

HCSNET WORKSHOP ON SOCIAL
TECHNOLOGY APPLICATIONS FOR
HEALTH AND MEDICINE

MELBOURNE ZOO

21-22 SEPTEMBER 2009



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WELCOME

A great deal of research supports the belief that social interactions affect people's health in various ways. Online communities have added a relatively new dimension to the lives of many people. This workshop brings together researchers and practitioners from medical, social and information technology communities to understand how social technologies might be used to support health and health initiatives: e.g. supporting people, their families and their communities in managing health; building and supporting communities of health workers and medical practitioners for improved communication and information sharing; allowing communities of health stakeholders (policy makers, practitioners, the public) to develop effective health-related policies and initiatives.

We intend this workshop to be a place to foster communication across the relevant disciplines in order to design and develop effective tools and user experience to support online health communities. In particular, we hope it will help the community build a collective understanding about online health and medical communities: from the health perspective, what support can a social network provide; from the social network community, how can they provide that support; overall, how can such systems be deployed, evaluated and adopted. We also hope that the workshop will build bridges across the communities (health and social networks), and even generate a sustained interest and community around this area. We envisage this workshop to be the first of a series.

We would like to thank all the presenters for their submissions and all the registrants for their interest in this topic. We would particularly like to thank our internationally renowned invited speakers: Dr. Patty Kostkova, of City University of London, and Dr. Frank Vetere, of the University of Melbourne. And of course thanks to the ARC, through HCSNet, for sponsoring this event, and Chris Cassidy for all her work in organising it. We look forward to an engaging and interesting workshop!
Lawrence Cavedon, Nathalie Colineau, Cecile Paris

ABOUT HCSNET

The ARC Research Network in Human Communication Science – HCSNet – was awarded five years' funding by the Australian Research Council in late 2004. The aim of HCSNet is to promote and facilitate interdisciplinary research in human communication science by connecting leading researchers in language, speech and sonics. Priority Research Areas in HCSNet are:

- Speech
- Effective Interfaces
- Next-Generation Search Technology
- Human Communication Disorders
- Perception and Action

By generating an explosion of new approaches and knowledge, the network aims to build Australia's reputation as a leader in communication science and technology via advances in areas as diverse as automatic speech recognition, distress call monitoring, hearing prostheses, web interfaces, and data retrieval and data mining systems.

Getting involved in HCSNet is easy: visit www.hcsnet.edu.au to sign up as a member of the network. You'll be added to our online profile database, and automatically receive our weekly electronic newsletter, HCSNet Update, which will keep you informed of HCSNet activities, including the annual SummerFest, and events in the range of HCSNet disciplines.

EFFECTIVE INTERACTIVE INTERFACES – HCSNET PRIORITY AREA

As our technology gets more complex, so do the interfaces we use to communicate with that technology. Communication breakdown in these interfaces is evident all around us: video recorder remote controls with

functionalities too complex to understand, and repeated frustration at call-centre automation via less than perfect speech recognition, are two very visible instances.

This doesn't need to be the case: humans are more complex than any devices we have yet created, but we communicate with each other effortlessly. This research priority area focuses on what it is that makes a human-computer interface, particularly one where speech is used as the mode of communication, effective. Can we achieve effectiveness by making these interfaces more 'natural', and if so, how natural should such interfaces be? In particular, what can we learn from human-human communication? What aspects of communication between humans does it make sense to attempt to mimic in human-machine interfaces? Can our understanding of the production and perception of music help make interfaces more effective and affective? By bringing together expertise from HCSNet contributing disciplines as diverse as speech processing, linguistics, psychology, human-computer interaction, graphics, music, and audio-visual communication, this priority area aims to shed new light on how we can improve human-machine interfaces.

VENUE INFORMATION

MELBOURNE ZOO

Be filled with awe and wonder as you explore the award-winning Melbourne Zoo. With more than 300 species of animals from all over the world, you won't believe that you're only 4km from the central business district. Stroll amid the lush tropical surrounds of the Asian and African Rainforests and be amazed by the rich wildlife that plays an important role in education, research and conservation

Melbourne Zoo is located only minutes north from the city centre, within Royal Park. The workshop is being held in the Rainforest Room at Melbourne Zoo. The Rainforest Room is next to the Lakeside Bistro, right near the Japanese Gardens.

Car parking is available (\$2 for 5 hrs) or you can take the tram or train. Tram 55 runs from William Street Monday through Sunday, stopping directly outside Melbourne Zoo. Trains run from Flinders Street Station on the Upfield or Gowrie lines Monday through Sunday, stopping at Melbourne Zoo's own Royal Park Station.



REGISTRATION AND GENERAL INFORMATION

VENUE

The workshop is being held in the Rainforest Room at Melbourne Zoo. The Rainforest Room is next to the Lakeside Bistro, right near the Japanese Gardens.

REGISTRATION DESK

The registration desk is the place for enquiries related to registration, the workshop dinner, and travel support reimbursement claims.

DELEGATE MATERIALS

Delegate materials include the following: Program, Information and Abstracts Book, name tag, pen and notepad, Workshop evaluation form, HCSNet Survey, and HCSNet brochure.

TRAVEL SUPPORT

Workshop participants who have been awarded travel support to attend the workshop are asked to submit travel and accommodation receipts to Chris Cassidy at the workshop to enable reimbursement to be made. For any queries regarding your award please contact:

Chris Cassidy
HCSNet Administrative Coordinator
Department of Computing
Division of Information and Communication Sciences
Macquarie University NSW 2109
Email: ccassidy@ics.mq.edu.au

REFRESHMENTS AND MEALS – INCLUDED IN YOUR REGISTRATION.

Morning tea, lunch and afternoon tea are provided for all registrants on both days.

Canape's and drinks will be served on Monday 21st September at 5pm.

WORKSHOP DINNER – OWN COSTS

7pm
Café Italia
56-66 University Street, Carlton
Sunny courtyard lunches, open air dining, dinners by the fire, Cafe Italia provides the most unique atmosphere.



PROGRAM

MONDAY 21ST OF SEPTEMBER

10:30am	Welcome and Introduction of Participants
11:00am	Presentations (15mins each including questions)
11:15am	Enrico Coiera, Annie Y.S. Lau, Farshid Anvari Healthy.Me: A “Facebook” for Healthcare
11:30am	Nathalie Colineau, Cecile Paris and Melody Wang Understanding the Use of Online Social Networks by Patients
11:45am	Barbara Kelly Establishing Support and Community in an Online Forum
12:00pm	Bernd Ploderer Opportunities and Risks of Social Network Sites for Bodybuilding, Health and Fitness
12:15pm	Lunch and Discussions
1:30pm	Keynote Speaker: Patty Kostkova (City University of London) Online Communities of Practise and Social Networking – What is the Potential?
2:30pm	Discussion Groups (topics TBD)
3:45pm	Afternoon Tea
4:15pm	Presentations (15mins each including questions)
4:30pm	Nguyen Lemai, Shanks Graeme, Vetere Frank and Howard Steve The Information Needs of Family Carers in Collaborative Healthcare
4:45pm	Hilary Davis, Victoria Hanna, Rens Scheepers, Steve Howard, Liz Sonenberg Envisaging ICT to Support Women with Type 1 Diabetes who are Either Pregnant or Considering Pregnancy
5:00pm	Russell Gruen Collaborative Development of Evidence Summaries for Clinical Decision-Making
5:30pm	Drinks and Canapés
7:00pm	Dinner with workshop participants – Café Italia, Carlton

TUESDAY 22ND OF SEPTEMBER

9:30am	Keynote speaker: Frank Vetere (Dept. of Information Systems, University of Melbourne) Problematizing Wellbeing and the Role of Pervasive Technologies
10:45am	Morning Tea
11:15am	Presentations (15mins each including questions)
	Jaiprakash Gupta and Vicki Biro Are We There YET? Using Technology to Keep Us on Track
	Shan Chen and Mary-Anne Williams Privacy Preservation as a Strategy for Developing Long-Term Engagement in eHealth Community
	Konstantinos G. Kazakos, Y.Fujiki, I.Pavlidis NEAT-o-Games: Novel Mobile Gaming for Obesity Prevention
	Desirée Kozlowski, Duncan Blair, Anna Brooks, Rick van der Zwan Toward an Interactive Assessment tool for Parkinson's Disease
12:15pm	Lunch
1:30pm	Wrap-up discussions: Where do we go from here?
2:30pm	Afternoon Tea

KEYNOTE PRESENTATION

PATTY KOSTKOVA

ONLINE COMMUNITIES OF PRACTISE AND SOCIAL NETWORKING – WHAT IS THE POTENTIAL?

“The impact of the Internet has largely been unforeseen, and it may have a revolutionary role in retooling the trillion-dollar health care industry in the United States” (June Forkner-Dunn 03). The amount of medical information available online and the increasing popularity of Web 2.0 and social networking tools, such as FaceBook and Twitter, has changed the way information are used by health care professionals and in particular by general public. Is there a real potential for improving the delivery of healthcare or are these just new buzz words?

This talk will address the issues surrounding the Internet delivery of medical knowledge to public and professionals, online communities for evidence-based quality assurance and the need for a personalisation and

user profiling. Social networking with increasing amount of user-generated content provides highly accessible source of real-time information for early warning systems (such as infection outbreaks) and can allow better understanding of public concerns about their health.

We will draw from the experience with the development and evaluation of the National electronic library of Infection (NeLI) www.neli.org.uk and international projects hosted by this infection portal accessed by over 400 000 users per month, and the recent study using Twitter to investigate user concerns about swine flu. Patty Kostkova is Head of the City eHealth Research Centre at the City University, London. Her research interests include e-learning, digital libraries and semantic web, Semantic Web and web services, health care ontologies, online communities of practise and the impact of Internet DLs on healthcare outcomes. <http://www.city.ac.uk/cerc/staff/patty.html>.

To contact Patty Kostkova please write to: patty@soi.city.ac.uk

KEYNOTE PRESENTATION

FRANK VETERE

PROBLEMATISING WELLBEING AND THE ROLE OF PERVASIVE TECHNOLOGIES

Frank Vetere from the Department of Information Systems, University of Melbourne will also be giving a keynote presentation. Frank's research interests are in Human-Computer Interaction (HCI) and Interaction Design. He works with colleagues in the Interaction Design Group to explore and understand the use of emerging ICTs (Information and Communication Technologies) and to develop methods for designing useful, usable and satisfying technology. He is Chief Investigator of a project investigating the use of social technologies to support young adults living with cancer, funded by the Peter MacCallum Cancer Institute.

ABSTRACTS

ENRICO COIERA, ANNIE Y.S. LAU, FARSHID ANVARI

Healthy.me: A "Facebook" for healthcare

At the Centre for Health Informatics, University of New South Wales, we have been awarded ~\$1 million in funding from the HCF Health and Medical Research Foundation to develop a new online research platform for healthcare consumers, called healthy.me. Through this platform, we are seeking to answer compelling questions on how Internet technologies shape and support the way healthcare consumers manage their health and decision-making. We think of healthy.me as a "Facebook" for healthcare, where consumers are encouraged to actively engage in the management of their health in a trusted environment. The concept "Healthbook" was one of the top 5 health ideas at the Australia 2020 Summit and has generated unprecedented interest and community support, with national radio coverage on ABC Radio's PM and Margaret Throsby shows, and extensive print coverage.

healthy.me contains an online personal health record that allows consumers to store their personal health information, share it with those they have given consent, and utilise the available services to manage their health together as a team. In addition, we are planning several novel designs using Web and social technologies to enrich consumers' online experience, promoting an online social environment where consumers actively engage and interact with each other. Overall, we are interested in designing a new model for consumers to manage their health, as well as evaluating how this new model of care supports consumers through different stages of their health.

BERND PLODERER**Opportunities and Risks of Social Network Sites for Bodybuilding, Health and Fitness**

This paper gives an overview of a field study on social network sites for bodybuilding. Many bodybuilders are role models for healthy living, but their passion for training and dieting sometimes borders on obsession and health-detrimental activities. This paper discusses the various challenges involved in such a passion and the role of technology therein. The contribution to this workshop is to illustrate how people appropriate social network sites to manage these challenges, while social network sites also change the nature of these challenges and potentially increase them. Understanding the opportunities and risks of social network sites is critical for the design of future technologies that promote sustainable healthy lifestyles.

BARBARA KELLY**Establishing Support and Community in an Online Forum**

When we speak face-to-face (F2F) we generally use different language than that used in written communication. Online interactions, however, tend to be blends of F2F and written communication. In this talk I will examine the language used by moderators and members in online medical and health support fora. In particular, this study tracks the language of new forum members and shows the evolution of their language use from more written-like standard forms toward the norms of established members, in particular moderators. I will show that new members seeking the support of the forum rapidly tailor their language use to that of the target community. By examining the metaphors employed across posts and the engagement of non-standard written forms such as reduced grammatical features and the use of acronyms I will show that language use can play a key role in establishing support and collaboration in an online health community.

HILARY DAVIS, VICTORIA HANNA, RENS SCHEEPERS, STEVE HOWARD, LIZ SONENBERG**Envisaging ICT to Support Women with Type 1 Diabetes who are Either Pregnant or Considering Pregnancy**

Our research examines technology-practice fit in healthcare, particularly in the context of the shared use of technology by different stakeholders such as individual patients and their families and key health professionals. This perspective is significant as existing theories of fit have been conceptualised around individual's use of IT only, and usability issues across the range of different stakeholder interactions in the health system are poorly understood. Utilizing a case study approach we explore the possibility of a novel ICT technology (social networking technology plus additional tools) to encourage social support for women with type 1 diabetes who are either pregnant or considering pregnancy. These women are often isolated as they represent a relatively small proportion of the diabetes community, and they lack the social support that peers or successful role models can provide. Drawing upon evidence from discussions with Type 1 diabetic women, we discuss how ICT may facilitate the sharing of diabetes management stories from successful role models, provide peer support through social networking and assist the women in the maintenance and control of their diabetes during what is a highly medicalised and emotionally challenging experience. We discuss how a novel ICT might enhance support for this group of women and its potential for effectively engaging a disparate range of stakeholders involved in their care.

NGUYEN LEMAI, SHANKS GRAEME, VETERE FRANK AND HOWARD STEVE**The Information Needs of Family Carers in Collaborative Healthcare Understanding the Use of Online Social Networks by Patients**

While the important role of family carers has been increasingly recognized in healthcare service provision, particularly for patients with acute or chronic illnesses, the family carer's information needs have not been well understood or adequately supported by health information systems. In this study, we explore the information needs of a family carer by analyzing the extensive online diary of a Vietnamese family carer supporting his wife, who was a lung cancer patient. The study provides a deep understanding of the information needs of the family carer and suggests a four-stage information journey model including identification, searching, interpretation and information sharing, and collaboration. A number of themes

emerge from the study including the key role of the carer, information filtering by the carer, information sharing and collaboration, and the influence of Vietnamese culture. The paper concludes with a discussion of the requirements for health information systems that meet the needs of family carers.

NATHALIE COLINEAU, CECILE PARIS AND MELODY WANG

Understanding the Use of Online Social Networks by Patients

In recent years, the development of social technologies, and, among them, the use of social networking sites, has become increasingly dominant. People generate and share content through wikis; they discuss and debate ideas through blogs; they follow friends and folks through tweets. While most online networking sites allow people to nurture their existing social connections, they have also been used to form communities of interest, bringing together people who share common interests or goals, or people who have similar medical conditions. In health in particular, social networking services have been flourishing, building on research supporting the connection between social relationships, wellbeing and health. However, in most cases, these networks tend to promote new online relationships rather than existing offline links, and quite often family and close friends are not part of these networks.

In an investigation of the currently available health related social networking services, our work focuses on understanding health related social networking sites and their users. Who are the users of such services? Would they want to involve their offline relationships in their online networks when it comes to health? Why do these people use online health communities? Is it mainly to gain information or to get emotional support? What kind of data do users share and with whom do they share this data? It is sometimes surprising to see how much personal information is disclosed with anonymous people. How do people use the existing technology to interact with others on matters of health? In this work, we investigate whether online health communities could be effectively used to encourage more social support from the patients family and existing friend relationships.

PROF. RUSSELL GRUEN

Collaborative Development of Evidence Summaries for Clinical Decision-Making

Evidence based health care practice is an approach to health care in which decisions are guided by the relevant evidence. Optimal use of evidence in health care is, however, hampered by the volume of information available and the rapid rate at which new information is produced. We propose addressing this issue through collaborative knowledge exchange supported by social technologies and novel ICT tools to deliver high quality, comprehensive, up-to-date evidence summaries for decision-making in clinical practice and policy development, thereby engaging multiple stakeholders in active communities and using a Web 2.0 platform for the collaborative development of evidence summaries.

Benefits of the proposed approach include:

- Identification and prioritisation of health questions to be subjected to evidence summary will shift from ad hoc decisions of individual research groups to the systematic and democratic choices of large communities of stakeholders.
- Individual evidence summaries will shift from being the work of a small group of collaborators to the shared product of global online communities.
- Evidence summaries will shift from being static documents to living online resources.

Some of the challenges to be addressed include:

- Designing engaging user experience for different participant communities;
- Implementing processes for collaborative authoring of resources that ensures a high level of quality of outputs;
- Engaging diverse stakeholders in a social technology platform and providing incentives for high-quality inputs.

JAIPRAKASH GUPTA AND VICKI BIRO

Are We There YET? Using Technology to Keep Us on Track

One of the key areas to improve the quality of service in a health system is to reduce health acquired infections (HAI). NSW Health has developed 22 HAI clinical indicators (CI). Some of the CI monitor intensive care units (ICU) some surgical procedures and others monitor the dangerous staphylococcus aureus related infection. Individual hospital's and Area Health Service's (AHS) performance is monitored by NSW Health by collecting data on a monthly basis on these CI. The goals have been set (CareSafe 2003-2009) as follows: 10% reduction in HAI rates by Jun 2008, 50% by Jun 2010 and 80% by Jun 2013. Currently data on 22 CI is collected using Excel spreadsheet format. The data collection method is as follows; individual sites send their data on various indicators individually on a templated spreadsheet and the information is collated by Area Clinical Governance Unit. The collated data is forwarded to Clinical Quality, Safety and Governance Branch of NSW Health. This process has some built-in issues; a) errors in entry/transferring data at site, area and state level, b) delayed feedback to sites as to how they are performing, c) time wastage in multiple entries and data cleaning process and d) reliability of data and consistency in reporting format. To resolve these issues we have developed an interface which we would like to share. The paper will demonstrate the program and discuss the advantages of using technology in health to keep us on track the goals that are set.

SHAN CHEN AND MARY-ANNE WILLIAMS

Privacy preservation as a strategy for developing long-term engagement in eHealth communities

Due to the rapid development of Web applications to support health professionals by providing health care services online (eHealth services), there is a need to develop long-term strategies for engaging consumers. Such strategies must retain consumers' confidence in providing clinical data to receive better services. One of the keys to achieving this aim is to preserve consumers' information privacy. Thus, developing privacy-preserving mechanisms is a fundamental strategy for consumers' long-term engagement. In recognition of such needs, this paper identifies underlying privacy problems in eHealth systems and investigates technologies that can be used or developed to secure consumer privacy in eHealth systems.

KONSTANTINOS G. KAZAKOS, Y. FUJIKI, I. PAVLIDIS

NEAT-o-Games: Novel Mobile Gaming for Obesity Prevention

The role of Non-Exercise Activity Thermogenesis (NEAT) has become a key component of obesity research, prevention, and treatment. Research that has started by the University of Houston and Texas Medical Center in early 2008 aims to suppress the obesity epidemic by infusing NEAT in the sedentary lifestyle of an average person. The method combines unobtrusive physiologic sensing and novel Human-Computer Interaction (HCI) technologies. It supports a strong motivational framework based on ubiquitous computer gaming, appealing enough to likely change the behavior of "couch potatoes" on their own volition. This novel generation of computer games (NEAT-o-games) is fueled by activity data recorded by small wearable sensors. NEAT-o-Games is a suite of games that runs on mobile terminals such as cell phones. Unlike other games, NEAT-o-Games' primary goal is to become part of people's everyday routines and attack the behavioral aspect of the sedentary lifestyle. Their main characteristic is that they are not carried out in short bouts, but are being played continuously and are interwoven in the daily routine of the players. Data from wearable accelerometers are logged wirelessly to a cell phone and control the animation of the player in a virtual race game (avatar) with other players over the cellular network. Players can use their excess of activity points earned from the race game to get hints in mental games of the suite, like Sudoku. Initial studies indicate that NEAT-o-Games may bring a positive physical, psychological, and social impact on players.

PD is a common neurodegenerative condition in which multisystem deficits occur. Motor symptoms including bradykinesia, hypokinesia, tremor or rigidity are generally most notable, particularly in the early stages of the condition. There is no established biomarker for PD and diagnosis and monitoring is by way of clinical assessment. A major challenge in the clinical management of PD is the highly variable nature of the condition, both in symptomatology and in the rate and pattern of disease progression. It is our aim with this project to develop a system of tests that might be administered regularly and remotely to gain a finer-grained picture of disease progression both to inform our understanding of the condition and as a tool to enhance clinical management. There are a number of simple tasks that have been shown to act as reliable indicators of symptom severity in PD including manual tracking and tracing tasks, spiral drawing, and verbal response tasks. The goal of this project is to develop a number of these in the form of online games for web delivery. This presentation will solicit ideas for developing on-line games that can evaluate PD progression in those living in regional and remote areas, and in those who otherwise socially are isolated.

WORKSHOP ATTENDEES

First Name	Surname	Email	Institution
Tania	Angelini	tania.angelini@dhs.vic.gov.au	Department o Services
Emily	Brennan	emily.brennan@cancervic.org.au	Centre for Behavioural Research in Cancer
Andrew	Campbell	A.Campbell@usyd.edu.au	The University of Sydney
Lawrence	Cavedon	lcavedon@gmail.com	RMIT University
Shan	Chen	shan.uts@gmail.com	University of Technology Sydney
Helen	Chenery	h.chenery@uq.edu.au	University of Queensland
Nathalie	Colineau	nathalie.colineau@csiro.au	CSIRO
Hilary	Davis	davish@unimelb.edu.au	University of Melbourne
Kathleen	Gray	kgray@unimelb.edu.au	University of Melbourne
Russell	Gruen	R.Gruen@alfred.org.au	Alfred Health and Monash University
Jaiprakash	Gupta	Jai.Gupta@sesiahs.health.nsw.gov.au	South Eastern Sydney Illawara Area Health

Victoria	Hanna	vhanna@unimelb.edu.au	University of Melbourne
David	Haubenschild	david.haubenschild@dhs.vic.gov.au	Department of Human Services
Konstantinos	Kazakos	k.kazakos@pgrad.unimelb.edu.au	University of Melbourne
Barbara	Kelly	b.kelly@unimelb.edu.au	University of Melbourne
Patty	Kostkova	patty@soi.city.ac.uk	City University of London
Desiree	Kozlowski	desiree.kozlowski@scu.edu.au	Southern Cross University
Annie	Lau	a.lau@unsw.edu.au	UNSW
Lemai	Nguyen	tieumoclan@gmail.com	Deakin University
Geradine	O'Sullivan	gerardine.osullivan@dhs.vic.gov.au.	Department of Human Services
Cecile L.	Paris	Cecile.Paris@csiro.au	CSIRO
Jon	Patrick	jonpat@it.usyd.edu.au	University of Sydney
Carol	Pedersen	carol@itee.uq.edu.au	University of Queensland
Bernd	Ploderer	b.ploderer@pgrad.unimelb.edu.au	University of Melbourne
Timothy	Smith	tim@variome.org	University of Melbourne
Liz	Sonenberg	l.sonenberg@unimelb.edu.au	University of Melbourne
Frank	Vetere	f.vetere@unimelb.edu.au	University of Melbourne
Jenny	Wale	socrates@q-net.net.au	Cochrane Collaboration Consumer Network
Terence	Harrison	terence.harrison1@gmail.com	Melbourne Health