The PLU problem: are we designing personal ehealth for People Like Us?

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Abstract: The near-pervasive introduction of ehealth systems, and the more recent implementation of systems intended for patient use offer patients the opportunity to participate in their own care, but these systems may work better for “People Like Us” than for those on the wrong side of the ‘digital divide’. This paper looks at the professional, practical and ethical implications of this conundrum.

Keywords: electronic health records, disadvantage, information systems

Introduction

As the diffusion of personal ehealth systems grows, we face a critical challenge. This paper argues that the current approach to the design of personal ehealth systems may serve to accentuate the gap between privileged and disadvantaged end users and healthcare recipients, rather than improving equity of access to health care services.

The problems facing healthcare services in the developed world are well documented and understood. They include financial challenges from increasing treatment costs [1], resource scarcity with an aging workforce, and an increasing burden of chronic disease [2]. Where healthcare is publicly funded, Governments also face the politically sensitive challenge of determining appropriate healthcare service levels in an environment of increasing citizen demands and expectations for care. Health reform remains a critical area for policy debate and has led to a range of solutions to address the problems we face. In Australia, ehealth systems are seen as one set of solutions to these problems. Unfortunately many of these ehealth systems have delivered mixed results or have not generated the predicted savings as a result of designs that under-estimate the complexity of healthcare practice.

One response to these design challenges has been to focus on personal ehealth systems tailored and customised to the needs of individual health users. One example is Australia’s personally controlled electronic health record (PCEHR) which was launched in July 2012. However, differences in the individual knowledge, skills and inclination to use such systems result in a system suitable for a privileged group of literate and motivated end users, rather than for those most urgently in need of improved health service delivery.
1. Background

Those working in ehealth see a potential for novel applications to support improved health outcomes. They are often enthusiastic proponents and early adopters of mobile health apps which allow access to electronic health records. Many share a vision that personal ehealth systems will improve the ‘quality’ of healthcare by reducing cost, improving safety, facilitating access to health services, and ensuring timely care.

Australia’s National E-Health Transition Authority (NEHTA), for example, suggests that a Personally Controlled Electronic Health Record will improve: “…the self-management of stable chronic diseases…communication between clinicians and individuals…[and] decision making by…individuals…” [3]. Pagliari and colleagues, writing in the British Medical Journal, suggest that personal electronic health records “…have the potential to empower patients through greater access to personal data, health information, and communications tools…increase patient safety…[and] improve[e] continuity of care and efficiency.” [4]

Broadly, the justification for the development and implementation of personal ehealth solutions relies on the notion that they will enhance one or more measures of the ‘quality’ of healthcare services, as shown diagrammatically in Figure 1.

![Figure 1: Typical approach to implementing patient-focused ehealth solutions](image)

2. Methods

We explored the literature in an attempt to better understand the relationship between literacy and personal ehealth. Using a combination of ehealth/personal ehealth and literacy/health literacy, we identified 100 papers, 17 of which we reassessed as being relevant to an examination of broader characteristics of healthcare recipients. The conventional approach to segmentation is to separate the population according to socioeconomic status (SES), which is essentially a linear scale. We preferred to view the population as a collection of groups or clusters determined by other factors in addition to SES.

We envisioned two clusters separated according to their willingness and ability to use a personal ehealth record – a high-uptake group, and those who would use ehealth the least. Our high-uptake cluster includes people who understand healthcare and health issues, take care of their own health, are literate, well to do, tech-savvy, and hold a tertiary qualification. We recognised ourselves as being members of this group. These are the People Like Us (PLUs). Those within our low uptake cluster are disinclined to take exercise for its own (or their own) sake, or to eat sensibly. They are not text-health- or technically-literate. They struggle financially, and may not have finished
secondary education. We see them as disempowered, disengaged and disconnected – the DDDs. This simplistic characterisation provided archetypes of two extremes and pointed to factors which could affect eHealth uptake, as noted below.

Clarke and Leigh [6] contend that differences in life expectancy between demographic groups in Australia provide stark evidence of continuing health inequality. They identified significantly increased mortality associated with income (odds ratio 1.88), education (1.25) and a low socioeconomic index (1.32). According to the Australian Institute of Health and Welfare [7] those living in the least advantaged areas of Australia are more likely to smoke, be physically inactive or obese, have diabetes, behavioural problems, asthma, heart disease or arthritis, and have higher mortality across most chronic conditions. Adult literacy also presents a problem for many in Australia. The Australian Bureau of Statistics reported in 2006 that 16.7% of adults were at prose literacy Level 1 (trouble completing a basic form; may find some information on a medicine label), and 29.7% at Level 2 (may not be able to summarise text) [8]. Health literacy is also a problem. The US Agency for Healthcare Research and Quality found that poor health literacy was “...associated with increased hospitalisations, greater emergency care use...and, among seniors, poorer overall health status and higher mortality.” [9] The disadvantaged are less likely to have home internet access, and there is evidence that living in a rural area and having a medical condition will make home internet use even less likely. [10] The inter-relationship between all of these factors is complex, and it can be difficult to separate cause from effect. However, it is apparent that there is an association between low income, poor literacy (textual, technical and health), chronic disease, and poor health outcomes.

For better or worse, healthcare systems are developed predominantly by white, educated middle class professionals – PLUs – who design systems and processes which they see as being appropriate and user-friendly. This tendency to design for ourselves (the PLU problem) results in patient instructions using complex language; patients receiving complex verbal descriptions of health issues using clinical terminology; and carries an assumption that online tools are an appropriate option healthcare services.

Catwell and Sheikh [11] considered the evaluation of eHealth systems, and argued that the evaluation should be continuous and systemic. They cautioned that “[…]large investments in eHealth may, by diverting resources result in a shortfall in funding for basic infrastructure, equipment, and staffing elsewhere in the system. …investing in developments such as telemedicine, which are only likely to be accessible to a minority, would exacerbate the digital divide and existing health inequities.” [11]
and facilitate a reduction in funding from other, more conventional healthcare services. This unintended adverse consequence of eHealth investment is shown in Figure 2.

Many of the processes, systems and technologies intended to provide supportive care and self-care are tailored for a potential user who is very like the designer. Patient-focused eHealth initiatives may well be suited to a demographic cohort that is well off, tech savvy and street smart, but may be less helpful in areas of healthcare where the individual’s needs are great, and the cost of meeting those needs is high.

PLU systems will place additional resources at the disposal of those who are adaptable and capable — those who probably do well with existing systems and services. Making reasonably healthy people a little bit healthier is not necessarily the most effective use of scarce health resources. Better cost benefits in terms of health outcomes are likely to be achieved by focusing on the DDDs whose health is worst, rather than designing and implementing for the PLUs.

A report from the European Union [12] comments on the introduction of Ambient Intelligence (AmI) in healthcare. The report notes:

“AmI claims to be particularly people-oriented, implying that it will also be inclusive - providing, of course, it lives up to its promises of being user-friendly, unobtrusive and controllable. But…the fundamental question remains…[will] AmI … include the majority of people or…benefit mostly young, urban and mobile technofreaks. In the latter case, AmI could become an additional source of exclusion in society.” The report cautions that “[t]he relation between social exclusion and health status is well known. Digital divides…can negatively affect health.” [12]

The greatest challenge (arguably) is providing healthcare services to those who lack the motivation and capacity to make positive changes in their lives. They show little interest in adopting a healthy diet; regular exercise doesn’t interest them; if they smoke, they’ll probably continue to do so. Their poor literacy will make it hard for them to adapt to a routine of regular medication, and they will struggle to monitor their symptoms effectively. They may benefit from some form of mentoring, possibly with a technology component, but it will need to be carefully targeted at their capability, skills and worldview. The solution to the challenge of poor uptake (by DDDs) is often framed as requiring better solutions, including eHealth, Internet access, or training. But many of the processes and systems designed for supportive care and self-care are tailored for the designers – for us. We believe that the consideration of a class of user who faces near-insurmountable barriers to technology uptake in any conceptualisation or design of personal eHealth systems will help to clarify the scope of intended users.

3. Discussion

Solutions to healthcare problems should be targeted at those with the greatest need. However, a PLU-designed health service, or a PLU designed eHealth system is unlikely to deliver benefit to all groups of patients. The needs of the DDDs should be considered as a special case, and explored in some detail. Once those needs are clearly understood, they should either be either incorporated into the overall design, or provided for through a focused alternative, which may not include citizen or patient use of an eHealth system. It may be more appropriate to design and implement solutions which are tailored for the limited capabilities of DDDs, and extend implementation progressively to other groups until marginal benefits become too small to fund. Designers should focus on user centred design, as many do, but in doing so should take
care to identify and specify the class of user to which the initiative is targeted. The sense of disempowerment among our DDDs will make them reluctant to participate in a design activity. They may struggle to express themselves, or to see their opinions as having merit. Because of the many categories of limited capability which interfere with the use of technology by our DDDs, this approach is likely to be more difficult to implement, and less interesting for designers and developers - these are unlikely to be solutions which creators and implementers would want to use. However, in terms of overall cost benefit, the approach could be very rewarding.

A modified design process could include: a positive effort to engage with “lowest common denominator” users; using observation as a way to understand how DDDs interact with systems and with healthcare; matching prompts and documentation to the reading level of users; and using pictograms (‘IKEA instructions’) to enhance understanding. Implementers should also be clear about whether there is a workable “non-e-” alternative to the personal ehealth option for those who cannot or will not use the technological solution. Can it be provided at the same or lower cost? And what is the overall cost to the health system to provide that service to those who need it most?

4. References