Moving Beyond eHealth Systems for ‘People Like Us’

Paul Turner\textsuperscript{a}, Andre Kushniruk\textsuperscript{b}, Pernille Bertelsen\textsuperscript{c}, Luis Falcon\textsuperscript{d}, Chris Showell\textsuperscript{e}

\textsuperscript{a} eHealth Services Research Group, University of Tasmania, Australia
\textsuperscript{b} School of Health Information Science, University of Victoria, in Victoria, British Columbia, Canada
\textsuperscript{c} Department of Development and Planning, Virtual Centre for Health Informatics, Aalborg University, Denmark
\textsuperscript{d} President, GNU Solidario Free Software, Argentina

Abstract and Objective

The tendency to design personal ehealth systems for well to do technically literate professionals, rather than average or disadvantaged users (the PLU problem), has been described previously, but is not yet well understood. This interactive workshop will introduce attendees to the PLU problem, expose them to a simulated experience of being a disadvantaged system user, and encourage them to share their experiences of systems which may exclude disadvantaged users. Attendees will also discuss ideas and potential solutions for the design of more inclusive ehealth systems, and identify positive steps which could ameliorate or avoid the problem in the future. Key outputs of the workshop will include a summary of the information provided by attendees, draft criteria for identifying potential PLU-type problems, and an interim list of possible or actual solutions.

Keywords:

electronic health records, health literacy, disadvantaged, vulnerable populations.

Workshop description

General topics

Healthcare systems around the world are facing persistent issues of cost, quality and access. eHealth systems are often proposed or implemented as a way to reduce cost and to improve the quality of healthcare services for underserved and disadvantaged patient groups.

When thinking about potential users of personal ehealth systems, the wide range the skills, abilities, needs and motivation which they bring to the interaction represents an extremely complex matrix of possibilities. As a thinking tool, it can be helpful to conceptualise two archetypal groups of users, the first with high levels of skills and motivation, and the second with much less.

The first conceptual group comprises individuals with a good understanding of health and healthcare (although they are not necessarily health professionals). They are motivated to take action to maintain their health (when they are well), or to restore their health (when they are ill). Members of this group show a high level of textual, technical and health literacy, and have sufficient financial resources to allow their access to technical and other resources whenever they wish. These are ‘people like us’ – PLUs.

The second group are much less familiar to us. We are unlikely to meet them socially, in family situations, or in the workplace, although we may see them as a client or patient if we are a service provider. In effect, they are largely invisible to us, which makes it all too easy to forget them as potential system users. Members of this archetypal group are unlikely to participate in sport or other exercise, and may consider ‘fast food’ to be a meal. They may not have completed secondary education, and if they are employed, they will be in a low-paid job, perhaps as a casual, and are not financially well off. Members of this group can be thought of as being disempowered, disengaged and disconnected (the ‘DDDs’).

Earlier work\cite{Showell, 2013} has highlighted that the systems which we design for healthcare (including information systems) are in the main designed by PLUs - people who are well-off, tertiary educated, and members of the ‘middle class’ (if class still matters). The first instinctive conceptualisation of the system that is being designed is one which meets our needs and makes use of our abilities and resources. This tendency to design systems which suit a partial (although perhaps large) group of users, and to ignore an important minority group of DDDs has been described as “the PLU problem”.

The PLU problem leads to healthcare services and systems which may not be suitable for the most needy patients. The complex tasks of scheduling and care coordination are left to the patient, advice is given to the patient verbally, or as complex written instructions, or using specialised clinical terminology, and rarely is a patient asked whether they can read. Similar problems are likely to be present with ehealth systems intended for use by patients.

The trend towards an increased reliance on ehealth for the delivery of patient care may not achieve the results that are sought, and may even be counterproductive. There is a risk that patients who are profoundly disadvantaged (DDDs) will struggle to gain benefit from personal ehealth systems, while their access to conventional health services grows worse. Additional on-line service options will be provided for the PLUs, who are well placed to take advantage of new technology. However, it is unlikely that these new services will be funded with ‘new money’. Indeed, ehealth services are often promoted as a way of saving money, and their introduction may lead to a reduction in the level of conventional services.

To date there have not been widespread discussions of the PLU problem, or a concerted focus on understanding the particular needs of disadvantaged groups such as the DDDs. It is now time to develop a shared understanding of the health ser-

\footnote{Showell, C. & Turner, P., 2013. The PLU problem: are we designing personal ehealth for People Like Us? Studies in Health Technology and Informatics, In Press.}
vice needs (including ehealth needs) of this often underserved group.

Good practice in health informatics requires that we consider the particular needs and requirements of the intended users of the system. Because of their invisibility, the DDDs are left out of this consideration by default, and will only be included within the scope of ehealth developments by specific intention.

It appears that this intention to include the DDDs in scope is rarely in evidence. A recent literature review identified 45 articles in PubMed which described the design, implementation or evaluation of personal EHRs. Only 8 of those articles specifically mentioned users who, through some form of disadvantage, may have difficulty accessing the system.

It was interesting that one of those articles suggested that the problem was with the disadvantaged users. The solution which was proposed was to require targeted education and training to raise the users’ skill levels to meet the demands imposed by new systems.

**Workshop structure and arguments**

This workshop will explore aspects of the PLU problem in three parts (A, B and C). In Part A of the workshop attendees will be introduced to the dimensions of the PLU problem as it emerges in the literature and in practice, and invited to reflect on their own experience in that context.

In part B of the workshop, attendees will participate in an interactive simulation which will provide them with the experience of being an ehealth system user whose access is inhibited by diminished literacy skills.

Part C of the workshop will include a discussion of approaches used in developing countries to counteract or sidestep barriers to the use of ehealth systems, and attendees will be invited to contribute ideas and opportunities which may have the potential to reduce or overcome the PLU problem.

With guidance from the presenters, they will prepare an interim list of interventions which could ameliorate or avoid the PLU problem in the future.

The outputs of the workshop will include a summary of the anecdotal evidence about the PLU problem and possible solutions, a set of draft criteria which will help to highlight and address PLU-type issues during the design, development, implementation and evaluation of personal ehealth systems, and an interim list of possible or actual solutions which could counteract the PLU problem.

These outputs will be published on a website, and maintained over time as comments and suggestions are contributed by visitors to the site.

Part A of the workshop will begin with two 10 - 15 minute presentations which will explore the nature of disadvantage as it applies to underserved healthcare recipients, and introduce the PLU problem. Attendees will then be encouraged to share their own experiences regarding the provision of health services and ehealth services to disadvantaged patients.

Part C of the workshop will provide two 10 - 15 minute presentations exploring both theoretical and practical solutions which can be applied to the challenge of healthcare service delivery in underserved and disadvantaged groups.

Specific educational goals

The workshop is designed to encourage all attendees to consider whether and how their personal biases might influence their approach to ehealth solutions. In particular, do the solutions to which they contribute show a “PLU-type” bias?

Attendees will learn to increase the skeptical attention which they direct to personal ehealth systems, and begin to develop an appreciation of implementation approaches which can limit or remove PLU problems.

In the weeks following the workshop, the threads of discussion will be collated, and distributed to attendees for review and affirmation. Following the receipt of feedback, the outcomes of the workshop will be prepared for publication and dissemination in a suitable forum, with the aim of providing informal guidance for clinicians, policymakers and health informatics practitioners to help with the early identification and remediation of PLU-type problems in system commissioning, design, development, implementation and evaluation.

Expected attendees

This workshop is intended for those involved in the development and implementation of health policy and ehealth policy, health informatics professionals, designers, developers and evaluators of ehealth systems, those in academia who are involved in teaching and research in the field of health informatics; and students and early career professionals with an interest in health informatics and personal eHealth systems.

**Workshop speakers (proposed – yet to be confirmed)**

- Paul Turner, PhD, MSc, BA(Hons), MACS, Associate Professor, eHealth Services Research Group, University of Tasmania, Australia
- Andre Kushniruk, BSc, BA, MSc, PhD, Professor, School of Health Information Science, University of Victoria, in Victoria, British Columbia, Canada
- Pernille Bertelsen, Cand.tech.soc, Ph.D, Associate Professor, Department of Development and Planning, Aalborg University, Denmark
- Luis Falcon, Computer Scientist and Medical Student, President, GNU Solidario Free Software, Argentina
- Chris Showell, B.AppSci (MLS), Grad Dip Prof Man, PhD candidate, eHealth Services Research Group, University of Tasmania, Australia