

# The Invisibility of Disadvantage: Why Do We Not Notice?

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**Abstract.** Personal health records (PHRs) offer tantalising benefits for patients and healthcare providers, including improvements in patient-provider communication, patient empowerment, and access to data and information. A suspicion that disadvantaged patients are less likely to use or benefit from PHRs stimulated a research agenda that included: (a) a literature review; and (b) empirical analysis of eight years' hospital admission and discharge data linked to measures of patient social disadvantage. The results demonstrated an association between disadvantage, increased use of public hospital services and barriers to PHR use. These findings may appear self-evident, but dramatically highlight how disadvantaged patients continue to be overlooked in many e-health design processes, and are rarely a focus of user centred design. The paper concludes by briefly considering the implications of this invisibility.

**Keywords.** Personal health records, Barriers, Disadvantage.

## 1. Introduction

Current trends in patient centred health informatics suggest that there are significant benefits for patients when they make use of personal health record systems (PHRs), which have been defined as "...a private, secure application through which an individual may access, manage, and share his or her health information." [1, p. 244] The potential benefits include better patient-provider communication, patient empowerment, access to health self-management, and improved access to data and information [2], [3]. However there is little evidence that the incorporation of PHRs into the everyday provision of health care will be an appropriate solution for all patients. As Rigby and Ammenwerth have recently noted, the development and use of informatics in health care has been marked by a "...lack of clear strategic investment decisions, and lack of evidence, [which] interlink." [4, p. 4]

This paper summarises and contextualises research completed as part of a doctoral thesis, based on empirical data analysis of eight years' hospital admission and discharge data linked to measures of patient social disadvantage [5]. The research originated in a lingering concern that patients who are at a socioeconomic disadvantage are likely to face a 'triple threat' because of the difficulties they face with low income, increased health needs, and challenges with textual, technical, and health literacy.

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These individuals are often ‘disempowered, disengaged and disconnected’, and have been largely invisible in the process of health records development. [6], [7]

The research was conducted in two phases. The first phase involved a critical appraisal of the research literature to characterise the relationship between socioeconomic disadvantage and personal electronic health records. In this phase refereed publications were used to delineate, test and validate ideas and concepts. These publications considered: the way in which ordinary literate citizens might be marginalised by the use within PHRs of specialised medical language and terminology, SNOMED CT in particular [8]; the omission of these same citizens from discussions about the direction of Australia’s ehealth policy [9]; and a widespread tendency for PHRs to be designed by and for an insider elite of ‘People Like Us’, with the approaches taken in the design, implementation and evaluation of PHRs being likely to ignore the preferences, needs and capabilities of disadvantaged users [6], [7].

Publications from the first phase of the research identified aspects of personal electronic health record systems that could limit their usefulness for disadvantaged patients, and prompted the subsequent research described below. This was conducted during 2013 and 2014, using a two-part approach. First, a literature review explored current evidence about barriers to the uptake and continued use of personal electronic health records. Second, empirical data analysis was used in an attempt to delineate, in an Australian setting, a group of disadvantaged healthcare users likely to face higher barriers to the adoption and use of PHRs.

## **2. Methods**

The literature review targeted publications providing evidence about barriers which might prevent the adoption of a PHR, or interfere with its continued use. The review covered refereed items published in English after 2003. Publications which focused on barriers for providers or provider organisations were excluded. Thematic analysis was used to identify core themes within publications

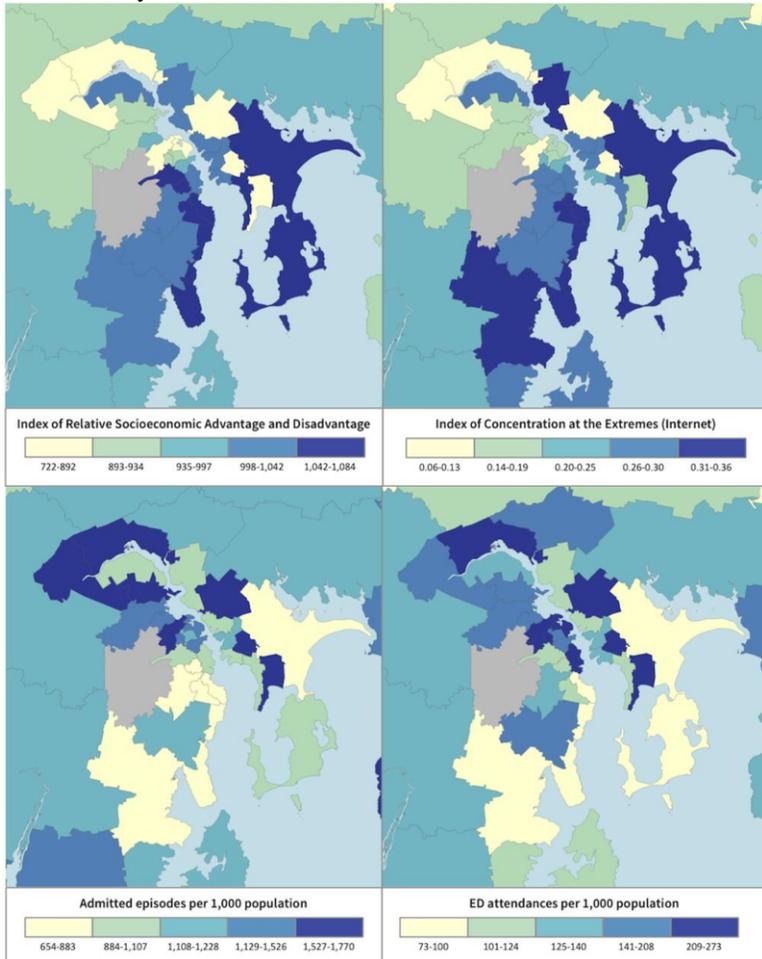
The investigation of disadvantage, health service use and PHR barriers involved an empirical analysis of data covering the 96 geographic areas in Tasmania. This data included: three of the Australian Bureau of Statistics’ Socio Economic Indicators for Areas (as measures of disadvantage); deidentified patient records for 800,000 public hospital admitted episodes and 1.3 million emergency department attendances (around eight years’ data); and area measures of education, internet access and qualifications (as proxy measures for text-, technical- and health literacy). Cluster analysis of measures for disadvantage, healthcare use and identified PHR barriers was used to identify groups within the data, with choropleth maps used to visualise significant trends.

## **3. Results**

The literature review [10] found evidence of a range of barriers that may interfere with the adoption and continued use of PHRs. Across the 40 included publications there were 21 individual barriers identified. These included: age; race or ethnicity; income and socioeconomic status; education; text, technical and health literacy; internet and computer access; and disability. Twelve of the 21 barriers identified had an association

with socioeconomic disadvantage. Barriers were found in all phases of PHR adoption, and in all types of investigation. As a secondary outcome, the review also identified a number of PHR evaluations that may have introduced a selection bias by actively excluding low capability participants. Since it was not possible to deduce the relative importance of particular PHR barriers from the frequency of their appearance in the research literature, the review did not attempt to rank the significance or prevalence of the barriers identified.

The analysis of hospital service use [11] showed that patients from areas with a low socioeconomic status used public hospital services at a higher rate, and had longer inpatient stays; these areas also had a higher incidence of factors associated with barriers to PHR use. Cluster analysis identified two distinct subgroups of areas with disadvantaged, low capability users receiving more public hospital care, and proxy measures suggesting barriers to PHR adoption and use, in contrast to more privileged capable subgroups using much less care. Figure 1 presents choropleth maps which highlight the dichotomy between these clusters.



**Figure 1.** Maps of increasing financial resources and internet use (top) and hospital and ED use.

The maps focus on the most populous area of Tasmania, with Hobart, the state capital, in the middle of each map, and the Derwent estuary to the bottom right. The upper two maps show measures of overall financial wellbeing (L) and internet access (R). Those in the second row show admitted hospital episodes (L) and emergency department visits (R), both measured per 1,000 population. Colours change from lighter to darker as values increase, with significant overlap between the palest neighbourhoods in the first row (more disadvantage and worse internet access) and the darkest neighbourhoods in the second (more health service use and PHR barrier factors).

#### 4. Discussion

This paper has briefly summarised detailed evidence identifying those areas in Tasmania whose populations have higher levels of socioeconomic disadvantage, higher use of public hospital services, and proxy measures suggestive of lower literacy. These areas also have a higher incidence of chronic disease and of capability barriers which are likely to limit any potential benefit from PHR use. PHRs as they are currently implemented are unlikely to provide a universal solution for problems with healthcare delivery or communication. These findings highlight a need for more attention to be paid to the implications of disadvantage during PHR design, implementation, and evaluation. A careful assessment is required of the relevance of each potential barrier within the population being considered as end users. From a health informatics perspective, this paper argues that those involved in the design, implementation and evaluation of personal electronic health record systems appear to be overlooking a crucial requirement for such PHR systems – that they be “fit for purpose” in the context of their intended use and intended end-users.

None of this is new, but this research dramatically highlights how disadvantaged patients continue to be marginalised in many e-health design processes, and are rarely a focus of user centred design. More specifically this research highlights that:

- Current approaches to research on personal electronic health records mean that the socially disadvantaged are invisible, often being discounted as ‘non-adopters’ or ‘not qualifying’ for participation in relevant PHR studies. Without special attention, PHRs will continue to ignore the ‘disempowered, disengaged and disconnected’;
- Patients from disadvantaged neighbourhoods in Tasmania use public hospital services to a greater extent than those from privileged neighbourhoods, and display characteristics which are indicative of barriers to PHR use;
- There is a risk that disadvantaged patients will receive worse healthcare as a result of a focus on personal electronic health records as currently realised. Diversion of health resources to the implementation of PHRs may result in an increased inequity in healthcare outcomes and contribute to a growing e-health divide; and
- User centred design for PHRs may help to address this issue, but only with the participation of a truly representative group of potential users, including the disadvantaged.

## 5. Conclusion

The findings of this research confirm what we already know – poor people have poor health, use more health services, and are less likely to benefit from PHRs. What is remarkable is how the disadvantaged have remained invisible in the development of e-health systems. When these results were shared with healthcare professionals who provide direct care to patients, a common response was “so what?” They saw the findings as so obvious that they did not warrant further commentary or action. This paper argues that this is simply not a tenable response for e-health professionals; we must not ignore these barriers in the design and configuration of health information systems intended for direct use by patients, or for healthcare services more generally.

Given that individuals experiencing some form of socioeconomic disadvantage represent 10% to 15% of the overall population in most Western societies, and a larger proportion of the demand on healthcare services, it is worrying that there seem to be so few recorded attempts to holistically tailor the design of PHRs to be suitable for patients who cannot read, have difficulty using technology, and struggle with the interpretation of health concepts and terminology. Just as perplexing is the observation that few patient healthcare services are specifically tailored for these same individuals.

Policymakers, informaticians, health service managers and healthcare providers need to look carefully behind the cloak of invisibility that marginalises any consideration of the implications of disadvantage in our technology initiatives. This is a crucial way of ensuring that any benefits generated by ehealth innovation are being shared equitably. If we do not, then those whose healthcare is most in need of improvement will be the least likely to benefit from having (at least theoretical) access to a PHRs, and our e-health initiatives may end up contributing to, rather than ameliorating the social divides that already pervade our societies.

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