70.9%) and reassurance that buying on the web is legal in 58 OPs (33.0%). The selling arguments regarding not having to undergo a doctor’s examination and avoiding costs, queues and embarrassment were present in 84 of nPOPs (61.8%). In about one third of OPs no side effects were declared for the most sold drugs. Regarding quality markers, they were found in 23 (13.1%) out of the 175 OPs. They were significantly more present in POPs than in nPOPs (p=0.000). Conclusion: The core issue is that online drugs are advertised in an argumentative fashion: while navigating on these websites consumers are more or less implicitly invited to buy a certain drug through a set of unequivocal arguments that justify the purchase itself. These ‘selling arguments’ play on aspects which are far removed from the intrinsic characteristics of the drugs in terms of benefits and side-effects. This strategy of persuasion results in a critical gap between the information that consumers should receive to make informed health decision and the actual pieces of information that they get. Considering that there is no international legislation regulating the existence of virtual pharmacies, it is reasonable to think that consumer education can, in fact, be in the long run the winning plan to limit the size of online trade of pharmaceutical products.

Christine Thoer, University of Quebec in Montreal, Montreal, Canada*

Internet: a Resource for Young Adults who Use Prescription Drugs for Recreation

Research

The increase in recreational use of prescription drugs and OTCs is becoming a serious public health issue among adolescents and young adults. The use and abuse of medication to get high or increase mental performance is on the rise. The Internet is a major source of information on pharmaceutical and recreational drugs and a means to access pharmaceuticals with or without a prescription. Studies show that Internet-based information on psychoactive substances can affect their use by young adults and adolescents. The objective of the present study was to analyze interactions on an online discussion forum within a community of ravers. We identified the pharmaceutical drugs participants discussed in the forum and the type of information shared. We also tried to understand how participants viewed, used, and determined what they considered to be a valuable expertise when it comes to drug diversion and abuse. We conducted a non participant observation of a forum within a community of Canadian ravers. We analyzed 10 threads of discussion focusing on prescription drugs. We also conducted online interviews with the forum administrator who is very active within the rave scene and developped this forum, in order to understand why the forum was created. We found that the forum provides information on prescription and non prescription drugs that can be used for recreation. Users exchange information on access to these pharmaceuticals, both online and offline, validation of the right product; and how to best use these pharmaceutical (the right dose, interesting interactions, strategies to maximize the effects, etc.) and prevent non-desired side effects. Ethnographic data from the forum indicate that biomedical knowledge is highly considered. However, users ignore traditional experts (MDs, nurses, pharmacists) unless they are relatives with whom they exchange on an informal basis on prescription drug effects and side effects. Science students with drug-diverted experience also emerge within the forum as valuable experts. Pharmaceuticals are described as stronger, and more accessible and secure than illegal recreational drugs. The forum is a place to share experience-based and biomedical knowledge on prescription and non prescription drugs. While scientific knowledge and pharmaceutical technology is highly considered, participants show a clear preference for “warm experts,” i.e. individuals who have access to biomedical knowledge but are closer to them because they are relatives or within the same age group. More research is needed to better identify these experts. Opportunities for online prevention interventions are discussed.

03:30 PM - 05:00 PM - CR3

Topic: Public (e-)health, population health technologies, surveillance

Chair: Matic Meglic

Michele Giacobazzi, Università della Svizzera Italiana, Lugano, Switzerland; Luca Camerini, Università della Svizzera Italiana, Lugano, Switzerland; Sara Rubinelli, Università della Svizzera Italiana, Lugano, Switzerland; Marco Boneschi*, Università della Svizzera Italiana, Lugano, Switzerland et al.*

Design and Implementation of a Web-based Tailored Gymnasium to Enhance Self-management of Fibromyalgia

Research

Background: This paper describes the design and development of an online gymnasium that proposes personalized exercise videos to users affected by fibromyalgia. Fibromyalgia syndrome is a chronic condition characterized by widespread pain in muscles, ligaments and tendons, usually associated with sleep disorders and fatigue. Physical exercise is considered as an important component of non-pharmacological treatments of this pathology and internet is praised as a powerful resource to promote and improve physical exercise. Yet, while online personalization of health interventions to consumers must be grounded on empirically based guidelines, guidelines for fibromyalgia-targeted exercises are scanty. Objective: Our objective was to create an online application that could select and display to users affected by fibromyalgia exercise videos that best fit their personal needs and preferences. More specifically we intended, firstly, to define the variables that are needed to personalize the exercise videos and, secondly, to design an appropriate technological framework based on these variables. Methods: The investigation of the variables was grounded on previous research on fibromyalgia and focused on the general characteristics of the syndrome, its management strategies and existing indications. Alongside this review, we collected original data through interviews with a team of experts and patients, where we applied the technique of ‘knowledge acquisition’. The general framework of the program is a revised version of the ‘tailoring’ approach proposed by Kreuter and colleagues (2000). Results: The achievements presented in this paper are twofold. Firstly, we illustrate how we reached definition of the relevant factors for tailoring exercise videos in relation to fibromyalgia. For reasons that will be clarified in the paper, eight variables were included in the application’s extraction algorithms, namely: the available time, the level of pain, the time of day (predictor of the level of fatigue), the available training tools, the localization of the pain, the preferred level of difficulty, the previous experiences with the application and the judgments formerly expressed by the user. Secondly, we explain the general framework of the application that is composed by an assessment module (that investigates the determinant values of a specific user), a feedback module (presenting the tailored set of exercises) and a tracking component (used to monitor users’ interactions with the website). The personalized sets of exercises are automatically retrieved through a set of algorithms that will be illustrated and discussed. These algorithms use the data retrieved from the assessment module and from previous uses of the site in order to rank the available exercises according to their relevance to a specific user’s conditions and needs. Exercises are then extracted according to their category of belonging (e.g. relaxation, mobilization and so forth). The distribution in categories is influenced by the moment of the day when the exercise is performed and the level of pain of the patient. Conclusions: This study led to the definition of relevant determinants and to the implementation of an algorithm to tailor physical exercises to fibromyalgia affected patients. However, the knowledge acquisition approach does not guarantee exhaustiveness in the identification of this variables; moreover, although we collected preliminary data from the use of the tool, a comprehensive evaluation is still missing.

Robyn Whittaker, University of Auckland, Auckland, New Zealand*

STUB IT: an RCT of a multimedia mobile phone smoking cessation intervention

Research

Background: While most young adults who smoke say they want to quit, few access cessation support services. Based on a previous successful text messaging smoking cessation intervention, we hypothesized that a multimedia mobile phone programme that utilises observational learning (from social cognitive theory) could help young adult smokers to quit smoking. Objective: To develop and test a multimedia smoking cessation intervention delivered solely by mobile phone. Methods: A role modelling intervention was developed by an expert group based on the principles of youth development, social cognitive theory, effective smoking cessation interventions, and social marketing. Over 240 young people participated in its development via focus groups, an online survey, content pre-testing, and a pilot study. The intervention involves a programme of short ‘video diary’ messages from a young quitter to participants’ phones. Participants select from seven role models and can change role models during the programme. Participants select their Quit Day and receive two messages/day for six weeks, including video diary messages, text messages and animations. The messages then reduce in frequency to a total of six months. Participants are able to request extra messages on demand to deal with cravings or lapses. An IT system was developed for message scheduling and delivery, and data collection by self-completed web-based forms. Results: Development phase findings included the importance of

selecting ‘real’ and honest role models with believable stories. Fifteen people joined the 4-week pilot study - twelve participants liked the programme, eight used the extra assistance for cravings and nine were happy with the regimen of two messages/day. Nine participants (60%) stopped smoking during the programme. Recruitment for a large randomised controlled trial took place during 2008 to early 2009 via radio and internet advertising targeted at young adults. Recruitment was more difficult than expected with many extra methods tried at intervals resulting in 225 participants. Approximately 24% of participants were Maori (indigenous population of New Zealand), and 45% of participants earned less than NZ$30,001pa. Around 14% of participants requested extra messages for cravings and 8% for lapses. There were some technological issues, mainly affecting data collection rather than delivery of the programme, which were exacerbated by difficulties in detecting them in a timely manner. Preliminary results will be available for presentation at the conference (not currently available). Conclusions: Recruitment into this mobile phone cessation intervention study was more difficult than expected. It may be that although many young adult smokers say they want to quit, they still do not value the benefits of quitting immediately enough to be prompted to do so by advertising or the attractions of a novel communications technology programme. Findings will be discussed in the presentation.

Amy Mckeown, University College London, London, United Kingdom; Henry W W Potts, University College London, London, United Kingdom*

Computerised Cognitive-behavioural Therapy for Prevention and Early Intervention in Anxiety and Depression: a Case Study of Xanthis

Research

Introduction: Mental health issues such as anxiety and depression are a leading cause of morbidity and a huge public health cost. Prevention and early treatment are effective, but are difficult to deliver in traditional forms to large populations. Internet-delivered approaches, such as computerised CBT (cCBT), appear promising as a cost-effective way of reaching populations for what are sensitive and stigmatised conditions. However, there are challenges to achieving this within a viable financial model. Objective: Explore the use of cCBT in sub-clinical or preventative care, within a work-based delivery model. Method: A realist methodology was adopted for a programme of research as it provides a flexible and pluralistic approach to deconstructing complex interventions. This included: a systematic literature review on cCBT in a preventative context; and data collected around use of Xanthis, a commercial sub-clinical cCBT package. Xanthis was made available to all employees, accessible over the Internet, in three large, UK, public sector organisations: Dyfed-Powys Police, Cardiff University and Oxford University. Its use was tied into Occupational Health/Human Resources policies. User numbers were monitored. Interviews were conducted with purchasers of the package. At Dyfed-Powys Police, a before/after questionnaire was conducted on users. Results: The literature on cCBT in prevention and early treatment is heterogeneous. Five papers specifically considered cCBT in the prevention of depression and anxiety, showing mixed results. There were further papers on cCBT as a community-based, sub-clinical treatment rather than specifically as prevention. These vary in terms of method, cCBT package, population and conditions treated. Outcomes were generally positive. Research was mostly on high risk groups rather than the general population. Terminology and definitions varied between and within papers. Attrition rates remain high in Internet-based spontaneous self help. Xanthis user numbers peaked after launch in all organisations before settling at 5-10% staff. Users find the tool a useful support and like that it is confidential, accessible, increases knowledge and understanding about problems, and links to sources of help. However, there were many problems associated with the implementation and launch of the tool. Different organisations sought to use Xanthis in different ways and in conjunction with other activity. How the tool was promoted internally was critical. Commercialisation was constrained by the resources typically devoted to Occupational Health. Conclusion: cCBT in prevention and early management of mental illness is a new but promising field. Technology offers a new delivery platform for reaching individuals at different illness stages, confidentially and accessibly. cCBT can reduce symptoms in sub-clinical populations, including spontaneous Internet users, but adherence and attrition rates are a challenge. The financing and implementation of sub-clinical cCBT packages must be researched, including determining which are suitable for use in different user populations and circumstances. Packages such as Xanthis have potential for use within sub-clinical care in a variety of contexts, but there are challenges in its commercialisation, delivery and use within a work-based delivery model which must be overcome.

Nienke Nijhof, Partner University, Utrecht, Netherlands; Lisette Van Gemert-pijnen, Partner University, Enschede, Netherlands; Theo De Vries, Professor partner University, Enschede, Netherlands; Nynke De Jong, Technology provider, Zevenaar, Netherlands et al.*

Ambient Assisted Living (AAL) For Dementia Patients And Their Caregivers: Effects On Care Coordination and Monitoring Sleep/Wake Rhythm

Research

Background: The number of people with dementia in the Netherlands is quickly growing. More people with dementia come into the Dutch nursing homes, but less people start working in these nursing homes. The people with dementia in a nursing home have a disturbed sleep/wake rhythm. This can cause very sleepy patients or very nervous patients during day and night. Objectives: To identify the potential for ambient assisted living (AAL) technology for dementia patients and caregivers; in particularly technology for monitoring the sleep/wake rhythm of dementia patients in a nursing home to make interventions for a better sleep/wake rythm and coordination of care possible. Due to these interventions and coordination improve care and realize work savings in the perception of caregivers and actual time savings Methods: A study has been carried out with the IST Vivago Watch to monitor the sleep/wake rhythm in a nursing home for 7 dementia patients for a period of 6 months. The IST Vivago Watch is a wrist worn activity monitoring device, which measures temperature and has a movement sensor particularly sensitive to low intensity movements. Only at the start of the project caregivers filled in validated questionnaires (response rate from 30%) about their work satisfaction (these data hasn't been used in the research because a re-organisation caused bias in the work satisfaction data), acceptance of the technology and some general questions about their education and date of birth. The activity data from the IST Vivago Watch has been analyzed; these data show the periods of sleep and being awake. Finally, based on these analyses several interviews with 5 caregivers and different stakeholders (director and projectleader) were hold, based on the chronic care model. This model says there are six fundamental areas identified that encourages high-quality chronic disease management. Because of the small size of the project most of the research done is qualitative. Results: The results of this IST Vivago Watch project confirm the results from earlier research and also from other studies with the IST Vivago Watch. In these studies the Watch can be assumed to be comparable to actigraphy in sleep/wake studies and gives indication of the overall sleep quality. To our knowledge, our study is the first that evaluates the effects on the coordination of care with the Watch. The caregivers are satisfied with the usability of the Watch. The Watch made it possible to start interventions in quality of life (give the patient a bad just before going to bed), medication (changing time or dose of medication) and sleeptime (let someone sleep longer in the morning). Due to the Watch it became easier to coordinate care during the night and day (see who's awake during the night and visit only these persons, wake up the patient when he had enough sleep etc.) The interventions and coordination of care results in better care (people sleep significant longer and better),work savings and actual time savings (no unnecessary walking, less visits to patients during the night). Conclusion: The IST Vivago Watch make it possible to start interventions and coordinate care better during day and night. This makes it possible to create time savings for caregivers by the perception of caregivers, but also actual time savings due to less unnecessary visits to patients. The Watch also makes better care possible for the patients due to improvements in the sleep/wake rhythm of patients. Further research with the Watch will focus on more quantitative efficiency results with more respondents wearing the Watch. This PhD research in general will focus on effects of technology (registration and social contact technology) for people with dementia and their caregivers as to their quality of life, feeling of safety, work satisfaction and work savings in actual time, money and staff respectively.

Poster Presentations (Foyer) - Thursday

Poster 1

Lisette Van Gemert-Pijnen; Fenne Verhoeven, University of Twente, Netherlands; Ron Hendrix; Michaël Steehouder

From expert-driven to user-oriented communication of infection control guidelines

Background: Currently, infection control protocols are more expert-driven than user-centered. In order to become more usable, protocols should externalize healthcare workers' (HCWs) tacit knowledge, which is context-dependent and made up of practical and experiential wisdom of individual HCWs. Objective:Based on a user-centered design process, we developed a web-based tool that facilitates HCWs with applicable infection control guidelines that enable them to deliver safe health care. Methods: We used a one-group pretest-posttest design. During the pretest, 28 HCWs together performed 141 'what if' scenarios simulating actual use of the paper-based, expert-driven protocol. HCWs' knowledge and skills were detected using the thinking-aloud technique. Based on the findings, we developed a web-based guideline tool and assessed its usability in the posttest. Results: The pretest demonstrated that HCWs faced 293 usability problems while working with expert-driven protocols, due to structure (40), a mismatch between HCWs' and experts' semantics (77), and information quality (176). Qualitative information problems could be attributed to actions or consequences that HCWs knew from daily practice but were not incorporated in the protocol, or information that was too concise to base a safe decision upon. These information problems produced 165 practical key questions that we used to restructure the existing expert-driven guidelines around. To overcome matching and structural problems we communicated the guidelines, comprising both expert-driven and practical information, via a web-based tool equipped with a search engine and index representing HCWs' terminology, and inserted multimedia features to enhance adequate guideline application and prevent incomprehensibility problems (see Figure). The posttest revealed that HCWs encountered fewer matching (66) and information quality (143) problems. However, the amount of structural problems increased (86), caused by the advent of sophisticated electronic healthcare applications that make HCWs nowadays expect to obtain information instantly and dynamically. E.g., our respondents required more hyperlinks to additional sources and more precise results of the search engine.

The user-centered guideline-tool significantly outperformed the expert-driven protocol in both effectiveness (successful scenario-completion increased from 47.5 to 87.9%, p<.001) and efficiency criteria (time spent with scenario dropped from 359 to 134 seconds, p<.001). Conclusions: The user-centered approach provided insights in HCWs' practical thinking and acting which helped to fully adapt the tool to HCWs' needs. This generated a more efficient and effective guideline-tool compared to expert-driven protocols. Moreover, we found that involving HCWs is important to create ownership and to foster the tool's applicability, which eventually might encourage compliance and reduce healthcare-associated infections.

Poster 2

Ryoma Seto, International University of Health and Welfare, Tokyo, Japan; Shigekoto Kaihara, International University of Health and Welfare, Tokyo, Japan*

Information Requirements of Citizens Using Hospital Information Services Provided by Prefectural Governments

Objective: Hospital information services in Japan were established in 2008 in accordance to the Health Service Law with the purpose of providing information to patients to enhance their hospital selection process. Prefectural governments are obligated to provide information to the public regarding hospital functions. However, according to our previous study, these services are not widely available. Seto and Kaihara (2009) found that 27.7% of the respondents, aged 30–50 years and living in metropolitan areas, were aware of the hospital information services, and 89.0% wanted to avail the services. The purpose of this study is to determine the type of information that citizens would like this service to provide. Method: A total of 875 candidates, aged 30–50 years, living in the Tokyo metropolitan and 3 contiguous prefectures, was selected from Research Monitor registered by NTT Resonant and Mitsubishi Research Institute (Goo Research) for the study. The study subjects were well versed in identifying a hospital that met their needs. We excluded single households from the study. We provided the candidates a web-based questionnaire. The questionnaire inquired about the awareness of the hospital information services, willingness to use the service, desirable information resources for selecting hospitals, and information requirements. We performed correspondence analysis to determine frequency. Information requirement queries were based on the search criteria provided by the California Healthcare Foundation. The response rate was 60.2% and 527 candidates responded. Result: Respondents aware of the hospital information service and willing to use it placed importance on the internet and word-of-mouth to search for hospitals and query about MD and RN staffing. Respondents who were not aware of the service but willing to use it placed importance on the internet, word-of-mouth, and books to seek information about wages of MDs, quality of a facility, quality of care, and turnover of MDs and RNs at the facility. Additionally, respondents who were not willing to use the service did not depend on the internet, word-of-mouth, or books to seek such information. Discussion: Our survey results suggest that information requirements regarding hospital services depended significantly on the awareness of the service and willingness to use the service. However, we found that the service did not provide certain information sought by the respondents. The existing service included information on staffing but did not include information on employee satisfaction, including wages and turnover rates. Because employee satisfaction correlates with customer satisfaction, it is natural for respondents to require this information. Conclusion: The hospital information services did not address all of the queries of the citizens willing to avail the services. We therefore recommend providing additional information through the hospital information services.

Poster 3

Umberto Gelatti, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia, Brescia, Italy; Grazia Orizio*, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia (Italy), Brescia, Italy; Caterina Belotti, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia, Brescia, Italy; Sara Rubinelli, Institute of Communication and Health – University of Italian Switzerland, Lugano, Switzerland; Loredana Covolo*, Section of Hygiene Epidemiology and Public Health, Department of Experimental and Applied Medicine – University of Brescia, Brescia, Italy; Luigi Caimi, “Quality and Technology Assessment, Governance and Communication Strategies in Health Systems” Study and Research Centre – University of Brescia, Brescia, Italy; Peter Schulz, Institute of Communication and Health – University of Italian Switzerland, Lugano, Switzerland*

What do Portals for Doctors Offer? A Qualitative Analysis of their Features for the Enrichment of Expert Knowledge

Background: The internet has deeply changed the way people share information, as well as the modalities of health communication both among citizens and health professionals. Great concern has been expressed regarding the quality of health information on the web, whose trustworthiness remains one of the most worrying and complex issues. Nowadays the majority of doctors use the internet to access scientific advances, with unquestionable advantages but even some problems. Indeed, on one hand the rapidity in getting information and its availability 24 hours a day are pointed out as positive features of the web. On the other hand doctors complain about wasting time in their searches: they have difficulties in understanding the best strategy to drive a web-search, and they remark the superficiality of a significant portion of the online content. Objective: To evaluate advantages and limitations in current services targeted to doctors, we conducted a study on the websites which are presented as portals for doctors, and assessed their features in terms of technical characteristics, contents and web 2.0 tools. Methods: The study analyzes portals in English, using the Google and Yahoo search engines through free searches and directories. The selection of the websites is currently ongoing through a scanning of the web; the sample will be explored through a qualitative analysis approach. A codebook was elaborated to investigate five areas: 1) the general orientation of the websites, including their geographical reference; 2) their technical characteristics with a focus on the tools which increase the accessibility of information (e.g. internal research engines and site maps), on transparency systems for checking last updates and counting accesses, and on informatics quality markers and links; 3) website labels, including the mention of managing companies, sponsorships, disclaimers and privacy policy; 4) interactive options such as tools that enhance communication among health professionals and enable them to share experiences about issues of relevance and 5) research and education, in the form of tools to access scientific material on clinical cases and medical events generally. Results: The analysis will provide specific data on doctors’ portals leaders, declared sponsors, transparency, typologies and reliability of contents. Here, particular emphasis will be given to the type of interactivity of the websites as a way to evaluate their role as virtual places to share experiences and ideas, and update expertise in light of the most recent advancements in a given field.

Poster 4

Andrew Creamer, Simmons College Graduate School of Library and Information Science, Cambridge, United States; Myrna Morales*, Simmons College Graduate School of Library and Information Science, Cambridge, United States*

Biomedical Information Evaluation for a Regional E-Science Portal to Support Learning and Collaboration among Health Information Professionals.

Health/Medical Librarians have traditionally focused on the retrieval of information through paper journals and books and their electronic equivalents. However, due to the accessibility and evolvement of the Internet, global collaboration among biomedical researchers has increased and produced large data collections and data sets at an alarming rate. Some information professionals have developed tools for accessing these data. No one entity has taken the opportunity to identify these collections and tools in order to foster information sharing. The New England Region of the National Network of Libraries of Medicine (NN/LM, NER) recognizes the training and one-stop shopping access to resources that will help health/medical professionals support this global collaboration. As a result, a subcontract was awarded to Elaine Martin DA, Director of the Lamar Soutter Library of the University of Massachusetts Medical School in Worcester, MA to create an e-Science portal to facilitate learning and collaboration among librarians. Andrew and I were recruited to this project by Dr. Martin to identify topics and resources that will assist the librarian in his/her training and learning in order to better support biomedical researchers. This poster presentation will document and outline methods by which health information professionals can identify and evaluate resources for an e-Science web portal that will be hosted by a major medical school library website and a regional National Network of Libraries of Medicine website. Using an Evidence-Based approach, Andrew and I will meet with Dr. Martin and the portal’s editorial review board to begin identifying topics and exemplar links, such as NCBI databases and Biotools, which are used by the molecular biology, research scientist community. Understanding that health information evaluation is a primary need on a global scale, it becomes important to document the criterion utilized by seasoned medical/health information professionals. It also becomes important to identify strategies that are efficient and effective for accessing biomedical research information. As the medical/health/molecular biology information field continues to rapidly evolve, traditional methods of identification and evaluation could potentially become more a liability than an asset for a librarian; therefore documenting and outlining innovative, unconventional, yet credible and valuable methods for identification and evaluation is a necessity. How librarians may use a resource that brings the variety of data sets, information seeking tools, and retrieval tools together will also be assessed.

Poster 5

Louise Walker, Centre for Addiction and Mental Health, Toronto, Canada; Tamar Meyer, Centre for Addiction and Mental Health, Toronto, Canada; Virginia Chow, Centre for Addiction and Mental Health, Toronto, Canada; Mary Jean Costello, Centre for Addiction and Mental Health, Toronto, Canada; Peter Selby*, Centre for Addiction and Mental Health, University of Toronto, OTRU, Toronto, Canada*

CAN-ADAPTT - Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-Informed Tobacco Treatment

Only about half of Canadian smokers reported receiving advice from their healthcare provider to quit or reduce the amount they smoke even though evidence shows that brief smoking cessation interventions effectively increase quit rates. The primary objective of the CAN-ADAPTT project is to facilitate knowledge exchange amongst those who are in a position to help smokers make changes to their behaviour (e.g., practitioners, healthcare/service providers) and tobacco control (TC) researchers in order to develop a set of smoking cessation guidelines that would identify and encourage the adoption of best practices in both clinical and community intervention settings. Using a practice based research network model, CAN-ADAPTT members will identify gaps in the current tobacco control practice guidelines and, in key areas, test a variety of cessation interventions at both the individual and population levels. CAN-ADAPTT's practice informed approach positions research to produce results that are clinically relevant, timely and readily useable by those who are in the position to help smokers. Utilizing a wiki platform to support discussion, collaboration and knowledge exchange, research will be translated into a dynamic set practice guidelines. The wiki guideline process is a continuous and prospective exercise where guidelines are updated as new evidence becomes available rather than one that occurs on arbitrarily pre-scheduled review dates. Select members of the network (i.e., Guideline Development Group) will make edits to the guideline content by incorporating new scientific evidence and expert opinion. Outdated or irrelevant recommendations can also be removed or modified to meet the needs of the given context. This iterative process will result in a set of national TC guidelines that will be adaptable as the smoking population changes and new knowledge is developed.

Friday, September 18, 2009

09:00 AM - 10:30 AM - Auditorium

Topic: Building virtual communities and social networking applications for health professionals

Chair: John Sharp

Chris Paton, University of Auckland, Auckland, New Zealand; Malcolm Pollock, University of Auckland, Auckland, New Zealand; Debra Warren, University of Auckland, Auckland, New Zealand*

The New Zealand Health I.T. Knowledge Base

Practice

The National Institute for Health Innovation at the University of Auckland in New Zealand has developed a Web 2.0 Health IT Knowledge base for the New Zealand Ministry of Health. The knowledge base is being developed using the Drupal open source content management platform and uses Web 2.0 tools to facility communication, networking and knowledge sharing in the New Zealand health sector. The website focuses on detailed user profiles of key decision makers and project leaders linked to Wiki documents about the projects the users are involved in. Users can update their profiles, collaborate on Wiki project documents and create blog posts to inform the network about news and updates to their projects. In addition, the site has a discussion forum and social networking capability to allow users to find colleagues with similar interests and generate new ideas and innovations within the sector.

Donald William Moore Juzwishin, JCI, Toronto, Canada*

Building Virtual Communities and Social Networking Applications for Health Care Policy Makers

Practice

Background: Since the emergence of Web 2.0 and Medicine 2.0 virtual communities and social networking applications have been created for health professionals, patients and consumers of health care. As the Internet matures heath care policy makers are beginning to appreciate the opportunity afforded by building a virtual community and social network applications for their purposes. The health care policy making community is defined as anyone who is a health care policy professional in a position of responsibility in a government, organization funding or delivering health care services, a health care policy think tank, health care policy consultant, leader for a health care policy periodical or health care policy researcher. Objective: This paper will identify, describe, inventory and assess the current use of Web 2.0 to advance the health care policy making communities role and responsibility in society. Recommendations for the future development of the virtual community and social networking applications will be presented for discussion. Methods: The policy making community in Canada, United States, Australia, New Zealand, and selected European counties will be surveyed on the Internet to determine what virtual communities and social networking applications have emerged. The goals, role and achievements of the virtual communities and social networking applications will be described and assessed against a set of criteria. Anticipated Results: It is anticipated that this will be the first inventory and classification of relevant blogs, RSS/XML applications, Mashups, video sharing, social bookmarking, and wikis with a focus on health care policy making. The content of the survey will be summarized, analyzed and synthesized to provide insights into the lessons for further advancing future health care policy making social networking applications. Challenges, issues and problems that face the policy community will be highlighted. Conclusions: The health care policy making community can benefit from becoming involved in the Web 2.0 opportunities. Caution is recommended to avoid negative consequences or risks associated with Web 2.0. Recommendations for future development are put forward for discussion.

Carlos A. Rizo, Health Strategy Innovation Cell, Toronto, Canada; Alton Ing, Health Strategy Innovation Cell, Vancouver, Canada; Neil Seeman, Health Strategy Innovation Cell, Toronto, Canada*

”Perfection,” “Micro-Thanks” and “Micro-Ideas”: New Crowd-sourcing Concepts to Improve the Patient Experience and Foster Constructive Deliberation on the Web

Practice

Crowd-sourcing as a model of distributed problem-solving and product generation has been successfully used in the corporate world to harness the innovations of large numbers of customers who seek to improve upon existing or potential products and services. Crowd-sourcing is challenging in part because potential contributors are busy and because building a new user community on the Web is resource- and time-intensive and therefore any new community faces considerable competition for attention from well-established Web communities such as Twitter, MySpace and Facebook. To address these challenges, myhealthinnovation.com (MHI) – a project of the Health Strategy Innovation Cell – introduced the twin concepts of “micro-thanks” and “micro-ideas”: crowd-generated sparks of insight relating to gratitude or to low-cost, low-tech healthcare innovations. Applying Twitter hash-tags, “#micro-thanks” and “#micro-ideas” feed directly to MHI via Twitter. A visitor to MHI can also build upon and comment on a “micro-thanks” or “micro-idea”. MHI was conceived to explore, with the public, the role of “the wisdom of the crowds” to generate healthcare innovations. Any visitor can submit ideas, vote, and build upon ideas submitted by other people or upon ideas found on the Web. Our focus is distinctive: ideas that rise in salience on MHI must be low-cost or no-cost, low-tech or ‘no-tech,’ and be ideas that aim to make the user experience with the healthcare system “perfect”. The word “perfect” is deliberately provocative since the concept of “perfection” is seldom associated with the client experience in healthcare. Drawing on insights from other sectors that have undergone dramatic transformative change to serve client needs, notably the hotel industry and the experience of the Four Seasons chain over the past half century, the hypothesis of the Innovation Cell is that by socializing concepts such as “perfection,” “micro-thanks,” and “micro-ideas”, Websites such as myhealthinnovation can help to promote a culture of ideas-exchange in which the contributions of visitors are constructive rather than critical. To measure Website success, we therefore seek to assess the degree to which contributions build upon, rather than criticize, existing ideas. During our presentation, we will demonstrate myhealthinnovation.com as a simple, transparent and experimental approach to harness the potential of the Web for collaborative healthcare innovations. We will also explain why concepts such as “perfection,” “micro-thanks” and “micro-ideas” are ideas worth socializing in order to inspire constructive deliberation to improve the quality of care delivered by healthcare systems and healthcare providers around the world.

Mark Scrimshire, None, Owings Mills, United States*

We Will All Be Patients Someday - Instigating Health Care Transformation One Community at a Time through HealthCamps

Practice

"We will all be patients someday" - Carlos Rizo (@carlosrizo) Instigating health care transformation one community at a time through HealthCamps In a health care context the 2.0 moniker begs the question "How can we rebuild health care on a participatory model using social media, open standards, open source and the best that the web and mobile internet technologies can offer?" The current HealthCamp initiative is a grass-roots movement that started in 2008. The movement grew out of an obvious interest in the intersection of web 2.0 and health at the Web 2.0 Expo. It re-ignited an idea that first came to light in 2007. HealthCamp sets out to address the health care transformation question. They are accessible to everyone. They are free or low-cost regional events open to all stakeholders (patients, providers, marketers, consultants, designers, students) based on the BarCamp concept that seek to stimulate vital conversations about the transformation of health care that involve everyone - the health care professional, institutions, pharmaceuticals and other commercial organizations, insurers, government, researchers, software developers and entrepreneurs as well as patients and consumers. HealthCamp has caught the attention of communities across the globe. It is a simple idea - 10-200 people meet to discuss topics of interest that are planned on the day of the event - that has empowered a vibrant community of passionate and engaged people that work to improve the "care of health." In this session we will: - Explain the background and objectives of HealthCamps - Provide guidance on how people can join this initiative - Provide a blueprint on how to organize a HealthCamp - Explain how people can create their own successful event by addressing issues such as: * Why hold a HealthCamp? * Embracing the strength of the local community * Leveraging social media tools to engage participants * It is more than just the event - leave a digital footprint * Engage in the wider HealthCamp community * Build on what has gone before * The day of the event - creating the right atmosphere * Finding a location and food, drink sponsors * Creating materials for attendees (buttons, tees, etc) * Building an event page * Talking up the event - using social media * Letting the real and virtual blur together - Examine what the future might hold for HealthCamp? - Explain how HealthCamp is more than just a conversation. It is a call to action.

09:00 AM - 10:30 AM - CR2

Topic: Web2.0-based medical education and learning

Chair: Larry Chu

Kevin A. Clauson, Nova Southeastern University, College of Pharmacy, Palm Beach Gardens, United States; Feroza Sircar-ramsewak, Nova Southeastern University, College of Pharmacy, Palm Beach Gardens, United States; Shine A Joseph, Nova Southeastern University, College of Pharmacy, Palm Beach Gardens, United States; John E Sandars, University of Leeds, School of Medicine, Leeds, United Kingdom*

Web 2.0-mediated Blended Learning: Separating Fact from Fiction

Research

Background: Due to a congruence of generational characteristics and technological capacity, there is a perceived potential to incorporate Web 2.0 technology into health professional education. Unfortunately, no clear guidance exists regarding the development or viability of blended educational initiatives. Objective:

The purpose of this study was to take the first step in addressing the identified knowledge gap by characterizing the knowledge, familiarity, and preferences regarding Web 2.0 tools among student learners. Methods: A 37-item questionnaire was developed by the authors. It consisted of multiple choice and Likert items designed to: 1) assess the use and knowledge of Web 2.0 and social media applications/technology by first year pharmacy students, 2) outline ownership of related hardware (e.g., laptops, smartphones), and 3) characterize perceptions of students towards Web 2.0 and social media. Open-ended attitudinal items were also used to generate qualitative data regarding the integration of Web 2.0 tools into their education. After the survey was modified to integrate feedback from a pilot administration, it was made available online to pharmacy students who attend class via live interactive videoconference from separate campuses. Descriptive statistics were used to summarize the findings of the quantitative data and a systematic thematic analysis was used to explore the qualitative data. Institutional review board approval was secured. Results: One hundred and ninety-seven first year pharmacy students completed the survey for a response rate of 94.9%. Diversity of the respondents was evident as 35.7% self-identified as White (non-Hispanic), 35.7% Hispanic, 19.9% Asian, 3.6% African American, and 5.1% Other. Females comprised the majority of respondents (64.3%) and only 62.8% of all surveyed identified their first or best language as English. The average age of the respondents was 25 years. Regarding awareness and use of Web 2.0 tools, 99.5% of students surveyed used wikis (12.3% contributed), 99.5% read blogs (16.3% contributed), and 86.2% used social networking sites (82.7% Facebook, 30.9% MySpace), whereas only 7% used microblogging applications like Twitter. In fact, approximately one-third of students were completely unfamiliar with social bookmarking (37.5%), microblogging applications (34%), RSS readers/aggregators (31.4%), and collaborative writing tools (26.3%). When asked about integrating Web 2.0 technologies into their courses, 74% reported that it would have a ‘Positive’ or ‘Very positive’ impact on their ability to learn and 67% of students responded that the integration would help them feel ‘Connected’ or ‘Very Connected’. Specific tools that students wanted incorporated into their education included: videosharing (50.2%), computer-based instant messaging (45.6%), podcasts (43.1%), social network sites (35%), and collaborative tools (34%). Conclusion: Aspects of Web 2.0 and social media for blended learning opportunities that appealed to students included enhanced communication and interactivity as well as timely access to information. Barriers identified included the need to develop new skills and competencies, security concerns, and that a digital divide still exists for a minority. However, in searching for ideal ways to capitalize on blended learning opportunities, the main obstacle to be navigated may ultimately be the lack of alignment between student preferences of Web 2.0 tools for personal versus educational purposes.

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Perceptions and Attitudes Toward Virtual-Reality Medical Training: The Ann Myers Medical Centre

Practice

Medical education is a discipline where science, practice and art meet to with one common goal - to improve the quality of life of patients and save lives. Since Socrates and Galen’s time medical professionals have gathered together to interact and share their knowledge and practical experience to become better health professionals. Today, the Social Web has changed how humans interact, think, learn and simulate. Unfortunately however, medical training remains dispersed, often varying significantly even within the same geographical regions. Second Life (SL) is the most prevalent 3-D virtual reality world on the Internet. With over 18 million users and a resident population that logged 124 million user hours during Q1 2009, SL has applications that extend from virtual reality to real-life, particularly in the field of medical education. The Ann Myers Medical Centre (AMMC) is a virtual hospital and collaborating centre founded by Dr. Ann Buchanan to explore real life health professional training using 3-D worlds. Constructed in 2006, the AMMC allows medical personnel from around the world to present clinical cases, interact, comment on novel emerging public health problems (i.e. swine flu) and perform real-life clinical teaching in the form of presentations, medical simulations or grand rounds -all foundations of interdisciplinary medical training. Using an audience response system, presenters and audience members will collectively explore perceptions and attitudes toward virtual-reality medical training, including challenges and barriers. Presenters will also provide a live tour and simulation of a typical “grand rounds teaching session" with the virtual attendance of medical professionals from around the globe.

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Research Issues of User-generated Medical Education Content

Research

Introduction Advances in Information Technology have enabled the development of virtual distributed pools of autonomous, self-described specialized educational modules, and the provision of mechanisms for searching, retrieving, evaluating and rating, adapting and revising educational content in medicine and life sciences. To this end, “mashup” and “Web 2.0” technologies have recently been used to implement efficient brokerage mechanisms for educational content sharing, thereby offering new and richer opportunities for health education by allowing open access to information, sharing of ideas, questions and opinions. It is also true that Web2.0 technologies have recently empowered the notion of active and collaborative learning, as well as, problem based learning (PBL). But how effective can the sharing of such content be among medical educators? What are those needs and requirements that the academic community needs to consider before investing further in this delightful new endeavour? So, the essence of this paper is twofold. First, to introduce a number of actions taking place along these lines in a European best practice network called “mEducator”; secondly, to draft a roadmap towards responding to the above set of questions. Material and Methods The “mEducator” project is a recently started EU funded initiative of 14 organisations on an effort to facilitate “best practice” towards the repurposing and sharing of medical educational multi-type content. Educational content in medicine includes numerous types of learning objects that address both the theoretical as well as the clinical aspects of medical education. Its uniqueness is strengthened by the fact that is produced by academics and clinical teachers, as well as, students, in a variety of places. An important aspect of mEducator content refers to user-generated content. Its extent and nature varies with the specific content type itself. For example, in typical use of PBL set in a Web2.0-rich environment, the problem/case is set, usually ill-posed by the educator to start with (e.g. in wiki), and questions are raised (in a blog or discussion forum); students/users are then engaged in trying to provide answers to the problem/case questions; it is this user interaction itself that in a way produces and enriches the content. Such content may itself be, if properly described by metadata, utilised as a learning material by the instructors, since it provides hints where possible student misconceptions may lie (the instructor may use this to show to current students what previous cohorts have done in attempting to solve the problem/case or where mistakes/misconceptions occurred, or to reshape the questions or the problem/case). Existing, concrete examples of such user-generated content already available at the mEducator partnership are: • Web2.0 based PBL • clinical cases on the MEDTING case repository • Interaction with Virtual Patients on Open Labyrinth • Cases in the form of e-traces (web traces of anatomical images) • Interactions with serious medical games (in Second Life or not). Is there a need to share such artefacts of medical education (user generated) content? The “mEducator” consortium believes there is need to do that. To accomplish this need though, ones has to standardize the sharing of this kind of content. So, in this paper, we present the efforts of the consortium and the associated difficulties to achieve this. In so, doing, a different number of available standards and technologies are visited and discussed. Results In this paper we demonstrate the first experiments towards the facilitation of the above effort. Appropriate metadata editors and environments are developed and tested; in parallel, a number of experiments are conducted towards new ideas stemming from the notions of social networking, learning object inheritances and semantics/ontologies. Discussion In the core of research related to user-generated content lies an ensemble of standards, protocols, technologies, as well as, development architectures, communication and sharing tools, and the creation of communities that bring people (medical educators, students, practitioners) together. Are the above mentioned existing ensembles capable of supporting all requirements and resolving all particular issues related to user-generated content? Probably not! For example, it is not well defined how current educational standards and metadata might be applied to describe the educational interaction within a PBL Web2.0 scheme facilitated by blogs, wikis and discussion forums. Thus, the mEducator project has initiated a discussion and a clustering effort with standardization bodies and scientific/professional communities in order to resolve such problems.

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Web Based Simulation Games With Multimedia E-learning Environment.

Research

Background Nowadays, the old Comenius`s motto – “schola ludus“ (“school as a play”) has found its modern use in interactive educational programs using simulation games. Through the simulation game we can test the behaviour of individual physiological subsystems, both under normal conditions and in the presence of a disorder. Objective Our goal was to design a web teaching tool, which helps to explain the function of individual physiological systems using interactive multimedia connected with simulation model. Methods Development of the e-learning web simulation games requires cooperation of many professionals and combination of research and development work. Research work consists in formalizing physiological reality by designing mathematical models, while development work is the very creation of multimedia simulators, which make use of the mathematical models designed. A scenario of good quality, created by an experienced pedagogue, still remains the foundation of the e-learning program. Creation of animated images is the responsibility of artists who make interactive animations in the Flash or now in the Expression Blend environment. In order to increase efficiency of creating the graphic layer in the Expression Blend, we have developed an auxiliary software tool – Animtester, which enables the designers – graphic designers to create such animation “puppets” and debug them without the need of any further programming. Thus created “puppets” can be then connected directly to model outputs and there is no need to add any separate program inter-layer for data propagation, as would be the case if using Flash animations. The core of the simulators is the simulation model, created in the environments of special development tools designated to create simulation models. Now, we use a very efficient environment, which utilizes the Modelica simulation language. We are working on the Modelica language compiler to compile into the .NET component form, which, together with the differential equations solver implemented on the .NET platform, as well, shall serve as the “data layer” of the simulator with the implemented model. The user interface is connected with the simulation model using the Data Binding concept, which provides intelligent automatic propagation of values between the layers, thus data transfer. The resulting simulator is a web application for the Silverlight platform, which makes it possible to distribute the simulator as a web application running directly in the Internet browser. Results We have designed the Atlas of Physiology and Pathophysiology as a web accessible teaching tool combining interactive multimedia with simulation models (http://www.physiome.cz/atlas). We have used this tool in biomedical education in Charles University Prague. Conclusions Educational applications using simulation games, available through the web, represent a new educational aid, very efficient from the didactic point of view in explaining complex pathophysiological processes. However, their process of creation is not very easy – it requires multidisciplinary team cooperation and use of suitable development tools. Creative interconnection of the various professions is the key to success (see http://www.physiome.cz/atlas/info/00EN/index.htm).

09:00 AM - 10:30 AM - CR3

Topic: Consumer empowerment, patient-physician relationship, and sociotechnical issues

Chair: Paula Hicks

Holly Witteman, University of Toronto, Toronto, Canada; Sarah Whyte, University of Waterloo, Kitchener-Waterloo, Canada; Jacqueline Bender*, University of Toronto, Toronto, Canada; Michelle Janutka, University of Toronto, Toronto, Canada et al.*

Apomediation and Women's Choices of Birth Place and Attendants

Research

Background: Many women use online communities to discuss their pregnancies and plans for childbirth. Knowledge shared and created within these groups may shape or reinforce opinions about birth place (home, hospital, birth center) and attendants (midwife, obstetrician, family physician, unassisted birth) within the broader social context of contested birth philosophies. Objective: In this study, we sought to explore the relationship between apomediation in online pregnancy communities and women's choices of birth place and attendants. Methods: We conducted: (1) content and narrative analyses of forum posts in established online communities based in Canada, the United States and Australia and (2) a cross-sectional online survey members of such communities. Communities were selected to represent a diverse range of opinions and comparable frequencies of different birth choices. The survey contained both closed- and open-ended questions and used purposeful recruitment and subsampling to ensure adequate sample size across all birth choices of interest in this study. Results: (1) Narratives describing different birth choices and experiences emphasize varying conceptions of risk and birth outcomes as well as varying levels of acceptance or rejection of medicalized birth. In communities that reflect greater acceptance of common medical practices, posts underscore dichotomous outcomes such as death versus health. In communities that promote out-of-hospital births and non-physician attendants, risks and benefits are discussed within a whole systems approach, incorporating factors such as morbidity, interventions, surveillance, continuous mother-baby contact, breastfeeding, physiologic pushing, and empowerment. Participants in all of these online communities establish, engage with, situate themselves within, and challenge norms and values within the online community and external systems. (2) Significant differences were observed between women's self-assessments of whether or not their opinions of various birth choices were influenced by their participation in online communities: Chi^2(5, N = 577) = 53.31, p < .001. Women who chose less medicalized options such as midwife-attended or unassisted birth were more likely to indicate that participation in these communities influenced their opinions. Responses to open-ended questions indicated that these communities offer increased awareness of alternative options, provide knowledge and practical skills for negotiating birth and postpartum experiences in different contexts, and help to normalize birth choices that are outside the statistical norm. Conclusions: Pregnant women assess and evaluate the risks and benefits of childbirth and postpartum practices in varying ways. Online communities about pregnancy and birth promote values and choices according to the characteristics and beliefs of the membership. Decision-making authority and knowledge are constructed differently in different communities. This exploratory study suggests that apomediation may play a role in the birth choices of subgroups of women who participate in these online communities.

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Analysis of Websites Offering Direct-to-consumer Genetic Tests: the Possible Implications on Public Health

Research

Background. An increasing number of websites offers genetic testing directly to consumer (DTC). The limited evidence about the possible improvement of patient health by genetic test and the complexity of test result interpretation could lead to further workup that could increase the expenditure of health care resources. Performing these tests without proper counseling support, could alter perceptions of risk and health behavior, cause psychological morbidity and have a significant impact on the demand for healthcare. Other concerns include issues of privacy and confidentiality and the potential for discrimination of individuals or communities. In order to evaluate possible implications of genetic testing on Public Health, we investigated the availability and the accessibility of genetic services offered DTC on the Internet. Methods. A systematic World Wide Web search was carried out in August 2008 using ©Google, ©Yahoo!, and ©Cuil search engines. The following keywords were used: “genetic” or “DNA” and “test” or “testing” combined with “direct-to-consumer”, “direct-to-patient“, “at-home” and “service”. We only selected health-related websites selling susceptibility genetic tests and/or pharmacogenetic tests. Websites were analyzed using a content analysis method, regarding their geographical characteristics, communication channels, conditions tested, typology of the offer, disclosure of risks and advantages, result reporting, availability of counseling, uses of genetic information and selling arguments. Results. A total of 31 websites were found, mainly located in the USA: of these, 51% offered also non health-related tests and 32% had an health-care professional section dedicated. Usually (48%), genetic tests were offered individually, and in 44% consumers could have a special offer. Private at-home context was the most frequent location of sample collection. After returning the kit to the company, consumers would receive their test results mainly online (41%), through a personal account. Only 1 site required the results to be sent to consumers’ health care practitioners, although 64% encouraged consumers to contact a health care practitioner for result interpretation. In 87%, consumers were not asked to answer health and lifestyle questionnaire before buying the service. Only 32% of websites offered a service of counseling, 26% mentioned specific risks relating to testing and 32% declared future use of genetic information. Patients’ empowerment, simplicity of sample collection, privacy policy and the availability of registered and fully accredited clinical laboratory, were selling arguments most frequently used. Conclusions. The Internet availability of DTC health related genetic tests has the potential to bring the benefits of genetic testing to a broad public. At the same time the availability of genetic tests with uncertain clinical value, the lack of a constant genetic counseling, raise concerns about how such tests could alter consumers’ health perception and behaviour and expose them to privacy and familial implications. Moreover, an increase in consumer interest in DTC genetic testing and the complexity of test result interpretation could lead patients to address their physicians, which would place the primary care system under additional stress, distort the patient-doctor relationship and generate demand with no evidence of health benefits.

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Improving Patient-Physician Communication about Internet Use: Why “Don’t Ask, Don’t Tell” Doesn’t Work

Research

Background: A disconnect currently exists between patients' use of the Internet and their consultations with their physicians. Too often, patients don't tell their physicians about their Internet use and physicians don't ask; both suffer due to the erosion of trust and missed educational opportunities. Better patient-physician communication about Internet use is needed to help patients become truly empowered healthcare consumers. Objectives: Too little attention is paid to improving how patients locate and use health Web sites and communicate about their use of these Web sites with their physicians. The very people who can best help patients, their medical providers, become disconnected from these so-called empowered healthcare consumers, who use the Internet instead of, before, or after consultations with their physicians without it being discussed or integrated into their care. Poor health outcomes can occur when patients have unexpressed concerns arising from the Web sites they have accessed, don't believe their physician when a diagnosis or treatment plan differs from what they obtained from the Internet, use their doctor for a second opinion without disclosing that they obtained their first online, make poor decisions without or disregarding medical input, or scour the Internet for miracle cures. Methods: Based on a literature review, extensive evaluations of health Web sites, and interviews with patients and physicians, better health outcomes for patients can be provided through the design of better user experiences, physician education about patient use of the Internet, patient education about effective Internet use, and the integration of Internet use into patient-physician consultations. Results: While the designers of e-commerce Web sites focus on user experience design to create successful initial and repeat visits, designers of health Web sites often overlook the importance of the user experience. To help healthcare consumers in all aspects of locating and using online health information, health Web sites need to accommodate the range of needs and varying degrees of health literacy of site visitors. Well-established user experience design techniques can facilitate this, namely the use of personas, competitive analysis, and formative evaluation at all stages of design and development. Health Web sites can also incorporate guidelines about when and how to communicate with healthcare professionals about the information on the Web site. Physicians need to have a better understanding of the extent to which and the reasons their patients are online before, and will likely go online after, a consultation. Currently, physicians rarely ask patients about their use of the health Web sites or any concerns that they have as a result, nor do they recommend reliable Web sites to newly diagnosed patients. Many fear the patient who arrives with a ream of printouts or who takes over a consultation. But worse than that is when patients have unexpressed fears or distrust their diagnoses because of what they accessed online. Physician training about how and when to ask patients can be aided by adding questions about Web sites used and any concerns to the form patients fill out in the waiting room, and physicians can receive guidance about reliable Web sites to recommend to their patients. When patients go online, they often start at a search engine and rarely determine the source or date of the information they are using. Better patient education is needed on how to discern credible Web sites and health information on the Internet, a skill that is becoming even more important with the wealth of user-generated content, the many erroneous or misleading Web sites that compete for their attention in searches, and the immediacy of access possible from Internet-enabled mobile devices. Furthermore, patients need guidance about how to discuss their Internet use with their physician appropriately, without taking over the consultation or providing conclusions to a physician who is probing for symptoms. Finally, patients need to seek recommendations for Web sites to use when they leave a consultation with unanswered questions. Conclusions: Patient use of the Internet disconnected from physician care can be detrimental. The benefits of Internet use can accrue with better design, education, and communication. More effective health Web site use can occur through improved design practices, physician and patient education, and patient-physician communication integrating patient Internet use. Better communication can be facilitated by questions on patient forms and guidelines on health Web sites. The next step is testing these hypotheses. The expected outcome is better informed patients whose Internet use is integrated into, rather than disconnected from, their medical care.

11:00 AM - 12:30 PM - Auditorium

Topic: Web 2.0 approaches for clinical practice, clinical research, quality monitoring

Chair: Carlos Rizo

John Sharp, Cleveland Clinic, Cleveland, United States*

Hospital Adoption of Medicine 2.0 - a Culture Shift

Practice

Hospitals have been conservative organizations especially in the United States where litigation and regulation hangs over medical practice. Yet hospitals and group practices are by definition collaborative making them idea proving grounds for social media. This presention will detail the gradual of social media in a large hospital and group practice. Specifically, we will discuss the initial emergence of medicine 2.0 through early adopters creating unofficial tools such as, blogs and wikis, and how the organization is now embracing aspects of social media and health 2.0 as both marketing efforts to reach out and listen to consumers but also enhance collaboration within the institution. The intersection of ehealth and medicine 2.0, particularly as it relates to personal health records will be included as a case study.

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Twitt-ER: Using Twitter in The E.R. for Dispatch, Order Com, Patient Alerts and Progress Reports towards the Waiting Room.

Practice

An effort is made in our E.R. to channel the work flow, to smoothen the sometimes chaotic processes which take place in the E.R., where the most unexpected is always very probable to happen. Because of the shortage of E.R. Physicians in Belgium (as in many surrounding countries) our doctors have to carry out very diverse tasks, on many categories of patients. It is however the triage nurse and a process coordinating nurse who dispatch patients and tasks towards the physicians, so as to enable the physicians to take care of the patients. Because of the large surface of the E.R, a trip to the dispatch room between every patient contact relatively costs a lot of time. Also, in an effort to eliminate unnecessary chatter, task assignation for nurses, doctors and other staff are not communicated by telephone. This means that all assignments are either passed on by paper (work) order, or computer order (via intranet). Most of these orders or tasks are assigned to a specific person, some are aimed at a certain workforce, such as transport of patients to X-ray, CT, or to their rooms after admission. The detail of this order is always stated in a paper or electronic document. As in other applications in Medicine, (medical) alerts have proven useful in different applications. Setting up an alert system however, is usually a task for the I.T. Department, after enlightening them about the system or process the E.R. is using for work flow determination. Because of the constant dynamics of the E.R., it is not always easy or efficient to communicate every task or change in task to every doctor, nurse or other personnel at the right moment. Also, it might be very dependent on the technological backup a hospital can provide. As we are bringing our E.R. and hospital workflow organisation grid into the 21st century, we are now making grateful use of Twitter for communicating assignments from dispatch and triage towards and between dispatch, triage, doctors and nurses. We do this through the use of closed twitter accounts. The Triage nurse sends a tweet to the respective doctors indicating which patient to see after the current one, updating in the same tweet the waiting room status with a code and a link to the patient overview. The lab tweets the doctor on his iPhone or GSM when results are ready and includes a link to the intranet page with those results. The doctor tweets the nursing station about an order to be executed. A Twitter feed on a large screen in the waiting room keeps the patients updated about the dynamics of the E.R. and involved in the process. The same page is displayed on screen in the patient treatment areas, as the only screen patients can see on the PC: the patients can tweet the nurse for specific requests while waiting. Patient names are never used. Patients and staff are better informed, feel efficient and have the impression of being more involved.

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Web 2.0 at Work: Building Healthy Hospital Policy

Practice

Background: Many healthcare institutions have banned employee use of social media sites, like Facebook and YouTube, on hospital computers. The most commonly sited reason for denying access to these sites is in order to mitigate the possibility that employees are wasting time on these sites while at work, thus decreasing productivity. While restricting access to these sites may optimize efficiency, it does not prevent employees from using these technologies for personal and work-related activities at home, including some activities which may be inappropriate. Objective: To qualitatively describe patterns of social media use and issues encountered by employees of The Hospital for Sick Children in Toronto, Canada. Methods: Twenty-four hospital employees, representing a cross section of departments (eg. IT, Quality and Risk Management, Bioethics, Communications and Public Affairs, etc.), and roles (eg. physicians, nurses, social work, allied health professionals, researchers, etc.) participated in three focus groups. Both open-ended written questionnaires and group discussions were used to explore patterns of social media use, rewards and risks. This study was approved under the Quality Improvement rubric. All focus groups were conducted by one individual from an external social media consulting agency and all data were recorded anonymously. A content analysis was used to determine themes within the focus groups. Results: Social media are being used by many staff for shift management/scheduling, research on best practices and new developments in their fields and to anonymously monitor patient's lifestyle choices, progress and behavior. However, there were also many concerns raised by staff regarding social media technologies in the workplace. Employees felt that the hospital had not put enough effort into providing safe online communities of patients and their families, ultimately driving families to use harmful online support groups. Furthermore, patients and families have limited connectivity to the internet at the hospital as well, making it difficult to maintain connections with their friends and family, ultimately affecting their well being. With increasing use of social media by both, patients and families and employees, numerous staff find it difficult to maintain appropriate professional boundaries. Similarly, hospital employees recognize problems in maintaining professional decorum between staff resulting from inappropriate media shared on social networking profiles. Other concerns raised related to social media use during work hours, corporate email overload and a lack of virtual collaboration between staff. Conclusions: Rather than reflexively prohibiting social media use at the hospital, arising from the fear that these technologies will compromise healthcare quality, The Hospital for Sick Children is taking a proactive approach in developing a comprehensive social media policy that reflects the opportunities in innovation, excellence and collaboration that social media present. In tandem with policy development, a social media education curriculum for staff and a social media guide for patients and families are necessary to facilitate the safe and ethical use of these communication technologies in healthcare.

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Clinical Care in the ‘Spaces in Between’: Web 2.0 and the Communicative Reformation of Clinical Practice.

Practice

Good relationships between physicians and those they care for is the “cornerstone to the medical system”. It is essential to the provision of high quality health care. However, an increasing number of patients report that they do not trust their doctors. Medical students tell stories of their rotations and observations of practicing physicians wistfully commenting on the ‘old school medicine’ they see performed with some and the harsh realities of the ‘new test based medicine’ they see in others. At the same time, web 2.0 tools facilitate patient and physician centric social networks of healing practice, surgery updates via Twitter, support groups for chronic conditions on Facebook and mobile healthcare over IM and VOIP. Old, new and now digital forms of clinical and communicative practice collide to shed light on our taken for granted assumptions and culturally constructed expectations of medicine and care. As we move from doctor to patient to relationship centered care, how might the participatory web with its commitments to participation, community, empowerment and engagement reconstruct the professional culture and communicative practice of medicine? What might be the consequences of such a transformation for all healthcare participants? Drawing on ethnographic studies in ER, intensive care, palliative care, cancer and pediatric genetics, and inspired by a dialogic approach to organizing and communicative practice, this presentation proposes that web 2.0 technologies have the potential to reconcile visions of old and new school medicine to create a “space in between”. These "spaces in-between" are places for translation and negotiation, and the disruption and displacement of the dominant structures and practices of clinical life. In such spaces, participants blur boundaries and question established ideas of culture and identity to enable a "spatial politics of inclusion rather than exclusion that initiate new signs of identity and innovative sites of collaboration and contestation". Such hybrid spaces “begin their presencing” at the boundaries of institutions, disciplines and philosophies of care to enable the (re)negotiation of intersubjective and collective experiences of health. They also create a complex architecture of reconfigured organizations in which all participants can connect, re-connect, and create partnerships and associations with others. Within this new architecture of health, many of the current struggles experienced in healthcare delivery such as the emergence of EMRs, recurring readmissions and conflicting professional roles are not erased, but instead engaged ecologically, as circles of care are expanded technologically to provide support for those who suffer. What emerges in this vision of web assisted relationship centered form of care is health from the ground and around, nothing short of a Reformation of medicine.

11:00 AM - 12:30 PM - CR2

Topic: Building virtual communities and social networking applications for patients and consumers

Chair: Alejandro Jadad

Paula Hicks, Trinity College, Dublin, Ireland; Prof. Jane B. Grimson, Trinity College, Dublin, Ireland; Prof. Owen P. Smith, The National Paediatric Haematology/Oncology and Bone Marrow Transplant Centre, Our Lady’s Children’s Hospital, Dublin, Ireland*

Solas - a Virtual Community for Children with Cancer

Research

Background: Approximately 10 – 15% of all children under 18 years of age have a chronic illness or condition. Challenges that impact a child’s ability to cope socially, emotionally, and or physically are often referred to as ‘psychosocial’ challenges and include isolation, change in family dynamics, and loss of social interaction with peers (at school). Developing secure web-based communities to address their specific needs has been at the core of some of the research work currently being carried out at the Centre for Health Informatics, Trinity College Dublin (TCD) in collaboration with the Children’s Research Centre, TCD and The National Paediatric Haematology/Oncology and Bone Marrow Transplant Centre, Our Lady’s Children’s Hospital, Dublin. This paper presents one such project entitled Solas from design and development considerations through to evaluation of the impact of the virtual community for children with cancer. Objectives: 1. Improve communication –providing the opportunity for children to communicate with each other, family and school, with the potential to develop support networks and share their experiences. 2. Improve socialisation with peers, family and healthcare professionals. 3. Provide a means to continue their educational objectives. 4. Provide appropriate activities, including a space for children to exercise their creative abilities. Methods: The research approach looked at four key tasks: Needs Assessment; A Steering Committee was established to guide the research. The Children's Research Centre designed a needs assessment methodology for gathering data from a sample of the target population, this provided the multidisciplinary team with critical empirical information which was used to define and develop the Solas prototype. System Design - The Solas environment offers an intuitive interface to a variety of services, seamlessly integrating current web technologies and securely accessible via a standard web browser. Solas components facilitate two key areas, communication (video link, sms texting, live chat and email) and a variety of tools for creativity. Implementation – Currently available on the Children's Cancer Unit at Our Lady's Children's Hospital, Dublin, and has over 180 registered users. Evaluation – Initial evaluation of the pilot phase using qualitative interviewing and quantitative methods is complete. A full independent evaluation of the impact of the system on this cohort is currently underway and due for completion June 2009. Results: It was evident at the end of the pilot phase that Solas had been enjoyed and appreciated by many of the users. The report from the Play Therapist on the level of interest amongst young people was very positive "the teenagers that have been in, most of them have had a shot of it." Half of the users use Solas 'a lot'. Some parents report their children 'perking up' when using Solas. More comprehensive evaluation results available June 2009. Conclusions: Web-based communities offer a framework to provide an efficient and effective means of supporting these children. Any web-development for children with chronic illnesses is also vulnerable to concerns regarding child safety and the dangers presented by the internet. Providing these communities within a hospital setting offer many new challenges, from facilitation, ethical to environmental considerations, but these are not insurmountable.

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Facebook: Awareness-raising, Fundraising and Support for People Affected by Breast Cancer

Research

Background: Breast cancer survivors value practical and experiential information from other survivors, and often go online to seek support to validate unanswered questions and concerns. Social network sites like Facebook present a convenient means to connect with a network of peers in similar circumstances. Unlike previous computer-mediated communication technologies such as email lists and message boards, social network sites are primarily structured around people rather than interests. Most online social network sites are used to maintain pre-existing relationships, as well as to form groups with strangers with similar interests. To date, there are no known published studies that examine the role of Facebook as a source support for people affected by breast cancer. Objective: The study aimed to characterize the use and function of breast cancer groups on Facebook. Methods: In November 2008 we conducted a search on Facebook (www.Facebook.com) using the keyword 'breast cancer'. We restricted our analysis to breast cancer 'groups' (pages for individual member profiles, organizations, events and applications were excluded). All eligible group pages were cached for offline analysis. We extracted information on the name, administrator and purpose of the group, as well as the number of members, posts, photos and videos. Using content analysis, we examined the description of group, as well as the discussion and wall posts to identify the function of each group. Results: In total, 638 breast cancer groups were identified. The groups were created and used to 1) raise funds to support breast cancer research (45%), 2) raise awareness about breast cancer (36%), 3) support an external breast cancer website for fundraising, awareness or political purposes (10%), or 4) provide support to people affected by breast cancer (7%). Analysis of the use statistics (number of members and contributions) for each group is in process. Conclusions: The majority of breast cancer groups on Facebook have been created for fundraising and awareness purposes. Unlike most other online breast cancer communities, which are used primarily by breast cancer patients and survivors to exchange information and emotional support, Facebook breast cancer groups do not appear to be used primarily for supportive care purposes.

Judith Feder, Brodeur Partners, New York, United States*

E-Patients and Chronic Illness:Commonalities and Differences among Breast Cancer, Multiple Sclerosis and Marfan Syndrome Health E-Community Members

Research

Background. Investigators have studied online health information and support seeking strategies for cancer and other common chronic illnesses, but there have been fewer studies of e-patients with other chronic conditions or comparisons across illness communities. Objective. To inform the development of Health 2.0 resources for Internet users living with chronic health problems by better understanding their current e-health information and support seeking behaviors and future needs. Methods. We used a web survey to explore how people with diverse conditions may differ in their experiences in four contexts: seeking treatment-related information (RQ1); seeking information from experts; seeking additional resources (RQ4); and seeking meaningful social support (RQ4). Recruitment. Listowners of three health e-communities (HeCs), the Metastatic Breast Cancer Information and Support list, Multiple Sclerosis World and Marfan Life Forum, permitted us to post invitations to their groups that included links to our web survey. Analysis. For each research question, we used multiple items to create indices of different kinds of e-patient experiences and attitudes. In the two-stage analysis, we performed descriptive analyses of participant responses for the entire sample and planned comparisons between illness groups. Results Sample size. 127 out of 160 surveys (82%) were completed. RQ1. Most participants had searched for information about current treatments (87.4%) or side effects (87.4%). Approximately 25% of these participants experienced problems finding what they needed. Approximately 40% of participants sought information about clinical trials or recommendations for health care providers. Of these, many reported that it was harder to find recommendations for providers (71.7%) than it was to find information about clinical trials (37.3%). RQ2. Regarding searching for online information on chronic conditions from experts, 86.6% of participants reported that they searched comprehensive health information websites, 76.4% sought articles in online scientific journals; 70.9% sought news articles and 55.1% searched for doctors' presentations on their specific conditions. Of those who searched for expert online information, over half found it hard to find relevant doctors' presentations on their conditions; approximately one third had trouble finding relevant news articles. RQ3. 55.1% of participants had searched for recommendations for products and services to alleviate symptoms or enhance wellbeing; 29.9% sought information on health insurance. Of those who sought information on health insurance, over three-quarters had trouble finding what they needed. (RQ4) 82.7% of participants reported that they had sought HeCs where they could find other people who had the same condition. Of these, nearly a fifth had difficulty finding HeCs that met their needs. 36.2% of participants reported that they had sought HeC support for problems related to chronic disease polymorbidity. Of these, over a third had problems finding HeCs addressing the same combination of conditions. Between group comparisons. Overall, MarfanLife members encountered the significantly more problems finding treatment-related information (p.>.05), relevant comprehensive websites(p<.05), and recommendations for health quality of life-related products and services (p<.05). There were no significant differences among groups in difficulty finding social support. Conclusions. Participants showed strong similarities in their activities and outcomes in seeking information or support online. They also expressed desires for—and interest in sharing--highly nuanced, individualized, and timely information for coping with the uncertainties of chronic illness trajectories, treatments and side effects. These findings point to the need for Health 2.0 e-community platforms that utilize Web 2.0 and social media capabilities to capture, organize and retrieve the relevant information on specific health conditions and the common concerns of people with chronic conditions.

11:00 AM - 12:30 PM - CR3

Topic: Web 2.0 approaches for behaviour change, public health and biosurveillance

Chair: Robyn Whittaker

Brian Cugelman, University of Wolverhampton, Wolverhampton, United Kingdom*

The Psychology of Mass-Interpersonal Behavioural Change Websites

Research

Background: As an interactive and widely-diffused media, the Internet promises health campaigners the potential to realize lower-costs, higher-impact campaigns. Despite many opportunities, health campaigners frequently apply mass-media communication models to public health interventions where interpersonal models may be more appropriate. Practitioners frequently treat the online component of mass health campaigns as just another one-to-many channel. Likewise, across the academic literature, social marketing authors rarely discuss using the Internet as more than another one-to-many communication channel. Within the fields of e-health and persuasive technology, a growing body of research indicates that intervention websites can motivate persons to adopt healthy behaviours, such as

quitting smoking, exercising more or eating better. Frequently, these online interventions are individually tailored programmes, resembling two-way interpersonal therapy. It is now conceivable that health campaigners can deploy mass-interpersonal campaigns, where online media are used to engage large populations in automated personal relationships, similar to relationships with doctors, councillors, trainers or friends. Meta-analyses show that online interventions can outperform non web-based interventions; while web and computer-based interventions can improve health-related knowledge, attitudes, behavioural intentions and actions. These studies provide evidence that online interventions can be effective; however, the studies to date do not fully explain the range of psychology and design factors that may account for intervention success. Objective: This paper presents a meta-analysis that investigates psychological design factors that can explain the efficacy of online behavioural change interventions. It makes a clear distinction between mass-media, interpersonal and mixed, mass-interpersonal communications. To this end, a model, called 'the Communication-Based Influence Components Model', is used to synthesize behavioural change and persuasion taxonomies. Methods: Following systematic review methods, papers were searched from 1999-2008 across five bibliographic databases. This resulted in 1,587 studies that were reduced to 29 relevant studies, which allocated 17,524 participants to 30 interventions. The study examines relationships between behavioural outcomes, intervention design factors and behavioural influence techniques. A secondary analysis examines relationships between study and intervention adherence, and associations with behavioural outcomes. Results: Interventions were selected and grouped on the basis of three control condition. Using a random effects model, the standardized mean difference effect sizes (d), 95% confidence intervals (CI), and number of interventions (k) are as follows: waitlist/placebo (d=.282, CI=.170 to .393, p=.000, k=18); static websites (d=.162, CI=.006 to .318, p=.041, k=8); major print interventions (d=-.110, CI=-.343 to .123, p=.353, k=4). Across the various online interventions, the top three behavioural determinants targeted by interventions are knowledge, intention and social norms. The top three behavioural change techniques included providing information on consequences of behaviour, goal setting and providing feedback on performance. Results indicate a significant correlation between study adherence, intervention adherence and behavioural outcomes, while interventions consistently loosing impact over time. Conclusions: Overall, online interventions, modelled on interpersonal interaction, work. Effective interventions follow common patters and the Communication-Based Influence Components Model is an effective framework for discovering their design patterns, and developing new interventions.

Matic Meglic, UP PINT, Koper, Slovenia; Andrej Brodnik, UP PINT, Koper, Slovenia*

Web and Mobile Process Support for Management of Patients with Depression: Preliminary Results of the Improvehealth.eu Randomized Controlled Trial

Research

Background: At Medicine 2.0 2008 we have presented the development of web and mobile environment for process support for management of patients with depression. The environment supports participation of all actors involved in the process of integrated care (patient, care manager, general practitioner/psychiatrist, psychologist, peer). Automated analysis of self-assessment questionnaires allows for stepped-care approach employed by care manager. Objectives: The objectives of the study are to measure the effectiveness and efficiency of this novel approach to depression treatment. By comparing the treatment involving the above intervention to existing treatment we aim to measure any changes in adherence and treatment outcome. Methods: To measure the changes we are performing a randomized controlled trial involving over 50 patients. Controls receive existing care whereas the experimental group receives existing care combined with participation in the improvehealth.eu environment and care management. Depression levels before and after 6 month treatment are gathered via on-line and paper questionnaires including psychosocial and clinical information and analysed to show differences in adherence and outcome of treatment in both groups. Delay of onset of improvement of clinical symptoms is being collected retrospectively. A multivariate analysis of psychosocial and intervention related factors influencing patient compliance and treatment outcome will also be conducted. Results: Preliminary results from experimental group are as follows: of 30 patients in this group 3 were no-shows (10%) and 3 were early drop-outs (10%). 62% of the remaining 24 patients completed stage 1 of on-line follow-up protocol (10 weeks of weekly reporting and analysis). Patients successfully submitted a total of 240 self-assessment questionnaires. Average participation was 83 days (SE=38 days). The chance for a non-early drop-out patient to finish stage 1 is 61% (SE=10%) based on K-M survival curve analysis. Adherence to treatment in experimental group was 83% at 10 weeks as compared to 60-70% in published managed care studies. Improvement in Beck Depression Inventory as measure of treatment outcome was 62% (SE=23%) or 18 points (SE=10 points). Conclusion: Preliminary results will show if there are any effects of web and process-support environments on adherence and outcome of depression treatment. Implications on disease burden and use of this approach in treatment of other long-term diseases will be discussed.

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Websites on Addictive Disorders

Research

This paper describes the findings of a research program in 2009 on alcohol and other drug (AOD) websites. It outlines a literature search, observations of internet searches, 9 focus groups on consumers' perceptions and preferences, an online consumer survey with 3,313 respondents, surveys of practitioners and online providers, and systematic evaluations of 56 AOD websites. Most visits to AOD websites are short in duration, and are to seek succinct information, although brief screening with personalised feedback are also valued. Few websites give interactive online treatment for alcohol or other drug problems, but as yet there is limited current acceptance of internet-based treatment without therapist guidance. Design and navigation quality is generally acceptable, but quality of content (aside from substance effects) is highly variable. There is little guidance on how users can judge the quality of website content. There are few high-quality trials on the impact of online treatment, although current results are positive. There is a need for further application of current technology to internet-based screening and treatment for alcohol and other drug problems, for additional outcome trials, and for effective marketing of online treatment to both practitioners and potential consumers.

12:30 PM - 01:30 PM Lunch with "unconference" (open microphone)

Munch your lunch and network with your peers. Open stage microphone for anybody to speak out, to make a short presentation, to talk about whatever they like - e.g. what they are working on (or what they would like to work on), what others are doing, what partners and collaborators they are looking for, what they deem important issues, etc. http://medicine20.crowdvine.com/posts/4815231

01:30 PM - 03:00 PM - Auditorium

Topic: Collaborative biomedical research, academic / scholarly communication, publishing and peer review

Chair: Theresa Bernardo

Hope Leman, Samaritan Health Services, Corvallis, United States*

ScanGrants: Reaching Out to Researchers in the Health Sciences

Practice

ScanGrants is a Web-based listing of grant, scholarship and other funding types in the health sciences. ScanGrants is an example of how librarians and other information professionals can employ free Web 2.0 tools such as those of FeedBurner and Google Analytics to create free services for library patrons, researchers and anyone in the world with an Internet connection. We determined to create a free, Web-based listing of grants and other funding types that would enable potential researchers (novice and experienced), public health workers and community public health advocates to garner funding for their projects. We also make an effort to list as many scholarships in the health sciences as possible in order to attract bright people into healthcare and so help alleviate the perennial shortage of nurses and allied heath professionals. ScanGrants is being adopted by a broad range of medical, academic and public libraries and institutions such as the Michigan State University Libraries, the Alameda County Library, the Medical College of Wisconsin, Washington University in St. Louis, the Office of Research Information Services at the University of Washington and so on. We wanted to make ScanGrants as easy to use as possible. Therefore, we list a broad range of categories (e.g., Academia, Academic Medicine, Acute Care, Aging, Alcoholism, Allergy Medicine, Alzheimer's Disease, Amyotrophic Lateral Sclerosis). Users can subscribe to either the main listings or by category via email, RSS and Twitter. It is an innovative service of particular value to those without access to expensive services such as Community of Science.

Enrique De Andrés Galiana, Institute of Health Carlos III, Madrid, Spain; Victoria Lopez Alonso, Institute of Health Carlos III, Madrid, Spain; Laura Salamanca Rodriguez, Institute of Health Carlos III, Madrid, Spain; Isabel Hermosilla Gimeno, Institute of Health Carlos III, Madrid, Spain et al.*

Bikmas 2.0: a BIomedical Knowledge Management Antenna System

Research

Background: The Internet has become the main routine method used by scientists to gather the information that they need to carry out their research work. Members of a biomedical research unit need to manage large amounts of articles, web references or newsletters content, that must be structured, organized and made readily available. The rise of the interactive and social web poses new challenges in this regard. Our experience shows that Web 2.0 might be better considered as an opportunity to improve the exchange of information, ideas and knowledge between peer researchers. Objective: To improve the process of collecting, structuring and sharing information from the Web 2.0 and make it available for its use in the daily work of a research department. The system has been designed using a metaphor: it could be compared to a radio receiver. Just as the radio allows the user to scan the radio-electric spectrum looking for a specific frequency, BIKMAS can be oriented as an antenna to find out concrete thematic contents over the web 2.0 and retrieve, annotate, organize and make this information available for all the members of a research group. Methods: The system has been implemented under open source software tools, (Liferay as portal manager, Glassfish as application server, MySQL as DBMS). The portal consists of six distinct work areas (Start, Personal, News, Content, Articles and Publications). “Start” and “Personal” areas represent a shared space that facilitates routine work, offering tools such as a calendar, forum or a web catalogue. “News” is the area where the system aggregates the information retrieved through the RSS (Really Simply Sindication) standard. This area is organized in 15 thematic areas of interest and is compliant with web 2.0 content formats: Text (news, wikis, blogs), folksonomies (i.e.: delicious bookmarks), presentations (such as Slideshare), multimedia (Pod and Videocasts). The “Content” area provides an easy and flexible manner to use the information obtained through the news area and create new documents. The “Articles” area assists the members of the Unit in managing the workflow towards publication of research information and finally the “Publications” area presents the articles in a RSS format in order to allow other users to subscribe to the newly generated information. Results: The system has been in use since January 2009 on the Intranet of our Institute and it is already connected with 79 different Web 2.0 information sources grouped in 15 thematic areas. The system currently includes 83 folders of research topics including a total of 116 documents and 33 folders dedicated to store information for specific uses or activities of the research unit (courses, grant proposal, scientific talks). A knowledge map is available in the form of a tag cloud. Conclusions: BIKMAS provides the research group with an integrated knowledge management toolbox that supports the workflow consisting of transforming multidisciplinary, multiformat information selectively collected from the Web 2.0 into structured knowledge that can be shared and used by the members of the group to accomplish their main research tasks.

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OrphanData.org: Enabling Transdisciplinary Scientific Collaboration Using Web 2.0

Research

Background: The interest in adopting and exploring the use of Web 2.0 in biomedicine has been increasing. Web 2.0 includes characteristics such as rich user experience, user participation, dynamic content, openness, freedom, and collective intelligence. It transforms the role of patients, doctors, and scientists into that of e-patients, e-physicians, and e-scientists. In this new role, information consumers do not only make use of the advent of the Internet to actively gather information of particular interest to them for making informed decisions, but they also make social connections with one another based on their common interests and goals. Objective: We have developed a prototype Web 2.0 site called “OrphanData.org” (ODDO) that promotes scientific collaboration in a manner that preserves the scientific process and scientists’ interests while efficiently and deliberately promoting (using Web 2.0 technologies) the removal of geographic and social barriers. ODDO provides an intellectually secure website designed to help scientists collaborate and share resources early in the scientific process, user centric, as it was conceived by a researcher to fill a major gap he/she encountered in his/her collaborative environment. Methods: In developing ODDO, we employ a process called “data driven collaboration” (DDC). In contrast to socially driven networking, DDC focuses on facilitating interdisciplinary and transdisciplinary collaborations based primarily on a shared interest in a particular gene, disease and/or pathway. The data/resource is the catalyst between the researchers, not the social profile. While this concept is simple, it has the potential to dramatically improve resource sharing and transdisciplinary scientific collaboration. Results: The initial version of this open access website has been launched and is available to the global scientific community (http://orphandata.org). Through this website, researchers can securely and efficiently find collaborators across disciplines, share data and/or reagents listed by gene, pathway, and/or disease. Listing researchers can adjust the amount of information that is posted (or not), control sharing, and through an internal email system can very quickly address inquiries from potential collaborators about the listing. Conclusions: The OrphanData.org website is unique, simple, secure and efficient to use. It allows researchers to develop collaborations, share resources and knowledge in the Web 2.0 spirit.

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One Year Later: The NextHealth Model in Theory and Practice - Implementing Participatory Medicine Strategies and Exploring the Evolution of Choice/Control Aware Care

Practice

Last year at Medicine 2.0 Congress Jen McCabe Gorman and Maarten den Braber launched a simplistic yet controversial visual/interactive planning model - neXthealth - explicating the current eHealth/teleHealth/mHealth environment and mapping a basic superstructure for strategic planning in healthcare innovation. The standing-room only session generated discussion in the Medicine 2.0 community for months afterwards, and has informed the authors' research to date. Fast forward almost 9 months. Stages detailed in NextHealth's 4 C's of consumer-centric care (content + community + commerce + coherence) which seemed far-fetched just a year ago are now commonly deliberated in global health/wellness policy and practice discussions. Many hospital and public health planning teams are struggling to connect brick-and-mortar care delivery with consumers' desire to access healthcare goods and services in 'the cloud.' This two part follow-up presentation, with visuals, tools and graphics offered free online in the spirit of open-source collaboration, will provide a conceptual interpretation of where global healthcare planning and delivery is headed, supported by a practical portion detailing case studies of NextHealth research in motion. The authors offer a fast-paced, next-generation re-examination of the NextHealth research methodology and model using data from the Pew Internet Life and Research Project, P2P Foundation, e-patients.net, and other organizations, 'black swans,' and research entities studying how people and healthcare intersect. It wouldn't be a NextHealth presentation without plenty of real-world data. Debating the realization of these stages is simple - calculating organizational ROI and planning for implementation is not. Jen McCabe has used the NextHealth model in practice to consult with leading Health 2.0 organizations and Medicine 2.0 researchers, and will share several case studies (including mHealth application design and social media metric creation & analysis) detailing results. Evolutionary sampling of relevant sectors will be used to show how companies like Polka.com, OrganizedWisdom Health, Change:Healthcare, ENURGI, and others are connecting the dots to crowd-source 'what's next' for consumer-centric, participatory healthcare. The authors will demonstrate harnessing social media channel Twitter as the 2nd C, community, for collaborative planning. A new articulation of the NextHealth theory, the move to "choice" and "control" aware care, will be used to demonstrate the previously hidden but vital 5th component of a comprehensive NextHealth model; "context."

01:30 PM - 03:00 PM - CR2

Topic: Usability and human factors on the web

Chair: Holly Witteman

Emily Seto, Health Policy, Management and Evaluation, University of Toronto, ON; Centre for Global eHealth Innovation, University Health Network, ON, Toronto, Canada; Heather Ross, Department of Medicine, University of Toronto, ON; Divisions of Cardiology and Transplant, University Health Network, ON, Toronto, Canada; Joseph A Cafazzo, Health Policy, Management and Evaluation, University of Toronto, ON; Centre for Global eHealth Innovation, University Health Network, ON; Institute of Biomaterials and Biomedical Engineering, University of Toronto, ON, Toronto, Canada; Kevin Leonard, Health Policy, Management and Evaluation, University of Toronto, ON; Centre for Global eHealth Innovation, University Health Network, ON, Toronto, Canada*

Designing a User-Centric Remote Patient Monitoring System to Facilitate Heart Failure Self-Care

Research

Background: Self-care among the heart failure patient population is generally poor and most heart failure patients have low self-efficacy in performing self-care practices. Non-adherence, such as to daily weight measurements and diet, has been found to be a major cause of morbidity and preventable hospital admissions of heart failure patients. Studies suggest that as many as one third to one half of heart failure hospitalizations are preventable. Remote patient monitoring is a potential tool to avert further deterioration of a heart failure patient's condition and to avoid the cost of re-hospitalization. Objective: The objective of this research was to inform the design of a user-centric remote monitoring system for heart failure self-management through extensive feedback from heart failure patients and their clinicians. Methods: Semi-structured interviews with 11 heart failure healthcare providers were conducted to elicit the system requirements and general utility of mobile phone based remote patient monitoring. Three iterative rounds of usability testing were then conducted with 20 heart failure patients throughout system development. A single round of usability testing was conducted with 9 clinicians near the end of system development. Results: A user-centric remote monitoring system for heart failure management was developed that monitors weight, blood pressure, heart rate, symptoms, and heart rhythm. The physiological data is sent wirelessly from the medical devices to a mobile phone, which then transmits the data to the servers. Patients receive specific instructions on the mobile phone depending on their measurements to help enable self-care, such as reminders to follow their salt and fluid restrictions. In addition, the monitoring system sends alerts to both patients and their healthcare provides as required. A web-based viewer was developed for patients to review their information in logs, graphs, and summary tables. A web application was also developed for the healthcare providers to review their patients' data and to record their clinical actions. The usability testing provided insight into the attitudes and concerns of the patients and clinicians, as well as recommendations on how to improve the system. One of the main patient concerns was improper use of the equipment leading to false alerts being sent to their clinicians, while a major concern for the clinicians was not having the time to follow-up on the alerts. Most patients thought that they would benefit from using the monitoring system by reducing their travel to the heart function clinic, centralizing and logging their data, getting information to their physicians quickly, and keeping on top of their own condition. Feedback from the patient and clinician usability testing was particularly useful for clarifying the terminology of symptom questions and alerts, informing the required website features, and determining the workflow for using the system. Conclusions: The feedback by patients and their clinicians enabled development of a heart failure monitoring system that met their needs, including helping patients perform self-care and providing their healthcare team with clinical decision support. To our knowledge, this is the first heart failure remote monitoring system designed using a formal, iterative, user-centered method throughout its development.

Tara McCurdie, Centre for Global eHealth Innovation, University Health Network, Toronto, Canada; Anjum Chagpar, Centre for Global eHealth Innovation, University Health Network, Toronto, Canada; Melanie Yeung, Centre for Global eHealth Innovation, University Health Network, Toronto, Canada; Department of Biomaterials and Biomedical Engineering, University of Toronto, Toronto, Canada; Joseph A Cafazzo, Centre for Global eHealth Innovation, University Health Network, Toronto, Canada; Institute of Biomaterials and Biomedical Engineering, University of Toronto, Toronto, Canada; Health Policy, Management and Evaluation, University of Toronto, Toronto, Canada*

Mobile Devices for Nursing: a Comparative Human Factors Evaluation

Research

Background Despite the potential for mobile devices to improve care through increased information provision and decision support, their adoption remains limited, in part due to the usability of the hardware platforms available. Objectives This study sought to compare the usability of 3 commercially available smartphones: RIM's BlackBerry Bold, Apple's iPhone 3G, Palm's Treo 680, and 2 Personal Digitial Assistant (PDA) platforms: Nokia's N810, and HP's iPAQ 210, for typical nursing tasks. Findings were analysed to provide insights into performance and adoption barriers and enablers. Methods Expert heuristic reviews were conducted on each device to determine how well each conformed to commonly held design principles. Following the heuristic evaluations, usability testing was conducted with twenty-four nurses from the Multi-Organ Transplant unit at the Toronto General Hospital to identify issues with the devices' ability to support user goals and expectations. This involved the objective observation of nurses while they performed four typical tasks: composing an email, a BMI calculation, and two online database queries. In addition, subjective user preference data was collected through surveys and debriefing interviews at the end of each evaluation. Results Overall, the BlackBerry had the least number of issues identified through the heuristic evaluation. The Nokia had the most overall issues but most of these were low severity. The iPhone and the iPaq had the most number of medium severity issues while the Palm had the least number of issues in total, but the most high severity issues. With respect to the usability testing, the Nokia performed the best in terms of task completion time and task completion rate for the web query and BMI calculation tasks. For the emailing task, the Palm Treo had the highest performance and perceived ease of use scores while the iPhone performed the worst. When users were asked to rank devices according to preference, more preferred the BlackBerry than any other device. Conclusions While the Nokia performed best overall, due to its physical keyboard, clear menu structure and information display, the BlackBerry was preferred by more users. Nurses reported that the Nokia was too heavy as compared to the other devices (223 g as opposed to 132 g for the BlackBerry which was the lightest). Also, the Nokia had the most heuristic violations and while the majority of these were not severe, in sum, they may have contributed to user frustration. The BlackBerry, on the other hand, had the fewest design principle violations revealed during the heuristic evaluation. In addition, it's fast browsing speeds and advanced page rendering contributed to it ranking second in overall task performance during the usability testing. It is likely that the BlackBerry's adherence to good design principles contributed to more nurses choosing it over the Nokia. The iPhone's performance closely followed the BlackBerry's in terms of overall task completion time and rate and was also 3rd most preferred device, after the BlackBerry and Nokia. The BlackBerry Bold and iPhone 3G were found to be the most appropriate devices to support the clinical tasks evaluated in this study. The Nokia N810 also met or exceeded the performance of these devices, but its form factor and weight could impact adoption by nurses, and its lack of phone functionality limits its application. The Palm Treo 680 and HP iPAQ 210 are not recommended.

Pierre Pluye, McGill University, Montreal, Canada; Roland Grad, McGill University, Montreal, Canada; Carol Repchinsky, Canadian Pharmacists Association, Ottawa, Canada; Barbara Jovaisas, Canadian Pharmacists Association, Montreal, Canada et al.*

The Information Assessment Method can help Information Providers to Integrate Health Professionals' Constructive Feedback into the Management of Electronic Knowledge Resources

Research

Background: Management studies show that the timely handling of user feedback benefits organizations and sustains relationships with users (Strauss & Hill, 2001). However, no studies have examined the integration of health professionals' feedback into the management of electronic knowledge resources when feedback is stimulated by a validated evaluation method. The Canadian Pharmacists Association (CPhA) publishes e-Therapeutics+®, an electronic textbook for treatment recommendations, and other pharmaceutical databases. Before the implementation of the 'Information Assessment Method' (IAM), CPhA received little feedback (on average one per week) from a free-text comment box only accessible when users were logged into e-Therapeutics+®. Since dissatisfaction rarely leads to formal complaint, e.g., negative written comments on e-Therapeutics+®, a method such as IAM might help users to provide more feedback. Taking feedback into account is crucial since it represents the 'tip of the iceberg', i.e., other instances of dissatisfaction that were not expressed. Objective: The purpose of the CPhA-McGill collaborative action research project was to explore whether feedback obtained from health professionals using IAM could be integrated into the management of e-Therapeutics+®. Methods: Based on a seven-year research and development program, IAM is a validated method for systematically assessing the relevance, cognitive impact, use and expected health benefits of information objects. Following a participatory research approach, a web-based survey on highlights (selected content from a chapter in e-Therapeutics+®) was conducted in a push (email) and a pull (login & search) context over a 20-week period. When participants read a highlight, they were asked to rate the content using the IAM pop-up questionnaire that includes a comment box. Respondents could then enter a contest to win a small prize. In PUSH, 36 highlights were emailed to 6,500 CPhA members (mostly pharmacists working in hospital, community or primary care, and pharmacy students). In PULL, e-Therapeutics+® subscribers made 220,898 logins (nurses, pharmacists and physicians). All push and pull IAM comments were reviewed to identify constructive feedback, defined as comments requiring further investigation. Weekly constructive feedback reports were sent to CPhA. Results: Responses varied depending on highlights and respondents. PUSH: Of 234,000 emails, 25.6% were opened, and 1.4% led CPhA members to complete a questionnaire (n=3,198). Of 120 constructive feedbacks, 15 led to some change in e-Therapeutics+® content: additional reference (n=4), more information (n=6), and rewording (n=5). PULL: 238 completed questionnaires were collected (on average 11.9 per week), leading to nine constructive feedbacks, but none lead to change. This increase of feedback was well-received by the editors, but increased their workload. Conclusion: Results show the implementation of IAM stimulated constructive feedback in push and pull context. Feedback from the push context allowed the CPhA to make modifications designed to improve e-Therapeutics+®. This study suggests the implementation of IAM and the integration of constructive feedback into information management of electronic knowledge resources may renew organizational routines.

01:30 PM - 03:00 PM - CR3

Topic: Health information on the web: Supply and Demand

Chair: Brian Cugelman

Julia V Bailey, University College London, London, United Kingdom*

Computer-Based Interventions for Sexual Health: a Systematic Review

Research

Background: Sexual health is a major public health challenge, and face-to-face interventions have had mixed success. Computer-based technology such as the Internet offers a different route for the delivery of sexual health interventions, and has advantages such as convenience, the capacity for individual tailoring, interactivity and multi-media features. There is therefore huge potential for health promotion via new technologies: we present the results of a Cochrane systematic review of interactive computer-based interventions (ICBIs) for sexual health. Objective: To determine the effectiveness of interactive computer-based interventions for sexual health promotion. Methods: We searched electronic bibliographic databases; grey literature; trials registers; reference lists of published studies; and contacted authors. Databases were searched from their start date to end November 2007. The search strategy comprised three overlapping concepts: 1) Randomized Controlled Trial study design AND 2) Computer/Internet-based applications AND 3) Sexual health. Two review authors screened abstracts and all candidate studies to determine eligibility, apply quality criteria, and extract data from included studies. Authors of included RCTs were contacted for missing data. Results of RCTs were pooled using random-effects model with standardized mean differences (SMDs) for continuous outcomes and odds ratios for binary outcomes. Heterogeneity was assessed using the I-squared statistic. Results: We identified 15 randomized controlled trials of ICBIs conducted in a variety of settings with a variety of populations, with interventions focusing mainly on the prevention of sexually transmitted infections including HIV. The total number of participants for which outcome data were available was 3917. 1) ICBI vs. minimal intervention: Meta-analyses showed a moderate effect on sexual health knowledge, with an SMD of 0.68 (95% CI 0.32, 1.04); a small effect on self-efficacy (SMD 0.11, 95% CI 0.02, 0.20); a small effect on safer-sex intentions (SMD 0.16, 95% CI 0.05, 0.27); and no significant effect on sexual behaviour measured as a dichotomous outcome (odds ratio 1.23, 95% CI 0.84, 1.80). There were insufficient data for analysis of biological outcomes. 2) ICBI vs. non-computerized, face-to-face sexual health education: Meta-analysis of the two studies with available data on sexual health knowledge showed a small effect (SMD 0.36, 95% CI 0.13, 0.58). There were insufficient data for analysis of other outcomes. Conclusions: Interactive computer-based interventions for sexual health promotion are feasible in a variety of settings and with a variety of populations. ICBIs are effective tools for learning about sexual health, with meta-analyses showing gains in knowledge. ICBIs also show promising but small effects on self-efficacy and intention. High quality trials which have the power to detect changes in behaviour and biological outcomes are needed. Studies could also embrace a wider definition of sexual health to include emotional, mental and social well-being in relation to sexuality and not just physical health.

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What Are Young Adults Saying About Mental Health? a Qualitative Analysis of Internet Blogs

Research

Background: One out of every four young adults will experience a mental disorder in any 12-month period. Despite this high prevalence rate, few young adults access treatment. Without treatment, these disorders are highly persistent, affecting many areas of development during the pivotal transition of adulthood. While much research has focused on understanding the barriers to service access, few studies have explored unbiased accounts of the experiences of young adults suffering from mental health disorders. It is through hearing these experiences and gaining an in-depth understanding of what is being said by young adults that improvements can be made to interventions focused on increasing access to care. Objective: The present study moves beyond past research by using an innovative qualitative research methodology where the blogs of 8 young adults (aged 18-25) who are suffering from problems with mood and anxiety disorders were analyzed in an effort to understand their experiences. Methods: An enhanced Internet search vehicle, DEVONagent (Mac OSx) was used to extract publicly available Internet Blogs using primary keywords related to mental health. All blogs were selected from the postings in the past 6 months from individuals aged 18 to 25 (6 female, 2 male) who were experiencing mental health problems. Blogs were analyzed using Grounded Theory and consensual qualitative analysis to determine emerging themes characterizing the experience of mental health problems. Results: Two core categories emerged in the analysis. First, young adults reported a pervasive lack of control or sense of 'powerlessness' over all-consuming mental health problems but simultaneously felt that they ‘should’ have control over these experiences (i.e., self-blame, guilt). Second, young adults reported experiencing a strong sense of disconnection and alienation from others including

significant others, their community, and mental health professionals. In the case of mental health professionals, they reported feeling under-treated or abandoned by the system and articulated strong mixed feelings regarding medication treatments. In contrast, they reported experiencing support and connection with others when blogging. This lack of support, understanding, and responsivity of others, including lay people, family/friends, and professionals, may perpetuate failure to seek help. Conclusions: The results stress the need for a community of practice approach that includes decreasing young adults' sense of disconnection and alienation by designing community systems, which are inviting and give young adults a voice, and include a range of treatment options. This could be achieved by developing alternative or supplementary forms of support in non-medical environments, capitalizing on peer support, providing vehicles for communication, friendship, support and connection, as well as education/awareness training to the those around the sufferer in terms of how to best offer support and help and to reduce stigma.

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Readability of the Top 50 Prescribed Drugs in Wikipedia

Research

Background: Wikipedia is one of the most frequently used resources by online health information seekers based on search rankings and page views. One benefit often ascribed to Wikipedia is its consumer-friendly content. However, the readability of Wikipedia's drug information content has never been systematically evaluated. While the average reading level of most Americans is between 6th to 9th grade, the average American seeking health information on-line typically has a college education, and by extension a likely higher average reading level. Objective: The purpose of this study was to assess the readability of Wikipedia entries for commonly used medications using a novel measurement tool and the Flesch-Kincaid Grade Level (FKGL). Methods: The 50 most commonly prescribed drugs in the USA were identified and the corresponding Wikipedia entry pages were located and saved as HTML files for evaluation purposes. Two investigators independently analyzed each entry using FKGL and the author-developed health information readability analyzer (HIReA) was also employed. HIReA was developed, in part, to integrate dimensions other readability tools lacked including: lexical, syntactic, semantic, cohesion and style and yields values of -1 (very hard) to 1 (very easy). FKGL and HIReA scores were generated, recorded, and subsequently examined using descriptive statistics for the sample described. Results: All of the top 50 drugs had entries in Wikipedia. The readability analysis yielded a mean FKGL of 15.4 for the Wikipedia entries, with a mean HIReA for the entries of -0.4999. The easiest to read entry by FKGL was for Dyazide (9.6), which was also the second easiest to read according to HIReA (-0.25). According to HIReA, Zestoretic (-0.17) was the least difficult to read. Those most favorably scored entries are both combination products. Alternately, the sample drug with most difficult readability value using FKGL was lansoprazole (19.8), whereas with HIReA the entry for hydrocodone (-0.845) was measured as the most difficult to read. Dimensional analyses from HIReA indicated the difficulty of the documents as primarily that of the semantic domain (i.e. hard vocabulary) (-0.8409) relative to cohesion (-0.5922), syntactic (-0.4845), lexical (0.0128), and style (0.0149). Conclusion: The reading skills required for the 50 drug entries in Wikipedia are appreciably higher than the targeted levels for consumers as measured by both the FKGL and HIReA. The greatest hurdle to overcome for the readability of the entries is the semantic aspect. While all Wikipedia entries can be made more consumer-friendly by simplifying the vocabulary, this may be insufficient to achieve the target readability; the lexical and syntactic constructs need to be concurrently improved without loss in cohesion in order to truly enhance consumer comprehension.

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Use of the Internet for Health-related Information in Japan: a Cross-sectional Population-based Survey

Research

Background: Previous studies have reported that the general public uses the Internet to obtain health-related information (40% in USA in 2002, 52% in Europe in 2007). However, the effects on actual health care utilization (e.g., number of physician visits) were less substantial than some have claimed. Cellular phones are also used widely to access the Internet, but little is known regarding e-health activities in a representative population in Japan. Objective: The present study aimed to measure prevalence of Internet or email use with personal computers and cellular phones to obtain health-related information, and to examine the relationship between their use and user characteristics. Methods: We designed a cross-sectional survey of the Japanese general population aged 15-79. Study participants were selected by stratified multistage random sampling. In September 2007, we conducted a questionnaire survey which used a self-reported placement method, where sample size was targeted at 1200. The survey contained questions pertaining to subject characteristics and use of the Internet or e-mail to obtain health-related information with personal computers or cellular phones in the last year, respectively. Logistic regression analyses investigated the relationship between Internet or e-mail use to obtain health-related information and user characteristics (age, sex, annual household income, educational attainment, self-reported health status, and residence). Results: Our analysis was performed on the 1200 survey respondents. Mean (±SD) age was 46.3 (±17.4), 49.6% were males, 18.7% had obtained at least a college education, and 41.0% reported at least six million yen as household income. We found that 23.8% (286/1200) used personal computers to obtain health-related information, and that access via personal computers was significantly related to the following: 50-64 years old (adjusted odds ratio [confidence interval]:0.6[0.4-0.9]), 65-74 years old (0.2[0.1-0.4]), over 75 years old (0.2[0.04-0.6]) (20-34 years old used as reference), over 10 million yen income (2.5[1.3-4.7]) (less than 3 million yen income used as reference), 13-15 years of education (1.7[1.2-2.6]), and over 16 years of education (4.7[3.3-6.8]) (less than 12 years of education used as reference). On the other hand, 6.4% (77/1200) used cellular phones to obtain health-related information, and access via cellular phones was significantly related to being 50-64 years old (0.2[0.1-0.5]). Conclusions: We found that the general public use cellular phones (6.4%) less than personal computers (23.8%) to obtain health-related information through the Internet or e-mail. As for user characteristics, older age, lower education levels, and lower income could be a deterrent in terms of obtaining digital health-related information.

03:00 PM - 03:30 PM - Auditorium

Topic: Web 2.0 approaches for behaviour change, public health and biosurveillance

Chair: Gunther Eysenbach

Jeana H Frost, PatientsLikeMe, Cambridge, United States; Sally Okun, PatientsLikeMe, Cambridge, United States; Paul Wicks, PatientsLikeMe, Cambridge, United States; James Heywood, PatientsLikeMe, Cambridge, United States*

Patients Informing Practice: Post-Marketing Drug Data in PatientsLikeMe, an Patient-Centered Online Community (closing keynote - winner of the JMIR Medicine 2.0 Award 2009)

Research

Background: Typically, evaluating a new use of an existing drug is either expensive and time consuming or anecdotal and unstructured. In some cases, researchers conduct clinical trials to test off-label uses. Yet in many situations where drugs are off-patent, or are only used by a small population, providers and patients must rely upon their own individual-level experience to inform clinical practice. In this work, we explore how a patient-centered online platform could supplement trials to create a richer understanding of medical products by efficiently aggregating structured post-marketing data. PatientsLikeMe is a tool for patients, researchers, and caregivers (currently 40,000 members) across 9 condition-based communities to help members make treatment decisions, manage symptoms, and reason about outcomes. Members enter demographic information, longitudinal treatment, symptom, and outcome data, and drug evaluations. These are reflected back as longitudinal health profiles and aggregated reports. Over the last three years, patients have entered treatment histories and drug evaluations on thousands of medical products. These data may suggest the efficacy and safety of some drugs more efficiently and for longer duration than is feasible through formal clinical trials. Objective: We present the illustrative case of Amitriptyline - a drug with a single FDA approved purpose (depression) which is commonly used to manage other symptoms. There are currently 14 Amitriptyline clinical trials recruiting subjects (clinicaltrials.gov) reflecting an ongoing interest in its use. Method: We conducted an analysis of treatment histories and drug evaluations across usage scenarios for Amitriptyline, examining prevalence, treatment purpose, and evaluations of efficacy, side-effects, and burden. Results: There are 602 treatment histories and 220 evaluations of Amitriptyline across 5 PatientsLikeMe communities (In MS, Parkinson's, Mood Conditions, Fibromyalgia, and ALS). Depression is the fourth most commonly reported purpose after pain, insomnia, and excess saliva. In Mood Conditions, the top purposes reported were headaches, pain, insomnia and then depression. Prevalence is highest in the ALS community, where 166 people (8%) report taking the drug with the most common purpose being to control excess saliva (39%). In the treatment evaluations, reported efficacy varies across purposes. More people reported a moderate or major effect of the treatment who were taking it for insomnia (67%, N=42), general pain (63%, N=51), or neuropathic pain (78%, N=18) versus those taking it as an anti-depressant (36%, N=25) or to control excessive saliva (37.5%). The burden and side-effects reported also differ by purpose. The small sample of patients taking Amitriptyline for excess saliva who evaluated the drug report nothing beyond mild side-effects (N=10) and no burden (N=10). Some patients taking Amitriptyline for the other common purposes (Insomnia, Depression, Pain and, Neuropathic Pain) do report moderate and severe side-effects (28%, N=136) as well as burden (23%, N=136). Dry mouth and daytime sleepiness are the most commonly cited side-effects. Conclusions: PatientsLikeMe offers a unique real-time approach to understand both utilization and performance of drugs across different populations. This patient-supplied data can provide evidence about

secondary uses such as control of excess saliva, or about drugs that are off-patent and therefore unlikely to be studied systematically.

03:30 PM - 04:30 PM - Auditorium

Topic: Ethical & legal issues, confidentiality and privacy

Joan H. Dzenowagis, World Health Organization, Geneva, Switzerland; Kevin A. Clauson, Nova Southeastern University, College of Pharmacy, Palm Beach Gardens, United States; Francisco J. Grajales Iii, eHealth Strategy Office, University of British Columbia Faculty of Medicine, Vancouver, Canada*

Ethics 2.0: Implications for Connected Health (Panel with interactive audience response system)

Research

Does the Social Web demand a new ethical paradigm? Not only is the broad adoption of Web 2.0 tools and services dramatically changing patterns of interconnection in the health domain; it is also raising new questions about content stewardship. Of concern from an ethical perspective is that health-related data are made available, or potentially available, through the actions of individuals, communities or websites. These technologies have created a Web 2.0 enabled nexus wherein consumers, health care professionals, business entities and "virtual Samaritans" are meeting, interacting and collaborating. This includes creating new types of relationships where health data are generated and shared, such as with bi-directional advising on health matters and problem-solving health related dilemmas. Less evident is that vast repositories of individual health "data" are being generated by users who voluntarily post and share personal information in various forms of virtual communities. Further, privately-owned websites may collect, store, share or sell health data as part of their terms of use. Individual search data and patient-generated content are also aggregated and characterized by search engines. Third parties may have access to the data, without the users' knowledge or consent, to study, advertise, profit from, and target consumers. In addition, publicly available application programming interfaces or embedded search capabilities enable any person with basic computing skills to obtain access to data and use or misuse it. These patterns and practices underscore the need to examine what Web 2.0 demands in terms of ethical conduct in the health domain. How do concerns about health data ownership, provenance, reliability, responsibility, liability and rights - or what can be collectively thought of as content stewardship - impact privacy concerns and trust in connected health? How should governments or organizations protect consumers? Are liability issues relevant in the virtual world? Should Web 2.0 business practices be re-examined? Does the nature of health in Web 2.0 require different rules, or should traditional rules still apply? This interactive session will use an audience response system to engage the audience in exploring key ethical challenges in connected health. Panel members from academic and international organizations will draw on their expertise in public health, consumer safety and Social Web consumer behavior to highlight the challenges of Ethics 2.0; together the panel and audience will assess these issues and consider possible approaches to shaping the next-generation ethics of connected health.