Hidden in Plain Sight

Personal health records and the invisibility cloak of disadvantage

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Dedication

This work is dedicated to May, who taught me that it's normal to care about other people, and to Libby, for ensuring that we are still an item, despite my periodic absences (both physical and mental) over the seven years that this work has taken.

Abstract

This thesis with publications sets out to present evidence which will answer the following research question:

RQ1:   What is the relationship between socioeconomic disadvantage and personal electronic health records?

This research question has been prompted by a concern that personal electronic health record systems as they are currently being realised in Australia are unlikely to meet the needs of those at a socioeconomic disadvantage. These individuals are often 'disempowered, disengaged and disconnected', and have been largely invisible in the process of health records development. If this concern is valid, any enhancement in the provision of healthcare which results from the use of personal health records is likely to bypass less capable citizens and patients. The research investigations contributing to the evidence in this thesis are presented as a number of peer reviewed publications; four have already been published and a further two are under review.

The thesis highlights how ordinary citizens have been inhibited in their adoption and use of personal health records by the use of highly specialised language, and in Australia by the way in which health records policies and procedures have been developed and implemented. Evidence is presented that validates a concern that even greater challenges exist for disadvantaged users. These users tend to display lower levels of text literacy, technical literacy and health literacy, all of which have been identified as barriers to the adoption and continued use of personal electronic health records. The thesis presents 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. From a health informatics perspective, this thesis argues that those involved in the design, implementation and evaluation of personal electronic health record

systems may have neglected a crucial requirement for such systems to be fit for purpose in the context of their intended use and intended users.

The research was conducted in two phases. Phase 1 of the research used exploratory investigations to delineate, test and validate ideas and concepts which were then exposed to critical consideration by peers involved in health informatics research, in the following publications:

1. *Language Games and Patient-centred eHealth.*

   This publication explored the way in which the use within ehealth systems of specialised medical language and terminology, SNOMED CT in particular, can be a barrier, even for ordinary citizens who read well and are familiar with technology. For potential users of such systems who are already at a disadvantage the barrier can appear insurmountable.

2. *Citizens, patients and policy: a challenge for Australia's national electronic health record.*

   This publication examined the development of Australia's ehealth policy, of which a personally controlled electronic health record is an integral component. Despite extensive consultation with information technology and health industry stakeholders, and with organisations representing health consumers, there was little evidence of direct engagement with ordinary citizens or patients.

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

   This publication raised concerns that the approaches taken in the design, implementation and evaluation of personal health records were likely to ignore the preferences, needs and capabilities of disadvantaged patients. The publication further suggested that this limited focus risks diverting resources from those more conventional options for health service delivery which currently provide services for disadvantaged patients.

4. *Personal Health Records are designed for People Like Us.*

   This literature review assessed the extent to which the design, implementation and evaluation of personal health records identified the particular needs and capabilities of disadvantaged

users. There were very few examples where patient capability as a barrier to use of the system was considered; in some cases, patients with low literacy skills were actively excluded from the process, and effectively rendered invisible.

These publications from Phase 1 identified several aspects of personal electronic health record systems that constrain their usefulness for disadvantaged patients. Given that some time had elapsed during completion of Phase 1, two additional questions emerged from these preliminary findings:

RQ2a: What is the current evidence about barriers to the uptake and continued use of personal electronic health records?

RQ2b: Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

In Phase 2 of the research two further investigations were undertaken in order to address these additional questions. The first investigation involved a review of literature about personal health records and barriers to uptake and continued use, with an emphasis on recent publications. The second investigation used cluster analysis to conduct an empirical analysis of local data about socioeconomic disadvantage, healthcare use and proxy measures of identified personal health record barriers. This analysis involved 2.1 million de-identified hospital records correlated with geo-location, census data and measures of social disadvantage.

The two publications from Phase 2 report the outcomes of these investigations:

5. *Barriers to meaningful use of personal health records by patients: A structured review (In review)*

This literature review sought publications about personal health records and barriers to adoption and continued use, predominantly from 2004 to 2014. Analysis of these publications identified a range of barriers which included age, race or ethnicity, income and socioeconomic status, education, text technical and health literacy, Internet and computer access, and disabil-

ity. The review also identified a number of evaluations which may have introduced a selection bias by actively excluding low capability subjects.

6. *Who will benefit most from a personal electronic health record? Analysing Tasmanian data about disadvantage, public hospital use and barriers to the adoption and use of personal health records. (In review)*

This empirical study of data from 96 geographic areas in Tasmania analysed three of the Australian Bureau of Statistics' Socio Economic Indicators for Areas (as measures of disadvantage), 800,000 records of public hospital admitted episodes and associated ICD10 diagnosis coding, and records for 1.3 million emergency department attendances as indicators of public hospital use (around eight years' data), and area measures of education, Internet access and qualifications (as proxy measures for text literacy, technical literacy and health literacy). Cluster analysis showed two subgroups of areas with disadvantaged, low capability users who were higher consumers of public hospital care, and proxy measures for barriers to personal health record adoption and use, in contrast to a privileged capable subgroup using much less care. Choropleth maps confirmed the dichotomy between these clusters.

In summary, this research has identified inequity in the design, implementation and evaluation of personal electronic health records, and has confirmed (in a Tasmanian context) that citizens who experience socioeconomic disadvantage also use public hospital services at a higher rate. These citizens also have a higher incidence of chronic disease and are subject to capability barriers likely to limit their ability to benefit from personal health records as they are currently configured.

None of this is new, but what drives this research is the apparent lack of interest in applying these concepts, about disadvantage, health and divides, to the design and implementation of personal health records.

The concluding remarks for this thesis note that:

1. 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 a

study. Without special attention, personal electronic health record systems will continue to ignore the 'disempowered, disengaged and disconnected';

2. 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 personal health record use;

3. There is a risk that disadvantaged patients will receive worse healthcare as a result of a focus on personal electronic health records as they are currently realised. Diversion of health resources to the implementation of personal health records may result in an increased inequity in healthcare outcomes;

4. User centred design for personal health records may help to address this issue, but only with the participation of a truly representative group of potential users, including the disadvantaged.

In conclusion, policymakers, informaticians, health service managers and healthcare providers should look carefully behind the cloak of invisibility which hides the disadvantaged, and ensure that any benefits generated by ehealth innovation are being shared equitably.

Surely it is in the exceptional degree of blindness and inattention among the proponents, developers and implementers of personal health records to that which is 'hidden in plain sight' - that those whose healthcare is most in need of improvement are the least likely to benefit from having (at least theoretical) access to a personal health record. This thesis provides evidence which removes that cloak of invisibility, and shines a light on this cluster of disadvantaged patients. Will anyone notice?

Contents

Index of Tables

Index of Figures

Statements and Declarations

Declaration of Originality

This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

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The publishers of the papers in Chapters 3, 4, 5 and 6 hold the copyright for that content, and access to the material should be sought from the respective journals. The remaining non published content of the thesis may be made available for loan and limited copying and communication in accordance with the Copyright Act 1968.

Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

In particular, the analysis reported in Chapter 9, and Appendix 5 of this thesis received approval from the Tasmania Health and Medical Human Research Ethics Committee on 28 February 2013 (Reference Number H0013013).

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Paper 1 (Chapter 3):
Language Games and Patient-centred eHealth

Candidate was the primary author, and with Authors 1 and 2, contributed to the idea, its formalisation and development.

Paper 2 (Chapter 4):
Citizens, patients and policy: a challenge for Australia's national electronic health record.

Candidate was the sole author on this paper.

Paper 3 (Chapter 6):
The PLU problem: are we designing personal ehealth for People Like Us?

Candidate was the primary author; Author 1 contributed to the idea, its formalisation and development.

Paper 4 (Chapter 7):
Personal Health Records are designed for People Like Us.:

Candidate was the primary author; Author 1 contributed to the idea, its formalisation and development.

Paper 5 (Chapter 8):
Barriers to meaningful use of personal health records by patients: A structured review

Candidate was the sole author on this paper. Author 1 and Author 2 provided advice during its formalisation and development.

Paper 6 (Chapter 9):
Who will benefit most from a personal electronic health record? Analysing Tasmanian data about disadvantage, public hospital use and barriers to the adoption and use of personal health records

Candidate was the sole author on this paper. Author 1 and Author 2 provided advice during its formalisation and development.

We the undersigned agree with the above stated "proportion of work undertaken" for each of the above published (or submitted) peer-reviewed manuscripts contributing to this thesis:

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Chapter 1: Introduction

" 'Would you tell me, please, which way I ought to go from
here?' 'That depends a good deal on where you want to
get to,' said the Cat. 'I don't much care where —' said
Alice. 'Then it doesn't matter which way you go,' said the
Cat."

- Lewis Carroll, Alice's Adventures in Wonderland

"If we knew what we were doing, it wouldn't be called
research"

- Albert Einstein

This Introduction provides context for the thesis, and outlines the structure of what follows.

There is an association between socioeconomic disadvantage and poor health outcomes that is so well accepted that it has come to be viewed as a commonplace observation. Similarly, the existence of a 'digital divide' is well understood, as is the reduced likelihood of personal health record (PHR) use by disadvantaged individuals. Given that these relationships are generally known and accepted, why then do PHR developments continue to deliver systems which disadvantaged patients find harder to use, or avoid altogether, and why is there so little interest within the health informatics community in addressing this significant risk of inequity in resource allocation and service provision?

This research had its origins in a mild but persistent sense of cognitive dissonance about the gap between the benefits which information and communications technology (ICT) systems promised

for healthcare and the results which were achieved. This dissonance had developed slowly over an extended period working with ICTs in a hospital and a health department. These concerns were initially explored through a broad range of discussions with professional and academic colleagues, in a spirit of mildly skeptical inquiry.

The initial 'thinking' phase of this research used a critical consideration of enthusiastic reports about ehealth systems which are intended for use by individuals (patients and citizens). These reports, some of which are discussed in Chapter 2, provided information about the benefits which could be expected from these systems, and about successful early implementations. However, most of the discourse about the benefits of personal health records seemed to discount or ignore any possibility that PHRs might be unsuitable for some high-needs users.

The concerns which emerged from this critical reading of the literature slowly crystallised around a problem situation. It seemed logical that the use of popular technical aids to living and leisure would be easier for those with the skills and resources to be able to use them effectively. It also seemed that this generalisation was likely to be true for personal health records. The relationship would be expected from first principles and from observation – inability to read text on a screen limits the ability to use text-based technology.

What was less evident from first principles was the extent to which deficits in those underpinning skills would inhibit or limit the use of a personal health record. There is evidence in the literature that this relationship holds true, and the research set out to explore the extent of those inhibitors and limitations through a critical examination of relevant literature. This thesis, then, sets out to answer the following Research Question:

RQ1:   What is the relationship between socioeconomic disadvantage and personal electronic health records?

Before this high level question can be addressed effectively, it is helpful to review four relevant concepts which are either embedded in the question, or drawn in by implication. These concepts are discussed at some length in Chapter 2, as background for this research.

Disadvantage. Socioeconomic disadvantage has come to be seen as a form of social exclusion. There are several markers of disadvantage which can be measured and reported – unemployment or under-employment; low income; limited financial resources; poor educational attainment; unsatisfactory housing; poor access to high quality nutrition; low levels of literacy; poor health. Living in disadvantaged circumstances can decrease the likelihood of socioeconomic improvement. For example, the reading skills, educational attainment and qualifications that privileged families are able to provide for their children present a much greater challenge for disadvantaged families, even with social and financial support.

Health is generally accepted as being more than simply the absence of disease (Bircher, 2005, p. 336); many definitions have been proposed, but scope and intent have been problematic. The World Health Organization's *Ottawa Charter for Health Promotion (World Health Organization, 1986),* for example, described health as a state of perfect mental and physical well-being. For those living with chronic disease, good health may mean no more than being well enough to get on with life. There are also health related concepts which are dependent on point of view: a citizen may *feel ill,* be *recognised as sick* when their limitations are acknowledged by the community, or *diagnosed as diseased* by a doctor (Marinker, 1975). In this thesis, the term 'health' is used in a broadly inclusive, rather than a restrictive sense

Personal health records, also referred to as *personal electronic health records,* are ehealth systems providing records which are accessible by the patient, and may be under the patient's control. In the context of this thesis, the term is used to refer specifically to electronic rather than paper records unless noted otherwise. Personal electronic health records may function as a standalone system, or be in-

tegrated with an electronic health record, possibly as a tethered system operated by their healthcare provider.

Divides. This thesis argues that impediments such as the 'digital divide' and the 'ehealth divide' create barriers which need to be overcome if ehealth in general, and personal health records in particular are to make a significant contribution to the delivery of healthcare for individuals. There are barriers for providers and provider organisations as well as for users. Some user barriers are attitudinal (such as users who don't want to spend the time, or "can't be bothered"), but more important in the context of this research are the barriers (such as poor textual, technical and health literacy) which require specific skills and abilities before they can be overcome. Alexander, Kinman, Miller and Patrick (2003) have observed that marginalised and under-served populations can often be identified geographically, by applying techniques which they refer to as 'medical geomatics'.

Approach to the research

This thesis with publications includes six papers, four of which (presented in Chapters 3, 4, 5 and 6) have already been peer reviewed and published, and two (presented in Chapters 8 and 9) which are in review.

The concepts outlined above serve to demonstrate the layers of complexity which are embedded within the research question, and this thesis has been developed using a collection of publications addressing facets of the research question as a way of dealing with that complexity. Not all facets of the question have been tested in a publication, although most of the untested aspects have been addressed in publications by others.

The publications and conference presentations were used to explore background issues related to the design and use of PHRs, and to examine the possibility that there is a mismatch between the healthcare needs which might be met by a PHR and the capabilities of potential users. The application of a skeptical viewpoint facilitated the framing of a proposition that some classes of potential

user, with a high degree of need for healthcare services, were overlooked in the process of designing and implementing PHRs. It is not suggested that these users were overlooked deliberately, or with malicious intent. However, some of us whose activities in health informatics involve the commissioning, design, creation or implementation of health record systems for personal use may often be blinded to the world outside our own – the 'People Like Us' (PLU) problem. Those who experience socioeconomic disadvantage, and are as a result 'disempowered, disengaged and disconnected' – the 'DDDs' – often remain outside the scope of our shared lived experience and our shared research interests. DDDs are likely to remain invisible until they are pointed out.

The thesis has been developed from a locally grounded Tasmanian perspective, but with the potential to provide insights into issues on a wider scale. The local context is described, and situated within a broader global setting.

The investigation has proceeded through two distinct phases. Phase 1 involved deductive analysis using exploratory research to examine, test and validate ideas and concepts related to issues of disadvantage and exclusion in ehealth generally, and personal health records in particular. Refereed publications (Showell, Cummings, & Turner, 2010; Showell, 2011; Showell & Turner, 2013a, 2013b) have been used to identify and explore issues of disadvantage and exclusion in ehealth, and expose those ideas and concepts to critical consideration by peers involved in ehealth research. The authors' final drafts for each of these publications are presented in Chapters 3, 4, 5 and 6.

Following a review of the outcomes of this exploratory research, Phase 2 involved additional research to strengthen the evidence provided in Phase 1. A literature review was used to enumerate the barriers to the uptake and continued use of personal electronic health records. Empirical research was then applied to evaluate the extent of disadvantage in local neighbourhoods within Tasmania, and the use of public hospital services, and to determine whether there was evidence of an association between this use and the social factors associated with a reduced capacity to benefit from personal health records (PHRs). This investigation entailed extensive analysis of census data

about the extent of disadvantage in local neighbourhoods, and primary sources of data about the use of public hospital services in Tasmania, which were analysed together to explore issues related to healthcare and disadvantage. The results of the Phase 2 research is presented in two further publications.

Structure of the thesis

The succeeding chapters are structured as follows:

Chapter 2 provides some background details and context about the areas of interest which are explored in this thesis, and gives an overview of a number of issues which contribute to the problem explored in this thesis. The chapter begins with a discussion of the nature of disadvantage, and its impact on health status and on healthcare services. This is followed by a brief summary of some well publicised challenges facing contemporary healthcare systems, and an examination of the nature of health and healthcare. The chapter goes on to explore proposals for the use of technology to alleviate the impact of those challenges, with a particular focus on personal health records (PHRs), and describes a number of the potential benefits which have been identified for PHRs. Next comes a discussion of the various 'divides' – digital, social, geospatial and ehealth – which form a barrier between those able to benefit from new technology and those who cannot. The chapter concludes with a reflection on the problem of the relative 'invisibility' of disadvantaged citizens and groups in the research canon. The associations between disadvantage, poor health and the digital divide are not new, although the apparent lack of interest in applying these concepts to the design and implementation of personal health records might suggest that they provide lessons which have not yet been learned.

Chapter 3 presents the publication *Language Games and Patient-centred eHealth*. After reviewing a range of background material, much of which appears in Chapter 2, the challenges facing disadvantaged patients attempting to use a PHR appeared obvious. Use of an ehealth system requires a degree of technical capability in order to be able to navigate the system effectively, but perhaps more import-

ant is the need to navigate the syntactic and lexical landscape embedded in the design. However, the obvious nature of these challenges seemed not to surface in the literature about PHR design and implementation. Perhaps there was a problem to be explored. This publication looked at the way in which specialised medical language and terminology, SNOMED CT in particular, is used in ehealth systems. Even skilled (non-health) professionals who read well and are familiar with the use of technology can face a formidable barrier when first using an ehealth system such as a personal health record. For potential users of such systems who are already at a disadvantage the barrier can appear insurmountable.

Chapter 4 presents the publication *Citizens, patients and policy: a challenge for Australia's national electronic health record*. This publication explores the role and importance of citizen engagement in the development of the policy framework for an ehealth system intended for use by citizens and patients. The development of Australia's ehealth policy, of which a personally controlled ehealth record was an integral component, involved an extended programme of consultation with information technology and health industry stakeholders, as well as with organisations representing health consumers. However, there was no evidence of any engagement with ordinary citizens and patients. The process is unlikely to have identified or addressed any concerns from ordinary citizens, or citizens with limited skills, about the need for a system which they were able to use.

Chapter 5 presents the publication *The PLU problem: are we designing personal ehealth for People Like Us?* A review of the findings from the first two publications identified that ordinary citizens might find personal health records complicated to use, and that they had not been extensively consulted during the policy development for Australia's national PHR. This publication raised concerns that the approach taken in the commissioning, design, creation, implementation and continued use of personal health records were biased in favour of the sensibilities, preferences, needs and capabilities of a privileged minority of potential users – 'people like us' (PLUs) – at the expense of the 'disempowered, disengaged and disconnected' (DDDs). The publication further suggested that focusing attention on personal health records which are best suited to this minority risks diverting resources

from more conventional options for health service delivery which currently provide services for disadvantaged patients.

Chapter 6 presents the publication *Personal Health Records are designed for People Like Us*. This conference poster (originally submitted as a full publication) used a literature review to assess the extent to which the design, implementation and evaluation of personal health records paid specific attention to the particular needs and capabilities of disadvantaged users. Very few of the personal health record initiatives which were included in the review considered patient capability as a barrier to use of the system, and in some cases, patients with literacy limitations were actively excluded from the process.

Chapter 7 reviews the outcomes of Phase 1 of the research, as described in the previous four chapters. It considers the findings, and maps out empirical evidence which is required to effectively address the research question. Two additional Research Questions emerge from this reflection:

RQ2a: What is the current evidence about barriers to the uptake and continued use of personal electronic health records? and

RQ2b: Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

There follows a discussion of the need to use a literature review to identify barriers to PHR adoption and use (and in doing so address the first of these questions) in order to facilitate the empirical research using data analysis which explores the second question. The chapter concludes with an exposition of the strategy for this research, and a discuss of methodological considerations which were considered in framing the data analysis.

Chapter 8 presents the first publication from Phase 2, *Patient barriers to meaningful use of personal health records: A selective review,* which describes a literature review designed to identify patient level barriers to the uptake and continued use of personal health records. This publication also notes a number of studies in which selection bias may have led to the general significance of barriers to PHR adoption and use being underestimated.

Chapter 9 presents the publication *Disadvantaged patients rely on public hospitals, but are unlikely to benefit from personal health records: an analysis of Tasmanian data*, which reports salient findings of the empirical analysis. This analysis used data from the Australian Bureau of Statistics' (ABS) Socio Economic Indicators for Areas (SEIFA) as measures of disadvantage; area measures per 1,000 population for inpatient admissions and bed days, dialysis episodes and dialysis patients, chronic diseases (identified with codes from the International Statistical Classification of Diseases and Related Health Problems 10th Revision [ICD10-AM]), and the rate of emergency department attendance per 1,000 population as indicators of public hospital use; and area measures of education, Internet access and qualifications as proxy measures for text literacy, technical literacy and health literacy respectively. Cluster analysis identified two clusters with disadvantaged, low capability users who were higher consumers of public hospital care, in contrast to a privileged, capable subgroup using much less care. Maps also highlight the dichotomy between these clusters.

Chapter 10 provides a summation of the results of the thesis, and discusses unanswered questions, and opportunities for further investigation and research in this field. The concluding remarks for this thesis note 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 a study. Without special attention, personal electronic health record systems 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 personal health record use;

- There is a risk that disadvantaged patients will receive worse healthcare as a result of a focus on personal electronic health records as they are currently realised. Diversion of health resources to the implementation of personal health records may result in an increased inequity in healthcare outcomes;

- User centred design for personal health records may help to address this issue, but only with the participation of a truly representative group of potential users, including the disadvantaged.

The thesis concludes with a list of all references cited, including those cited within the publications.

Five Appendices accompany this thesis. They provide additional material at a level of detail which was not suitable for inclusion within publications or within the thesis, and they include some duplicated material:

Appendix 1 describes the considerations which guided the selection of data for analysis;

Appendix 2 describes the data provided by DHHS;

Appendix 3 outlines the process of evaluating and cleansing this data;

Appendix 4 summarises the techniques used for the analysis; and

Appendix 5 gives a more comprehensive account of the results of the analysis.

This thesis presents the various elements of background material, research in Phase 1 and Phase 2, and conclusion in a structured way in order to provide a logical and coherent narrative. However, as with many other investigative pursuits, the realities of execution have not always matched this idealised path, and a number of the steps have been cyclic, revisited, revised and reworked a number of times. The account which is presented here is far smoother and more ordered than the prac-

tical steps which were involved in the research process. Nevertheless, this thesis is presented in its entirety as a reliable and defensible proposition and resolution.

> "In all affairs it's a healthy thing now and then to hang a
> question mark on the things you have long taken for
> granted."
>
> > - Bertrand Russell

> "All tribal myths are true, for a given value of 'true'."
> > - Terry Pratchett, "The Last Continent"

2.1 Introduction

The research question addressed by this thesis asks what relationship exists between socioeconomic disadvantage and personal health records. This chapter provides background information for that exploration of the research question, highlighting a number of issues which have relevance for the discussion in subsequent chapters.

This chapter starts with a review of the concept of disadvantage, and considers the close relationship between several aspects of disadvantage, including income, education and employment. The chapter then considers the nature of health, and the meaning of the related concepts of illness, sickness and disease, and explores the link between disadvantage and health. Next the chapter considers personal health records (PHRs), the benefits which they offer, and the limits to the scope of those benefits. The chapter goes on to discuss digital, social, geospatial and ehealth divides, which can have the effect of isolating disadvantaged groups within a community; the role of barriers to the adoption and continued use of personal health records is considered within the context of the

ehealth divide. The chapter concludes with a discussion of the concept of 'invisibility' which appears in the title of this thesis.

2.2 Disadvantage

2.2.1 The nature of disadvantage

The concept of disadvantage is commonly associated with a lack of financial resources, but this is only one aspect of the problem. Increasingly, disadvantage has been extended to encompass non-financial components. The 'basic needs' approach identifies disadvantage and poverty as being a lack of basic human needs such as food, shelter, schooling, healthcare and opportunities for employment. Recent approaches to disadvantage in Europe, and more recently in the United Kingdom, extend the scope of disadvantage to social exclusion, which includes a range of factors associated with marginalisation (Scutella, Wilkins, & Horn, 2009).

Tania Burchardt suggested the following as a working definition for social exclusion, with a deliberate lack of precision to allow some flexibility in its application:

> An individual is socially excluded if he or she does not participate to a reasonable degree over time in certain activities of his or her society, and (a) this is for reasons beyond his or her control, and (b) he or she would like to participate.
>
> (Burchardt, 2000, p. 388)

Tsakloglou and Papadopoulos (2002) evaluated accumulated chronic disadvantage as a measure of social disadvantage in twelve european countries. They found widely differing patterns of deprivation in the dimensions of income, living conditions, necessities of life and social relations, finding for example that there was a reduced risk of social exclusion for older citizens or couples living in Northern Europe, but a higher risk in some Southern European countries.

These findings clearly demonstrate that disadvantage within a country is about more than what is measured by the Gross Domestic Product. As Peter Whiteford observes:

> ...European debates about social exclusion are more concerned with social relations and ruptures in the social contract. They are also implicitly focused on sub-sets of the low-income population who are distinguished within themselves and from the 'mainstream' by location, attitudes and behaviour. Not all low-income people are excluded from society, nor do all excluded people have low income.
>
> (Whiteford, 2001, p. 69)

The nation of Bhutan has long recognised that its citizens require more than just financial security in order to maintain wellbeing, and since the late 1980s, has included a measurement of 'Gross National Happiness' as a part of the national accounts (Bates, 2009).

Work on social exclusion in Australia lags behind that in Europe and the UK. Although Labor Prime Minister, Julia Gillard established a Social Inclusion Unit within the Department of Prime Minister and Cabinet, in 2007, this was disbanded by the incoming coalition government in September 2013. Australia still has no agreed measure of poverty.

Work by the Brotherhood of St Laurence and the Melbourne Institute has established a framework for the measurement of poverty and social exclusion in Australia (Scutella et al., 2009). This framework includes 25 individual components across the domains of material resources, employment, education and skills, health and disability, social, community, and public safety. Measurements against the framework are conducted using data from the annual *Household, Income and Labour Dynamics in Australia* (HILDA) Survey. It is a panel study which currently collects data from 9,835 households (25,391 individuals) about wellbeing and financial security, employment, and family situation. The Survey is designed and managed by the Melbourne Institute of Applied Economic and Social Research (University of Melbourne), with funding from the Australian Government. The chart in Figure 1 below summarises the most recent results of the survey
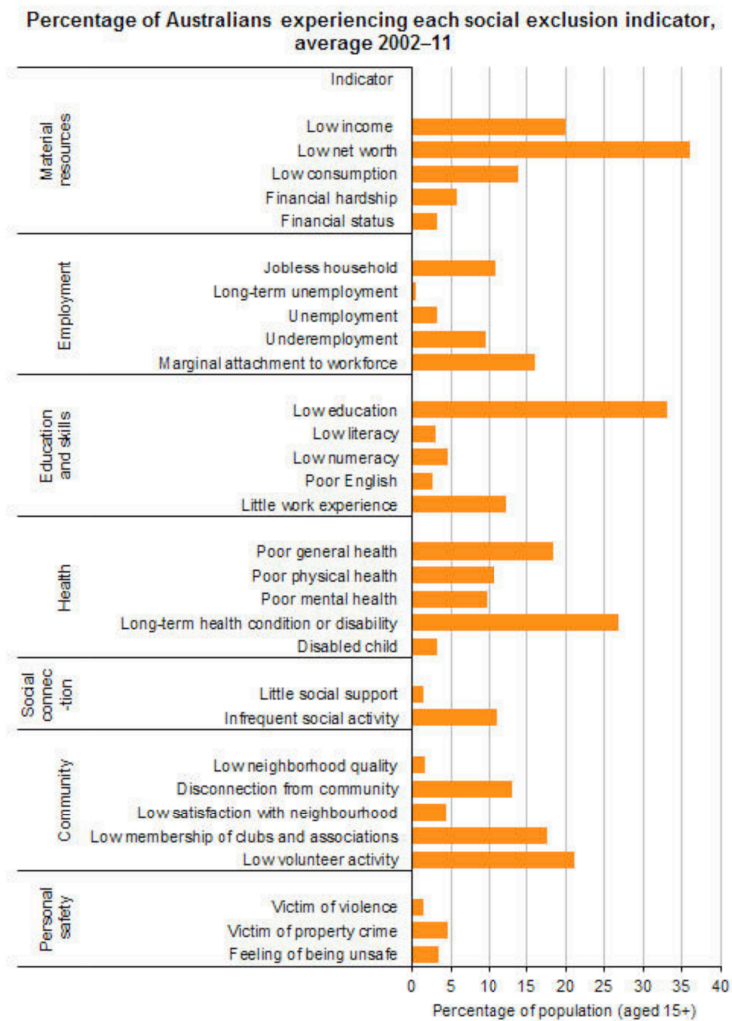
Figure 1: Social Exclusion in Australia.
(Brotherhood of St Laurence and the Melbourne Institute, 2013)

Many aspects of disadvantage can be measured – unemployment or under-employment; low income; limited financial resources; poor educational attainment; unsatisfactory housing; poor access to high quality nutrition; low levels of literacy; poor health. The interrelationship between these various factors has the effect of compounding and entrenching that disadvantage, for individuals, families and communities. For disadvantaged families the reading skills, educational attainment and

qualifications that privileged families are able to provide for their children present a much greater challenge, even with social and financial support. Exploiting technology for personal and financial benefit can also be more challenging for those who experience disadvantage: using technical aids to living and leisure is easier for those with the skills and resources to be able to use them effectively, including the ability to read the text on a screen.

The world is becoming more complex and uncertain, and many skills are needed to negotiate the regular tasks and interactions that are a part of everyday life. One might argue that it was ever thus. However, the last few decades have seen the introduction of new tools to manage and deliver social, commercial and government services. Learning to use these new tools takes time, and requires a range of skills.

Jonathon Wolff (Wolff, 2009) discusses at some length the relationship between disadvantage and the social determinants of health:

> At least as far as social policy is concerned, the idea of advantage and disadvantage is complex, having many elements that cannot all be reduced to a single one. While, again, this may seem perfectly reasonable, it dramatically complicates matters for political philosophy and for the project in hand. For a pluralistic understanding of disadvantage appears to undermine the 'consensus' project of identifying the least advantaged and taking steps to ensure that their lives are improved. For who are least advantaged on a pluralist view? Those in the poorest health? Those with the worst housing? Those who are least educated? This apparent tension between proposing that governments have a special obligation to help the least advantaged, and the difficulty of identifying the least advantaged, appears problematic. However, it also appears that empirical work on the social determinants of health helps provide an answer. In fact there are two questions on which it may well assist: first, who are the least advantaged, and second how can their lives be improved?
>
> (Wolff, 2009, p. 215)

Wolff supports Nussbaum's view (which follows the work of Amartya Sen) that disadvantage represents one or more limitations to ten essential capabilities (which include life; bodily health; bodily

integrity; and sense, imagination and thought). He makes the case that the inherent process of assessing relative disadvantage is somewhat simplified by the tendency of aspects of disadvantage to cluster together. He also reiterates Nussbaum's (and Sen's) distinction between capability and functioning in the context of disadvantage. A wealthy person who chooses to fast, and becomes unwell, has the *capability* for adequate nutrition, but not the *functioning*.

Conventional thinking identifies a group within society who are at a disadvantage when compared with the rest of society. There are many dimensions to this disadvantage. It may be evident in the context of employment, economic and financial capacity, education, health status, domicile, use of information and communications technology, or access to services (such as transport, healthcare and retail services). Many of these dimensions show significant associations, and some have suggested a causal relationship in an attempt to identify and implement appropriate corrective action.

Regardless of whether the various dimensions of disadvantage involve causal relationships or merely close associations, most societies accept a greater or lesser degree of responsibility to support those who experience disadvantage, and to ensure that they have access to an appropriate level of funded services.

2.2.2 Location and disadvantage—area level and individual disadvantage

There is a significant, but not inevitable association between disadvantage and location. The distribution of per capita wealth and income between countries is well understood, measured and reported. However, as noted above, financial measures give only a partial indication of relative disadvantage. Relative differences between areas and neighbourhoods within countries are more significant, because of the closer alignment of societal norms, expectations, and smaller differences in basic living costs.

Relativity within a country can have a greater impact – considerations such as how well the poorest individuals are supported, how wealth is redistributed, and to what extent, and how inequality

changes over time can have a significant impact on the effectiveness of the democratic process (Piketty, 2014).

The Gini coefficient, is an *ad hoc* measure of equality of income inequality within a population, which can also be used as a measure of the extent of relative of financial deprivation for an individual within a group (Dorfman, 1979; Yitzhaki, 1979). Massey's Index of Concentration at the Extremes (ICE) (Massey, 2001) provides a comparable single measure for measures reported across multiple categories. Taking school attendance data for selected Tasmanian Statistical Area Level 2 (SA2) regions as an example, those who completed Year 12 were categorised as the privileged group, and those who left school at or before grade 8 or who never attended school as disadvantaged. Using values from four SA2s, we find the following:

Table 1:   Example of ICE score calculation (for school attendance)

| | Years of school completed (adults) | | | | | |
	a) Year 12 or equivalent	b) Year 11 or equivalent	c) Year 8 or below	d) Did not go to school	e) Total	ICE(school) = (a − (c+d))/e
Lindisfarne - Rose Bay	2,667	485	353	9	6,716	0.343
Youngtown - Relbia	1,195	332	237	16	4,696	0.201
Southern Midlands	1,165	419	339	18	6,070	0.133
West Ulverstone	747	263	323	13	4,339	0.095

Differences in disadvantage between neighbourhoods

Measuring the level of disadvantage within a neighbourhood, and evaluating differences between neighbourhoods, requires an assessment of the attributes of individuals, and may also involve measure of community resources, and services, such as transport and education. As Baker and Adhikari observe:

Individual level socio-economic disadvantage is a more personal concept relating to a person's own ability to access resources and participate in society. Individual disadvantage is related to a wide range of personal circumstances including personal and household income, educational background and qualification levels, employment status and occupation, health and disability, and family structure.

(J. Baker & Adhikari, 2007, p. 5)

Within a country, homogeneity within neighbourhoods may vary to some extent. Some neighbourhoods can be popular with those who are well off. In these neighbourhoods property prices and rents will be high; a wide range of services will be available, transport will be efficient and well provided, and travel times to work and leisure will be short. There may be a degree of exclusivity which suits the affluent. Other neighbourhoods will be unpopular; property prices and rent will be lower. There will be fewer services, and options for transport will be less satisfactory. Neighbourhoods such as these may well be in outlying areas, some distance from work and leisure. Depending on the geographic boundaries used for measurement, there may be a range of smaller localities within a neighbourhood with differing levels of affluence and disadvantage. Alternatively, the neighbourhood may include a relatively homogeneous mix of low income and high income households.

The level of disadvantage within Tasmania which is described in national statistics presents significant economic, social and policy challenges. The State of Public Health 2013 report from the Tasmanian Department of Health and Human Services (Population Health, 2013) highlighted that in 2011. Tasmania had Australia's lowest median weekly gross household income ($948); South Australia (SA) was next lowest, at $1,044, and the Australian Capital Territory (ACT) the highest at $1,920. Tasmanian also had the highest proportion of its population receiving income support, with 23.1% receiving an aged or disability pension, and 7.9% receiving other forms of support; the next highest was SA (21.6%/7.9%), and the lowest ACT/Northern Territory (6.1%/4.8%).

To put this data about Tasmania into context, it should be noted that while it is a poorer state, there are fewer neighbourhoods with extreme poverty, and even fewer with extreme affluence. Statistically, Tasmania showed a low level of advantage/disadvantage diversity within 2006 census districts (Wise & Mathews, 2011, p. 33), probably in part because of its the small size: Tasmania doesn't have enough millionaires to fill an entire exclusive suburb.

> If the SEIFA scores however are used as a proxy for individual level socioeconomic advantage and disadvantage, then there is a risk of misclassification – the area level score is not reflective of an individual's score. It is important to note that SEIFA can still be used for individual level analysis provided the interpretation is correct; namely, the index score represents the average socio-economic characteristics of the area in which a person lives.
>
> (Wise & Mathews, 2011, p. 27)

This section has explored the concepts of inequity, social exclusion and socioeconomic disadvantage and provided some Australian context. The section also provided a brief description of ways in which disadvantage has been quantified. Before moving on to consider the relationship between disadvantage and health, it is appropriate to review the concept of health, and the related concepts of illness, sickness and disease.

2.3 Health

The literature on health and healthcare is voluminous, although much less attention is given to the issue of what health actually *is*, and what healthcare represents (to patients and citizens, to healthcare providers, and to funders and governments). Historically, the concept of 'health' was framed as an absence of disease. However, since disease tended to be seen as a lack of good health, this resulted in an unhelpful definitional circularity. Lester Breslow suggested that the tendency to focus on pathology in the measurement of health was a reflection of a human history beset by disease.

> Morbidity and mortality caused by microorganisms, toxic agents, injury, and nutritional defi-
> ciency have plagued and still plague much of mankind. It was only natural then to concen-
> trate on defining and measuring the specific entities against which medical science had some-
> thing to offer, or at least some hope of achievement.
>
> (Breslow, 1972, p. 347)

Improvements in living standards and medical science by the mid-20th Century meant that combating disease was no longer the sole activity required for good health, and the definition of health enshrined in the constitution of the World Health Organization (WHO) reflects this broadened focus:

> The Preamble [to the Constitution of the World Health Organization] enumerates nine basic
> principles considered … to be fundamental 'to the happiness, harmonious relations and se-
> curity of all peoples'. Health is defined, not negatively or narrowly as the absence of disease
> or infirmity, but positively and broadly as 'a state of complete physical, mental and social well-
> being' the enjoyment of which should be part of the rightful heritage of 'every human being
> without distinction of race, religion, political belief, economic or social condition'.
>
> ("Official Records of the World Health Organization No 2," 1948, p. 16)

This definition of health can be seen to establish an exemplary state of wellness as a health goal. By implication, it suggests that each of us should aspire to be a super-athlete in perfect physical and mental condition. Daniel Callahan provided a critique of this definition, and saw its broad scope of the definition as an attempt to secure world peace through the pursuit of improved health and wellbeing, despite a lack of evidence that poor health had played a part in the origins of the Second World War (or any recent conflict). He saw within the definition a tacit implication that medicine had been assigned the responsibility for health, and by implication an end to all of the world's problems. He believed that there was a trend to redefine problems of social wellbeing as medical problems, and saw the blame-free nature of the sick role as giving license for all physical, mental and communal disorders to be lumped into that category. "The whole world is sick, and no one is responsible any longer for anything." (Callahan, 1973, p. 82)

The WHO's First International Conference on Health Promotion in Ottawa in 1986 culminated in the signing of the Ottawa Charter for Health Promotion, which moderated the earlier definition somewhat, suggesting that:

> …[t]o reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.
>
> (World Health Organization, 1986, p. 1)

More recently, Johannes Bircher (2005) has suggested that advances in clinical practice have led to medicine being a significant asset for developed countries. He offered the following as an appropriate contemporary definition of health:

> Health is a dynamic state of wellbeing characterized by a physical, mental and social potential, which satisfies the demands of a life commensurate with age, culture, and personal responsibility. If the potential is insufficient to satisfy these demands the state is disease.
>
> (Bircher, 2005, p. 336)

and suggested that health "...may be described as the potential that individuals have at their disposal to master the short-, medium- and long-term demands of their lives" (Bircher, 2005, p. 336). He proposed that good health requires an appropriate a balance between the demands placed on an individual, and their capacity to meet those demands, and notes that:

> …the WHO itself has on several occasions reinterpreted its definition albeit without changing its wording, which is part of its constitution (Burci and Vignes, 2004). More recent definitions have emphasized various aspects (Gadamer, 1993; Agich, 1997; Boorse, 1997; van Hooft, 1997; Schad, 1998; Nordenfelt, 2001; Bullington, 2003; Hellström, 2003; Jakobson, 2003; Nordenfelt, 2003; Petersen, 2003) including the relationship between the capacity to cope and the demands of life. They are given in greater or lesser detail and range from more social to more individual and from value-free naturalist to normative points of view.
>
> (Bircher, 2005, p. 339)

Machteld Huber and colleagues (2011) criticised the 1948 WHO definition as overambitious, with their principal objection being to the use of the word "complete". By implication, this component of the definition consigns each individual with any degree of physical, mental or social malady, any patient with a chronic disease or disability, to the role of a patient. They avoid the prescriptive nature of a new definition, and propose a more moderate formulation: "...health, as the ability to adapt and to self manage". (Huber et al., 2011, p. 236)

Despite the scope of these discussions, from a sickness oriented or disease oriented view at one extreme, and a 'super-athlete' as the archetype of the healthy human at the other, there is a need to acknowledge that health is more about the ability to self-rectify, to 'bounce back' from an episode of illness, and to 'get on with life', rather than a steady and perfect state of disease absence. But in the end the discussions fail to clarify whether the state of being healthy is a decision for the individual, an assessment by society, or a categorical assignment by a medical professional.

2.3.1 The 'sick role'

On first inspection the cycle of health, treatment and recovery could easily be viewed as an essentially linear process: a well person becomes sick, and seeks professional care, receives treatment, and gets better. Talcott Parsons (1975) argued that, in adopting a 'sick role', patients acquire rights and responsibilities. They gain the right to seek social withdrawal from normal activities (including work), and the right to be exempted from responsibility for their illness (with an underlying assump-

tion that they need care from a health professional). The patient also assumes a responsibility to seek professional help, and a responsibility to get well by following any professional advice offered.

Eliot Freidson (1988) extended Parsons' model of the 'sick role' by introducing the notion of a 'lay referral' system, involving consultation with social peers. Professional help is sought only after immediate kin and members of the community are seen to accept that the individual is unwell. This concept was firmly based in Freidson's view of the professional structure of the medical profession, which he saw as retaining for itself the right to judge the quality of its own work. Freidson believed that society recognised a profession's right to this autonomic status because of the professional characteristics of altruism, expertise and self-regulation (Freidson, 1988). In this context, he saw little room for an autonomous role for patients. In essence, then, this professionally focused model would have the citizen choosing to become a patient in need of care, and when that care is no longer required, ceasing to be a patient.

Issy Pilowsky's work on 'abnormal illness behaviour' (Pilowsky, 1978) emphasised that not all 'sick role' behaviour matched Parsons' idealised model of patient-clinician interaction. An individual might seek medical attention for a nonexistent illness (as is the case with Munchausen's syndrome) or deny being unwell despite a medical diagnosis. Bryan Turner elaborates on Pilowsky's observations, noting that "[n]ot all sick people are patients and not all patients are sick people" (Turner, 1987, p. 46).

Doctor's perception of illness

	—	+
	Munchausen's syndrome	Normal sick role
	Normal health role	'Flight into health'

Patient's assertion of illness

+

—
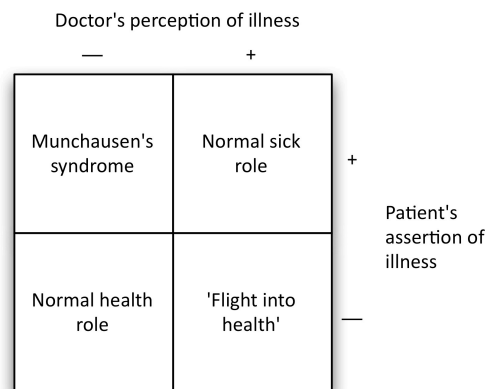
Figure 2:   Normal and abnormal illness beha-
viour After Turner (1987)

In this digital age, the central role of healthcare providers as gatekeepers and interpreters of expert information has diminished; much information and advice is now freely available from websites, and online social networks offer an adjunct to or a replacement for direct societal interaction. In this context, it is likely that use of the Internet and social networks has drastically altered Parsons' model of the 'sick role', and Freidson's process of lay referral. It has almost certainly changed the balance of Pilowsky's framework for normal and abnormal illness behaviour.

2.3.2 Sickness, illness and disease

While the clinical view of the process of becoming a patient may rely on a simple binary transition, the citizen's perspective of the process can be less straightforward. The words 'sickness', 'illness' and 'disease' are sometimes used interchangeably to refer to someone who is unhealthy. However, there are subtle differences in the meanings which can be ascribed to the three terms.

For example, when Marshall Marinker addressed the 1975 London Medical Group Conference on Iatrogenesis on the topic "Why make people patients?" (three years before Pilowsky's discussion of illness behaviour) he gave his own view of disease, illness and sickness, the three principle modes of what he referred to as "unhealth". He described disease as a deviation from a biological norm, "…

a pathological process, most often physical as in throat infection, or cancer of the bronchus, sometimes undetermined in origin, as in schizophrenia." (Marinker, 1975, p. 82). He saw disease as having objective characteristics – 'central facts' – which allowed identification. Illness, for Marinker, was the personal experience of unhealth, which could be present without an associated observable disease; this misaligned state of unhealth was likely to cause distress for the doctor. Finally, he described sickness as the external, public manifestation of illness which represented a negotiated agreement between the individual and a society which agreed to provide recognition and support. Marinker suggested that the security that sickness provided was greater for acute ailments, for surgical interventions, and for the young, rather than for chronic ailments, psychiatric disease, and the elderly (Marinker, 1975).

Arthur Kleinman (1981) had a somewhat different view, and explored the relationship between culture and the healing process. The way in which Kleinman differentiated the three states is summarised by Allan Young as follows:

> DISEASE refers to abnormalities in the structure and/or function of organs and organ systems; pathological states whether or not they are culturally recognised; the arena of the biomedical model.
>
> ILLNESS refers to a person's perceptions and experiences of certain socially disvalued states including, but not limited to, disease.
>
> SICKNESS is a blanket term to label events involving disease and/or illness.
>
> (Young, 1982, p. 264)

Young offers the following explanatory diagram:
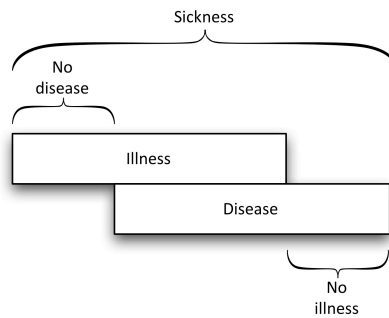
Figure 3:   The disease-illness approach
(after Young, 1982)

According to Andrew Twaddle, *disease* is defined as "...a health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities and/or a reduced life expectancy" (Twaddle, 1994a, p. 8). Ontologically, disease is an organic phenomenon (a physiological event) independent of subjective experience and social conventions. Epistemically, it is measurable by objective means (Twaddle, 1994a, p. 9).

Twaddle defines *illness* as "...a subjectively interpreted undesirable state of health. It consists of subjective feeling states (e.g. pain, weakness), perceptions of the adequacy of their bodily functioning, and/or feelings of competence" (Twaddle, 1994a, p. 10). Ontologically, illness, is the subjective feeling state of the individual often referred to as symptoms. Epistemically this can only be directly observed by the subject and indirectly accessed through the individual's reports.

Sickness is defined by Twaddle as "...a social identity. It is the poor health or the health problem(s) of an individual defined by others with reference to the social activity of that individual" (Twaddle, 1994a, p. 11). Sickness in this sense is a social phenomenon constituting a new set of rights and duties. Ontologically Twaddle frames sickness as "...an event located in society . . . defined by participation in the social system" (1994a, p. 11). Epistemically, sickness is accessed by "measuring levels of performance with reference to expected social activities when these levels fail to meet social standards ..." (1994a, p. 11). Furthermore, Twaddle outlines the temporal relationship between dis-

ease, illness, and sickness. The paradigm case is when a disease leads to illness, which then results in sickness.

In an idealised model of this transition, an individual would self-identify as being ill, receive license from society and the community to be seen as sick, and then visit a physician to have their disease identified and treated. Successful treatment would cause the disease to abate, remove the sickness, and eliminate the individual's sense of being ill.

This uncertain relationship between 'unhealth' and the states of illness, sickness and disease was explored by Wikman, Marklund, & Alexanderson (2005) . They used cross sectional data from comprehensive interview surveys of 3,500 employed and self-employed Swedish people to evaluate perceptions of illness, disease and sickness preventing normal work ("sickness absence"), defining these concepts as follows:

> *Illness* is defined as the ill health the person identifies themselves with, often based on self re-ported mental or physical symptoms. In some cases this may mean only minor or temporary problems, but in other cases self reported illness might include severe health problems or acute suffering. It may include health conditions that limit the person's ability to lead a nor-mal life. According to this definition illness is seen as a rather wide concept.
>
> *Disease*, on the other hand, is defined as a condition that is diagnosed by a physician or other medical expert. Ideally, this would include a specific diagnosis according to standardised and systematic diagnostic codes. This would in most cases also mean that the specific condition has a known biomedical cause and often known treatments and cures. However, it should be mentioned that there are several limitations to this ideal in practice. One is the fact that a number of medical diagnoses have to be based on subjective information from the patient concerning pains and feelings. Another limitation is the fact that a number of diagnoses are based on syndromes and complex interrelations between different organ systems and thus are not always very specific.

Sickness is related to a different phenomenon, namely the social role a person with illness or sickness takes or is given in society, in different arenas of life. One type of data concerning a more limited aspect of sickness is that relating to sickness absence from work. Such data are often used to measure social consequences for the person of ill health. Here data on sickness absence will be used to measure sickness. [Emphasis added]

(Wikman et al., 2005, p. 450)

The study by Wikman and colleagues confirmed Marinker's view that the overlap between illness, sickness and disease was imperfect. A large minority of citizens (40%) reported just illness, sickness, or disease without mention of the other two conditions. Others identified two of the three. Only 22% of those with an identified disease also reported both illness and sickness absence. The authors used the following diagram to summarise their results:
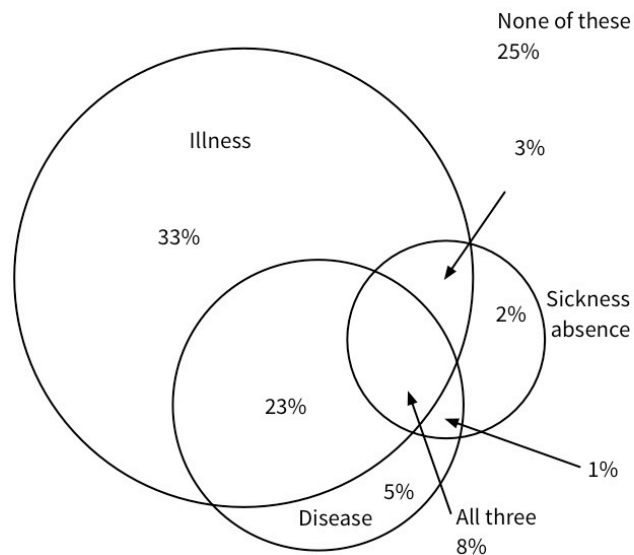
Figure 4: Relation between illness, disease and sickness absence.
Percentage of employed aged 16-64 in Sweden 1998-
2001 (n = 13,387) (Redrawn from Wikman et al., 2005)

And in the real world (as distinct from the objectively measured world of the researcher), the boundaries which separate the ill, the sick and the diseased can be less rigid than those delineated by Wikman et al. Kazem Sadegh-Zadeh (2000) proposed an extension of conventional set theory which reduced the precision with which members of a set were defined ("fuzzy set theory"). In areas where the assignment of set membership is governed by subjective assessments, he proposed that the boundaries of a set should be less rigid. Each member of a set could be assigned a degree to which they belonged to a particular set. In the context of this discussion of illness, sickness and disease, it is helpful to consider the Wikman Venn diagram as representing fuzzy sets with poorly delineated boundaries.

Medical sociology has broadened the market-oriented view of the ill citizen as a rational actor choosing to seek care from a qualified professional. Pescosolido found that the widening range of alternatives for complementary or alternative care, self care and so on reframes the choice to visit a medical practitioners as one path among many, several of which may be pursued concurrently (Pescosolido, 1992, p. 1111). She identifies a range of choices which an individual may make when seeking care:

Table 2:   The range of choices for medical care and advice (Pescosolido, 1992, p. 1113)

Option	Advisor	Examples
Modern medical practitioners	M.D.s, osteopaths (general practitioners; specialists), allied health professions	Physicians, psychiatrists, podiatrists, optometrists, nurses, midwives, opticians, psychologists, druggists, technicians, aides
Alternative medical practitioners	"Traditional" healers	Faith healers, spiritualists, shamans, curanderos, diviners, herbalists, acupuncturists, bonesetters, granny midwives
	"Modern" healers	Homeopaths, chiropractors, naturopaths, nutritional consultants, holistic practitioners
Nonmedical professionals	Social workers Legal agents Clergymen Supervisors	Police, lawyers
Lay advisors	Family Neighbors Friends Co-workers, classmates	Bosses, teachers, spouse, parents
Other	Self-care	Non-prescription medicines, self-examination procedures, folk remedies, health foods
None		

In summary, an individual who is ill does not feel totally well; if news of this unhealth or malady is shared with others in society (family, friends, employers), and the individual is granted license to avoid normal daily activities then she is sick. If a medical practitioner decides that the individual has an identifiable collection of signs, symptoms and test results ('makes a diagnosis') the individual has a disease. For an individual, their state of health is not seen as a state of total absence of disease (and of illness and of sickness), but of the individual being well enough to successfully take on his desired daily activities, responsibilities, and projects.

The forgoing discussion of health-seeking and health-preserving behaviour and an individual's recourse to health services may have fallen victim to the narrowed perspective of an educated elite. Most authors appear to take for granted that an individual in a state of 'unhealth' will abandon unhealthy behaviour, and seek attention from a healthcare provider.

2.3.3 The Desire to be Well

This thesis will return a number of times to a discussion of a group who are well educated and financially secure, with good text, technical and health literacy. These are 'People Like Us' (PLUs). Our default view of the world is focused through a lens of competence, privilege and security, and framing the world with that particular view can affect any work that we might do in healthcare or informatics. This 'PLU problem' can have an impact on several aspects of health services and personal health records. People Like Us are likely to make the unspoken, unexamined assumption that taking advantage of an opportunity to improve one's wellbeing is a matter of course, and that all citizens will take positive actions in support of their own wellbeing and health.

However, this assumption may not hold true in all cases. The notion of self-actualisation (Goldstein, 1940) was incorporated by Abraham Maslow into his theory of human motivation (Maslow, 1943). Maslow saw the human need for self-actualisation as the highest level of a hierarchy, underpinned by more basic needs for esteem, love, safety and physiological security. This hierarchy is depicted in Figure 5 below.

Figure 5: Maslow's Hierarchy of needs. Maslow (1943)

Maslow suggested that each of these levels of need was likely to be suppressed unless the lower order needs had been addressed. In the context of healthcare, self-actualisation can be evident in the positive actions which an individual may take to restore, maintain or improve their health or wellbeing. However, the drive for self-actualisation may not always be strong, and may in some cases be absent altogether when lower order needs (for respect from others for example, or security of employment and resources) take precedence. PLUs may view an absence of self actualisation as a lack of willpower, motivation or 'drive', but the consequence for disadvantaged individuals of having lower order needs take precedence over self-actualisation can play out as an inability or unwillingness to take action to support or enhance health and wellbeing. Hence it would be wise to avoid any assumption that the mere existence or availability of a health resource offering benefits for an individual's health and wellbeing will ensure that the resource will be universally adopted and used.

The desire to be well is often assumed to be universal within a population or community, but it may not be. Even if it is, the intensity of that desire is likely to vary between individuals, and within individuals over time (and may diminish when they are unwell).

2.3.4 Patient empowerment

As discussed in the previous section, there is a pervasive (although not universal) view that an absence of self actualisation among disadvantaged patients, and an unwillingness to adopt health preserving and health promoting behaviours is due to a lack of willpower, or perhaps a moral failure. A trend which has developed over a few decades promotes the practice of healthcare in a way which focuses on the needs of the patient, rather than on the needs of the health professional or provider organisation (R. M. Anderson & Funnell, 2010). This move towards 'patient centred care' includes an expectation that patients will welcome an opportunity to be involved in making decisions about their care, and perhaps to provide some aspects of their own care.

Although patients are often described as being the principal beneficiaries of this move towards patient engagement and self care, there is also an underlying theme of reductions in workload for health professionals and healthcare systems. However, this trend may not change the unequal power relationship which exists between patient and provider (and particularly between patient and doctor). Furthermore, the extent to which patients are able to truly engage as a part of the 'treating team' depends on their level of written and verbal communication skills, their understanding of health concepts and terminology, their confidence in framing and expressing an opinion of their own, and above all their capacity for self actualisation. It is likely that "People Like Us" (which group includes those who design and implement new models of care) will be more likely to benefit from this arrangement as 'empowered patients'. Not all patients are equally positioned to be able to take advantage of the benefits of being involved in decisions about their own care, or of participating in that care.

2.3.5 Healthcare challenges (for providers)

The systems which are in place to provide healthcare face many challenges including issues of cost, quality, workforce and equity. These challenges exist both in the developed ('Western') world, and in the developing world. The developing world also faces challenges with poor access to basic healthcare services, particularly services for those who are less well-off; a shortage of healthcare

providers; meeting the costs of care, medication and treatment; and the availability of and access to specialised treatment centres. These challenges may also be present in the developed world, together with additional challenges resulting from over servicing, undue commercial influence, an ageing workforce, and an increase in life expectancy which extends the time during which citizens can be afflicted by complex and chronic diseases. The developed world is also troubled by 'diseases of affluence', which are closely associated with 'first world problems': inactivity, poor diet, obesity, and the iatrogenic effects of overdiagnosis, overmedication and overtreatment. In the developing world these diseases of affluence also become more evident as economic progress enables citizens to move towards higher levels of income.

Health systems also face problems with organising and managing the provision of care. Issues of cost and funding; staffing; and avoiding the fragmentation of care for multiple conditions may present differently in different countries, but with no country immune from the challenges they present. The coordination of fragmented care presents a particular problem for patients. Evidence is emerging that multimorbidity – when a patient has three or more chronic conditions – can create a significant extra pressure on healthcare systems. An effective response to multimorbidity is not helped by the prevailing 'single disease' model of treatment, in which patients with multimorbidity receive multiple uncoordinated types of care.

In addition, the compartmentalisation of the healthcare system can be very effective at creating additional clinical work, with treatment guidelines and quality frameworks likely to recommend that a complete parcel of care be provided for each of the morbidities that comprise the multimorbidity. (Schoen et al., 2005) This approach may also increase the workload and cost for the patient, who is likely to have more medications, more visits to healthcare providers and more travel than would be the case within a well coordinated package of care. As Barnett et al note in their study of multimorbidity:

Existing approaches focusing on patients with only one disease dominate most medical educa-
tion, clinical research, and hospital care, but increasingly need to be complemented by sup-
port for the work of generalists, mainly but not exclusively in primary care, providing continu-
ity, coordination, and above all a personal approach for people with multimorbidity.

<div align="right">(Barnett et al., 2012)</div>

Some of the solutions that have been proposed for these challenges include engaging citizens in an attempt to reduce health-damaging behaviours, the transfer of some aspects of patient care from institutions to community settings (including patient homes), to support the frail well in living longer in their own homes, and to engage patients as partners in the delivery of their own care. If ICTs are to be a part of that response, they must be accessible by citizen non-experts.

2.3.6 (Why) does equity matter for health services?

Amartya Sen gave a keynote address (later published as an editorial in *Health Economics*) to the Third Conference of the Health Economics Association in 2001 (Sen, 2002). He made three obser-
vations about health equality. Firstly, health equity is inextricably linked to social factors: it cannot be assessed simply by examining the way in which health care is distributed. Secondly it is not equitable for any group to be discriminated against (on any basis). Finally, health equity must take account of the way in which resources are allocated, and of the social factors which link health with other aspects of life. He noted that equity issues may present themselves in the initial alloca-
tion of resources to the healthcare system, as well as in the distribution of resources within health-
care.

Since health equity has to be seen, as I have tried to argue, as a broad discipline, rather than as a narrow and formulaic criterion, there is room for many distinct approaches within the basic idea of health equity.

<div align="right">(Sen, 2002, p. 663).</div>

In a commentary included within a 'mini-symposium' in the Journal of Medical Ethics, Norman Daniels framed equity in healthcare service delivery and equity in health more generally as a moral and ethical issue, on the basis that good health is needed in order to ensure equitable access to the

benefits which arise from opportunity. The intricate melding of the social determinants of health, and the role of good health in helping to address socioeconomic disadvantage means that it becomes difficult to separate the two, or to evaluate them as independent factors (Daniels, 2009).

In her Masters thesis (2011), Malinche van der Hoog from Tilburg University explored issues of equity in the provision of health services. She reached the conclusion that equity in the provision of health services requires both formal equality, treating all cases alike (horizontal equity), as well as proportional equality, treating all citizens according to their due (vertical equity). It appears that many ehealth initiatives focus on horizontal equity, providing similar opportunities for access to all potential participants, at the expense of vertical equity, focusing on the provision of enhanced access for those most in need. Because of distortions introduced as a result of the PLU problem, there may be a need to adopt a formal and deliberate focus on vertical equity, which may entail some form of 'positive discrimination', applying additional resources and effort to a disadvantaged subset of the population.

2.4 Health and Disadvantage

The chapter has provided an exploration of concepts of disadvantage (in Section 2.2) and health (in Section 2.3). It is now appropriate to give some consideration to the way in which disadvantage and health interact. These interactions will be considered in more detail in the publications which appear in subsequent chapters.

One aspect of disadvantage which is well described is the association between low income, poor health status and worse health outcomes. This health disadvantage has been linked to low levels of literacy, poor diet, and difficulty in accessing care. The association between disadvantage and poorer health outcomes is now well understood, and generally accepted, although causation is less obvious (and the distinction between the two may sometimes be missed).

Mackenbach et al (2008) used data on mortality, education and occupational class to review the association between socioeconomic inequality and health in 22 countries in Europe. They found significantly higher levels of mortality and self-reported ill health in groups with a lower socioeconomic status. This relationship held in most countries, although the magnitude of the effect varied. The authors found that the variations were to some extent associated with smoking and alcohol use, and the degree of medical intervention. These findings were largely confirmed by Marmot, Allen, Bell, Bloomer and Goldblatt (2012), who found that, despite significant improvements in living conditions in Europe, persistent health inequities remain both within and between countries of the WHO European region. Their report recommends health policies which are effective across the whole social gradient, as well additional services for those at the bottom of the gradient. They also identify as need to address the *process* of exclusion, rather than focusing on excluded groups.

In a report for the UK's Joseph Rowntree Foundation, Karen Rowlingson (2011) explored the relationship between inequality and health and social problems. She found that there was a clear association between the level of income income inequality within a country and a range of health and social problems. Although the evidence of a causative chain was less clear-cut, several of the studies she reviewed identified small but statistically valid causative effects. She also noted that the relationship between disadvantage and poor health may be worsening as the gap between the richest and the poorest in society becomes wider.

The relationship between socioeconomic status and mortality has also been observed in Australia. Clarke and Leigh (2011) used data from the Household, Income and Labour Dynamics in Australia (HILDA) survey to evaluate the association between socioeconomic status and mortality. They found that the relative mortality risk for the poorest quintile in the survey was 1.88 times that of the richest quintile, equivalent to a difference in life expectancy of 6 years (at 20 years of age). They also observed an association between attaining a higher level of education (more than 12 years) and a reduced risk of death. However, after controlling for individual level factors, they were

unable to identify an association between mortality and area-based measures of socioeconomic disadvantage.

A study by Schoen et al (2010) of health insurance arrangements in 11 OECD member states, conducted between March and June 2010, found that 22% of Australian respondents reported cost-related problems with access to healthcare in the preceding year. They found that 18% had avoided a visit to a doctor, or did not get recommended care, while 12% did not fill a prescription, or missed doses of medication.

In Tasmania, the State of Public Health 2013 report (Population Health, 2013) compared health indicators for quintile measure of socioeconomic status. Some results are shown in Table 3 below.

Table 3: Health indicators (Tasmania, 2011)

	Lowest quintile (%)	Highest quintile (%)
Self reported health status		
Excellent or Good	31.0	51.7
Fair or Poor	31.7	12.1
Smoker	20.6	10.9
'Obese' BMI	25.8	13.2
Experienced food insecurity	10.0	0.6

Multimorbidity

There is good evidence that the problems which are associated with multimorbidity (both for the patient and for the healthcare system) can be greater for groups with a lower socioeconomic status Marengoni et al. (2011) used a literature review to summarise evidence about multimorbidity in the elderly, and its causes and effects, and also explored aspects of the care of patients with multimorbidity. They summarised their findings as follows:

(1) multimorbidity affects more than half of the elderly population; (2) the prevalence increases in very old persons, women and people from lower social classes; (3) very little is known about risk factors for multimorbidity... (4) functional impairment, poor quality of life and high health care utilization and costs are major consequences of multimorbidity; and (5) data are insufficient to provide scientific basis for evidence-based care of patients affected by multimorbidity.

(Marengoni et al., 2011, p. 436) (p436)

Barnett et al. (2012) used data from Scottish general practice records to evaluate the extent and distribution of multimorbidity in a cohort of 1.75 million patients (around one third of Scotland's population). They found that the onset of multimorbidity in the most deprived areas occurred 10 - 15 years sooner than in the most affluent areas.

Health literacy

Berkman, Sheridan, Donahue, Halpern, and Crotty (2011) updated a 2004 systematic review of the impact of poor health literacy on health outcomes. Their review found moderate evidence that patients with low health literacy had higher levels of hospital and emergency department use, and lower uptake of preventative services; were less able to take medications appropriately and interpret labels and health messages. The review also found evidence of poorer health status and higher all-cause mortality among older patients with low health literacy.

Low literacy is acknowledged as a contributor to low health literacy, and a barrier to effective healthcare. What has not previously been recognised is the extent to which low literacy can also interfere with verbal communication in a healthcare setting, an effect which appears to be associated with the personal stigma attached to low literacy. For individuals with poor literacy, the problem often remains hidden from healthcare providers, through the individual's poor awareness of the problem, and low awareness in healthcare staff of literacy as an issue. In addition, the stigma associated with poor literacy may lead low literacy individuals to hide the problem (Easton, Entwistle, & Williams, 2013).

Using semi-structured interviews and focus groups, the authors explored the origins of the fear of being 'found out', which often stemmed from experiences in childhood. The fear of being exposed as illiterate during a healthcare interaction would often result in stress, diminished attention, or a keenness to terminate the appointment early.

2.5 Personal health records

The preceding sections of this chapter have considered the concepts of disadvantage and health as background for this thesis. It is now appropriate to broaden the conceptual framework of this thesis by discussing the concept of personal health records (PHRs).

2.5.1 What are PHRs?

eHealth

Much attention has been given to the impact of ehealth on healthcare and on wellbeing. Technology is applied to solve a wide range of problems, actual, perceived or invented. 'ehealth' is a loosely defined term which is in common usage to describe the application of information and communications technology to healthcare. eHealth is seen as holding out a promise of better efficiency, safety and convenience. In commencing this thesis, an attempt was made to find an accepted a definition for the term, or at least to identify a consensus position on its meaning. A Delphi study intended to evaluate the current meanings attached to the term, involving a wide range of participants did not identify a consensus definition (Showell & Nøhr, 2012), but work continues. For the purposes of this thesis, the term *ehealth* is generally used to refer to the use of information and communications technology for activities which support, maintain, restore and promote good health.

eHealth systems, and in particular personal electronic health record systems, are being promoted as a way to improve the efficiency of care delivery, with a view to involving patients as active participants in their own care, and transferring some of the care workload from providers.

Personal health records

Personal health records (PHRs) are a subset of ehealth technologies which provide information systems designed and tailored for use by patients and their carers, in part to realise the goal of providing care in a way which is more 'patient centred'. The underlying logic is that the use of PHRs will empower patients, resulting in better care.

The term 'personal health record' (PHR) describes a type of health record which is intended for use by both the patient and the healthcare provider. The PHR is accessible by the patient, may be under the patient's control, and is often separate from the health record maintained, controlled and managed by the provider or provider organisation.

The practice of keeping personal notes about one's treatment from a healer, and the day-to-day progress of one's condition, has a long and honourable history. For example, the writings left by Dr Samuel Johnson (1709-1784), and his friend and biographer James Boswell have provided sufficient detail to identify for Johnson retrospective diagnoses of tuberculous scrofula (Lane, 1975, p. 17), and of Tourette's syndrome (Murray, 1979). However, it was probably not common for patients or families to maintain their own records of care.

The burgeoning of diagnostic investigations from the 1950s onwards saw an explosion in the quantity of health data. The notion emerged that this abundance of data could provide evidence of significant trends in a patient's health or wellbeing over time. The maintenance of longitudinal records of care became common, first among providers and later by patients themselves, or by their carers. Donald Berwick, for example, describes how he kept records of his wife's results during her treatment for a serious autoimmune disease in 1998:

> As far as I know, the only person who ever drew a graph of Ann's fevers or white blood cell counts was me, and the data were so complex and crossed so many settings that, short of a graph, no rational interpretation was possible. As a result, physicians often reached erroneous conclusions, such as assuming that Ann had improved after a specific treatment when, in fact, she had improved before it, or not at all.
>
> (Berwick, 2002, pp. 24–25)

One well known example of a PHR provided or sponsored by a healthcare provider is the 'clinic book' maintained for each newborn, and used to record measurements of height and weight at birth, and during infancy. Additional data about symptoms of illness and developmental milestones are recorded by the child health nurse at each clinic visit. Height and weight are plotted on a growth chart, providing an early warning of developmental delay or failure to thrive (Hawley, Janamian, Jackson, & Wilkinson, 2014; NSW Health, 2014; Stacy, Sharma, & Torrence, 2008).

Patients see a paper based personal record as a helpful part of their care (Norden, Marincowitz, & Fehrsen, 2004), and paper records have been shown to be effective in supporting beneficial changes in lifestyle (Jerdén & Weinehall, 2004). However, most of the current interest in and expenditure for personal health records is now focused on electronic versions.

Electronic PHRs

This thesis is focused in particular on electronic record systems which are primarily intended for use by citizens and patients, and beyond this point in the thesis, the term 'personal health record' is used to refer to electronic versions unless specifically noted otherwise. The growth of the Internet saw the emergence of online options for patient accessible health records. PHRs may function as as standalone system, or be integrated with an electronic health record, possibly as a tethered system operated by their healthcare provider. PHRs are typically Internet based, although there are some examples of PHRs which are stored on transportable electronic media, such as a USB drive (Jian et al., 2011).

The definitional uncertainty about what is meant by the term "ehealth" also extends to the notion of a personal health record (PHR). Two working definitions help to elucidate the meaning of the term. The Final Report of the Working Group on Policies for Electronic Information Sharing Between Doctors and Patients, sponsored by the Markle Foundation and the Robert Woods Johnson Foundation, defined a personal health record as:

> …an electronic application through which individuals can access, manage and share their health information in a secure and confidential environment. It allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.
>
> (Markle Foundation, 2004)

while the Kaiser Permanente Institute for Health Policy observed that:

> The definition of a PHR is open to interpretation by its various sponsors, vendors, and users. While existing PHRs differ in functionality and degree of integration with other health information systems, they share several common characteristics:
> - They allow individuals to manage their personal health information.
> - The individual patient is the primary user.
> - They contain information provided by the individual
> - They are portable, meaning they can be accessed anytime, anywhere via the Internet, or carried with the individual in a digital media storage device
> - They are tools for managing information relevant to lifelong health and wellness."
>
> (Kaiser Permanente, 2007)

These descriptions provide sufficient breadth and clarity to support a wide ranging discussion about PHRs, and no attempt has been made to identify specific criteria for the inclusion or exclusion of a particular implementation as an instance of a PHR. For the purposes of this thesis, *personal electronic health records* are considered to be ehealth records which are accessible by the patient, and often include an option for patient data entry.

2.5.2 Types of PHR

Tang, Ash, Bates, Overhage and Sands (2006) identify a range of approaches which are being used to establish personal health records. Individuals can use a standalone PHR to manage their own health information; at its most basic, this will involve manual data entry, while more sophisticated systems may include options for web-based storage of data, and facilities for codified data entry. Tethered systems provided by healthcare providers or provider organisations may offer patients secure online access to their own records, or, with appropriate consent, to the records of a patient for whom they are a carer. Integrated systems may include the secure exchange of the patient's clinical data, with automated retrieval of on-line records and results, and options for electronic communication with healthcare providers. They note that the range of functionality offered by various PHRs is quite broad:

> The EHR-based systems may include additional functionality, such as allowing the patient to request appointments and prescription renewals and providing a communication channel to clinicians. In some cases, patients may add supplemental in- formation that may or may not subsequently be incorporated into the provider's EHR.
>
> (Tang et al., 2006, p. 122)

The US Center for Information Technology Leadership (CITL) has gone further, and developed a patient focused taxonomy for PHRs. (Vincent et al., 2008) This taxonomy recognises that PHRs will have an application component (providing information exchange and self-management) and an infrastructure component (allowing for the sharing and viewing of data) as well as taking note of the architecture for the system (a tethered system provided by the healthcare provider or the funder, a third party system, or an interoperable system). Their taxonomy also takes account of the degree of automation used for data exchange (machine interpretable or machine organisable), whether there are single or multiple data sources, and whether the data which is stored is clinical, administrative, or a mix of the two.

Some instances of integrated and tethered systems can also provide a degree of benefit without the active involvement of the patient, by providing a repository which gives healthcare providers a col-

lated view of data about the patient from a number of disparate sources (as a summary, in detail, or both). This particular use case for PHRs, with the record used *on behalf of* a patient by a trusted proxy user or health professional is not at the core of most of the literature about PHRs, and is not considered extensively in this research, which is primarily focused on the adoption and use of PHRs by patients.

Examples of these different options for a PHR are described below.

Standalone PHRs

A *standalone* PHR is one which operates locally on the user's computer or through access to a user account on a web site. Notable early examples of standalone PHRs were provided by Google and Microsoft. Google Health offered a web based PHR, which showed early promise, but was shut down in January 2012 because "...the service did not translate from its limited usage into widespread usage in the daily health routines of millions of people.".(Brown & Weihl, 2011)

Microsoft's HealthVault was launched in October 2007, initially in the US only. HealthVault includes a specialised health search engine, provides electronic storage for the user's health data, and allows data integration with personal fitness devices. HealthVault also supports a number of standard exchange formats for health data, although data exchange with provider systems is not automatic. HealthVault coverage was extended to the UK in 2010. RememberItNow is a standalone PHR whose functionality include email or SMS medication reminders, biometric tracking, and personalised health information.

Standalone PHRs have the advantage for patients that they retain full control of their data. Disadvantages include the incomplete integration of the PHR with data from health provider systems, which may necessitate re-entry of data, and an absence of content curation. Health professionals may have less trust in data which a patient manages independently.

Integrated (non-tethered) PHRs

Integrated PHRs are Internet based systems which are capable of automatically obtaining data about an individual's health and healthcare from other systems.

The Danish *sundhed.dk* Internet site, established in 2003, offers patients secure access to their medical records, medication details, laboratory results and hospital visit data. Health records and laboratory results are also accessible by the patient's health provider. (Kierkegaard, 2013)

In Australia, the national Personally Controlled Electronic Health Record (PCEHR) has the capacity to incorporate shared health summaries, hospital discharge summaries event summaries and clinical letters, as well as health-relevant administrative data about Medicare services, medications and immunisations. (Pearce & Bainbridge, 2014)

PHRs which are integrated, but not tethered, have the advantage that they are independent of an individual healthcare provider; details of healthcare services from multiple providers can be added to the record. One disadvantage is that the safe and reliable correlation of data from multiple sources can depend on accurate translation of data standards between the PHR and the various source systems. Confusion about different data standards in different systems may lead to unforeseen and unwanted data errors (Bundgaard, 2014).

Tethered PHRs

A subset of integrated PHRs are referred to as *tethered* PHRs, (also referred to as patient portals) and function as an extension of an electronic records system operated by a healthcare provider or provider organisation. (Detmer, Bloomrosen, Raymond, & Tang, 2008; Kaiser Permanente, 2007) Kaiser Permanente's Internet based PHR (kp.org) provides Kaiser-enrolled patients with access to a range of functionality including appointment scheduling, dispensing, laboratory results, secure messaging with health professionals and general health information. Patient data shared within the PHR is obtained from the patient's electronic health record. (Roblin, Houston, Allison, Joski, & Becker, 2009)

The US Department of Veterans Affairs provides health services for entitled military veterans. The services provided include secure Internet access to the MyHealth*e*Vet PHR. Enrolled patients have access to a range of information including hospital discharge summaries, clinic notes, laboratory and imaging test results, medications, and allergies. Patients can also enter personal measurements, and export data using 'Blue Button' functionality (Woods et al., 2013).

Tethered PHRs have the advantage that they are typically 'transaction based' systems, closely linked to administrative and clinical processes in the provider's system. Data is updated in real time, and the PHR can provide the patient with secure communication with providers, and the ability to view and make appointments, and renew and fill prescriptions. The principal disadvantage is that patients may not be able to easily transfer data to other systems.

Proxy use of a PHR

A small number of PHR implementations cater specifically for the use of the PHR by a trusted third party (such as a health professional) on behalf of the patient. In Northern California, the *MiVia* system, intended primarily for use by migrant farm workers, was designed to support continuity of care for patients who may not always have access to their medical record. The *My eHealth Record* system in Australia's Northern Territory, provides summaries of hospital and general practitioner visits, pathology and medical imaging results. The design for each of these systems caters for low-literacy patients by explicitly providing for use by health providers, with the patient's permission, as well as providing for access by the patients themselves.

2.5.3 Why implement a PHR?

Drivers for introduction

A popular theme in discussions about PHRs suggests that a well-informed public – well aware of the changes which the Internet can provide, and familiar with policies about the rights of patients – is pushing healthcare providers to offer flexible access to information: "Public demand for flexible access to health information and services is growing, encouraged by internet trends and policies

promoting patient rights and empowerment" (Pagliari, Detmer, & Singleton, 2007, p. 330) and that PHRs are highly sought after: "…many consumers have high satisfaction levels with existing early versions of PHRs. In particular, consumers place value on easy access to test results and better communication with clinicians." (Tang et al., 2006, p. 123)

Promised benefits

The reasons for the implementation of a PHR system in a particular setting may be explicitly described, often in an extensive business case. In other cases, the motivation may be less clear. Early implementations of PHRs were conducted in a spirit of exploratory research, intended to determine whether it was feasible to provide a patient with access to his record. Clinicians who were familiar with the use of technology and anxious to communicate more effectively with their patients attempted small scale implementation of PHR functionality. The market for ehealth software depends to a significant extent on new software and new functionality, and a new opportunity for patient-facing systems was seen as a business opportunity, and widely promoted. In the US, 'meaningful use' criteria mandated the provision of PHR functionality as a requirement for certification. Eventually, public discussions about PHRs and their benefits resulted in the emergence of demands from a discerning public for online access to their records, at least among technically literate patients, and by 2010, there was a widespread view that the use of personal health records (PHRs) offered a range of benefits to patients, to healthcare providers, and to organisations.

> …there is both a clinical and societal rationale for ensuring that underserved populations have ready access to PHRs. From the clinical perspective, PHRs can lead to active engagement in health affairs for a segment of the population that has high rates of chronic disease. From a societal perspective, PHRs may aid in the public health goal of ensuring improved health and health conditions throughout the country.
>
> (Horan, Botts, & Burkhard, 2010)

The various benefits offered by PHRs have been identified as being able to assist with many of the challenges facing healthcare, although the identification of those benefits may not necessarily have

preceded the the move towards widespread implementation. A range of possible benefits have been identified in the literature, a number of which are outlined below.

Better data and information

Use of PHRs can expose diagnostic and medication errors, integrate disparate clinical records, and improve the accuracy of records (Pagliari et al., 2007), as well as enhancing the quality and timeliness of health information (NEHTA, 2011). PHRs will also support emergency department care, by providing immediate access to a patient's prior history (Tang & Lansky, 2005). Better availability of information within integrated PHRs will also offer the prospect of improvements in interactions between patients and their healthcare providers. Practitioners will spend less time taking the patient's history, and more time in detailed exploration of the patient's questions and concerns. Email communication will support direct communication at the patient's and doctor's convenience, instead of playing 'telephone tag' (Detmer et al., 2008). Patients will also be able to enter additional data into their record, thus helping their clinicians to make better decisions (Tang et al., 2006).

Patient-provider communication

PHRs will improve communication between patients and providers (NEHTA, 2011) and increase the level of trust between them, and support shared decision making (between patients and providers) (Pagliari et al., 2007). This improved communication means that it will be easier for patients to ask questions, schedule visits, and ask for repeat prescriptions. The improved connection between patient and provider will mean a continuous, rather than an episodic relationship (Tang et al., 2006).

Empowerment of patients

A number of the benefits provided by personal health records are seen as contributing to the empowerment of patients. The improved access to health data, information and knowledge which PHRs can provide will help them to improve their health and manage their illness (Pagliari et al., 2007; Tang et al., 2006).

> The PHR may also become a conduit for improved sharing of medical records. Patients who are more engaged in their health are more active participants in the therapeutic alliance, for example, when patients with chronic conditions collaboratively manage their illnesses with clinicians to reduce pain, improve functional outcomes, and improve medication adherence.
>
> (Tang et al., 2006, p. 124)

PHRs will also allow patients to secure more control over their health information, allowing joint management of the record, and foster patient-oriented decision support (Detmer et al., 2008). Use of a PHR will also provide for better decision making, both by healthcare providers and by patients (NEHTA, 2011).

'Virtual' care

The use of personal health records can reduce geographical barriers to care (Pagliari et al., 2007). A PHR can collect data from monitoring equipment in the patient's home, provide a link to patient support groups, and deliver on-line coaching, allowing face to face visits to be replaced by on line consultations (Detmer et al., 2008).

Health self-management

Personal health records will help patients with self care, give them more confidence, and improve their compliance with treatment (Pagliari et al., 2007), as well as helping with the management of stable chronic disease (NEHTA, 2011). Tang et al note that "…[p]atients with chronic illnesses will be able to track their diseases in conjunction with their providers, promoting earlier interventions when they encounter a deviation or problem." (Tang et al., 2006, p. 123)

Education and lifestyle changes

Personal health records can provide educational materials explaining current clinical practice for specific diseases (S. Kahn & Hickner, 2009), and interactive health evaluations and reminders about preventive services, which can support changes in lifestyle (Kaiser Permanente, 2007).

System and organisation goals

Personal health records also provide benefits for health provider organisations, and for the health system overall. They can improve the use of scarce resources (NEHTA, 2011), reduce the cost of managing chronic disease, and reduce the cost of medications and wellness programs (Tang et al., 2006). Use of PHRs will also lead to a decrease in hospital admissions, and result in better policy development (NEHTA, 2011).

Demonstrated benefits

Although PHRs have been in routine use in some settings for a number of years, evidence about improvements in patient outcomes is slow to emerge. Many of the benefits reported in studies of PHR adoption and use relate to process measures, such as the frequency of PHR use by patients (Wagner et al., 2012), their satisfaction with the communication process (Lin, Wittevrongel, Moore, Beaty, & Ross, 2005), the provision of preventive services, or the number of times that patients attend a clinic (Druss, Ji, Glick, & von Esenwein, 2014). However, some evidence is emerging that there are real benefits to be obtained through the use of PHRs. When 83 patients with Type 2 diabetes (with an HbA1c of 7% or above) were randomised to receive either Internet based care management or usual care for 12 months, those in the intervention group showed a 0.7% reduction in HbA1c, compared to controls (Ralston et al., 2009). Another pilot study supplemented home monitoring of hypertension, using the chronic care model, with advice from a pharmacist via the Internet. Pharmacist advice increased the proportion of patients whose blood pressure was deemed to be controlled (Green et al., 2008).

It is not yet clear whether the potential benefits which might result from the use of a PHR are equitably distributed among all patients, or more likely to be experienced by less disadvantaged patients.

2.6 Divides

The concept of 'divides' has been a part of the discussion of disadvantage for more than a decade. The *social* divides which delineate disadvantaged social groups often become apparent as *geospatial* divides, with clear separations between disadvantaged and affluent neighbourhoods. Disadvantaged individuals and groups who struggle with access to or the use of technology are identified as experiencing a *digital* divide, which can extend to the use of technology for health related activities – the *ehealth* divide. This section discusses those four divides, but in a temporal rather than logical sequence.

2.6.1 The Digital Divide

The notion of a 'divide' separating the technology 'haves' from the 'have nots' came to prominence in the late 1990s, in the context of technologically mediated government services ('e-government') in the US. The digital divide represented a barrier to the increased use of online service delivery, particularly to disadvantaged groups. In a US context, this group included older people, the disabled, low-income households, rural locations, and African American and Latino communities. (Lenhart, 2000) The response to the digital divide was often to provide targeted free or low cost options to help them 'get on line'. Such interventions were shown to be able to narrow the divide, but not to eliminate it:

Groups that have traditionally been digital have-nots are now making dramatic gains. Gaps between rural and non-rural households and between seniors and younger people have begun to narrow. Some divides, such as that between women and men, have disappeared altogether. Indeed, some have proposed thinking about the problem as the digital continuum rather than the digital divide.

And yet the larger problem persists. Inequities remain between those who possess the resources, education, and skills to reap the benefits of the information society and those who do not. Persistent gaps remain between different racial and ethnic groups, people with and without disabilities, single and dual parent families, the old and the young, and people with different levels of income and education. People on low incomes, and minorities, particularly when they reside in inner cities, are among the groups being left behind.

(Servon & Pinkett, 2004, p. 321)

Although now somewhat dated, a comprehensive evaluation of data about home use of information and communication technologies (ICTs) in Australia in 2001 (Lloyd & Bill, 2004) showed a similar pattern of use to those seen in other countries. Among high income households (more than $2,000 per week) more than 60% used computers and the Internet at home, while fewer than 25% of households with weekly incomes of $300 to $399 per week were users. An anomaly was apparent with very low income households (less than $120 per week, including 'negative' weekly income) where more than 30% were computer and internet users. The authors suggested that this may in part be due to student households, although the cohort may include households with both significant gross income and significant tax deductions. Level of education was also associated with the rate of home computer and Internet use: 70% for those with a degree, 40-50% for those with a degree, and 30-40% for those with no post-school qualification. The authors identified specific demographic factors which were associated with a high level of non-use: inability to speak English (94.6%), no school attendance (93.9%), no schooling after Year 8 (90.9%) and age greater than 65 (85.5%).

Newman, Biedrzycki and Baum (2012) used focus groups to conduct a qualitative evaluation of access to and use of digital information and communication technologies (ICTs) by residents from lower income and disadvantaged backgrounds in South Australia. Their analysis identified a num-

ber of factors influencing access and use of ICTs. These included English literacy (including for native English speakers), technological literacy, education, income, housing situation, social connection, health status, employment status, and trust. Among the participants, formal training in the use of ICTs was uncommon, with most acquiring skills from friends, or through trial and error. The authors suggest that these barriers to ICT use for those of lower socioeconomic status should be taken into account when planning and implementing ICT mediated options for healthcare. The authors provided the following conclusion:

> Our study findings augment the scant literature to provide insight into the implications of increased ICT-mediated health services for disadvantaged groups. Although qualitative findings from non-random selected groups are not generalisable, this limitation was partly addressed by our participants having broadly representative characteristics of the more disadvantaged in the Australian population. Our study suggests that ICT-mediated health initiatives should be considered in more complex and diverse ways to ensure that health inequities are not exacerbated by digitally-mediated communication methods, excluding those who lack skills, resources or capabilities to use ICTs. Unless lower SES groups receive appropriate support (e.g. skills training, funded equipment), ICT-mediated communication may become a new barrier to health service access. Consumers should be included in communication planning, rather than taking a 'one-size-fits-all' approach, and further research on the topic is indicated. Without such compensatory measures, Australia's E-Health Strategy may end up increasing inequities in health service access.
>
> (Newman et al., 2012)

2.6.2 The Social Divide

There was also a view that the digital divide was not just about access to and the use of technology; it came to be seen as part of a larger 'social divide'. Pippa Norris saw the digital divide as being a part of a more pervasive phenomenon of social exclusion, with multiple instantiations, dependent on the underlying causes (and likely remedies):

The global divide refers to the divergence of Internet access between industrialized and developing societies. The social divide concerns the gap between information rich and poor in each nation. And lastly within the online community, the *democratic* divide signifies the difference between those who do, and do not use the panoply of digital resources to engage, mobilize and participate in public life… (273).

(Norris, 2001, p. 273)

Manuel Castells had described a somewhat utopian view of an emerging global 'network society' (Castells, 2004, 2010); Matthew Payne, however, expressed reservations about this vision, and the implications it had for those who are not 'networked'. Payne suggested that the conventional discourse about the 'digital divide' was a too simplistic, and risked leaving the 'have-nots' behind:

The failure to have equitable social access to these tools, or a lack of skills to operate them, is to be a point in a network without links. And, disconnected points in a network might as well not exist. The divide, then, is not about computers or connectivity per se; rather, the divide is a simplifying metaphor that questions the social gaps between humans that use, and societies that rely on ICTs. Framed as such, the digital divide is not only a technological predicament, it is also an ethical crisis. As ICT innovations proliferate at exponential rates, and as our communal dependency on ICTs strengthens, the opportunity to leave others behind increases in kind. This techno-social dilemma poses the question, 'What do we owe the have-nots, and how might we help?'

(Payne, 2005)

Mark Warschauer saw the issue of information and communication technology (ICT) access as situated within a broader realm of literacy in general:

There are many similarities between literacy and ICT access. First, both literacy and ICT access are closely connected to advances in human communication and the means of knowledge production. Second, just as ICT access is a prerequisite for full participation in the informational stage of capitalism, literacy was (and remains) a prerequisite for full participation in the earlier industrial stages of capitalism. Third, both literacy and ICT access necessitate a connection to a physical artifact (a book or a computer), to sources of information that get expressed as content within or via that physical artifact, and to a skill level sufficient to process and make use of that information. Fourth, both involve not only receiving information but also producing it. Finally, they are both tied to somewhat controversial notions of societal divides: the great literacy divide and the digital divide.

(Warschauer, 2004, pp. 38–39)

These skeptical views about the benefits of technology emphasise that while PLUs may have the capacity to derive a benefit within a networked, digitally connected world, there is a real risk that those who are disadvantaged, and subject to social exclusion, may find themselves digitally excluded as well.

2.6.3 The Geospatial Divide

As noted in Section 2.2.2, there is an aspect of disadvantage which is associated with place. Disadvantaged families live where living costs are more affordable; those cheaper suburbs may have fewer services, and may have fewer options for healthy living (such as public transport, open spaces for recreation, and access to fresh nutritious food). This may particularly be the case where 'social housing' has enforced the aggregation of families with low measures of socioeconomic status into a defined area (such as public housing estates).

Alexander, Kinman, Miller and Patrick (2003) have observed that marginalised and under-served populations can often be identified geographically, by applying techniques which they refer to as 'medical geomatics'. They advocate for the use of geographical information systems as a tool for use in the evaluation of marginalised groups.

2.6.4 The eHealth Divide

Cummings, Chau and Turner (2008) identified a concern that emerging expectations about patient use of technology as part of their care could increase inequities in care delivery for vulnerable patients. They expressed

> ... a concern that the existing inequities of access to quality healthcare faced by many patients will be further compounded by an emerging e-health divide. We must avoid widening this divide to allow the existing inequalities between information "haves" and "have-nots" to be compounded by presenting additional financial, technological, and skill barriers to chronically ill patients (many of the poorest, oldest, and most vulnerable members of our societies) as more health information and services come to be provided primarily online.
>
> (Cummings et al., 2008, p. 168)

Socioeconomic or other factors may interfere with an individual's capacity to benefit from personal health records. A number of authors have identified aspects of disadvantage which may affect the ability of potential users to benefit from ehealth systems. Han, Sunderland, Kendall, Gudes and Henniker (2010) noted the likely relationship between disadvantage, chronic disease, and limitations in access to ehealth services:

> …complex relationships appear to exist between Internet access, chronic disease and socioeconomic status. Both the prevalence of chronic disease and access to the Internet are likely to be influenced by socioeconomic disadvantage. It is plausible, therefore, that those who are most unwell are also least likely to access Internet e-health initiatives, but are also least likely to have the resources needed to address their health through other mechanisms. Socioeconomic disadvantage is known to be influenced by (or influence) place of residence, meaning that e-health has the potential to significantly exclude large sectors of the community and contribute to the cyclical disadvantage of particular geographic locations.
>
> (Han et al., 2010, p. 31)

They applied a case study approach to evaluate the relationship between access to the Internet (and by implication to ehealth resources) and the self-reported incidence of chronic disease. They distributed a questionnaire in the Logan-Beaudesert health service district in Queensland, and achieved a response rate of 14%. The authors caution that simply endorsing the prevailing rhetoric

about ehealth benefits will not adequately address the challenge, and that those introducing ehealth services should pay particular attention to geographic inequalities. The PLU problem (Showell & Turner, 2013b) is likely to add to this geographic aspect of disadvantage to limit the uptake of ehealth options.

Lustria, Smith and Hinnant (2011) explored issues with the use of online technologies for healthcare in the US. They summarised evidence linking better health outcomes with patient use of ehealth technologies for information seeking, communication with care providers and managing their own health data. However, they noted that recent initiatives to improve access to digital technologies had not necessarily resulted in comparable improvements in health outcomes. They analysed data from the 2007 Health Information National Trends Survey (HINTS) to identify factors which might influence the use of technology for healthcare. Respondents were categorised according to socioeconomic characteristics, rurality, numeracy and internet access, and their use of the internet for seeking health information, managing their own health information, and communicating with providers.

Their results showed that internet access was a strong predictor of online health information seeking, but not of email use to communicate with healthcare providers. Younger respondents with some post-secondary education were more likely to use the internet to find health information, but these characteristics did not predict online management of personal ehealth information. They found that respondents who were female and better educated were more likely to use email to communicate with healthcare providers. They found no statistically significant factors which predicted the use of ehealth tools for managing personal health information

> …despite increased access to technology, underserved populations (e.g. minorities, elderly, patients living in rural areas, etc.) continue to face significant barriers to accessing, or using, health information. Aside from differences in eHealth technology use related to ethnicity, education and income, other aspects of the digital divide have surfaced related to geography, computer and health literacy, disability, availability of eHealth services and local infrastructure requirements, to name but a few.
>
> (Lustria et al., 2011, p. 227)

Despite the evident enthusiasm for ehealth, and for personal health records, the evidence outlined above identifies that there remains a group for whom the capacity to benefit from the use of a PHR remains small. The members of this disadvantaged group are barred from direct use of a PHR by a number of factors, including poor textual, technical and health literacy, and lack of financial resources. This group has been characterised as being 'disempowered, disengaged and disconnected' – the 'DDDs' (Showell & Turner, 2013a, 2013b). The barriers are associated with a low socioeconomic status, which may also inhibit their capacity to benefit from other community resources, including health resources.

2.7 Invisibility

Some research in health service delivery and in health informatics has a particular focus on the needs of low income patients, the way in which disadvantage interacts with health status and health outcomes, and the ways in which changes to systems can to some extent redress the imbalance in favour of the disadvantaged (Zarcadoolas, Vaughon, Czaja, Levy, & Rockoff, 2013). While this affirmative action focused on the needs of underserved subgroups is laudable, it can lead to the disadvantaged being seen as a disconnected 'other', to be dealt with separately, as a special group.

However, of more interest in the context of this thesis is way in which a majority of research attends to the needs of 'average' patients, often without any conscious consideration of the demographic characteristics of the population under study. This approach carries with it an assumption (often unexamined) that some version of the 'trickle down effect' (Aghion & Bolton, 1997), or Ro-

gers' 'Diffusion of Innovations' (Rogers, 1983) will eventually result in benefits for all patients, across all sociodemographic strata. This expectation may be misguided.

The association between socioeconomic disadvantage and poor health outcomes is so well accepted as to be viewed almost as a commonplace observation. Similarly, the existence of a 'digital divide' is well understood, as is the reduced likelihood of PHR use by disadvantaged individuals. Given that these separate but related factors are generally known and accepted, a question arises as to why PHR developments continue to deliver systems which disadvantaged patients find harder to use, or avoid altogether. This observation also raises a question about why there is so little interest within the health informatics community in addressing this significant inequity in resource allocation and service provision. Invisibility can take many forms:

- Many research projects use written or electronic invitations to participate, and criteria for inclusion may require the ability to read and write in English;

- Engaging disadvantaged participants in a design process is likely to be challenging. If they are not carefully selected and carefully managed, disadvantaged subjects are likely to be overawed by the confident, verbally adept 'experts' that they encounter They may well feel that they are being 'tested' – asked to provide the 'correct' answer – and respond by being unwilling to venture an opinion of their own, or saying what they think is expected;

- Disadvantaged patients may not realise that care is required or available, or may avoid seeking care because of concerns about affordability;

- The geographic segmentation of society is also effectively a socioeconomic segmentation. It is unusual for members of the household or adjoining neighbours to have a markedly differing socioeconomic status;

- Careful assessment and documentation of a patient's literacy (including health literacy) is not yet common practice in healthcare. The stigma of low literacy can impair verbal communication, and can interfere with face to face interactions. Communication with healthcare providers may be less successful as a result (Easton et al., 2013); and

- There is no continuum between 'can't read' and 'can read'; between 'can use a computer' and 'can't'; between 'finished Grade 10' and 'didn't finish'. Statistical measures of literacy are usually reported along an implied continuum. In reality, 'can't read' is an absolute lack of this capability. Area measures say nothing about the capability of individual at the lowest end of the spread. With text literacy, for example, this is compounded by the tendency to measure literacy only at higher level of geographic aggregation, which further limits the spread of measurements.

Each of these factors may be a contributor to invisibility, or it may not. But whatever the cause of the phenomenon, it seems that the group of potential PHR users who have the greatest need remain outside the current scope of PHR design and implementation.

2.8 Closing comments

This chapter has elaborated the background for this thesis by providing an overview of a number of related concepts which will be explored during the course of the research. Socioeconomic disadvantage and social exclusion are often geographically situated, and are associated with worse wellbeing, earlier onset of chronic disease and a reduced propensity for self efficacy. Disadvantage and exclusion are also associated with greater difficulties in using information technology, including healthcare technology such as PHRs.

Health is a complex interaction between illness, sickness and disease, shaped by the interaction of the views of the individual, the community in which they live, and the medical profession about wellbeing and malady. This complexity guarantees that the delivery of better health through patient facing technology will never be straightforward.

A number of divides – digital, social, geospatial and ehealth – have the effect of separating disadvantaged individuals and groups from the rest, and making it harder to implement successful interventions, including PHRs, which might benefit disadvantaged patients. Lastly, the disadvantaged

sometimes seem invisible, left out of research and thinking, resulting in systems which they may not use. None of this is new, although the extent and strength of the evidence may a little surprising. What drives this research is a concern about the apparent lack of interest in applying these concepts, about disadvantage, health and divides, to the design and implementation of personal health records.

This background has provided a foundation for the chapters which follow. Each of the next four will present a publication which explores facets of the relationship between barriers to PHR use, healthcare and disadvantage.

Chapter 3: Language games and patient-centred eHealth

> "The girl had the making of a poet in her who, being told to
> be sure of her meaning before she spoke, said: 'How can I
> know what I think till I see what I say?' "
>
> - George Wallas

> "There are things known and there are things unknown,
> and in between are the doors of perception."
>
> – Aldous Huxley

3.1 Preface

After reviewing a range of background material, much of which appears in Chapter 2, the challenges facing disadvantaged patients attempting to use a personal health record (PHR) appeared obvious. The use of an ehealth system requires a degree of technical capability in order to be able to navigate the system effectively, but perhaps more important is the need to navigate the syntactic and lexical landscape embedded in the design. However, the obvious nature of these challenges seemed not to surface in the literature about PHR design and implementation. Perhaps there was a problem to be explored.

In beginning to address Research Question 1, this publication explored questions about the capacity of a single system of nomenclature to capture all of the richness of meaning involved in an individual's need to integrate the experience of sickness, illness and disease with the overlapping requirements of medical diagnosis, treatment and long term management, together with self-management of the malady (which may involve multiple chronic conditions) and the practical realities of living a life. The paper explored the use of specialised medical language and terminology,

SNOMED CT in particular, in ehealth systems, and raised particular concerns about the constraints which SNOMED CT may impose.

The issues explored in this publication did nothing to allay the initial concerns about limits to the usability of health focused information systems for individuals who lack training and experience in the use and interpretation of specialised medical language.

3.2 Paper as submitted and accepted

Publication details

This paper was submitted to the tenth Special Topic Conference of the European Federation of Medical Informatics, held in Reykjavik in June 2010, and subsequently published as:

Abstract

The sharing of clinical information between ehealth systems requires a common terminology, and SNOMED CT is seen as an acceptable solution for this task. Widespread adoption of SNOMED CT may mean that other language games, particularly those of citizens and patients, are sidelined or ignored. This paper considers the role of a citizen's "voice" in a connected ehealth world.

Introduction

The last decade has seen remarkable growth in the use and scope of information systems in healthcare, with a significant increase in the inter-connectedness of disparate systems. The adoption of SNOMED CT as a common terminology standard to support communication of clinical details between systems offers the prospect of a much more connected ehealth domain. SNOMED CT

has its origins in medical "language games", and brings with it some anomalies and issues to be dealt with over time. However, there appears to be a significant gap between the language games of medicine and those of citizens and patients. This paper explores the notion that the use of SNOMED CT alone as a terminology for ehealth will introduce a risk that citizens and patients will be disempowered, and left voiceless in an ehealth environment that should be both supporting and providing patient centred care.

ICTs in health

Information and communications technologies (ICTs) provide a codified, structured way of recording and managing data. At its core, an ICT environment provides a technical, objective tool to help humans deal with large amounts of information. As with any tool, humans can adapt to the requirements of a computer system. Humans have little difficulty using ICTs which allow the recording of free text. However, systems which use a highly structured lexicon and terminology make processing faster, clearer and more certain. Standardised terminology also facilitates automated communication between systems, automated workflow processing, alerting, pattern recognition and reporting.

An ICT using a standard terminology (anything other than free text) can push meaning towards the language games of a particular group, and can in some cases generate ambiguity in communication between groups. Exclusive use of the terminology will impose the conceptual view of the world that provided the foundation for the terminology. Other perspectives cannot be described, and disappear from view.

Wittgenstein (2001) observed that there is a specialised use of language within particular interest groups. He referred to these specialised subsets of language as "language games" (but without the sense of "playing games with language"). In the context of an information system, the language games of the purchaser and end user of the system guide the way in which data and information are represented.

The first use of ICTs in healthcare was predominantly within hospitals, for finance and accounting functions (Berner, Detmer, & Simborg, 2005). These systems also collected a range of administrative data needed to identify patients, and to track healthcare utilisation. A range of "point" solutions followed in specific areas of healthcare. The majority of the systems were used in a hospital setting. The advent of affordable office-based systems also led to the introduction of systems into family and community practice.

Administrative ICTs in healthcare reflect the language games of health business. Patients are accounted for in terms of admissions, separations, care types, financial class and diagnosis related groups. The language games used in a clinical information system are predominantly those of medical and other clinical groups.

Over the last decade the focus of ICTs in healthcare has changed from standalone systems managing the business of a health organisation, hospital, clinic or department to a comprehensive shared electronic health record (sEHR) for each patient. Local code sets may be an acceptable way of representing language games for a system working in isolation. However, the high level of integration and interoperability required for a sEHR involves the language games of disparate groups. The introduction of common regional, national or global terminologies becomes inevitable.

SNOMED CT

The College of American Pathologists published the first edition of its Systematic Nomenclature of Pathology (SNOP) in 1964. Between 1972 and 1975 SNOP was redeveloped as the Systematic Nomenclature of Medicine (SNOMED). SNOMED RT (Reference Terms) was introduced in 2000.

In the UK, the National Health Service introduced Read Codes to record administrative and clinical details in general practice. Versions 1 and 2 of the Read Codes were mapped to a range of other clinical and administrative terminologies, and Version 3 was developed by organisations rep-

resenting medical, nursing and allied health clinicians, with the aim of providing greater specialist detail and including a broader domain of health care.

SNOMED CT (Clinical Terms) was developed by combining SNOMED RT with NHS Clinical Terms (Read Codes); the first version was released in 2002. The intellectual property of SNOMED CT was acquired by the International Health Technology Standards Development Organisation (IHTSDO) in 2007, and it is now in use in more than 50 countries around the world.

Both SNOMED and Read Codes were initially structured as hierarchical classifications of medical phenomena, grounded in medical language games. Attempts have been made to fit or map non-medical terminology to SNOMED-CT term by term, but the underlying semantic framework is still constructed with a predominantly medical gaze.

It is hard to overstate the significance of the endorsement of SNOMED CT as a common language for the exchange of clinical information between systems. There have been and will continue to be problems with its implementation and use. However it is unlikely that any of these will prove insurmountable.

SNOMED CT is not without its peculiarities. Patrick, for example, has noted that it blurs metonymic and holonymic roles (Patrick, 2006), and incorporates a range of administrative detail without particular clinical relevance (Patrick, 2008).

Despite some recognised flaws, SNOMED CT is a comprehensive and extensible terminology. It is widely accepted by a range of clinician groups in many countries and has a demonstrated capacity to interoperate with other health data and communication standards as a way of supporting communication between systems (MacIsaac et al., 2008).

Significant effort is being expended currently on the further development of SNOMED-CT, and addressing issues which arise in the introduction of SNOMED-CT into clinical systems. With this work it will probably prove to be a fine tool for the tasks that it's designed to facilitate. However, it's not the end of the story for the codification of information about all aspects of healthcare.

Medical language

Structured terminology is the expert's considered view of the concepts and language games of a specialised field. It provides a conceptual framework for the textual body of the discipline. McCray observes that "…it is necessarily the case that every conceptualization is biased…because representing, or categorizing, the world depends on at least two crucial factors (1) the purpose for which the conceptualization is being created, and (2) the world view of its designer" (McCray, 2006, p. 267).

For SNOMED-CT this underpinning conceptualisation is predominantly medical. SNOMED's origins within pathology may have coloured its structure with the hues of a pathologist's understanding of disease, although it has been revised many times since 1964. The terminology reflects medical language games and medical expertise - a medical clinician's view of health, sickness and disease, and of the patient. The language game of medicine serves to maintain the exclusivity of the medical "tribe"; it raises barriers to participation and communication for other health professionals, and even stronger barriers for citizens and patients. As a group, doctors may espouse the virtues of patient centred care, but have long been seen to use specialised language as a way of protecting their expertise. "They have been admitted to the mysteries; they, more than anyone the layman meets, use special language, though it often means merely that you have 'a pain in the ache.' " (Garceau, 1966, p. 61).

SNOMED-CT is exactly what it says – medical and clinical terminology. It provides an expert's structured analysis of the modes of failure of the human machine, and the therapeutic actions undertaken for repair. It does not begin to provide a convenient terminology for the unwell citizen to

discuss his condition. It is evident that information systems grounded in medical and clinical terminology will struggle to effectively engage those from outside the medical/clinical tribe.

The adoption of SNOMED CT as a common terminology for healthcare is not surprising. The predominant language of healthcare in the early 21st Century is the language of medicine, and clearly expressed medical language is an essential tool for communication between medical professionals. Medicine has a rich and complex vocabulary, much of which is shared among Anglophone clinicians. Increasingly over the latter half of the 20th century, English became the *lingua franca* of medicine, in both international and intranational communication (Maher, 1986).

As Whetton and Walker (2003) have observed "[o]ur understanding of health and disease is structured by the biomedical discourse, which uses the language of science and technology to shape our knowledge about, attitudes to, and treatment of health and disease." (Whetton & Walker, 2003, p. e1) Arguably, medical language games can reflect a mechanistic view of healthcare, and describe the patient as if she were a broken machine in need of repair (Yawar, 2008), and the non-patient citizen as a machine free of flaws, defects or abnormalities.

Clinical language games do not provide a voice for patients who wish to talk about their experience of illness and disease, or to participate in their own care. The patient's sense of self deters him from having an objective clinical view of his own body as an aggregation of components, some of which work and some of which do not (R. Anderson, 1988).

Language, visibility and control

It can be difficult or impossible to frame and express one's point of view if one does not have the right word to describe a thing. Our use of language guides how we see the world, how we think about it, and how we understand, and things for which we have no language can be hard to recognise (Winawer et al., 2007).

Healthcare providers and administrators will only see, manage and think about those things which have been documented within an information system. If the language within the system fails to name phenomena related to a particular aspect of healthcare, then those things will disappear from view.

Healthcare providers, patients and carers will be unable to see features of the patient's disease, wellness or life that the information system doesn't describe.

A language which we do not understand prevents our participation in dialogues which are conducted in that language. Language shapes thought and enables participation in human activity.

Language is a powerful human tool. It is neither neutral nor benign – it shapes thought, and frames the discourses which govern collective action (Foucault, 1982). Illich commented at length on the nature of medical monopolies, and their effect on the wellbeing of society. He described a notion of "social iatrogenesis", and observed that it "…is at work when … the language in which people could experience their bodies is turned into bureaucratic gobbledegook" (Illich, 1982 Chapter 2).

All this matters because the move towards the use of information systems for collection and storage of a sEHR for each patient seems destined to rely on the language games of the experts, language games which have the capacity to exclude the citizen and the patient.

Citizens' language

Healthcare systems in most countries are identified as being "under pressure" or "in crisis". Increasing costs, staff shortages, and an increased proportion of elderly patients are all seen as contributors to the problem. Some of the solutions that have been proposed include engaging citizens in an attempt to reduce health-damaging behaviours, the transfer of some aspects of patient care from institutions to community settings (including patient homes), to support the frail well in living

longer in their own homes, and to engage patients as partners in the delivery of their own care. If ICTs are to be a part of that response, they must be accessible by citizen non-experts.

There are conflicting views of the proper role of the citizen/patient/consumer within the healthcare system. At one extreme, the patient is seen to play a passive role as the subject of study and the recipient of care. At the other extreme, the fully informed and clinically aware consumer is invited to make thoughtful choices between options for treatment, and to participate as an active member of the treating team in the delivery and management of her own care (Arora & McHorney, 2000; Brody, 1980; Stiggelbout & Kiebert, 1997).

Engaging patients in the development of ehealth solutions is generally seen as an optional extra, an add-on or an afterthought. By the time attempts are made to engage patients in a discussion about a patient facing information system, the basic design will have been established as a clinical, rather than a citizens' system.

Citizens and patients use their own language conventions and terminologies when they communicate about issues of heath and wellness, but this language has received limited attention. Smith (2007) analysed the use of language in Web-based bulletin boards, and was surprised by the frequency with which obscene or childish terms were used in place of their formal anatomical equivalents. She noted that "…vocabulary developers must, like dictionary makers, make a choice between description— capturing what exists—and prescription, capturing the words that "should" be used." (Smith, 2007, p. 679).

Healthcare providers tend to adopt one of three approaches in addressing the disjunction between consumer and clinical terminology:

- Mould patients' use and understanding of the medical language game when they interact with health ICTs;

- Map patients' terms to their clinical equivalents (in SNOMED-CT or another terminology); or

- Model citizens' language games, and develop and maintain a consumer terminology to be used when discussing health issues with patients and citizens.

The first approach has focused on highlighting the poor quality of the patient's language game in comparison with that of the health professionals, and devising ways to mould that use to align patient language more closely to medical norms. For example (Lerner, Jehle, Janicke and Moscati, (2000) asked emergency department patients to identify matches between pairs of common terms (bleeding/haemorrhage, broken/fractured bone, stitches/sutures). They found that patients often failed to understand medical terminology, particularly those who were younger or less well educated. Since most citizens are unversed in the medical language game, this observation is not surprising.

Consumers' use of terms other than the accepted clinical term when seeking information is framed as a problem with the consumer's use of the system. A truly patient centred framing of the problem would identify that consumer-facing information resources crafted in specialised clinical language are not appropriate for communication with patients, and thus are not fit for purpose.

Consumers increasingly use Internet resources when seeking health information. However their lack of knowledge or understanding of health terminology can raise barriers. Zielstorff (2003) noted that the consumer's failure to associate "heart attack" with "myocardial infarction", "sugar" with "diabetes", or "nose bleed" with "epistaxis" frustrated their attempts to find information when they needed it.

Brennan and Aronson (2003) explored the use of automated lexical mapping to extract clinical terms from free-text in patient emails, as a way of improving the provision of information to patients, and avoid a situation where "[p]recise understanding of the concerns raised by lay people in

… electronic messages … requires interpretation by a skilled health professional" (Brennan & Aronson, 2003, p. 335).

Both Zielstorff, and Brennan and Aronson, proposed the mapping of common consumer terms to their formal clinical terminology equivalents as a way of translating between language games where possible. Neither suggested that the consumers' language games or terminology warranted further study.

Few of the information systems in healthcare have been designed to record information using the patients' terminology about their disease, fears, concerns or life. Mapping and translation may be of value, but is unlikely to provide a complete solution. However, it is evident that patient centred care needs one or more additional terminologies to capture those important things about the healthcare of citizens which are not at their core medical or clinical issues.

Zeng and Tse (2006) commented on efforts to align consumer and health professional language, but noted the lack of systematic work to develop and evaluate consumer health vocabularies (CHVs). They identified a need for development of CHVs as a way to support information seeking, understanding and retrieval by consumers. They described a bottom up approach to concept mapping between CHVs and professional terminology, and developing a preliminary "first generation" CHV.

Conclusion

A number of changes and challenges in healthcare over the next few years will serve to emphasise the importance of effective and usable ICTs for citizens and patients. Berwick (2002) speaks eloquently of the need to include the patient as a valued member of the treating team, as an active participant in her own care. Additionally, it is probable that as baby boomers become more frequent users of healthcare services, they will expect greater autonomy, involvement and choice than earlier generations.

If ICTs are to support these changes, they will need to be provided in a way that makes them easy for citizens and patients to understand.

It must be acknowledged that SNOMED-CT is an excellent tool for codifying clinical knowledge, and supporting communication between information systems. However, it can only hope to capture a subset of what there is to be known about the health and care of a patient. Other types of language will be needed in health ICTs if the goal of patient involvement in patient centred care is to be realised.

There is a risk that the adoption of SNOMED CT as a universal terminology for ehealth systems will be seen by some as a universal solution for all terminology issues in health. However, the active participation of the citizen in the maintenance of his own health, and in the management of his illness, is likely to require a more flexible approach.

If patients and their citizen carers are to have an independent voice in the provision of healthcare, and if care is to be truly patient centred (and citizen centred) then there will need to be at least one companion terminology, and perhaps a handful of them, that provide a voice for those citizens who have an interest in health and wellbeing – most of all the citizens who fund and use healthcare systems.

3.3 Commentary

Even skilled (non-health) professionals who read well and are familiar with the use of technology can face a formidable barrier when first using an ehealth system such as a personal health record. For potential users of such systems who are already at a disadvantage the barrier can appear insurmountable.

These concerns were later echoed by Keselman and Smith (2012), who introduced their study classifying patient errors in comprehending medical documents with this caveat:

Emphasis on participatory medicine requires that patients and consumers participate in tasks traditionally reserved for healthcare providers. This includes reading and comprehending medical documents, often but not necessarily in the context of interacting with Personal Health Records (PHRs). Research suggests that while giving patients access to medical documents has many benefits (e.g., improved patient–provider communication), lay people often have difficulty understanding medical information. Informatics can address the problem by developing tools that support comprehension; this requires in-depth understanding of the nature and causes of errors that lay people make when comprehending clinical documents.

(Keselman & Smith, 2012, p. 1151)

Chapter 4: Citizens, patients and policy: a challenge for Australia's national electronic health record

> "Whenever you find that you are on the side of the
>   majority, it is time to pause and reflect."
>
> <div align="right">Mark Twain</div>

> "There is no shame in not knowing; the shame lies in not
>   finding out."
>
> <div align="right">- Russian proverb</div>

4.1 Preface

Consideration of Research Question 1 evinced curiosity about how the policy framework for Australia's national personal health record, now known as the Personally Controlled Electronic Health Record (PCEHR), had incorporated the needs and aspirations of citizens, including those experiencing socioeconomic disadvantage, into that policy.

Australia's PCEHR was developed following a recommendation from the National Health and Hospitals Reform Commission in 2008. The PCEHR, which was described as being designed around the needs of consumers, was launched in July 2012.

The development of Australia's ehealth policy, of which the PCEHR was an integral component, involved an extended programme of consultation and discussion with information technology and health industry stakeholders, as well as organisations representing health consumers.

The experience of participating in workshops and focus groups organised by Australia's National eHealth Transition Authority (NEHTA) and Health*Connect*, its precursor, had led to a suspicion that some examples of supposedly 'open' consultation were guided by outcomes which seemed to have been in the minds of the sponsors of the consultation at the outset. Participation in discussions about personal health records was accompanied by an awareness of the difficulties involved in engaging with participants representing all communities within society, and all members of those communities. Challenging or uncomfortable concerns could easily be discounted in favour of the preferred outcomes. Those concerns prompted the critique of the consultation in this paper, which explores the role and importance of citizen engagement in the development of an ehealth system intended for use by citizens and patients.

4.2 Paper as submitted and accepted

Publication details

Abstract

Australia will implement a personally controlled electronic health record (PCEHR) over the next three to five years. Development of an e-health policy framework to support this initiative has involved healthcare providers and patients, but the discussion appears to have bypassed non-patient citizens. There is a risk that this omission may result in difficulties with implementation and uptake of the new system.

Introduction

Australia, like many other developed countries, is in the process of implementing a national shared electronic health record (EHR) system. This implementation has raised a number of interesting policy issues, including those concerning patient privacy, patient identification, and the management of patient consent for participation and for primary and secondary use of information. Achieving effective citizen participation in the development of public policy is an important part of a participatory democracy. Although the use of interest groups as proxies may be convenient, it may not provide a reliable substitute for direct citizen engagement. Patient organisations have been actively consulted about Australia's EHR, and involved in discussions about relevant policy issues. However, the development of the underlying policy framework does not appear to have involved citizens directly, other than in their role as patients.

While this paper provides a commentary on Australia's approach to the development of national e-health policy, it does not attempt to provide a comprehensive summation or analysis of the policy itself, or to examine EHR developments within individual states and territories.

Citizen, patient or consumer?

Some tensions exist between the differing roles and terminologies of citizen, patient and consumer. Talcott Parsons (1951) first formulated the notion of a 'sick role' which exempted patients from responsibility for their incapacity, and from the obligations of their normal social roles, while imposing an obligation to try to get well, and to seek competent professional help to do so. Subsequent analyses of the sociology of healthcare, and of the role of the patient, have moved on from Parsons' view. Patients are now reframed as 'consumers', with an assumption that they have a consumer's right to select and choose in the health marketplace. However, this viewpoint is not universally accepted. Keaney (1999) suggests that patients ought to be considered as partners in a continuing process of inquiry, rather than as passive consumers of pre-packed healthcare. Although Parsons' notion of the patient's role in society may now seem somewhat dated, the transition from citizen to patient still provides a valid conceptual framework. Church at al. (2002) cite Tuohy and

Evans' observation (1986) that in healthcare citizens assume two major roles. They are on the one hand collective taxpayers, and on the other, individual users of services. A citizen's view of a policy debate may reveal a dichotomous position, with views as a funder distinct from those as a recipient. In the context of the discussion presented here, the separate roles of patients and of non-patient citizens are considered to offer differentiated viewpoints on matters of health policy. Not all citizens are patients, but (almost) all patients are citizens.

Engaging citizens in health policy

A brief review of the relevant literature shows a body of work dealing with the challenges and benefits of engaging citizens in public policy, and more specifically in health policy. One of the earliest considerations of the issues associated with citizen engagement came from the discipline of urban planning. Sherry Arnstein (1969) described a 'ladder of participation', with eight levels or 'rungs' of citizen participation, in three stages. Arnstein's first stage is Nonparticipation, which can involve Manipulation – an attempt to 'educate' participants to an acceptable viewpoint - or Therapy, which sets out to 'cure' their deviant perceptions. The second stage encompasses Degrees of Tokenism: Informing; Consultation (which may include what Arnstein refers to as 'window-dressing participation'); and Placation, when participants hear and are heard, but are not necessarily heeded. The third stage involves Degrees of Citizen Power: Partnership, Delegated Power, and finally Citizen Control, which can provide citizens with opportunities for trade-offs, decision making seats, and possibly managerial control.

There have been increasing trends towards the direct engagement of citizens in the development and implementation of health policy. A discussion paper on citizen participation (CP) prepared for the Commission on the Future of Health Care in Canada identifies that:

> … reported advantages to CP in health planning include a system that addresses the specific needs, values, culture and attitudes of the community. Furthermore, it provides the opportunity for greater support of resulting decisions and services, a more efficient use of scarce resources, an enhancement of community awareness of health issues, a mechanism for public feedback and increased networking, access to local resources and skills of community members, and an enhanced sense of control and empowerment within the community.
>
> (Pivik, 2002, p. v)

Curtain (2003) uses the OECD's three-stage model of citizen relations (similar to the three stages of Arnstein's ladder) to review the extent to which Australian governments are engaged with citizens. He identifies three roles for citizens in this process: as taxpayers, as users of services, and as members of the local and national community, and notes that:

> By bringing three perspectives to bear on an issue, citizens as citizens are often better placed than politicians or public servants to identify policy priorities, reconcile conflicting values and work out what choices are more consistent with their community's values.
>
> (Curtain, 2003, p. 35)

Abelson et al. (2003) reviewed the use of deliberative methods for public participation in healthcare. They identified a need for approaches which strengthen two-way interaction between decision makers and the public, and noted that deliberative democracy involves a collective 'problem solving' discussion, with persuasion and altering of participants' views. Power relationships are not necessarily excluded from this process. They identify four broad approaches to deliberative participation:

- *Citizen juries* (known as 'planning cells' in Germany) which involve 20 or so participants, and have been in use since the 1970s;
- *Citizens' panels* which are similar to juries, but have more permanency, providing a resource to consider different issues over time;
- *Consensus conferences* which typically involve small sub-group meetings with experts, followed by a larger meeting to present main observations and conclusions; and

- *Deliberative polls* which incorporate a deliberative component within a conventional opinion poll.

Citizen participation can have its drawbacks. A number of challenges have been identified, including:

> … time constraints, lack of representation, difficulty reaching marginalized populations and a lack of education and training specific to CP… a lack of resources, perceived status differentials, processes that are not fully accessible, poor communication, differing definitions of participation, conflicting vested interests, incongruence between stated purpose and practice, tokenism and role strain.
>
> (Pivik, 2002, p. v)

There have been few evaluations of the effectiveness of deliberative methods in health policy. Church et al. (2002) reviewed the use of citizen participation in Canada, and offer two perspectives on the interest of provincial governments in citizen participation in healthcare. The first perspective embraces the assumptions that citizens want to participate, and that their participation results in better decision-making. They found little evidence for either assumption. Their second perspective was that governments use participation as a means of co-opting citizens to a larger political agenda.

Arnstein's conception of citizen participation has been criticised as being overly simplistic, and its transferability to the more complex domain of health service planning questioned:

> A linear, hierarchical model of involvement – Arnstein's ladder – fails to capture the dynamic and evolutionary nature of user involvement. Nor does it recognise the agency of users who may seek different methods of involvement in relation to different issues and at different times.
>
> (Tritter & McCallum, 2006, p. 165)

Despite these concerns, Arnstein's ladder remains a useful tool with which to gauge the extent of citizen involvement in matters of public policy.

Australia's national EHR

The last decade has seen significant progress towards the implementation of national EHR systems in many developed countries. In Australia, work on a national EHR system was initiated following the House of Representatives 'Health On-Line' report (Slipper & Forrest, 1997). Australia's health ministers established the National Health Information Management Advisory Committee (NHIMAC) in 1998, and The National Electronic Health Records Taskforce was established as a sub-committee of NHIMAC in 1999. The Taskforce produced *A Health Information Network for Australia*' (2000), which included a recommendation for a national approach to the implementation of EHRs. This national implementation was initially pursued through the Health*Connect* program (Australian Government Department of Health and Ageing, 2010), but in 2005 Health*Connect* was recast as a 'change management strategy' (Abbott, 2005). Responsibility for the development of the national EHR was transferred to the National e-Health Transition Authority (NEHTA), which had been established by Australian Federal, State and Territory governments to develop essential foundations for ehealth.

In 2009, Commonwealth, state and territory health ministers announced the introduction of an individual health identifier for all Australians (*Healthcare Identifiers Act 2010*, 2010 (Cth)), and the 2010 Federal Budget included an allocation of $446.7 million over two years as initial funding for the introduction of a personally controlled electronic health record (PCEHR), which is to include a patient summary. A draft Concept of Operations for the PCEHR was released in April 2011 (DoHA & NEHTA, 2011).

Policy issues

Policy issues related to electronic health records and e-health have proved challenging and divisive. Sound policy for e-health necessitates a fine balance between security and privacy for individuals and groups, and improved sharing of health information to support better care. Australia's e-health policy debate has many of the characteristics of a 'wicked problem', which are:

> …social system problems which are ill-formulated, where the information is confusing, where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing.
>
> (Churchman, 1967, p. B–141)

Wicked problems usually have no 'right answer', and any compromise solution risks leaving most stakeholders dissatisfied. Westbrook at al. (2007) note that information systems have been identified as a way of improving health service delivery, but caution that the 'wicked' nature of the task presents challenges for both implementation and evaluation. Broadly, the policy debate has involved: those with an interest in the design and implementation of an EHR system to improve care through better information sharing; those with expertise in legal and privacy matters, who generally advocate for a cautious approach; healthcare providers (particularly medical practitioners) who understand the need for caution, but also see significant future benefits in a functioning EHR system; and to a lesser extent those who will make use of aggregated health data. The views of patients have been represented in the debate by health consumer organisations, notably the Consumers Health Forum of Australia (CHF), whose successive e-health projects have been effective in eliciting patient views on e-health (Bresnan, 2004).

A number of e-health policy issues have generated significant public discussion and debate including: concerns about patient privacy; the introduction and management of health identifiers; whether consumers will opt-in to the national EHR system, or be included by default with an opportunity to opt-out; and mechanisms for direct and the secondary use of health information.

Consultation and engagement

Both the introduction of health identifiers legislation and the design and planning of the PCEHR have been accompanied by well-managed consultation processes.

DoHA released a discussion paper on the identifiers legislation in July 2009, with a consultation period that ran for just over a month. Two stakeholder forums were held to discuss the draft, and

public submissions were invited. Over 90 submissions were received, 21 in confidence. Of the 72 submissions available for review, eight were from individuals (in a population of 22 million). Further consultations were conducted for the exposure draft legislation (between 20 November 2009 and 7 January 2010), the exposure draft regulations (between 12 March 2010 and 9 April 2010) and NEHTA's draft HI Service Implementation Approach and draft HI Service Communications Plan (between 1 June and 28 June 2010).

NEHTA has undertaken a comprehensive and thorough approach to consultation about the planned national EHR. Draft descriptions of the proposed system have been published, and public comment invited. During 2008 NEHTA conducted workshops involving a wide range of stakeholder groups in Alice Springs and in Brisbane, with the outcomes presented to a 'peak body' summit in Canberra. The Privacy Blueprint was discussed at roundtable sessions specifically considering privacy and secondary use of data. Two workshops (in Alice Springs and Brisbane) included 142 participants, with one person attending both workshops. Of these, 71 represented health provider organisations (46 medical, 12 nursing, 13 allied health). In total there were 11 representatives of a disease interest group (such as the Heart Foundation and the Cancer Council), and seven health consumer representatives, three of those from CHF. The extent of consumer involvement in the roundtable discussions of privacy and the secondary use of data were also limited. In addition, NEHTA commissioned a quantitative survey of 2,700 participants (UMR Research, 2008), using a public opinion poll.

Given the background knowledge required for effective participation, the involvement of representatives of patient organisations rather than individual patients is understandable. And in light of the significant efforts of CHF over a number of years to broadly canvas patient views about e-health, this approach was entirely appropriate. However, there is little evidence of direct citizen involvement in the discourse about the EHR, or about health identifiers. Neither is there much visible evidence of widespread public discussion or debate about the policy issues, or evidence that the

general public has any working knowledge of the proposed EHR system, and how it will operate in practice.

EHR policy framework

Like many areas of emerging public policy, there are few clear published statements of the policy. The shape of policy emerges from successive iterations of documents which describe the proposed system. Much of Australia's policy for implementation and use of Health Identifiers (HIs) becomes apparent from legislation passed in June 2010, while the most comprehensive description of what is intended for the PCEHR is in the Draft Concept of Operations (DoHA & NEHTA, 2011), released as a discussion document, which provides details of the policy direction for the development and implementation of Australia's national PCEHR. However, there remains some doubt that newly elected governments, particularly those in Victoria and New South Wales, will consider that they are rigidly bound by their predecessors' e-health policy commitments.

The current policy framework for the PCEHR is described in some detail in the DoHA/NEHTA Draft Concept of Operations (DoHA & NEHTA 2011). Extensive safeguards are provided for patient privacy. Patients can control the addition of information to the record, and selectively allow or deny access by healthcare providers and provider organisations. A healthcare provider may access records in an emergency, except those flagged as 'no access' (DoHA & NEHTA, 2011, p. 59).

Patient records in the PCEHR are to be identified using an Individual Health Identifier (IHI) assigned by Medicare as IHI service provider. IHIs are assigned automatically, based on existing records for Medicare cards and Department of Veteran Affairs healthcare cards, and activated at the request of the individual. There does not appear to be an option for an individual to prevent the assignment of an IHI.

The PCEHR system operates on an opt-in model; an individual's participation is entirely voluntary. Individuals who decide not to have a PCEHR will not be disadvantaged in terms of their ac-

cess to healthcare services. An individual may choose to withdraw from the PCEHR at any time. Their record is then de-activated; information will still be stored, and available to the PCEHR operator for maintenance, audit and other approved purposes, but not to health care providers or individuals.

An individual may choose to make their information available to all health care providers who are providing their care, or only to those who have been given the individual's Provider Access Code. The individual can also establish an 'include list' (providers who have access) and an 'exclude list' (providers who are denied access) (DoHA & NEHTA, 2011, p. 54). It should be noted that some stakeholders have raised concerns about the complexity inherent in the limited access features. Access to an individual's PCEHR record may involve transfer of information to a local system, for which PCEHR access controls no longer apply.

The PCEHR system includes a reporting service which can analyse information from multiple records, audit trails and activity logs to produce operational reports, and details of system uptake and usage. Most reports will contain de-identified data, and those with identified data will be restricted to authorised users. The types of reports are expected to evolve over time, and may be extended to support additional approved uses. Reports will be available to users evaluating the PCEHR system, and those with permission to use the PCEHR for approved uses. In the first release, the reporting portal will only be used for operational reporting and evaluation. It appears that patient consent for secondary use of their information is either taken for granted, or to be obtained only at the time of record activation.

Does policy match expectations?

Although most research into health system preferences are focused on patients (and often on patients receiving many health services), it is possible to elicit and codify the policy expectations of citizens (who may or may not currently be patients or carers) about aspects of the healthcare system, while also taking note of the concerns of interested commentators.

Although the issues they raise are not directly related to the proposed PCEHR, Handelsman, Turner and Conway (2011) have recently expressed concerns about what they see as legislated breaches of privacy and trust in areas of healthcare such as infertility treatment and genetic testing. Their concerns raise a question about the potential for future legislation to retrospectively change the policy under which the PCEHR operates, effectively creating a structural privacy breach for data which is held within it. The custodian of PCEHR data would be bound to provide the data to a third party, even if that action was against the express wishes of healthcare provider and patient.

Greenleaf (2010) reviewed a number of unresolved privacy issues which emerged from the legislation intended to introduce individual health identifiers. These concerns included: the iterative introduction of the IHI – subsequent stages of implementation were not clearly elaborated at the time the legislation was presented; the capacity of organisations to assign and use an identifier without the subject being aware; and the lack of effective controls over subsequent use of data identified with an IHI (including potential for use by other agencies, including police and social services).

In Australia, the Menzies Centre for Health Policy and The Nous Group (2008) conducted a survey of the attitudes of 1,200 Australians to the health system. The vast majority (90%) preferred the option of health providers having direct access to their health information, while 65% believed that confidential access to the record without specific consent was acceptable. A vast majority believed that the health record should be available to the treating doctor (99%), to other health professionals providing care (97%) and to the patient (95%). The policy as described appears to match these expectations.

In New Zealand, Parkin and Paul (2011) used a citizens' jury to explore public views about the use of identified data for the evaluation of medication safety. Over the course of its deliberations, the jury came to a unanimous view that researchers contracted by a public body should have access to identified data, provided relevant legal and ethical considerations were met. In Ireland, Buckley,

Murphy and MacFarlane (2011) used a questionnaire to evaluate the attitudes of Irish citizens to the use of health records held by their general practitioner (GP) for research. A majority (83.7%) were willing to let their GP decide when to provide anonymous data without informing them; 71.9% said they would like to be asked before the GP provided identified data. The means by which any future use of PCEHR information would ensure that legal and ethical considerations would be addressed, and that clinician approval might be sought, remain open questions.

Conclusion

In the context of Australia's PCEHR, there is little discernible evidence that the views of citizens have been considered. As a community, Australians will have had little prior exposure to policy issues of privacy, consent and secondary use, and may feel that they have not been adequately consulted. Mistrust, scepticism and caution may lead to resistance to the introduction and uptake of the EHR system, and result in a reiteration of adverse views which may already have been addressed effectively. It is possible that the policy framework which has been established for Australia's PCEHR meets the wishes and expectations of the majority of citizens whose health information it may hold, and whose taxes will fund it. However, if that proves to be the case, it will be by accident, and not by design or deliberation. Arnstein (1969) would identify patient consultation as her fourth rung of citizen involvement, among the Degrees of Tokenism; the engagement of non-patient citizens would struggle to reach the first rung.

There have been significant tensions in the Australian e-health policy debate between legal and privacy advocates, healthcare providers, and health informatics professionals involved in the design and implementation of e-health systems. It is almost inevitable that policy is, in the end, politically enacted.

There has been little apparent concern in these deliberations for the views of the citizens whose taxes will pay for the system, and whose health details will be recorded in it. That omission could result in unnecessary challenges to implementation and uptake.

There may well emerge in the community at large a sense that the policies governing the PCEHR have been framed by politicians, bureaucrats and technocrats, with scant regard to the attitudes and expectations of patients (through organisations as their proxies), and none to those of non-patient citizens.

4.3 Commentary

The research underpinning this publication found no evidence of any engagement with ordinary citizens and patients during policy development. Consultation about the policy framework which surrounded the PCEHR was conducted almost entirely within a restricted coterie of health industry 'insiders', a process unlikely to have identified or addressed any concerns from ordinary citizens, or citizens with limited skills about the need for a system whose use was within their capabilities. Subsequent PCEHR consultations included ordinary citizens, although not many. The process still showed no evidence of a focus on the needs or concerns of disadvantaged users, or any comments from disadvantaged patients. At the time of writing, the PCEHR is still being 'rolled out', but uptake has been slow.

Chapter 5: The PLU problem: are we designing personal ehealth for People Like Us ?

"People who like this kind of thing will find that this is the kind of thing that they like."

Abraham Lincoln

"I wouldn't belong to any club that would have me as a member"

- Groucho Marx

5.1 Preface

A review of the findings from the first two publications identified that ordinary citizens might find personal health records complicated to use, and that they had not been extensively consulted during the policy development for Australia's national personal health record (PHR).

The exploration of the relationship between socioeconomic disadvantage and personal health records involved a consideration of how other researchers had explored similar issues about the nature of groups within a community. The way in which Bourdieu (1987) sought to differentiate different classes within French society – not along a single, linear axis, but according to clustering behaviour – provided an insight into the way in which the nature of groups of profoundly disadvantaged and privileged individuals within society could be conceptualised. This approach provided a fresh perspective, allowing the framing of groups and classes of PHR users as clusters rather than as a simple dichotomy of 'users' and 'non-users', or Rogers' categories of innovators, early adopters, early majority, later majority, and laggards (Rogers, 1983, p. 246), which carry with them an inherent assumption that we all become users in the end.

This paper raised concerns that the approaches taken in the commissioning, design, creation, implementation, adoption and use of personal health records was biased in favour of meeting the sensibilities, preferences, needs and capabilities of a privileged minority of potential users – 'People Like Us' (PLUs) – at the expense of less privileged groups who are disempowered, disengaged and disconnected (DDDs).

5.2 Paper as submitted and accepted

Publication details

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. Unfortunately the design of these systems means that they may work better for "People Like Us' rather 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

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 improve 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 (Holman, 2005), resource scarcity with an aging workforce, and an increasing burden of chronic disease (ABC News, 2009). 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 faced. 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 individual knowledge, skills and inclination to use such systems may be resulting in system designs primarily suitable for a privileged group of literate and motivated end users, rather than for those most urgently in need of improved health service delivery.

Methods

To explore the argument that the design of contemporary personal ehealth systems maybe problematic, a literature review was conducted to better understand research on the relationship between literacy and personal ehealth. Using a combination of search terms ehealth/personal ehealth and literacy/health literacy 100 papers available through PUBMED were identified and reviewed. 17 of these papers were also identified as providing insights on the characteristics of healthcare recipients.

Analysis

From an analysis of the literature, a conventional approach to segmentation of the population of healthcare recipients is to use socioeconomic status (SES) along a linear scale. However, there was also evidence of other factors and as a result this population was viewed as a collection of groups or clusters that could not easily be plotted along the SES scale. Two clusters providing simplistic archetypes of healthcare recipients were identified to focus the analysis of ehealth design issues in the literature. These two clusters were differentiated according to their willingness and ability to use a personal ehealth record. One 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. These are the People Like Us (PLUs). The other cluster includes people disinclined to take exercise for its own (or their own) sake, or to eat sensibly. They are not textually, technically or health literate. They struggle financially, and may not have finished secondary education. We characterized them as disempowered, disengaged and disconnected (DDDs).

The literature review highlighted a general enthusiasm for personal ehealth systems and their capacity to 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..." (NEHTA, 2011). 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" (2007, p. 331). 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.

Significantly however Clarke and Leigh (2011) highlight how 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 (AIHW, 2006), 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) (ABS, 2008a, p. 100). Health literacy is also a problem. The US Agency for Healthcare Research and Quality found that poor health literacy was "...associated with increased hospitalizations, greater emergency care use…and, among seniors, poorer overall health status and higher mortality." (Berkman et al., 2011, p. v).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 (Wang, Bennett, & Probst, 2011). 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 the explicit assumption that online tools are an important and appropriate option for healthcare service delivery.

Catwell and Sheikh (2009) considered the evaluation of ehealth systems, and argued that the evaluation should be continuous and systemic. They cautioned that

[l]arge 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.

(Catwell & Sheikh, 2009, p. e3)
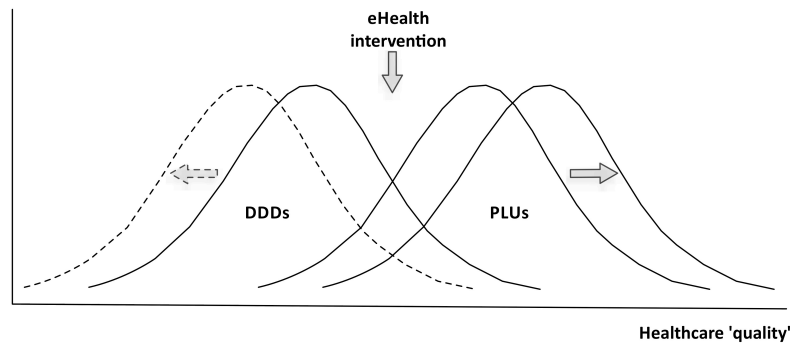
Figure 6: Risk of unintended consequences – the disadvantaged may end up worse off

Any diversion of health budgets towards generic personal ehealth systems is likely to deliver benefits to PLUs, while leaving the 'quality' of healthcare for DDDs unchanged. In fact, there is a risk that diversion of health budgets to ehealth will be used to justify and facilitate a reduction in funding from other, more conventional healthcare services. The potential for these unintended adverse consequences from ehealth investment for DDDs is illustrated in Figure 6.

Results

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 (Cabrera, Burgelman, Boden, da Costa, & Rodriguez, 2004) 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 techno-freaks. 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.
>
> (Cabrera et al., 2004, p. 39)

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 and PLUs. This paper argues that there is a greater need in the design of personal ehealth systems to recognize the constraints imposed by a class of potential users who face very high barriers to technology adoption and effective use.

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 equitable benefit to all groups of patients and has the potential to further disadvantage some groups. 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 incorporated into the overall design, or provided for through a focused alternative, that may not initially require citizen/patient use of an eHealth system.

It may be more appropriate to design and implement solutions tailored for the capabilities of DDDs, and to then 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 DDDs will make them reluctant to participate in design activities. 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 DDDs, this approach is likely to be more difficult to implement. These solutions may also be less interesting for designers, developers and academic researchers due to the lack of feature and functional complexity. Indeed the design activities may produce systems that their creators and implementers might not want to use. It is argued however, that in terms of overall cost benefit, approaches like these could be potentially very rewarding as illustrated in Figure 7.
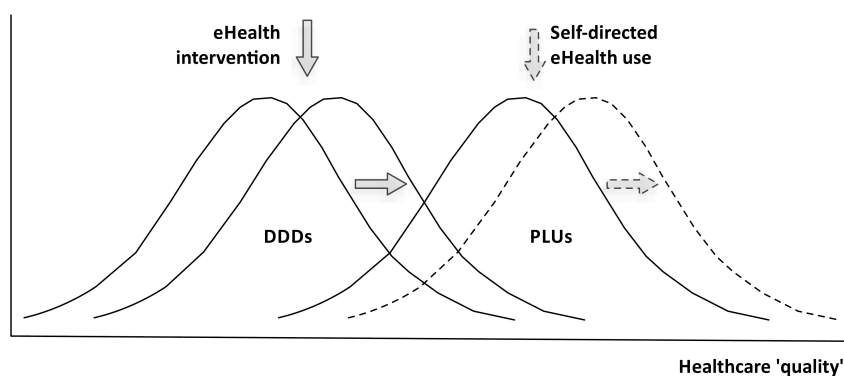
Figure 7: Preferable to adopt a specialised focus on those with greatest need

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?

5.3 Commentary

The paper gave voice to a concern that those developing technology have a tendency to deliver products which suit their own needs and aesthetics, and can, at times, ignore the practical limitations which affect the intended users. The paper further suggested that focusing attention on personal health records which are best suited to this minority could divert resources from those more conventional options for health service delivery which currently meet the need of disadvantaged patients.

Chapter 6: Personal Health Records are designed for People Like Us

"If you are in a shipwreck and all the boats are gone, a piano top . . . that comes along makes a fortuitous life preserver. But this is not to say that the best way to design a life preserver is in the form of a piano top. I think that we are clinging to a great many piano tops in accepting yesterday's fortuitous contrivings."

- Buckminster Fuller

A conference is a gathering of important people who singly can do nothing, but together can decide that nothing can be done.

Fred Allen

6.1 Preface

Having raised a concern that personal health records (PHRs) may not be suitable for users who lack text, technical and health literacy, a question emerged as to why that situation had arisen. Were PHRs envisioned as a tool for a universal group of users, including the disadvantaged, but poorly realised and implemented? Were PHRs deliberately tailored for 'People, Like Us', at the expense of the disempowered, disengaged and disconnected ? Or were disadvantaged users just forgotten about, effectively remaining an invisible group within a statistically 'average' population? This brief literature review looked for evidence to resolve these questions. This conference poster (originally submitted as a full paper) used a literature review to assess the extent to which the design and implementation of personal health records gave specific attention to the particular needs and capabilities of disadvantaged users.

If personal health record systems are to be used as a solution or partial solution to the problem of providing more effective healthcare, then these systems should be available for use by all those who should benefit from the solutions. Published accounts of personal health record developments rarely describe the process used to identify the demographic characteristics of intended user groups, or their capacity to use the technology.

6.2 Paper as submitted and accepted

Publication details

This publication was submitted as a full paper, but not accepted for publication. It was subsequently accepted for presentation as a poster. It was subsequently published as:

Showell, C., & Turner, P. (2013). Personal health records are designed for people like us. *Studies in Health Technology and Informatics*, *192*, 1037.

6.2.1 As submitted for publication

Abstract:

This paper presents evidence to validate a concern about contemporary approaches underpinning the design, implementation and evaluation of personal health records (PHR) systems. This concern is that PHR systems are primarily based on criteria that reflect the attributes and assumptions of well-educated and well-to-do users (People Like Us − PLUs) rather than the needs of the most disadvantaged in society (the disempowered, disengaged and disconnected − DDDs). This paper argues that without care, these electronic systems for increasing accessibility to personal health information may end-up further accentuating rather than mitigating the emerging ehealth divide. In this paper we use a PubMed review of literature on the design, implementation and evaluation of personal health record systems. We identified only seven of 73 papers, and one of 29 abstracts which made specific mention of users who were subject to a disadvantage because of issues such as

low literacy levels or difficulties with access to technology. This paper is part of a larger study into personal health records and disadvantage.

Keywords:

electronic health records, disadvantage, information systems

Introduction

Healthcare services in most parts of the world are attempting to address concerns about cost, equity and capacity in the delivery of healthcare services. Responses to these concerns have included a move towards greater involvement of patients in aspects of their own care, and the wider application of electronic health records. The growth of interest in personal health records (PHRs) lies at the intersection of these two trends.

In a previous paper (Showell & Turner, 2013b) we have expressed concerns that an increasing reliance on PHRs as a part of the provision of healthcare services may not be the most appropriate way to meet the needs of the most disadvantaged healthcare recipients, and that such systems are targeted at the needs and expectations of a privileged elite. We sought to crystallise the gap between those two groups by characterising the two extremes (the privileged and the disadvantaged) as "People Like Us" (PLUs) and the "disempowered, disengaged and disconnected" (DDDs). We described this issue as the "PLU problem".

DDDs are underserved

There is evidence from other sources that our concerns are well founded. A number of authors have documented their concerns about issues with the use of PHRs in vulnerable and underserved populations.

Chang et al (2004) reported on the AMIA 2003 Spring Congress "Bridging the Digital Divide: Informatics and Vulnerable Populations". In describing the extent of the vulnerable population in the US, they noted that

> …at least 50 million Americans (20%) face one or more content-related barriers to the benefits of the Internet such as lack of local information (21 million), literacy barriers (44 million), language barriers (32 million), and lack of cultural diversity (26 million).
>
> (Chang et al., 2004, p. 449)

The authors also detailed the extent of the risk and proposed some solutions to the problem:

> Low computer literacy and health literacy pose barriers to accessing and using health information and consumer-oriented e-health tools. Moreover, the relationship between health literacy and health is poorly understood. Consequently, the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association identified four significant research issues: (1) literacy screening and measurement; (2) methods of health education including those that are computer based; (3) costs and outcomes of poor literacy; and (4) understanding association between health literacy and health.
>
> (Chang et al., 2004, p. 452)

The report by Chang et al went on to frame what we have called the PLU problem as an issue for developers and implementers of PHRs:

Developers may not understand the needs and cultures within target communities or the strategies for seeking input from members of these communities. In addition, application developers may lack the appropriate skills to translate health information for use in underserved populations. The diversity among individuals (even within specific communities) makes developing standard, uniform systems difficult.

Consumer health informatics is a young science in which the scientific bases for effective informatics for underserved populations are not well articulated. Hence, there is limited evidence for usability and effectiveness in improving outcomes of consumer health informatics interventions for the underserved. There are several issues in this regard. First, ivory tower world views may be myopic and may lack commitment to reaching the ideal vision proposed in this report. There is a need to look past technology to projects that reflect important health access questions and to take advantage of cross-fertilization of various stakeholders, including those from the target community. Second, different investigators may conduct small, redundant pilot studies that do not contribute generalizable knowledge. Third, there is a lack of valid, reliable evaluation instruments. Fourth, time for evaluation often is insufficient because of length of time required to observe the effect of an informatics innovation, changes in technology, and community needs. There is also a lack of institutional understanding of issues that affect research involving underserved populations, for example, obtaining informed consent in underserved populations often requires different mechanisms in line with environment, beliefs, and perceptions.

<div align="right">(Chang et al., 2004, p. 452)</div>

Hibbard, Peters, Dixon and Tusler (2007) tested 303 adults (recruited using newspaper advertisements and flyers), and compared the subjects' health literacy and numeracy, with a measure which was designed to assesses their knowledge, skill, and confidence in managing their own health and health care. The authors noted that:

> …health literacy skills, which encompass the ability to process and understand basic informa-
> tion needed to make appropriate health decisions, are strongly associated with health-related
> outcomes. Those with poor health literacy skills are less knowledgeable about health…receive
> less preventive care…have worse chronic illness control…poorer physical and mental health
> function…, and have higher emergency department and hospital utilization…
>
> <div align="right">(Hibbard et al., 2007, p. 380) (p380)</div>

Kahn, Aulakh and Bosworth (2009) explored the characteristics of an ideal PHR in a US context. They noted that:

> …[w]ider consumer adoption of PHRs will require attention to at least three important but
> non-technology-based areas: computer competency, Internet access, and health literacy. If
> these are not made policy priorities, PHRs risk becoming a tool that is limited to groups of
> people who are already linked to the Internet with high health literacy and computer skills. …
> The relationship between literacy and health is complex. Low health literacy is associated
> with being poor and with engaging in fewer activities that influence good health. The groups
> with the greatest limitations for health literacy include people older than age sixty-five; minor-
> ity, immigrant and low-income populations; and people with chronic mental or physical con-
> ditions.
>
> <div align="right">(J. S. Kahn et al., 2009, p. 371)</div>

In this paper, we now take the opportunity to explore the extent to which the particular requirements of DDDs are taken into account during the design, implementation and evaluation of PHRs.

Methods

In order to evaluate whether disadvantaged users (our 'DDDs') are taken into account, we conducted a brief literature review to identify publications which refer to the design, implementation or evaluation of PHRs. A search in PubMed for "personal health record design" yielded 585 results. Articles not in English, and those which did not directly address issues associated with PHRs were discarded. Additional searching and citation tracking retrieved a further 29 articles, giving a total of 102 for evaluation. Full text articles were retrieved where possible (73 articles); for publications not available as full text (29 citations), we used the abstract of the article for the review.

For each of the full text papers which were in scope, we read the article to identify whether the authors had used terms referring to disadvantage, socioeconomic status, literacy, technology access or the "digital divide". We also categorised the content as being either about the design, implementation or evaluation of one or more PHR systems, or a more general commentary about issues associated with PHRs.

We found that 45 of the articles were about a system, while the remaining 28 articles provided more general commentary on PHRs. Each article or abstract which described a specific PHR was evaluated to determine the extent to which the needs and capabilities of our "DDDs" (users with limited textual, technical or health literacy) had been considered, or given particular attention.

Results

Only seven of the 64 articles describing experience with a PHR, and one of the 29 abstracts, made specific mention of issues relating to users for whom some form of disadvantage might result in a reduced capacity to use the system.

Design

Sox et al (2010) describe the design process for a web based tool to support parents of children with a diagnosis of ADHD. Health literacy, but not text literacy, was assessed in assembling the cohorts of parent carers for user testing during the design process. The authors do not appear to have considered the possibility that there may be a group of parents whose low levels of literacy meant that they would struggle to use a text-based system. They "…assumed that subjects would be (1) knowledgeable about the child's medical history and recent behavior and (2) motivated reporters." (Sox et al., 2010, p. e3)

Welch et al (2010) described the development of a PDA-based dietary tool for patients undergoing haemodialysis. The authors considered in some detail the need for a reasonable standard of health literacy in order to benefit from the application they were developing. However, they acknowledge

that they were dealing with a select group of health literate patients, and note that "[h]emodialysis patients must have certain skills to comply with the complex diet described here, such as the ability to read, interpret, and calculate daily intake on an ongoing basis." (Welch et al., 2010, p. 195) It appears that patients with lower levels of literacy would be unlikely to be considered as possible users of their system.

Evaluation

Greenhalgh, Wood, Bratan, Stramer, and Hinder (2008) conducted an evaluation of attitudes to, and perceptions of. the NHS's Summary Care Records (central EHR) and HealthSpace (PHR) systems. The health literacy of respondents was assessed in order to provide appropriate written information to subjects as part of the consent process, and was included in the evaluation. The authors found that a low level of health literacy in an individual often manifested itself as an apparent lack of interest. "Many participants whom we judged to have low health literacy gave 'not bothered' or 'don't care' responses to the question 'Would you like to have an SCR?' often citing limited capacity to understand ('I can't get my head round it')." (Greenhalgh et al., 2008, p. e9)

Roblin, Houston, Allison, Joski, and Becker (2009) reviewed factors which were associated with patient registration on kp.org, Kaiser Permanente's patient health portal. Socioeconomic factors were identified in the analysis as having an impact, and literacy was mentioned as a factor in the discussion.

> If our results of a digital divide for PHRs are confirmed, and if evidence of the effectiveness of PHRs in improving access, quality and safety increases, then PHRs have the potential to widen disparities in health care and health, at least in the short-term. Appropriate attention to further research on the causes of this gap in use is critical.
>
> (Roblin et al., 2009, p. 687)

The authors noted that participants were selected from among existing Kaiser beneficiaries, and hence those in lower socioeconomic levels were likely to be under-represented.

Hassol et al (2004) al., 2004) evaluated patient experience and satisfaction with the Geisinger My-Chart PHR. The patients who were included responded to a survey sent to a group who had "...registered, activated their account, and logged on to the system at least once". The authors noted that "…[p]atients without access to computers with browsers other than Internet Explorer 5.x or higher would not have been able to respond to the survey". (Hassol et al., 2004, p. 510)

Kim et al (2009) evaluated the use of a PHR in a low-income, elderly population during a 33 month study. PCs and Internet access were provided at no cost to the study participants, and staff were on hand to provide support and mentoring when required. Out of an eligible population of 330 subjects there were 70 who started in the study, and 44 completed it. Only 14 participants completed the survey, and 9 of those had used the system more than three times.

Yamin et al (2011) evaluated the use of a PHR in a US healthcare system. They found that non-white patients and poorer patients were less likely to use the system. The authors mentioned literacy and health literacy as possible causative factors, but did not assess their impact.

Ahern et al (2012) (paper reviewed as an abstract only) evaluated two options for home blood pressure monitoring, Patients were provided with either a "high tech" blood pressure monitoring device, or the device together with access to a support person, referred to as a "patient navigator" (PN). They abstract noted that "…[c]urrent e-health technology and limited technological literacy of many patients suggest that a PN or some other personnel resource may be required for the adoption of patient-facing technology in primary care."

Exclusion

Some of the articles described a design or evaluation process which appeared to actively exclude potential users with limited capability from participating in the design process, or becoming users if the system. As noted above, the development of a PDA-based tool for haemodialysis patients described by Welch et al (2010) focused on a patient cohort whose involvement in their own care ne-

cessitated a reasonable standard of numeracy and health literacy, thus excluding our DDDs from the pool of potential users. In addition to this example, when Or et al (2011) evaluated user acceptance of a technology supported homecare program, they exclude users who could not read or write English, and when Atreja et al (2005) organised focus groups to evaluate user requirements for a PHR designed to support patients with multiple sclerosis, they noted that all of their subjects were able to access the Internet at home or at work.

Whose problem is it anyway?

One interesting paper suggests that all of these limitations in the ability of system designers and implementers to take account of the needs, skills and abilities of patients are somehow the fault of the patients themselves. When Tang, Ash, Bates, Overhage and Sands (2006) reported on a symposium on PHRs conducted by the American College of Medical Informatics in February 2005, they suggested that

> …health care consumers must understand and accept their roles and responsibilities related to their own health care…An individual's PHR can only be useful if the person understands the importance of maintaining and coordinating health-related documentation and activities with health care providers. Consumer-related interface, technology, and access issues specific to PHRs are not yet well understood.
>
> (Tang et al., 2006, p. 125)

Or perhaps it's the fault of the education system: the authors further suggest that "…[i]ndividuals' education about health management techniques should begin early. Even in elementary school, the educational system can teach the importance of managing their health using simple tools. " (Tang et al., 2006, p. 126)

Discussion

Limitations of this study

We acknowledge that the current study is subject to a number of limitations. Our brief literature review was intended to be representative, rather than exhaustive, and it may be that we have failed to identify a large number of published accounts of the design, implementation and evaluation of PHRs in which careful attention is given to the needs of disadvantaged users. We would welcome advice about the existence of those publications.

There may be instances in which work on a PHR did include careful attention to the needs of disadvantaged users, without that attention being referred to in the published article. Again, we would welcome advice about those instances. The articles we retrieved showed a degree of publication bias. There were two particular PHR initiatives which were described in multiple publications. Aspects of the ProjectHealthDesign initiative sponsored by the Robert Wood Johnson Foundation appeared in six articles, and the MyHealth*e*Vet system provided by the US Veterans Administration was the subject of three articles.

Despite those reservations, we believe that the overwhelming message which emerges from our research remains valid.

Implications

On the basis of the evidence provided by this review, it appears that most health informatics professionals do not routinely consider the needs of disadvantaged users when designing, implementing or evaluating PHRs. This oversight could result in innovative ICT solutions for personal healthcare increasing the extent of disadvantage and exclusion experienced by this high-risk high needs group.

Much greater attention needs to be given to the task of providing ehealth solutions (much may include some form of PHR) for those with a limited capacity to take advantage of technology. We have previously suggested (Showell & Turner, 2013b) that the scarce resources which funders make

available for personal ehealth initiatives should be targeted specifically at disadvantaged groups (our "DDDs"), and that People Like Us have sufficient financial and intellectual capacity to facilitate our own self-directed ehealth solutions.
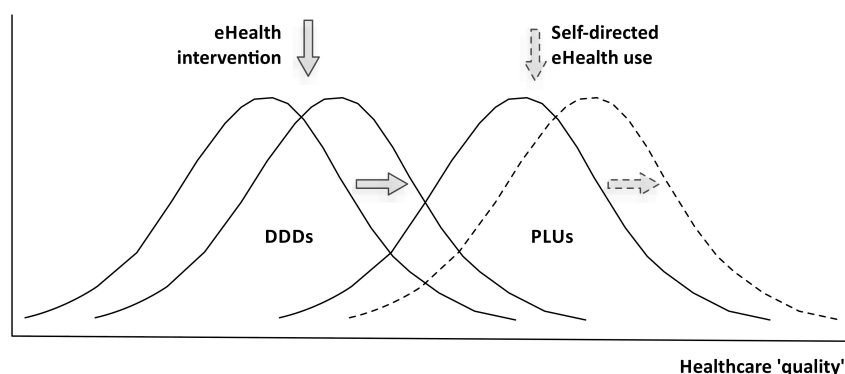
Figure 8: Preferable to adopt a specialised focus on those with greatest need

We believe that this situation must change, and that further work is needed on this issue. Consideration should be given to mechanisms by which to secure agreements that exclusion of vulnerable healthcare recipients is unacceptable. Consideration should also be given to mechanisms to encourage more inclusive practices in the design, implementation and evaluation of personal health record systems.

Comment

We have previously expressed a concern that PHRs are designed for People Like Us (PLUs), and are thus not appropriate for use by patients who are "disempowered, disengaged and disconnected" (DDDs). The current research demonstrates that our concern is justified, with a significant majority of published reports of the design, implementation and evaluation of PHRs failing to take into account the needs and capabilities of the DDDs . Whether this occurs as a result of deliberate choice or by oversight, the consequence is likely to be a widening in the gap between the PLUs and the DDDs, creating the risk of an increasing level of disadvantage as health systems take advantage of technical efficiencies offered by the use of ICTs.

6.2.2 As accepted for poster presentation

Abstract and Objective:

Current approaches to designing, implementing and evaluating personal health record systems reflect the attributes and assumptions of well-educated and well to-do users (People like Us: PLUs) rather than the needs of the most disadvantaged in society (the disempowered, disengaged and disconnected: DDDs). These electronic systems for increasing accessibility to personal health information may accentuate rather than mitigate the emerging eHealth divide. Using a PubMed review of literature on personal health record systems, we identified only seven of 73 papers, and one of 29 abstracts which made specific mention of users who were disadvantaged by low literacy levels or difficulties with access to technology. This work is part of a larger study into personal health records and disadvantage.

Keywords: electronic health records, health literacy, disadvantage.

Introduction

We have previously identified (Showell & Turner, 2013b) that personal health records (PHRs) may not meet the needs of disadvantaged users; PHRs are designed by and for a privileged elite; we describe this issue as "the PLU problem". We used two archetypal groups - "People Like Us" (PLUs) and the "disempowered, disengaged and disconnected" (DDDs) – to crystallise the gap between the privileged and the disadvantaged. Other sources confirm our concerns. Chang et al (2004) reported that "…at least 50 million Americans (20%) face one or more content-related barriers to the benefits of the Internet" (p.449) and that "[l]ow computer literacy and health literacy pose barriers to accessing and using health information and consumer-oriented e-health tools" (Chang et al., 2004, p. 452). Kahn, Aulakh and Bosworth (2009) note that "…consumer adoption of PHRs will require…computer competency, Internet access, and health literacy." (J. S. Kahn et al., 2009, p. 371)

Methods

We used a search in PubMed for "personal health record design" to find evidence about the design, implementation and evaluation of PHRs. Of the 585 results, we discarded 512 which were not in English, or did not directly address PHRs. Additional searching gave 29 more articles, a total of 73 full text articles and 29 abstracts to be evaluated. Forty-five were about a system, with 28 giving more general commentary on PHRs. Each item describing a specific PHR was evaluated to determine the extent to which the needs and capabilities of our "DDDs" had been considered, or given particular attention.

Results

Only eight items (7 articles, 1 abstract) made specific mention of users for whom disadvantage might reduce their capacity to use the system. DDD users were often excluded from the design process (Sox et al., 2010) or discouraged from access as a result of low socioeconomic status (Roblin et al., 2009). Low health literacy could manifest itself as a lack of interest in using a PHR in the UK (Greenhalgh et al., 2008), while non-white patients and poorer patients in the US were less likely to use a PHR (Yamin et al., 2011). Curiously, Tang et al (2006) suggest that the need to take the abilities of users into account is somehow their fault: "…health care consumers must understand and accept their roles and responsibilities related to their own health care" (Tang et al., 2006, p. 125).

The evidence provided by our review shows that health informatics professionals rarely consider the needs of all users when designing, implementing or evaluating PHRs. This oversight could result in solutions for personal healthcare which increase the extent of disadvantage and exclusion experienced by this high-risk high needs group. Attention needs to be given to providing ehealth solutions (which may include a PHR) for those with limited capacity to use technology. The neglect shown to the needs of the DDDs must cease, and further work is needed on the PLU Problem.

6.2.3 Formatted as a poster
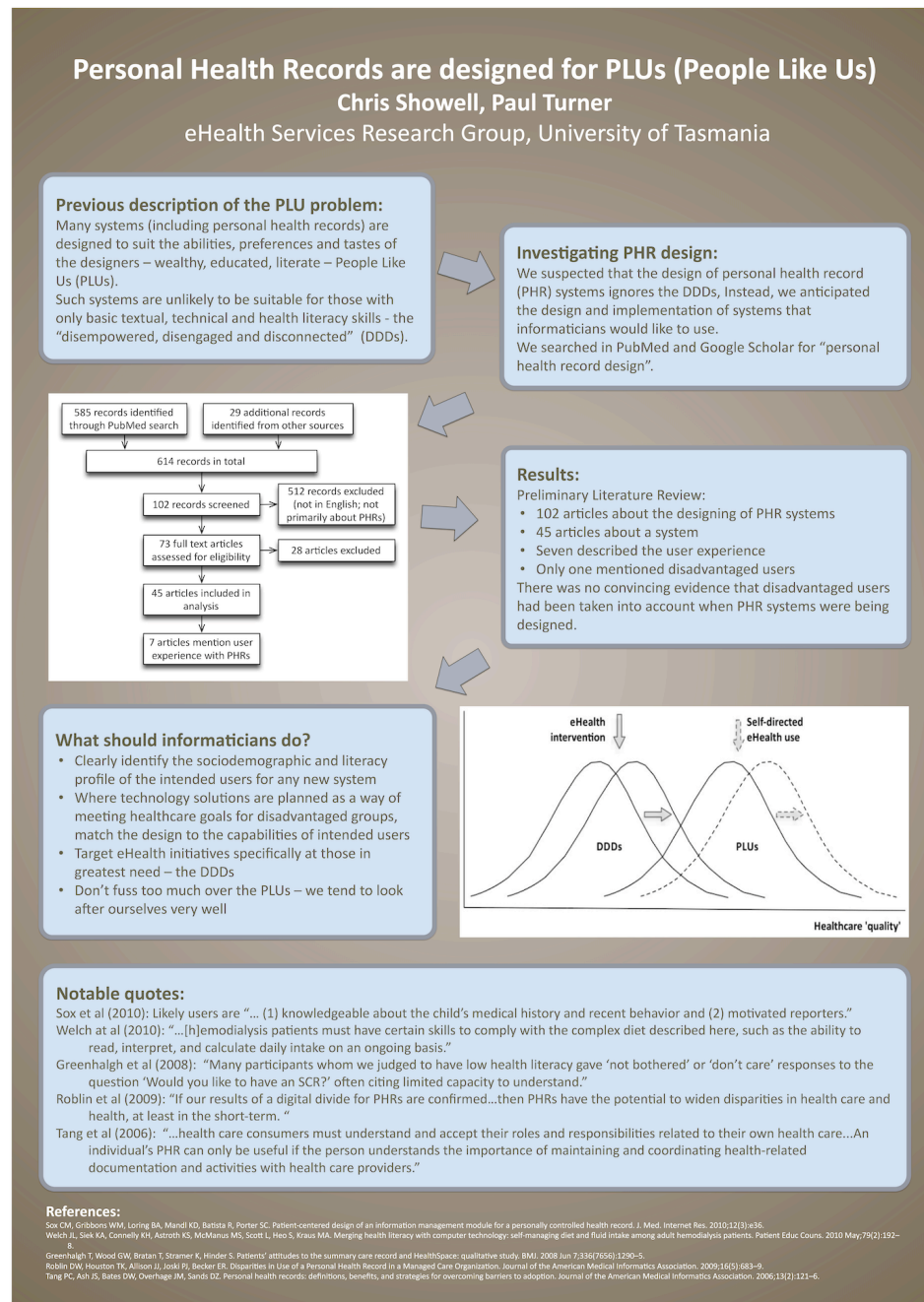
6.3 Commentary

This brief literature review was intended to investigate the reasons for disadvantaged users remaining invisible during the design and implementation of PHRs. Were they left out of the scope of PHRs through poor design, and mistakes in implementation; were they deliberately excluded; or were they simply forgotten and invisible? The rarity with which references to socioeconomic disadvantaged were included in the publications reviewed suggested that invisibility was the problem, with disadvantaged users absent from the scope by neglect or omission, rather than as a result of defective realisation or deliberate exclusion.

Chapter 7: Review and reflection

> "However beautiful the strategy, you should occasionally
>   look at the results."
>
> > - Winston Churchill

> "Discovery consists of seeing what everybody has seen,
>   and thinking what nobody has thought."
>
> > - Albert Szent-Gyorgi

7.1 Introduction

This chapter revisits the initial aim of this thesis, which was to explore whether socioeconomic disadvantage affects an individual's adoption and continued use of a personal health record (PHR), by answering the following Research Question:

RQ1:   What is the relationship between socioeconomic disadvantage and personal electronic health records?

The chapter evaluates the extent to which the exploratory analysis in the four publications from Phase 1 of this research (Chapters 3, 4, 5 and 6) provides an answer for that question, and considers what aspects remain unresolved or unanswered. The chapter restructures these unresolved issues as additional research questions (RQ2a and RQ2b) and maps out a strategy to provide a resolution. The chapter then considers what further research is warranted, and how it could be planned and conducted, using a literature review and empirical data analysis, and concludes with some design considerations for the data analysis. Results of the additional research are presented as publications in Chapter 8, which describes a literature review providing evidence about the barriers

which individuals face when adopting and using a PHR, and in Chapter 9, which summarises the key findings of the empirical analysis of data about socioeconomic disadvantage, healthcare use and PHR barriers.

7.2 Review

7.2.1 Phase 1 evidence

The thesis set out to explore Research Question 1, about the relationship between socioeconomic disadvantage and personal electronic health records. The publications presented in Chapters 3, 4, 5 and 6 respond to this question by highlighting several aspects of personal electronic health record systems which could limit their usability, and in particular their usability for those with limited capabilities. Each of these four publications was evaluated by multiple reviewers. Although some expressed reservations about the strength of the evidence presented to support the related notions of exclusion and barrier factors, none expressed a view that the problems described were nonexistent.

The first publication, *Language Games and Patient-centred eHealth* (Showell et al., 2010), explained that, although SNOMED-CT is often adopted as a *lingua franca* within ehealth systems, there may be a need for greater flexibility in the use of terminology in order to secure full participation by patients in the delivery of their healthcare. The use of specialised language such as SNOMED-CT in personal health record systems could limit their use by ordinary citizens, and systems intended for patient use may require a more flexible approach to the use of terminology within the system. The second reviewer for this publication expressed some concern that little empirical evidence had been presented regarding the inadequacy of SNOMED-CT as a citizen terminology.

The second publication, *Citizens, patients and policy: a challenge for Australia's national electronic health record* (Showell, 2011), showed that the development of the policy framework surrounding Australia's Personally Controlled Electronic Health Record involved little engagement with patients, and none with ordinary citizens. It was suggested that this omission was likely to result in a low level of trust

in the system. In an Australian setting, the policy directions for PHRs have been set with little direct engagement of citizens and patients, with the likely result that the expectations, needs and capabilities of patients have been under-represented in the policy itself, and within the resulting design process. It appears that in this case the PHR has been designed, developed and implemented with scant regard for the needs and abilities of disadvantaged users, and no overt attempt to engage this group in the policy discussion, leaving them invisible throughout the process. The first reviewer criticised the use of the term 'citizen' as a US-centric terminology, rather than 'consumer' as a more common Australian usage. The second questioned the level of evidence that neither citizens nor patients had been involved directly in the consultation process.

The next publication, *The PLU problem: are we designing personal ehealth for People Like Us?* (Showell & Turner, 2013b), built on the concerns which had emerged from the first two publications to make the case that personal electronic health records are unlikely to provide significant benefit for those at a socioeconomic disadvantage, and may result in worse care for disadvantaged patients. Furthermore, the capability barriers (such as low text, technical and health literacy) experienced by disadvantaged individuals may make their participation in the design of such systems more difficult. This paper introduced the concept of a group within society who are "disempowered, disengaged and disconnected" (DDDs). The first reviewer noted that the submission presented a methodology, rather than concrete findings, suggested that more research was needed, and encouraged the pursuit of the concerns raised in the submission.

The final publication from Phase 1, *Personal Health Records are designed for People Like Us* (Showell & Turner, 2013a), submitted as a conference presentation and accepted as a poster, used a literature review to assess the extent to which disadvantaged low capability users were considered during the design and implementation of personal electronic health records. The literature review found few instances in which socioeconomic disadvantage affecting potential users was considered during the process, and none of which catered specifically for those users. The third reviewer agreed that most personal electronic health records had not looked at vulnerable and underserved populations, but

was concerned that the methodology was subject to a degree of bias, and that the search strategy had not been sufficiently broad.

7.2.2 Phase 1 findings and gaps

In exploring the relationship between socioeconomic disadvantage and personal electronic health records in response to Research Question 1, the first publication identified that the use of specialised language within ehealth systems could create barriers for even ordinary citizens, not just for those at a socioeconomic disadvantage. The second publication demonstrated that the process of developing the policy framework for PHRs in Australia had done little to directly engage even ordinary citizens in discussions about privacy, confidentiality, and usability.

Having established that ordinary citizens may be excluded from effective use of a PHR by the use of specialised language, and by limitations in the consultation about ehealth policy, the third publication raised the concern that PHRs appeared to be designed for People Like Us, and that, for users with a low socioeconomic status, the effects of these potential limitations were likely to be compounded by low levels of text, technical and health literacy. The fourth publication confirmed that the process of designing and implementing PHRs often fails to take these limitations into account, and rarely pays special attention to the particular needs of disadvantaged users.

Taken together, these four publications suggest that the relationship between socioeconomic disadvantage and PHRs involves a complex web of linked interactions, which could make it difficult for disadvantaged patients to obtain a benefit. It appears that there may be a group of potential PHR users who:

- Have low socioeconomic status;
- Have lower capabilities, including limited text, technical and health literacy;
- Are significant users of healthcare service;
- Face barriers to PHR adoption and continued use; and

- Are less likely to derive a benefit from PHR use.

By this stage in the research, this concern was so clearly apparent to the author that it seemed obvious, almost trite. But why was this concern not more widely discussed? The association between socioeconomic disadvantage and poor health outcomes is so well accepted as to be viewed as a commonplace observation. Similarly, the existence of a 'digital divide' is well reported and understood, as is the ehealth divide which reduces the likelihood of PHR use by certain disadvantaged groups. Given that these separate (but related) factors are generally known and accepted, why then do PHR developments continue to deliver systems which disadvantaged patients either find harder to use, or avoid altogether; and why is there so little interest within the health informatics community in addressing this significant inequity in resource allocation and service provision?

While the first four publications show that the relationship between socioeconomic disadvantage and PHRs is one of varying accessibility and usefulness, with disadvantaged patients less likely to benefit, the evidence does not conclusively identify the existence of a group who;

- Experience socioeconomic disadvantage;
- Use healthcare services at a significant rate; and
- Face barriers to PHR adoption and use.

Neither do those publications conclusively establish the number, nature or scope of those barriers, or the particular barriers faced by disadvantaged patients. In the sections which follow, these gaps in the Phase 1 evidence are structured as two additional research questions, and the research evidence which will be needed to address these additional questions is considered.

7.3 Barriers to PHR adoption and use (RQ2a)

In order to use empirical research to identify whether this disadvantaged group, excluded from PHR use, exists, it will first be necessary to fully understand the barriers which they may face in attempting to use a PHR. As noted above, the four publications in Phase 1 of this research suggest

that there are barriers for potential PHR users, and that these barriers are worse for those with low socioeconomic status, and with limited text, technical and health literacy. However, these publications do not conclusively establish the precise nature of these barriers. An investigation of the association between socioeconomic disadvantage and barriers to PHR adoption and use should be based on an authoritative list of identified barriers, but this had not emerged from the Phase 1 publications. This residual gap in the evidence about the nature of personal health record barriers was now structured as the additional research question:

RQ2a   What is the current evidence about barriers to the uptake and continued use of personal electronic health records?

Evidence would be required in order to provide a definitive answer to Research Question 2a. The papers in Chapter 3 and Chapter 4 were published in 2010 and 2011, and the investigation and conceptualisation of the papers in Chapter 5 and Chapter 6 occurred during 2011 and 2012. The time which has elapsed made it prudent to examine what contemporary evidence there was regarding barriers to personal electronic health record uptake and continued use. Two options were considered for providing this evidence. The first would be to identify recent literature reviews about PHR barriers, and to apply their findings. However, a scan of relevant reviews (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Goldzweig, Towfigh, Paige, Orshansky, & Haggstrom, 2012; Jimison et al., 2008; McInnes, Li, & Hogan, 2013) identified that their findings were shaped by the differing purposes for which they had been conducted, and that barrier identification was inconsistent between reviews.

The second option was to respond to this question by conducting a new literature review specifically focused on evidence about those barriers which could limit the adoption and use of a PHR by an individual, identifying as many barriers as possible. This updated literature review was conducted in early 2014, and is presented as a publication in Chapter 8.

7.4 A group facing PHR barriers (RQ2b)

The Phase 1 publications suggest that there is a complex relationship between socioeconomic disadvantage and PHRs, and that disadvantaged patients may not obtain a benefit. In particular, the third and fourth publications suggest the existence of a group with low socioeconomic status, significant use of healthcare services, and limited text, technical and health literacy, who face barriers to PHR adoption and continued use. However, the evidence does not clearly make the case that such a group exists. This gap in the evidence about the existence of a disadvantaged group facing barriers to PHR use is structured as the additional research question:

RQ2b   Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

Empirical analysis of the relationship between socioeconomic status, use of healthcare services, and the barriers which may inhibit the adoption and subsequent use of a personal electronic health record was considered to be the most appropriate research option to address this question.

The remainder of this chapter provides a discussion of issues and methodological choices which guided that research. This includes a discussion of data about disadvantage, health and PHR barriers, and a summary of the analytical techniques applied. The research is reported in the publication presented in Chapter 9, and sets out to provide evidence about this hypothesised group of disadvantaged individuals within Tasmanian society.

Geographic segmentation of Australian data

In order to assist with the understanding of the discussion which follows, and the research which is reported in Chapter 9, it is helpful to understand the structures used in the categorisation of geographic data in Australia, and to review the impact of sample size and granularity on data analysis.

Since 2011 Australian Government data collections have used the Australian Statistical Geography Standard (ASGS), a schema which has 347,627 Mesh Blocks (at the lowest level of data aggrega-

tion), 54,805 Statistical Area 1s (SA1s), 2,214 Statistical Area 2s (SA2s), 351 Statistical Area 3s (SA3s), 106 Statistical Area 4s, (SA4s) and 9 States and Territories. The component structure of the ASGS is shown in Figure 9 below.
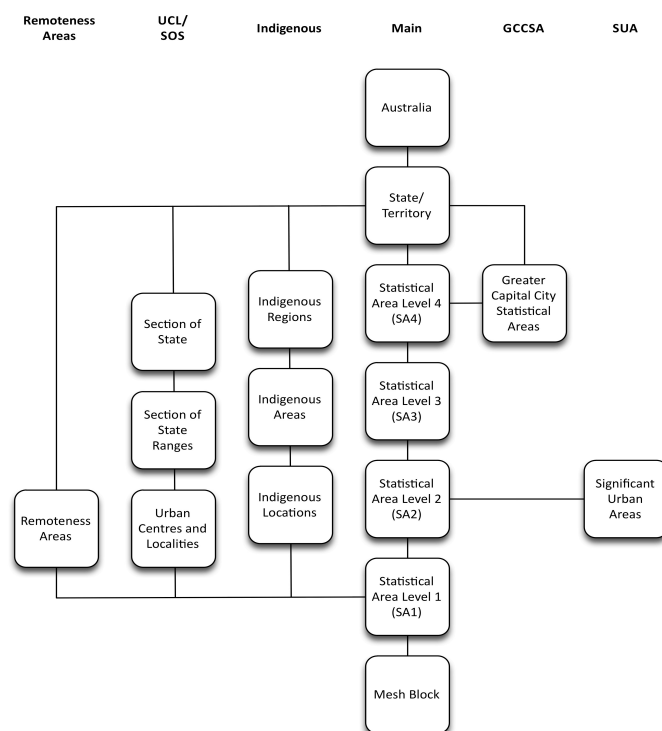
Figure 9:   ASGS ABS Structures
             (Australian Bureau of Statistics, 2011, p. 3)

The lowest level of aggregation commonly used for published data is at Statistical Area Level 2 (SA2). SA2s are designed to represent suburbs and localities, with the aim of including a population of around 10,000 (with a range from 2,000 to 25,000).

Granularity and the sample effect

The term 'sample size effect' refers to the way in which analysing data about a population as a homogeneous group can hide the most dramatic differences between population measures for areas.

This impact of this effect can be illustrated through the use of a practical example. Census data at SA2 level includes the number and proportion of individuals attaining various levels of pre-tertiary education. A calculation of the proportion of individuals for each level of attainment for the whole of Tasmania and its SA4s, SA3s and SA2s is shown in Table 4 below.

Table 4:   Level of schooling attained in Tasmania (Percentage of individuals in region)

		Year 12 or equivalent	Year 11 or equivalent	Year 10 or equivalent	Year 9 or equivalent	Year 8 or below	Did not go to school
State	Average	38.2	9.5	35.2	10.2	6.5	0.4
SA4 (4 regions)	Range	26.7-46.7	09.0-10.0	29.9-42.2	8.1-12.8	5.5-7.9	0.3-0.4
SA3 (15 regions)	Range	25.3-68.5	07.2-11.4	16.0-43.7	4.2-14.5	3.6- 8.5	0.1-0.7
SA2 (93 regions)	Range	19.8-75.3	06.4-12.6	12.6-47.7	3.2-15.7	1.9- 10.8	0.0- 2.2

It can be seen that an average measure for the whole state masks a broad range of results for individual SA2s. The statewide average of 38.2% for Tasmanians completing Year 12 or equivalent becomes a range from 26.7% to 46.7% for SA4s, and 19.8% to 75.3% for SA2s. Similarly, the proportion of those leaving school at Year 8 or below is 6.5% for the state, with individual SA2s showing a range between 1.9% and 10.8%.

Relying on the statewide average would lead to a conclusion that roughly one third of those in a Tasmanian neighbourhood had completed Year 12. However, SA2 level data would suggest that, depending on the neighbourhood in question, the completion rate could be anywhere between one fifth and three quarters. Similarly, a statewide perspective indicates that one in sixteen Tasmanians left school in Year 8 or sooner, while rates for individual neighbourhoods indicate a rate which ranges from one in ten to one in fifty.

Data options

A theoretically perfect data set for this analysis would consist of a large collection of matched, deidentified person level data including measures of socioeconomic status, health service utilisation, and barriers to PHR adoption and use. Unfortunately (but unsurprisingly), it was not possible to identify such a collection of data. Given that this perfect data set was not available, options for gathering other types of data were considered. The empirical research could use either small scale

or large scale data sets, containing data about socioeconomic disadvantage, by use of healthcare services, or by PHR adoption use.

Small data

Analyses of small-scale data collections typically rely on the prospective collection and analysis of data and information from a relatively small number of subjects. With prior consent, a researcher could use semi-structured interviews, surveys and questionnaires to evaluate intended or actual PHR use, gather details about individuals' use of healthcare services, and identify any barrier factors which could inhibit use of a PHR. Using this approach, participant selection could focus on users of a personal health record, such as Australia's nascent personally controlled electronic health record (PCEHR). This research approach would have the benefit providing data capable of demonstrating a direct association between healthcare use, PHR adoption and use, or usage intention, and socioeconomic status.

However, there are a number of drawbacks to the use of direct, small scale data collection in the context of this research. The data collection process could be difficult, and may involve a degree of sensitivity. As noted in Section 2.6.4, there can be a significant degree of shame associated with aspects of disadvantage such as poor text literacy, and this could lead to a reluctance to identify reasons for not using a PHR. Individual level data about disadvantage can be difficult to obtain in an ethical way, and specifically identifying disadvantaged individuals for inclusion in a study can be mildly insulting at the least. Howard Stone expresses the view that although the ethical constraints which are designed to protect vulnerable populations as research subjects do not specifically apply to the disadvantaged, they should be applied (Stone, 2003).

Collection of data about socioeconomic status might seem intrusive to potential participants, and this could result in the selection of a cohort of subjects whose demographic composition is different from the overall population of healthcare service users, or of all potential users of the PHR. Furthermore, in the absence of demographic information about those who choose not to provide con-

sent for participation it would be difficult to assess the extent of any bias resulting from demographic differences between participants and non-participants.

Large data

The second option which was considered was to use larger data sets for the analysis, such as person-level data collected for reasons other than research of this nature.

The analysis of a large data set increases the likelihood that the sample is representative of the population as a whole, with very little selection bias. Furthermore, the use of a large collection of data increases the likelihood of identifying small subsets within the data, and may be capable of demonstrating more subtle variations between groups. There may be pitfalls with data whose structure is poorly understood, or where data quality issues may influence the findings, and careful processes for selecting and processing the data are essential.

Large scale analysis of existing data collections presents a number of challenges. Existing data collections are rarely assembled specifically to answer questions posed by future researchers. Furthermore, the management of data quality during the collection process may not be adequately described, or conducted to an explicit standard. Unless prior consent has been sought, obtained and documented, data from large scale collections can only be used in a deidentified or anonymised form; this usually means that data analysis must be conducted at some level of abstraction or aggregation.

Another limitation of the use of large collections of population-based data is the need for caution when a statistic (such as level of school completed) about a particular geographic area is to be applied to individuals within the group. Although the population statistic may suggest that relatively few people in the group stayed at school until the end of Year 12, it is not possible to deduce the level of schooling of an individual group member, or even estimate the probability that the individual completed a particular year. It is inevitable that individuals will be misclassified by a group

statistic. However, it is valid to identify an individual as being a member of a group within which a relatively smaller number completed Year 12, for example a resident of the SA2 with only 19.8% completing Year 12, as shown in Table 4 above.

This problem was first described by Robinson (1950) who termed it the 'ecological fallacy'. In the context of analysing mortality statistics, Fox, Jones and Goldblatt noted that

> …[d]ifferences…between clusters are observed. However, when clusters are either aggregated…or disaggregated according to the characteristics of individuals, little homogeneity is retained. This preliminary analysis would suggest that when it is possible to record the circumstances of an individual, such as their housing tenure, this provides a considerably better measure of their risk of mortality than surrogate measures derived from a knowledge of the area in which they live, the interpretation of which is subject to the ecological fallacy.
>
> (Fox, Jones, & Goldblatt, 1984, p. 314)

For this research, a careful balance was necessary between research methods which would minimise the impact of the ecological fallacy and the sample size effect, while maintaining confidentiality by using deidentified data. The implications of granularity and the sample size effect also influenced the decision making.

After giving careful attention to these considerations, a decision was made to analyse the relationship between health service use, PHR barriers and socioeconomic status using existing (and available) large scale data collections.

7.4.1 Data about disadvantage

In order to minimise the sample size effect, a decision was made to use only data which could be coded to a location at the finest level of detail available. In the absence of available Mesh Block and Statistical Area level 1 information, data for SA2s was considered to be the most appropriate option for analysis, providing the best level of detail for areas. This decision limited the range of data sources which were relevant for the study.

The Australian Bureau of Statistics (ABS) reports census data at SA2 level for a wide range of reported measures. This includes a collection of index measurements (Socio-Economic Indexes for Areas – SEIFA) which ABS describes as "…a product…that ranks areas in Australia according to relative socio-economic advantage and disadvantage. The indexes are based on information from the five-yearly Census." (Australian Bureau of Statistics, 2013a, p. 1). Measures associated with socioeconomic status are usually reported as totals and percentages for categories (as shown in Table 4). The calculation of SEIFAs uses principal component analysis to construct a single measure for the Index. The four SEIFAs for 2011 were prepared using data from Australia's 2011 census, are determined for each of the SA2 regions, and are published on the ABS website (Statistics, 2013). The calculation of SEIFAs uses Principal Components Analysis to summarise a large number of relevant variables within the census data, with each Index designed to focus on a particular aspect of disadvantage (Pink, 2008).

The *Index of Relative Socio-economic Disadvantage* (IRSD) aggregates 17 census measures associated with relative disadvantage. These measures include the proportion of: those who are unqualified, unemployed or working as labourers; individuals with a long term health condition or disability; households with modest income; low rent or public rental accommodation; and dwellings without an Internet connection. A low IRSD indicates an area which is relatively disadvantaged; a high IRSD indicates a low level of disadvantage, but does not indicate a high number of relatively advantaged (or 'privileged') residents in the area.

The *Index of Relative Socio-economic Advantage and Disadvantage* (IRSAD) aggregates measures associated with relative disadvantage, but also takes into account measures of relative advantage, such as households with a high mortgage or rent payment; dwellings with broadband Internet; individuals working as professionals, receiving a high salary, or with an advanced diploma or diploma. IRSD and IRSAD scores for an area may be divergent if that area has a heterogeneous mix of disadvantaged and privileged residents.

The *Index of Education and Occupation* (IEO) aggregates census indicators of the skills and qualifications associated with different occupations, including those who are unemployed, in a low-skilled job, without certificate qualifications, with a university qualified. A high IEO indicates a higher proportion of people with high qualifications or more skilled jobs, while a low IEO suggests more residents without qualifications, and who have low skilled jobs or are unemployed.

The *Index of Economic Resources* (IER) aggregates measures of income and wealth, such as individuals with high income or low income; households with a mortgage, a high mortgage, or four or more bedrooms. An area which has a high IER is likely to have better access to economic resources.

7.4.2 Data about healthcare

A range of possible sources of data about healthcare were considered, including Australian Government health activity data, census collections, and Tasmanian Health Department data.

Healthcare in Tasmania is is provided by general practitioners, specialists, private hospital and public hospitals (including emergency departments). This core health service provision is supported by community nursing, private pharmacists and allied health professionals, and complementary and alternative health providers.

The Australian Government collects administrative records of a range of health payments for private hospital admission, general practitioner and specialist visits and the dispensing of medications. Because of concerns about the confidentiality of information, data from the private sector is only available as high level summaries. For example, published details about private hospital activity group Tasmanian private hospitals with those in the Northern Territory and the ACT, with hospitals grouped into broad categories based on bed numbers. Deidentified extracts of this data for research generally involve aggregation to a large geographic area (such as SA4 or federal electorates (of which there are five in Tasmania). Privacy concerns also limit the ready availability of data

about general practice and private specialists to high level summary data, for example by electorate (of which there are five in Tasmania).

The Tasmanian Department of Health and Human Services (DHHS) holds data on all public patients, including demographic data, outpatient activity data (clinics and emergency departments) for the last 3 years, and Casemix data about public hospital admissions over an extended period (around 10 years). Discussions with DHHS staff indicated that, subject to appropriate arrangements for ethics approval, privacy and security, it would be possible to obtain a deidentified (potentially re-identifiable) copy of this data with an appropriate subset of relevant data items. This option was selected for health data for analysis. A description of the data supplied by DHHS is provided in Section 9.2, with additional details in Appendix 2.

Health service utilisation

The hospital episode data was used to calculate for each patient the number of inpatient admissions, the number of bed days, and the number of bed days in excess of what might have been anticipated based on the diagnosis related group (DRG) assigned to each episode. While these variables, in aggregate, provide a definitive measure of public hospital inpatient activity, they underestimate the total hospital use by the Tasmanian population, since private hospital data are not included. The degree of underestimation is likely to be skewed towards a higher deviation for patients with higher socioeconomic status. The private hospital system includes two smaller emergency departments (in the South) and does not provide haemodialysis.

Individuals

Admitted care services for each patient was measured as the number of admissions (same day and overnight), the number of bed days, and the number of bed days in excess of the benchmark stay for the episode DRG. Use of emergency department services was measured as the Number of ED visits, and as the Total time spent in the department. Multimorbidity was recorded as the number of chronic diseases (as indicated by specific ICD diagnosis codes), and as a weighted Deyo/Charlson score.

Areas

Use of admitted care services by residents of SA2s were measured used similar parameters, measured per 1,000 residents: number of admissions (same day and overnight), the number of bed days, and the number of bed days in excess of the benchmark stay for the episode DRG. Use of emergency department services was measured as the Number of ED visits, and as the Total time spent in the department. Multimorbidity was measured as the number of chronic diseases (as indicated by specific ICD diagnosis codes), and as a weighted Deyo/Charlson score, again measured per 1,000 residents.

Measuring of multimorbidity

As discussed in Section 2.4, multimorbidity (the presence of multiple chronic conditions) results in increased health service utilisation, and unless specialist medical care is well coordinated between specialists, an increased burden on the patient in managing multiple, often conflicting 'single disease' treatment regimes. Although multimorbidity has been well identified as a problem, there is no agreed process for identifying multimorbidity.

Marengoni et al. (2011) used a literature review to summarise evidence about multimorbidity in the elderly, and its causes and effects, and also explored aspects of the care of patients with multimorbidity. They noted that multimorbidity was commonly identified in one of three ways: as a number of diseases (commonly two or three) in the same individual; using a cumulative index of both the number and severity of diseases; or the simultaneous presence of diseases and symptoms, together with physical, cognitive and functional limitations.

Charlson, Pompei, Ales and MacKenzie (1987) developed a method for identifying multimorbidity using ICD codes extracted from patient administrative records. Their weighted calculation, the Charlson Comorbidity Index, relied on the presence of one or more of 17 chronic disease entities within the coded data. This method has since been revised to allow calculation using ICD10 codes (Sundararajan et al., 2004; Thygesen, Christiansen, Christensen, Lash, & Sørensen, 2011), rather than the ICD9 codes used in the original calculation. For the current analysis, an algorithm was de-

veloped in R which evaluated all ICD10 diagnosis codes assigned to a patient (across multiple epis-
odes) to count the number of identified chronic diseases, and calculate the weighted Deyo-
Charlson score.

7.4.3 Data about PHR barriers

PHR adoption and use

Research with this focus would collect or re-use person-level data about PHR use obtained during
the implementation of a PHR, and details of registration and use over time. Data about users and
usage patterns would be obtained about PHR users, as well as potential users who choose not to
use the system, those who had registered for a PHR but not begun to use it, and those who had
abandoned its use. This research using this approach is reported in a number of publications (Goel,
Brown, Williams, Hasnain-Wynia, et al., 2011; Nielsen, Halamka, & Kinkel, 2012; Yamin et al.,
2011), predominantly in US settings.

Collection of data about non users can present practical and ethical challenges, making it difficult
to obtain a statistically valid and representative sample. Researchers must take care to avoid select-
ing a biased sample of participants, which could lead to skewed or misleading results. Examples in-
clude the use of an email invitation to solicit participation (Lin et al., 2005), or using a web based
survey to collect data (Hilton et al., 2012).

The routine use of personal health records in Australia is in its early stages. There are currently no
PHRs that are widely used by a majority of patients within a community. The pool of potential
participants is likely to include a disproportionate number of enthusiastic 'innovators' and 'early
adopters' (Rogers, 1983, p. 248) such as professionals from the fields of healthcare, health informat-
ics and information technology; other groups – members of Rogers' early and late majority, and es-
pecially the laggards – could be under-represented or missing altogether.

The alternative which presented itself was to examine the question from the opposite direction, by identifying areas with a higher proportion of DDDs, and evaluating the occurrence of likely barriers to PHR uptake and continued use. In addition, it would be possible to make some assessment of the use of health services by area, particularly for public hospital services, for which extensive data is available.

Barriers to PHR use

The literature review which is reported in Chapter 8 identified 21 barriers which could interfere with a patient's adoption and subsequent use of a personal health record. These barriers are listed in Table 6 on page 160 and include Individual factors (Age, Sex, Race/ethnicity); Demographic factors (Income and socioeconomic status, Education, Internet and computer access); Capability factors (Text literacy, Numeracy, Health literacy, Technical literacy and skills); Health related factors (Health and chronic disease, Generalised disability as well as physical, cognitive and visual impairment); PHR factors (Usability, Cost, Lack of information); and Other factors (Discomfort with computer use, Privacy concerns, Lack of motivation)

Given the inherent complexity involved in conducting an analysis with each of these 21 possible barriers to PHR adoption and continued use, it was necessary to select a smaller number. Some of the barriers were addressed by other measures which would be considered in the analysis, and were discounted on the basis that their inclusion would lead to a degree of 'double counting'. These included barriers which are also measured within the SEIFA indexes (Income and socioeconomic status, Education), or closely associated with the available data about healthcare utilisation (Health and chronic disease, Generalised disability, physical, cognitive and visual impairment). Some of the barriers, such as Race/ethnicity, PHR cost, Lack of information, and Privacy concerns had been identified within a localised or uniquely US context. For other barriers such as Internet and computer access, Text literacy, Numeracy, Health literacy, Technical literacy and skills, Discomfort with computer use and Lack of motivation it was deemed difficult or impossible to obtain representative population data at the level of detail being considered.

In order to manage the complexity of the analysis, and guided by the findings of the Phase 1 exploratory research, and having regard to the close association between socioeconomic status and barrier factors., a decision was made to consider four barriers: text literacy, health literacy, technical literacy and financial resources.

Barrier factors and proxy measures

Measures of text literacy, technical literacy and health literacy are not included in Census collections, and are not available for SA2s. As an alternative, the use of proxy measures was considered. Proxy measures inevitably provide a less accurate assessment of the PHR barriers being evaluated, but give a more granular assessment of the extent of these barriers within the population.

The substitution of proxy measures for text literacy, technical literacy and health literacy in place of direct measures is not generally well regarded; level of schooling attained has been used as an indicator for health literacy, but direct measurement is preferred.

Based on the availability of suitable measures within the data sets an attempt was made to identify a measure at the level of an SA2 region for each of the factors identified above as being a likely barrier to the use of ehealth systems.

It should be noted that the measures considered for use as proxies for PHR barriers are each included in some form as components in Principal Component Analysis used in the derivation of SEIFAs.

Text literacy (Education)

The Australian Bureau of Statistics describes text (or 'prose') literacy is "... the ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures."(ABS, 2008a, p. 99) Adult literacy is not recorded in the Australian census, and was last measured in the 2006 Australian Life Skills Survey (reported in 2007).

Data about literacy and numeracy is not collected during the census, but is included in the periodic small-sample collections such as the Programme for the International Assessment of Adult Competencies, Australia, 2011-2014 (Australian Bureau of Statistics, 2014). Because of the small sample used for surveys such as this, data is not available for smaller areas.

Educational attainment (final year of school attended) is recorded in the Australian census, and published at SA2 level. This measure is also included in the calculation of the SEIFA index of education and occupation (IEO). However, educational achievement (final year of school attended) which is recorded in the Australian census, and published at SA2 level, has a relationship with text literacy.

> An individual's literacy skills are related to the number of years of schooling completed. In 2006, after excluding those still at school, just over half of Australians aged 15–74 years had not completed school to Year 12 (or equivalent). This group was more than twice as likely to have poor prose literacy skills than were those who had completed Year 12 (63% compared with 29%).
>
> On average, literacy skills increase with each additional year of school completed. For example, 71% of those who had completed school at Year 12 (or equivalent) had adequate or better prose literacy skills compared with 56% of those who only completed Year 11, and 10% of those who finished school at Year 8 or below.
>
> <div align="right">(Australian Bureau of Statistics, 2008, p. 2)</div>

This association between schooling and literacy is clarified in the following diagram:

Highest level of school completed(a): proportion with adequate or better prose literacy(b) – 2006

Year 12 or equivalent

Year 11 or equivalent

Year 10 or equivalent

Year 9 or equivalent

Year 8 or below(c)

0   25   50   75   100
(%)
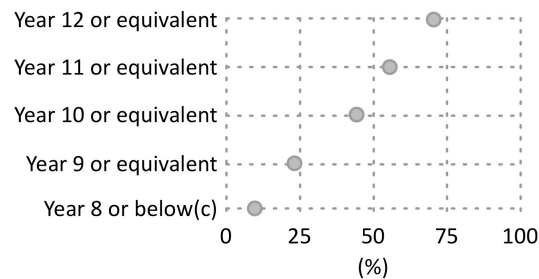
(a) Excludes people still at school.
(b) Prose literacy skill levels 3, 4 and 5.
(c) Includes those who never attended school.

Source: ABS 2006 Adult Literacy Life Skills Survey.

Figure 10: The relationship between years of schooling and text literacy(Redrawn from Australian Bureau of Statistics, 2008, p. 3)

Based on these observations, it was decided use education as a proxy for text literacy levels within SA2 regions.

Technical literacy (Internet access)

In the book *Technically Speaking: Why All Americans Need to Know More About Technology*, the US Committee on Technological Literacy, the National Academy of Engineering, and the National Research Council describes technical literacy in the following terms:

> A technologically literate person will not necessarily require extensive technical skills. Technological literacy is more a capacity to understand the broader technological world rather than an ability to work with specific pieces of it. Some familiarity with at least a few technologies will be useful, however, as a concrete basis for thinking about technology.
>
> (Pearson & Young, 2002, p. 21)

Although this statement provides a useful description of technical literacy, it lacks the degree of precision which is necessary for reliable quantification of the concept. Other descriptions of tech-

nical literacy are of little additional help. Technical literacy is also viewed differently in contexts other than adult technical literacy, for example in evaluating the extent of skills and learning in students, or teachers' ability to teach technical subjects. The International Technology Education Association, for example, defines technological literacy as "...having the ability to use, manage, assess, and understand technological products and systems..." (ITEA, 2007, p. 114) and notes that "[t]his ability, in turn, demands certain mental tools, such as problem solving, visual imaging, critical thinking, and reasoning.". Technical literacy is closely associated with other concepts such as computer literacy, Internet literacy and ehealth literacy.

This definitional uncertainty translates to an absence of agreed standards for measurement, and an absence of useful population measures of technical literacy in the Tasmanian population.

As an alternative, Internet access at home was considered to provide an appropriate proxy measure. Internet access is determined in part by socioeconomic factors: having an internet connection requires a level of financial resources to pay for the connected device, the connection and the continuing fees, and the ongoing fees. Market forces may also play a part – internet providers may be less likely to focus their attention on the provision of a reliable connection in areas where levels of uptake are low.

The rate of broadband internet connection to households as a measure of aspects of disadvantage associated with technology is likely to measure both the technical skills and capability present within the household, and the availability of sufficient discretionary financial resources to pay for the connected device(s), the connection, and the usage costs.

The recent implementation in Tasmania of the National Broadband Network (NBN) its successor, the Coalition Broadband Network (CBN) may have resulted in changes to the overall status of Internet connection types, but these are largely subsequent to the health data that is available for analysis. Internet access via mobile devices is becoming increasingly common, and likely to skew the

data on recent home-based Internet connections. However, it should be noted that an individual's access to broadband Internet does not guarantee text, technological or health literacy.

Health literacy (Qualifications)

Early definitions of health literacy focused on the ability to read health related text. However, more recent attempts at a definition have broadened the concept. The British Columbia Health Literacy Research Team saw health literacy as:

> The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course.
>
> (Kwan, Frankish, & Rootman, 2006, p. ii)

David Baker quotes the IOM expert panel in identifying that health literacy incorporates four domains: "...(1) cultural and conceptual knowledge, (2) oral literacy, including speaking and listening skills, (3) print literacy, including writing and reading skills, and (4) numeracy" (D. W. Baker, 2006, p. 878).

A number of approaches have been used to measure health literacy, including the Test of Functional Health Literacy in Adults (ToFHLA), and its abbreviated version (ToFHLA-S), and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). More recently, Hanchate, Ash, Gazmararian, Wolf and Paasche-Orlow, (2008) described the derivation of a tool which they termed the Demographic Assessment for Health Literacy (DAHL), a proxy measure for an individual's health literacy. DAHL was a computed measure, calculated from data about each individual's sex, ethnicity and years of schooling. However, the tool does not appear to have been tested elsewhere, or to have been validated using Australian subjects.

The Australian 2006 Adult Literacy and Life Skills Survey, defined health literacy as "...the knowledge and skills required to understand and use information relating to health issues such as drugs

and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy" (ABS, 2008b, p. 5).

Data from the Survey showed a clear relationship between post secondary qualifications and health literacy. Of those with a Bachelor's degree or higher qualification, 3.7% were at Health Literacy Level 1, and 15.4% at Level 4 or 5; for those without non-school qualifications, 29.8% were at level 1, but only 2.9% at Level 4/5.

Based on this observation, and in the absence of a more accurate measure at SA2region level, the level of post-secondary qualifications has been applied as an (imperfect) proxy for health literacy.

Calculating a single measure from category data

Many measures of socioeconomic factors report on the proportion of the population within each of a range of subgroups. For educational attainment, for example, the ABS reports on the number and proportion of individuals within each of six categories, 'Did not go to school' to 'Year 12 or equivalent' (as shown in Table 4 on page 125). While this distribution is informative, it can be more convenient to use a single statistic which summarises this distribution.

While the ABS SEIFA indexes provide a useful overview of disadvantage for areas, the ABS does not derive region summary statistics which are focused on those factors being investigated as possible barriers to PHR uptake. Instead, a previously identified summary measure was used.

Massey (2001) commented on a trend in American sociology to attempt to highlight concentrations of affluence within neighbourhoods, as well as concentrations of poverty. He expressed dissatisfaction with this approach, pointing out that affluence and poverty represent two ends of a continuum. Instead, he recommended the use of a measure that would represent a neighbourhood's position along that continuum – the Index of Concentration at the Extremes.

The Index of Concentration at the Extremes (ICE) is calculated as:

$$ICE_i = \frac{P_i - D_i}{T_i}$$

Where P_i is the number of cases in the privileged group, D_i is the number of cases in the disadvantaged group, and T_i is the total number of cases in the neighbourhood. Values for ICE can range from $+1.0$ (in a neighbourhood where all are affluent) to -1.0 (where all are poor). An ICE value of 0.0 indicates a balance between the numbers of privileged and disadvantaged within a neighbourhood.

Carpiano, Lloyd, & Hertzman (2009) applied Massey's Index as a measure of relative disadvantage in an evaluation of the association between education outcomes and affluence in British Columbia, and the use of ICE scores has been extended in the current research to quantify more general measures of advantage and disadvantage which affect the ability of citizens to benefit from PHRs.

7.5 Analytical techniques

7.5.1 Software tools

The software tools used for the analysis are described below.

MacVim

MacVim provides an open source implementation of the vi text editor for OS-X, with a graphical user interface. MacVim was used in the process of identifying minor errors in the data (such as the presence of CR-LF characters within a data field) which would otherwise interfere with data imports.

Hex Fiend

HexFiend is an open source hex editor for OS X, and was used to correct the minor data errors identified using MacVim.

R

R is open source software, available for Windows, OS X and Linux, which provides a data processing environment which is suitable for comprehensive statistical analysis. The functionality of R can be easily extended by the installation of additional packages. Packages used in this analysis include *plyr*; *reshape*; *charlson*, and *psych*. Data can be imported in to R from a variety of file formats, including csv files, and stored as variables, vectors, matrices or data frames. R was used for the vast majority of the statistical processing during this analysis.

Rstudio

RStudio is an open source implementation of a graphical user interface for R, and is available for Windows, OS X and Linux. RStudio allows the creation of extensive scripts which can be used repeatedly to process data according to a standardised protocol. Some examples of the scripts used for data processing are include in Appendix 4.

Excel

Microsoft Excel is a powerful spreadsheet program, available for Windows or OS X. It provides a multipurpose environment for simple and complex calculations, sorting, filtering and graphing. Excel was used for the preliminary inspection of the data sets (including the preparation of some graphs), and independent review of data produced in R.

QGIS

QGIS is a powerful open source geographical information system, available for Windows, OS X and Linux. It was used for the preliminary processing of SA2 shapefiles, including the addition of SA2-based measures of privilege and healthcare use.

TileMill

TileMill is an open source application, available for Windows, OS X and Linux, and is able to produce display quality maps from shapefiles.

7.5.2 Cluster analysis

Cluster Analysis

Cluster analysis can be used in three ways – to test a developed theory, to develop a theory based on an understanding of the underlying data (or suspicions about the data), or to explore a data set to bring to light interesting features inherent in it. This research has adopted the second approach, using the analysis to develop a theoretical viewpoint about ehealth and disadvantage through an analysis of available data.

Cluster analysis was used with two sets of summarised data. The first investigated patient level summaries which aggregated all hospital episodes (including Charlson morbidity scores), or all emergency department attendances for each patient. The second applied similar analysis to activity summaries at the level of SA2s. Cluster analyses at patient level were universally unhelpful. Some examples of the results produced are included in Appendix 5.

The cluster analysis of SA2 summary data used the *k-means* technique, repeated with a range of *k* values, with the results reported in the publication Chapter 9 use a value of 6 (that is, with six clusters produced).

Balijepally, Mangalaraj and Iyengar (2011) caution against the careless use of cluster analysis, and remind us that the technique is capable of identifying clusters within a dataset where none exist:

Cluster analysis is a powerful statistical procedure for extricating natural configurations among the data and the populations. Cluster analysis, with its seemingly limitless power to produce groupings in any dataset, has all the trappings of a super-technique. However, the method produces clusters even in the absence of any natural structure in the data, and has no statistical basis to reject the null hypothesis that there are no natural groupings in the data. Application of cluster analysis, therefore, presupposes sound researcher judgment and responsible analysis and reporting.

(Balijepally et al., 2011, p. 375)

In this thesis, the application of cluster analysis has been based on underlying data about disadvantage, healthcare use and proxies for barriers to PHR adoption and use, as described in the background in Chapter 2, and the findings of the Phase 1 research. The credibility of the results have been critically evaluated against what is known about socioeconomic problems in the SA2 within each cluster.

7.5.3 Maps

Analysis of geographic and spatial distribution is complex, and many of the techniques to be applied rely on point locations rather than area measures. Mapping was considered as an option for providing an accessible overview of the data retrieved from online sources, and derived from those sources by calculation, as well as providing an option for summarising the public hospital utilisation data obtained from DHHS. For simplicity, SA2 region measures have been displayed as choropleth maps, allowing a direct visual comparison. It should be noted that "…a single map is but one of an indefinitely large number of maps that might be produced for the same situation or from the same data" (Monmonier & Blij, 1996, p. 2).

Geospatially distributed data can be represented visually as a choropleth map, using monochrome shading or colours to indicate data values. There are three options for the choice of colour: a linear progression from light to dark versions of the same hue (sequential), a graded progression from one colour to another via a neutral shade (diverging), or a collection of different colours (qualitative). The choice of a suitable colour scheme is guided by the nature of the data being represented. A se-

quential scheme, with a progressive colour transition from light to dark, is appropriate for data that covers a range of values from low (or zero) to high. A diverging scheme is appropriate for data that is distributed about a midpoint (which is typically represented by a neutral shade), while a qualitative scheme is best used with nominal or categorical classes of data, with no implied numerical hierarchy between them (Brewer, 1994). Colours should ideally be chosen to ensure optimal visibility and impact, and avoid difficulties in data interpretation for users with common forms of colour blindness. The number of steps in the colour gradient should also be chosen with care: too few steps will result in a loss of sensitivity, while too many will make it difficult to distinguish between adjacent colours. Choropleth maps typically use five to seven colours.

Data to be represented in a choropleth map may be either classed (distributed between a small number of categories) or unclassed (with the shade of each polygon determined by the value of the parameter for that polygon). In practice, 'unclassed' choropleth maps effectively become 'classed' according to the vagaries of the presentation medium. The particular characteristics of the display monitor or printing process will tend to mask small differences between adjacent shades of colour, and in an unpredictable way. It is usually considered preferable for the map designer to make explicit decisions about classification, rather than to leave the output, and its interpretation by the user, to chance.

Several methods have been used for the classification of data in choropleth maps. These include the segmentation of data in equal intervals (a 'quantile' method), allocating data between classes with equal frequency, and using one of a number of 'statistically optimal' algorithms. Brewer and Pickle (2002) evaluated the performance of a range of methods for classifying data for choropleth maps of epidemiological data. Their conclusion was that both a quantile method and the minimum boundary error method provided satisfactory results. The quantile method offers a simpler implementation approach, and has been adopted for the maps produced in this thesis.

7.6 Closing comments

This chapter has reviewed gaps in the evidence which Phase 1 of the research provided in response to Research Question 1:

RQ1:   What is the relationship between socioeconomic disadvantage and personal electronic health records?

In order to address those gaps, two additional research questions were formulated:

RQ2a   What is the current evidence about barriers to the uptake and continued use of personal electronic health records?

RQ2b   Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

These questions were addressed using a literature review, described in the publication in Chapter 8, and empirical research, whose results are reported in the publication in Chapter 9.

Chapter 8: Barriers to meaningful use of personal health records by patients: A structured review

> "Everything of importance has been said before by
> somebody who did not discover it."
>
> - Alfred North Whitehead

> "The secret to creativity is knowing how to hide your
> sources."
>
> Albert Einstein

8.1 Preface

As noted in the previous chapter, this publication (currently in review) describes a literature review which was designed to enumerate and categorise barriers to the uptake and continued use of personal electronic health records, with a particular interest in those barriers which are likely to affect disadvantaged users. The review was conducted in order to address the additional research question:

RQ2a: What is the current evidence about barriers to the uptake and continued use of personal electronic health records?

The review was was undertaken in the first half of 2014, and focused on more recent publications ($2004 - 2014$). Only publications in English were retrieved, which may have reduce the likelihood of identifying barriers which exist in countries where English is not the first language. During the course of the review, it became apparent that the publications included examples of selection bias

against disadvantaged study participants; an account of this the bias was included as a secondary outcome.

8.2 Paper as submitted (in review)

Publication details

This work has been submitted for publication, and is in review.

Showell, C. (2014). Barriers to meaningful use of personal health records by patients: A structured review. *In Review*.

ABSTRACT

Background:

An increasing focus on personal electronic health records (PHRs) offers healthcare benefits for patients, particularly those in underserved and marginalised populations, at risk of receiving less effective healthcare and worse health outcomes. However, PHRs are likely to favour text, technical and health literate users, and be less suitable for disadvantaged patients. These individuals may be less likely to access an online record or contribute to the EHR Incentive Programs 'meaningful use' Measure #2 (5% of patients accessing their record). These concerns have prompted this review of the literature, which seeks evidence about barriers to the adoption and continued use of PHRs, the nature of the evidence for those barriers, and the stage of PHR implementation where particular barriers apply.

Methods:

Searches in PubMed, Embase, CINAHL and ProQuest databases were used to retrieve articles published in English after 2003 in a refereed journal or presented in a refereed conference or scientific meeting. After screening to remove items which were out of scope, the phase of the PHR implementation, the type of investigation, and PHR barriers were categorised using thematic coding.

Results:

The search retrieved 439 items; screening identified 40 in-scope publications, which provided evidence of 21 barriers to patient adoption and continued use of PHRs, categorised here as Individual, Demographic, Capability, Health-related, PHR or Attitudinal factors. Barriers were identified in most phases of PHR implementation, and in most types of study. A secondary outcome identified that eleven of the publications may have introduced a bias by excluding participants who were less affluent, less capable, or marginalised.

Conclusions:

PHR barriers can interfere with the decision to start using a PHR, with the adoption process, and with continued use, and the impact of particular barriers may vary at different phases of PHR adoption. The complex interrelationships which exist between many of the barriers is suggested in some publications, and emerges more clearly from this review. Many PHR barriers appear to be related to low socioeconomic status. The 5% meaningful use criterion will measure the activities of more capable PHR users, for whom the barriers are not insurmountable, but is less likely to include online activity by disadvantaged patients. A better understanding is needed of how the effect of barriers is manifested, how that that effect can be countered, and how planning and implementation of PHR initiatives can make allowance for patient level barriers to PHR adoption and use, with appropriate actions to mitigate the effect of those barriers for more disadvantaged patients.

KEYWORDS

eHealth; personal health records; barriers; bias; systematic review

Introduction

Background

There is an increasing focus on personal electronic health records (PHRs) as a part of the implementation of ehealth services to support improvements in healthcare. PHRs have been defined as

> ...a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers.
>
> (Jones, Shipman, Plaut, & Selden, 2010)

Most publications about personal health record systems now focus on electronic versions providing online access for patients, which may be through provider portals. PHRs offer a number of benefits including better access to data and information, improved communication between patients and providers, the empowerment of patients, and opportunities for health self-management (Pagliari et al., 2007; Tang & Lansky, 2005) .

These benefits are certainly worthwhile, particularly for disadvantaged patients, who face challenges in receiving safe effective healthcare (Adler & Newman, 2002), and are likely to have worse health outcomes than more privileged patients (Olshansky et al., 2012). However, the benefits which result from the use of a PHR cannot be guaranteed. The use of specialised medical language within a PHR can marginalise non-specialist users (Showell et al., 2010), and in Australia, patients have largely been left out of discussions about policies affecting national PHR developments (Showell, 2011).

However, information about demonstrated benefits to patients is limited, with most evidence of benefit applying to technically competent patients (Green et al., 2008; Ralston et al., 2009), with few details about how beneficial outcomes can be provided for other types of patients and patient groups. Concerns have been expressed previously about a risk that the development of PHRs may be skewed in favour of users with good levels of text, technical and health literacy, and as a result make them less suitable for users who are at a socioeconomic disadvantage (Showell & Turner, 2013a, 2013b). Low levels of text, technical and health literacy can act as barriers to the effective use of technology (Wilson, Wallin, & Reiser, 2003), including personal health records (Angaran, 2011; Newman et al., 2012), and a number of other barriers have been identified (Sarkar et al., 2011).

In the US, the Centers for Medicare and Medicaid Services' (CMS) EHR Incentive Programs mandate two measures for patient electronic access to their records. The first (for Stage 1 participants) requires that patients are provided with online access to their health information within four working days of their health professional visit or hospital discharge. The second (for both Stage 1 and Stage 2) requires that more than five percent of patients either view their health information online, or send it to a third party ("Patient Electronic Access Tipsheet," 2014). It is probable that disadvantaged patients facing barriers to PHR use will be less likely to access an online record and contribute to the 5% target.

Objectives

The concerns outlined above suggest that there are significant barriers to the adoption and continued use of PHRs by patients, particularly for those among disadvantaged and underserved populations. This literature review seeks information about those barriers, and the nature of the available evidence, as a way to inform the management and maintenance of equity in the development and implementation of PHRs. The review is designed to address three specific questions:

- What patient level barriers to the adoption and continued use of PHRs have been identified?
- What is the nature of the evidence for each of those barriers?
- At what stage of PHR adoption and use are those barriers most likely to apply?

The review also considers the type of study reported, the number of participants in the study, and whether any aspects of the methodology in each case would make the identification of barriers less likely.

Methods

Eligibility criteria

The literature search identified publications providing evidence about barriers which might interfere with a patient's decision to adopt a personal health record, or discourage continued use. Publications were included if they considered any stage of patient involvement with a PHR, from their willingness or ability to use the Internet or health information technology in the context of PHR use, through to long term use of a PHR as a part of their healthcare.

Publications were included only if they were published in English after 2003, in a refereed journal, or presented in a refereed conference or scientific meeting. Publications were excluded if they focused on barriers affecting healthcare providers or organisations rather than patients, or if the description of barriers was not based on objective evidence, for example white papers, opinion pieces or editorials.

The types of publication which were retrieved included:

- Comparative trials involving multiple participating sites;
- Evaluations which involved the collection of data from patients about PHR barriers (using focus groups, interviews, surveys or questionnaires);
- Observational studies;
- Details of the attitudes and opinions of patients about possible future PHR use;
- Observations from health professionals about patient use of PHRs; and
- Literature reviews about barriers to PHR use.

Study selection and data extraction

The review process followed published guidelines on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Liberati et al., 2009). Full literature searches were conducted in PubMed, Embase, CINAHL and ProQuest databases between January and April 2014, with ad-

ditional searches conducted in May 2014. Details were retrieved for all publications in English from January 2004 to the date of the search.

As an example, the search conducted in PubMed used the terms [personal health record OR personal electronic health records OR patient portal] AND [barrier OR barriers], retrieving 51 citations. Searches were also conducted in Embase, CINAHL and ProQuest using comparable search terms. Additional items were retrieved by tracking citations within publications, and from a small number of other sources.

All publications were initially screened to remove items which were considered to be out of scope, for example where the reference to PHRs was incidental (Abimbola, Okoli, Olubajo, Abdullahi, & Pate, 2012; Bonacina & Pinciroli, 2010), where the barriers identified were exclusively those affecting healthcare providers and organisations (Gaskin, Longhurst, Slayton, & Das, 2011; Hart, 2009), and where the focus was on PHR infrastructure issues (Hammond, 2005; Tejero & de la Torre, 2012). The screening process also removed items which made only incidental mention of PHRs (Stead, Kelly, & Kolodner, 2005) or barriers (Burke et al., 2010). Publications were included if they provided specific evidence about barriers which might influence the intended or actual adoption of PHRs by patients or their continued use. Literature reviews were removed if they included only publications which had already been retrieved for this review and added no helpful additional commentary.

Data from the publications which remained after screening were extracted using an iterative process of reviewing full text publications. The data variables which were recorded included the phase of PHR implementation, the type of investigation undertaken, barriers which were identified, the location of the study and the PHR system in use. Details were also recorded where relevant of the number of individuals in the population being studied, and the number included in the study. For studies which obtained information or participation from individuals, aspects of the methodology which might discourage or exclude low capability subjects from seeking to enrol in the study, or re-

duce the likelihood of their selection as participants were noted. Following an initial review of the data from all in-scope publications, frameworks were developed for the phase of PHR implementation studied, the type of investigation and, and the evidence it provided about barriers.

Implementation phase

For each publication, the authors' description of the phase of PHR implementation under investigation was reviewed, and thematic coding used to establish a schema describing each phase of implementation. This schema was then used to categorise all publications. The majority were focused on a single phase of implementation, with three (Atreja et al., 2005; Cho et al., 2010; Luque et al., 2013) addressing two phases.

Investigation type

For each publication, descriptions of the type of study were reviewed, and used to develop a categorisation by type of investigation. Publications were assigned to a category of investigation type, with the majority of publications using a single type of investigation, and three (Butler et al., 2013; Gordon et al., 2012; Nijland, van Gemert-Pijnen, Kelders, Brandenburg, & Seydel, 2011) spanning two types.

Barriers

Each of the publications was reviewed to identify evidence about barriers which might inhibit patients' adoption or continued use of a PHR, as well as barriers to Internet use more generally (in the context of PHR use). An iterative process of thematic coding was used to classify barriers, with each included publication reviewed at least three times to ensure that meanings were not misinterpreted, and that the thematic structure remained consistent.

Results

Summary

Searches in PubMed, Embase, CINAHL and ProQuest retrieved a total of 439 publications. Another 36 items were identified from citation tracking and other sources, giving a total of 475 publications. After removing 81 duplicates, 395 publications remained for initial screening. This resulted in the exclusion of 256 records, leaving 138 full text articles to be evaluated for eligibility. This evaluation removed 98 articles which provided no direct evidence about PHR barriers or did not address patient barriers to PHR adoption and use, and literature reviews whose content duplicate other retrieved publications. This left 40 articles for the synthesis of evidence. This process is outlined in Figure 1 below:
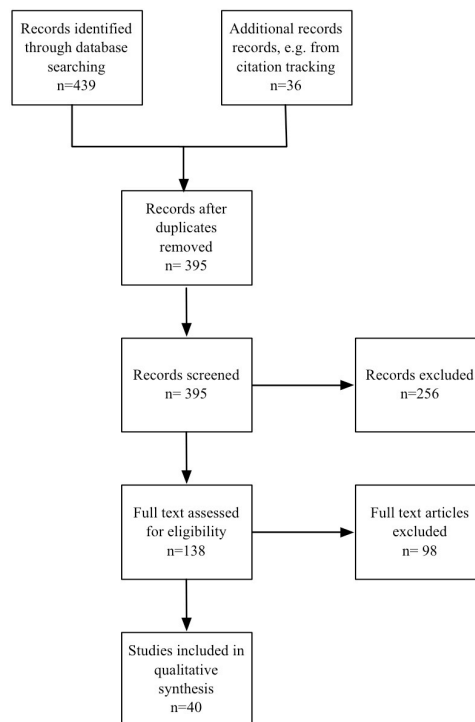
Figure 11: PRISMA flowchart

Each of the included publications was coded in order to identify the particular phase of the PHR

implementation which was being evaluated, the type of investigation conducted, and the barriers which were identified.

Key features of selected studies

Details of the included publications, including method, size of target population and number of participants is shown in Table 1 below, categorised by Investigation type.

Table 5: Summary of included publications

First author(yr)	Investigation type	Population	Participants
A: Collection of data from PHR users, or non-participants			
Anderson (2004)	Telephone interview survey	3,000	186
Atreja (2005)	Focus groups/interviews with clinic staff; observation		15
Cho (2010)	Postal survey questionnaire		201
Chrischilles (2014)	Mixed methods: UCD with evaluation; questionnaire	15,000	1,075
Crabb (2011)	Interview survey	75	50
Emani (2012)	Postal survey questionnaire	1,500	760
Fuji (2014)	Interviews with trained users	59	23
Goel/Cooper (2011)	Telephone interviews with non adopters		159
Greenhalgh (2008)	Mixed methods: Interviews/focus groups		103/67
Hall (2014)	Trial of result communication via PHR	66	49
Hilton (2012)	Online survey (within supported PHR use	2,871	338
Kim (2009)	Mixed methods: Paper questionnaire, analysis of user logs	330	70
Kruse (2012)	Interviews about Internet use	713	638
Lober (2006)	Analysis of data about PHR use	170	41
McCleary-Jones (2013)	Interviews	350	88
Mishuris (2014)	Semistructured interviews with patients		3
Roblin (2009)	Paper survey with online option (non-adopters	5,309	1,777
Taha (2013)	Lab usability test of a simulated PHR		107
Weitzman (2009)	Focus groups, usability testing, emai		302
B: Observational study			
Byczkowski (2011)	Retrospective observational study	1,900	498
Goel/Hasnain(2011)	Retrospective data analysis with adopters	7,088	4,891
Nielsen (2012)	Retrospective chart review	240	154
Sarkar (2010)	Telephone, web and written survey	14,102	5,671
Sarkar (2011)	Telephone, web and written survey	141,02	5,671
Yamin (2011)	Data analysis comparing adopters and non-adopters	75,056	32,274
C: Patient attitudes and opinions			
Logue (2012)	Survey questionnaire)		38
Luque (2013)	Mixed methods: Written questionnaire/Focus group	120/8	90/
Noblin (2012)	Paper survey on health literacy and PHR usage intention		562
Patel (2011)	Telephone survey		200
Patel (2012)	Paper survey of support for HIE and PHR		117
Zarcadoolas (2013)	Focus groups		28

First author(yr)	Investigation type	Population	Participants
Multiple types			
Butler (2013)	Mixed methods: Semistructured interviews with staff/Telephone interviews with patients (A, D)	9/404	/39
Gordon (2012)	Mixed methods: Surveys, database analysis, usage logs (A, C)	8,249	509
Nijland (2011)	Mixed methods: Survey; interviews; log files; usability assessment (A, B)	350	50
Literature reviews			
Archer (2011)			
Goldzweig (2012)			
Jimison (2008)			
McInnes (2013)			
Or (2009)			
Urowitz (2012)			

The publications retrieved for this review displayed a distinct geographic bias, with 38 out of a total of 40 studies describing PHR implementations in the USA (with one each from the United Kingdom and the Netherlands). Three particular PHR systems – MyHealth*e*Vet, kp.org and My-Chart – accounted for nine of the publications (with three each). Data about a possible bias in the selection of participants was retrieved during the data extraction, and evaluated as a secondary outcome.

Implementation phase

For the purposes of categorising publications, the following schema was adopted in order to identify which phase of PHR readiness, adoption and use was being considered.

1. Readiness to use a PHR, including evaluations of Internet use:

    1.1 – Patient use of technology, including the Internet;

    1.2 – PHR usage intentions; or

    1.3 – Design of PHRs, with User Centred Design (UCD), or usability studies.

2. Initial registration for an account within a PHR system;

3. Initial use of a PHR; publications which studied any use of a PHR at an unspecified time after registration were included in this category;

4. Continued use of a PHR, including long term use; or

5. PHR benefits affecting the patient's health and wellbeing.

Investigation type

Publications were categorised according to the investigation types, with publications categorised as either a literature review, or one of:

A   An evaluation involving the collection of data about barriers about PHR users, or participants who did not initiate or continue PHR use (using focus groups, interviews, surveys or questionnaires);

B   An observational study providing a qualitative or quantitative evaluation of demographic data and records of users and non-users;

C   Details of attitudes and opinions of patients about barriers to possible future PHR use, and the demographic characteristics of those with particular usage intentions; or

D   Observations from health professionals about patient use of PHRs.

Barriers

Each of the included publications provided statements about barriers to patient adoption and continued use of a PHR. This evidence was either: described by potential users in advance or anticipation of PHR use; reported by potential users as a reason for not commencing use of a PHR, or not continuing that use; inferred from demographic differences between users and non-users; or identified in a literature review.

Thematic analysis was used to identify barriers and categorise barrier types. This process involved a degree of simplification for some of the barrier concepts described in publications. For example, while 'Age' could be applied as a straightforward description for a barrier, the term 'Health literacy' was applied to a number of terms, including "Patient comprehension of medical terminology and health-related information…" (Urowitz et al., 2012), and 'Lack of motivation' was assigned to

descriptions such as "Participants did not perceive the PHR as having added value for managing their existing self-care behaviors..." (Fuji, Abbott, & Galt, 2014)

The analysis identified 21 distinct barriers, which are listed by barrier category in Table 2. Age, sex and race or ethnicity are innate characteristics of an individual user, not amenable to change, and were grouped together as Individual factors. Income, socioeconomic status, level of education and Internet and computer access were categorised as Demographic factors related to an individual's circumstances. Functional or text literacy, numeracy, health literacy, and technical literacy and skills were categorised as Capability factors. Health related factors included the individual's health and wellbeing, including the presence of a chronic disease, disability generally, and specific physical, cognitive or visual limitations. Barriers associated with the usability of a PHR, the costs associated with access or lack of information about the PHR were categorised as PHR factors. The remaining barriers – discomfort with computer use, concerns about privacy security and confidentiality, and lack of motivation were grouped as Attitudinal factors.

Primary outcome: PHR barriers

Most barriers were identified in most phases of PHR implementation, and in most types of study. The number of references to each barrier by phase of PHR implementation and type of study are shown in Table 2, together with the number of publications in which each barrier was identified; barriers which are likely to be associated with socioeconomic disadvantage are flagged. It should be noted that failure to identify a barrier within a particular publication does not provide evidence that the barrier was absent in the population studied, merely that it was not identified. Also note that some of the publications report multiple phases or investigation types, and totals by Type and Phase for some barriers may exceed the number of occurrences.

Table 6: PHR barriers by implementation phase and investigation type

	Implementation phase							Investigation type				Literature review	Number of occurrences
	1.1	1.2	1.3	2	3	4	5	A	B	C	D		
Individual factors													
Age	4	4		1	4	3		8	3	2	1	2	16
Sex		3	2	1					3	1			6
Race/ethnicity[a]				2	3	4		5	4			2	11
Demographic factors													
Income, socioeconomic status[a]	4	3			2	2		3	3	2		2	11
Education	4	2		1	1	1		4	1	1		3	10
Internet and computer access[a]	3	3		3	2	2		8	1	2	1	4	15
Capability factors													
Text literacy[a]			1			1		1		1		2	4
Numeracy[a]					1			1				1	2
Health literacy[a]	2	2				2	1	4	1	1		3	10
Technical literacy, skills[a]	4	4	2		2	5		10	1	4	1	5	19
Health related factors													
Health, chronic disease[a]	1	2		1	2	4		6	2	2	1	1	11
Disability (general)[a]	1			1					1				2
Physical disability[a]		1	1			1		2				1	3
Cognitive disability[a]		1	2		1	2		5		1		1	6
Visual disability[a]	1	1	1			1		3					3
PHR factors													
Usability		2	1			1		2		1		1	4
Cost	2	1	1					2		1		1	4
Lack of information		1	1	2				3					3
Attitudinal factors													
Discomfort with computer use	2		1		1	2		5		1	1	2	7
Privacy concerns	3	3	1	1				4	3				7
Lack of motivation	1	2		2		2		4	1	1		1	7

[a] Barrier associated with socioeconomic disadvantage

Key: Implementation phase

1.1   PHR readiness - use of technology

1.2   PHR readiness - usage intentions.

1.3   PHR readiness - participation in design of PHRs,

2   Initial registration

3   Initial use

4   Continued use

5   PHR benefits

Key: Investigation type:

A   Collection of data from PHR users, or non-participants

B   An observational study using demographic data and records of users and non-users;

C   Attitudes and opinions of patients about barriers

D   Observations by health professionals.

Individual characteristics

The characteristics of each barrier, and salient details of the evidence are outlined below.

Age

A total of 15 of the included studies and two literature reviews identified patient age as a barrier which has an impact on the adoption and continued use of PHRs. However, the effect was not clearly delineated. A literature review by Or and Karsh (2009) noted that "[a]ge was examined in 39 studies and did not show a consistent effect. Among those 39 studies, 26 (67%) found significant relationships and 13 did not. Among the 26 studies with significant relationships, only one showed that higher age was associated with increased acceptance, 19 found that age was negatively associated with acceptance, and six found a nonlinear relationship." (Or & Karsh, 2009, p. 553) It is likely that age has a variable impact on ability, usage intention and the motivation to continue using a PHR after enrolment. Internet use was more common for younger patients, with use declining with increasing age (Kruse et al., 2012) and PHR 'innovators' were younger than other other users and 'non-adopters' (Emani et al., 2012), with older patient less likely to enrol for a PHR (Goel, Brown, Williams, Hasnain-Wynia, et al., 2011), although one study found that, once receiving a password, older patients were more likely to log on to the system (Sarkar et al., 2011) .

Sex

The sex of participants was noted as a barrier in statistical analyses, but the effect was generally modest, and inconsistent between publications. Studies found that found that men were more likely to find computer use enjoyable and be confident about using the Internet and online PHR (Logue & Effken, 2012), more likely to go online (Cho et al., 2010), and more likely to be higher users of PHRs, and more engaged (Chrischilles et al., 2014). However, one study found that women were 15% more likely to adopt a PHR (OR 1.15, CI 1.08-1.21) (Yamin et al., 2011).

Race and ethnicity

Race and ethnicity were identified as a barrier in nine studies and two literature reviews, either inhibiting the adoption of a PHR (Emani et al., 2012; Goel, Brown, Williams, Hasnain-Wynia, et al., 2011; Kim et al., 2009; Roblin et al., 2009), or making its continued use less likely (Byczkowski, Munafo, & Britto, 2011; Sarkar et al., 2011; Yamin et al., 2011). Publications did not always clarify the extent to which this tendency was associated with related barriers such as education, income and socioeconomic status, literacy or computer and Internet access.

Demographic factors

Income, socioeconomic status

PHR barriers for those with lower income and lower socioeconomic status were identified in nine studies and two literature reviews. PHR adoption was less likely in groups with lower socioeconomic status (Yamin et al., 2011) and those without private health insurance (Byczkowski et al., 2011), although for those who did adopt a PHR, level of income did not appear to affect the degree of use (Yamin et al., 2011).

Level of education

Level of education was identified as a barrier in seven studies and three literature reviews, associated with both computer and Internet access and use (Kruse et al., 2012) and with the adoption and use of a PHR (Emani et al., 2012; Roblin et al., 2009), although the association with continued use of a PHR following enrolment appeared less pronounced (Sarkar et al., 2011).

Internet and computer access

Lack of Internet and computer access were identified as barriers in 11 studies and four literature reviews. Problems with access did not appear to have a marked effect on PHR usage intention (Goel, Brown, Williams, Cooper, et al., 2011), although they did affect actual use of a PHR (Kruse et al., 2012; Lober et al., 2006; Luque et al., 2013; Nijland et al., 2011).

Capabilities

Text literacy/functional literacy

Only two studies and two literature reviews specifically identified low levels of text literacy or functional literacy as a barrier to the use of a PHR, with functional literacy identified as a potential barrier by a focus group discussion (Gordon et al., 2012). This limited evidence was despite the obvious limitation that an inability to read would impose on a potential PHR user.

Numeracy

Numeracy was identified as barrier in only one study, and in one literature review. The study authors found that poor numeracy skills accounted for 4-5% of users' failures with overall task performance and the performance of complex tasks in a simulated PHR (Taha, Czaja, Sharit, & Morrow, 2013). It should be remembered, however, that an element of numeracy is often included as a contributor to overall health literacy.

Health literacy

Low health literacy was identified as a barrier in seven studies and three literature reviews, and was noted as having an impact on both adoption (Noblin, Wan, & Fottler, 2012; Sarkar et al., 2011) and continued use (Kim et al., 2009; Lober et al., 2006). Greenhalgh (2010) found that many subjects who described their attitude to portal use as "...'not bothered' or 'don't care'..." were also judged by the researchers to have low levels of health literacy.

Technical literacy and skills

A lack of technical literacy and computer or Internet skills were the most frequently identified barrier, with 19 publications identifying this as a barrier to either technology use (Olshansky et al., 2012) or the use of a PHR (Butler et al., 2013; Hilton et al., 2012; Lober et al., 2006; Luque et al., 2013; Nijland et al., 2011; Roblin et al., 2009). Early adopters of a PHR were significantly more likely to self-report being 'comfortable' or 'very comfortable' with Internet use (Butler et al., 2013) while those with rudimentary computer skills showed little improvement in PHR use over time (Hilton et al., 2012).

Health related

Health, Chronic disease

Data from ten studies and one literature review identified a complex relationship between health and both Internet use and PHR adoption and use. Those whose self-reported health status was excellent or very good were more likely to be Internet users (Kruse et al., 2012), while patients with poorer health overall were less likely to adopt a PHR (Emani et al., 2012). However, those with multiple comorbidities were identified as being more likely to adopt a PHR (Emani et al., 2012; Roblin et al., 2009) or expressed willingness to choose a healthcare provider based on the provider's use of information from their PHR (Logue & Effken, 2012).

Disability

Disability can create practical barriers to the use of information technology, including PHRs (Angaran, 2011). Two publications identified disability as a generic barrier to PHR use; physical impairment was identified in two studies and one literature review; cognitive impairment in five studies and one literature review; and visual impairment in three studies. Physical, visual and cognitive impairment have all been identified as barriers to successful use of a PHR (Kim et al., 2009; Lober et al., 2006), although design adaptations may help to reduce the severity of those barriers (Atreja et al., 2005).

PHR factors

Usability

Three studies and one literature review identified usability as a barrier to successful adoption and use of a PHR by patients. One study which looked for specific barriers affecting patients with multiple sclerosis (Atreja et al., 2005) found that issues such as a cluttered display, small font size, and poor contrast created barriers while another (Fuji et al., 2014) reported patient difficulties with navigation between pages and repeated clicking during data entry.

Cost

Three studies and one literature review identified costs to users as a barrier for PHRs, with patients reporting that they could not afford the cost of a computer and a broadband Internet connection (Kruse et al., 2012; Luque et al., 2013).

Lack of information

Three studies identified that a lack of information about the availability of a particular PHR (Mishuris et al., 2014), or accessibility of information about options within a PHR (Atreja et al., 2005) could interfere with use.

Attitudinal factors

Discomfort with computer use

Five studies and two literature reviews identified some form of discomfort with the use of a computer (Kruse et al., 2012) as a barrier to the adoption and use of a PHR. This barrier was also described as a lack of confidence and fear of failure (McInnes et al., 2013), and as 'computer anxiety' (Kim et al., 2009; Lober et al., 2006).

Privacy and confidentiality concerns

Patient concerns about privacy or confidentiality of personal health information stored in a PHR were reported in 7 studies (J. G. Anderson, 2004; McCleary-Jones et al., 2013). In some cases these

concerns were specifically related to the need to access a PHR from a public or shared computer (Luque et al., 2013; Mishuris et al., 2014).

Lack of motivation

Three studies and one literature review provided evidence that a lack of motivation could be a barrier to the use of a PHR. Potential users did not see the PHR as providing added value (Fuji et al., 2014; Mishuris et al., 2014) or thought that using a PHR would take up too much time (Fuji et al., 2014; Nijland et al., 2011).

Secondary outcome: Selection bias

Eleven of the publications which identified PHR barriers introduced a bias by using a data collection methodology which could exclude participants who were less affluent, less capable, or marginalised. Those methodological choices fell into four broad categories, with one publication (McCleary-Jones et al., 2013) including more than one type of bias.

A focus on those already using technology

In five publications participation was restricted to subjects who already had experience using a web browser (Lin et al., 2005; Nijland et al., 2011), had an existing portal account (Byczkowski et al., 2011), who had received training in the use of a PHR (Fuji et al., 2014), or who were required to complete web based surveys during the study (Hilton et al., 2012). These studies did not report barriers related to Capability factors, or to disability.

Exclusion of participants with serious illness or infirmity

In two publications subjects were excluded if they were prevented from participating in an interview as a result of a serious comorbidity (Atreja et al., 2005) or if obvious cognitive deficits were observed (McCleary-Jones et al., 2013). These studies did not report any barriers associated with Individual or Demographic factors, and only health literacy was identified as a Capability factor.

Excluding participants on the basis of language and literacy

Selection of participants for these four studies (Kruse et al., 2012; Logue & Effken, 2012; McCleary-Jones et al., 2013; Patel et al., 2012) required them to be able to speak, read or write English. These studies identified a wide range of barriers in all categories (11 in all).

Selection of subjects from within a population less likely to be disadvantaged

In these three publications data collection was restricted to participants with a landline telephone (J. G. Anderson, 2004), to university undergraduates in schools of business and information systems (Whetstone & Goldsmith, 2009), or to members of a community less likely to be disadvantaged. (McCleary-Jones et al., 2013) Health literacy and privacy concerns were the only barriers to PHR adoption and use identified in these studies.

Identification of these potential sources of bias is not intended as a criticism of the studies, or of the authors. However, bias within a methodology may mean that any evaluation of barriers within publications (such as that provided by this review) is likely to underestimate the prevalence and significance of barriers, particularly if those barriers are related to exclusion criteria used in the selection of participants.

Discussion

Barriers

This literature review has identified evidence for 21 barriers, categorised as Individual, Demographic, Capability, Health related, PHR related and Attitudinal factors, which could interfere with or prevent a patient's adoption or continued use of a personal health record. The evidence is consistent, with 12 of the barriers being identified in six or more publications. However, the frequency with which a particular barrier is identified provides little indication of that barrier's significance. The low incidence (four publications or fewer) of reports identifying text literacy, numeracy, generalised disability, and physical and visual impairment as barriers is more likely to result from re-

search bias and the relative invisibility of disadvantaged participants than from the insignificance of these barriers.

The complex interrelationship which exists between many of the barriers is suggested in some publications, and emerges more clearly from this review. Socioeconomic status and educational attainment are closely related, and associated with text, technical and health literacy, and with numeracy; Internet and computer access, computer skills and discomfort with the use of a computer are closely intertwined; and lastly PHR usability is likely to have a greater impact on users with lower capabilities, and PHR costs will be more challenging for poorer patients. Furthermore, socioeconomic disadvantage is likely to be statistically more prevalent among older citizens, and within non-Caucasian communities. The review identified predominantly US data, including specific issues for elderly, African American, and Latino communities.

Barriers by type of investigation

The evidence about barriers to PHR adoption and use varies with the types of investigation (coded in Table 2 as A, B, C and D). Firstly, data collected from patients themselves provides direct evidence about actual barriers which they face in adopting and continuing to use a PHR, although there may be a tendency for self-reports to underestimate the importance of barriers such as socioeconomic status, text literacy, health literacy and numeracy, which can carry a social stigma.

Secondly, observational studies using PHR usage logs and health administrative data for PHR users and non-users can provide evidence about barriers, but only from the data items which are included in those records. In many cases socioeconomic status, text and health literacy or computer and Internet use are not recorded although an area measure of socioeconomic status can be imputed from the patient's home address.

Next, attitudes and opinions of patients about PHR benefits and barriers, and usage intention can be instructive, although there may be a gap between stated intention and future actions. Observa-

tions by health professionals about barriers to patient use of PHRs may also be instructive, although these could be based on assumptions rather than data.

Lastly, literature reviews provide a summation and interpretation of publications about PHRs, including barriers which might interfere with adoption; the reference sources included in these reviews are likely to fall within one of the categories described above. The evidence provided by the review is shaped by the evidence being reviewed, with some moderation as a result of the authors' analysis and expertise.

Barriers by phase of implementation

Evidence about PHR barriers also varies by the phase of implementation being investigated (coded in Table 2 as 1.1-1.3, 2, 3, 4, and 5). In Phases 1 and 2 (pre-adoption and initial registration) evidence about barriers is most likely to be about usage intention. Evidence suggests a gap between usage intention and actual PHR use. Disadvantaged and low capability users may see use of a PHR as beneficial, but may overestimate their own capabilities, and underestimate the challenges involved in using a PHR; individuals may lack full awareness of the extent of their limitations, or see those limitations as a making PHR use more difficult.

In Phase 3 (early use) enthusiasm about first use may revert to a lack of interest once the reality of PHR use becomes apparent; evidence about barriers from evaluations of registration and first use are likely to provide an indication of those barriers which might interfere with the decision to use a PHR.

Barriers identified in Phase 4 (continued use) provide insight into the constraints which are likely to interfere with long term use. Depending on the particular PHR, maintaining regular use could be difficult, although moderated by the skills and capabilities of the user. Continued interest in PHR use is likely to be influenced by a perception of healthcare need, and how that need is met by the PHR, relative to other care that they receive. Barriers may also be context-sensitive, and influenced

by PHR usability and user capabilities. PHRs need to be suitable for all users; testing with volunteers with good text-, technical-, and health literacy may overestimate the suitability of the PHR for a broader population.

Bias

A number of the included studies chose participants in a way that might result in a lower proportion of disadvantaged and low-capability users, compared with the initial population, resulting in a probable underestimate of PHR barriers. Some degree of bias may be unavoidable. Acquiring evidence about PHRs, including evidence about barriers, must rely on subjects who are able to participate: studies of PHR usage must rely on PHR users, participants must read a written questionnaire in order to respond, and it can be difficult to ethically engage research subjects with cognitive limitations. On the other hand, PHRs are intended for users who are unwell, not just healthy, educated, well-off patients. Note that one study (Zarcadoolas et al., 2013) (not included in the evaluation of bias) deliberately introduced an inverse bias by seeking out participants with a low socioeconomic status.

Limitations:

This review has produced a biased evaluation of PHR barriers. Selecting publications in English has given an Anglophone, US-centric account of PHR barriers, from a restricted range of study sites, with little information from other countries. There may also be a publication bias: many of the publications from the US are from large (and possibly well resourced) healthcare organisations and academic institutions able to provide early support for PHR users; results for PHR implementations in smaller, less well resourced settings might report barriers differently.

Conclusions:

Principal findings

This review has found evidence of a range of barriers which interfere with the adoption and continued use of PHRs, with 155 instances of 21 distinct barriers identified across 40 publications.

This evidence was found in all types of investigation, and in all phases of PHR adoption. Further research may find other as yet unidentified barriers, as well as variants of barriers identified in this review. A close relationship is evident between socioeconomic status and other barriers, with 12 of the 21 barriers being associated with socioeconomic disadvantage. This confirms that the use of a PHR is likely to be harder for disadvantaged patients; PHRs as they are currently implemented may not provide a universal solution for problems with healthcare delivery or communication. The relative importance of a PHR barrier cannot easily be deduced from the number of appearances within the research literature. Rather, there is an obligation during PHR design, and during PHR implementation, to make a careful assessment of the likelihood of each barrier being present within the population being considered as users.

In the US, the meaningful use compliance criterion for Stage 2 which requires that 5% of patients access their record ("Patient Electronic Access Tipsheet," 2014) is more likely to measure record access by competent PHR 'early adopters' than by disadvantaged users. Despite the problem of a growing 'ehealth divide' (Cummings et al., 2008) this criterion as currently defined provides little impetus for health professionals or hospitals to encourage PHR enrolments among disadvantaged patients.

Future research priorities

While this review has identified a broad range of PHR barriers, there was insufficient consistency across multiple studies to provide a comprehensive picture of the effect of barriers during PHR implementation and use.

If those barriers affecting the population of potential users are to be addressed early in the process of design and implementation, there is a need for better identification and characterisation of both barriers and users. As Kushniruk and Turner have observed, "...greater consideration of who the user is and how the user is involved and their inputs mediated needs to be further articulated. To address these issues it is useful to try to be more precise about who the users are, when and where

they are engaged, what expectations we have about our users and why." (Kushniruk & Turner, 2011). Developing a better understanding of the impact of barriers on PHR users will help to ensure that resources allocated to PHR systems are used most effectively.

There is also a need for a better appreciation of how barriers affect PHR adoption and use, and how that that effect can be countered. Simply being aware of the possibility that a particular barrier may inhibit PHR use for some patients should be enough to ensure that this barrier is taken into account during PHR design and implementation. However, the apparent bias evident in a number of the studies suggests that the existence and significance of barriers is not universally recognised, and that further research in order to provide stronger evidence may be warranted.

Finally, the results of this literature review raise a number of interesting questions which may suggest possibilities for future research:

- What does a PHR designed specifically for 'low functional literacy' users look like?
- What assistive options within a PHR could help to reduce the negative impact of poor health literacy?
- How can attention to PHR design minimise the impact of cognitive limitations for older patients?

The response to these question may help to identify a path towards PHRs designed for specific groups of disadvantaged patients, or with an interface sufficiently simple, and adaptable to meet the needs of all users.

Funding

Acknowledgements

8.3 Commentary

This review of the literature has identified 21 distinct barriers which could limit the ability of individuals to adopt or continue to use a PHR; 15 of those barriers are identified in the publication as having an association with socioeconomic disadvantage.

The review did not identify any publications providing a detailed evaluation of PHR barriers, or identifying the number or variety of barriers found by this review. Neither were there any publications found which specifically focused on barriers for disadvantaged individuals.

Chapter 9: Who will benefit most from a personal electronic health record?

> "Demographics is destiny"
>
> — Arthur Kemp

> "Have the courage to be ignorant of a great number of things, in order to avoid the calamity of being ignorant of everything."
>
> Sydney Smith

9.1 Preface

As noted in Chapter 7, this publication, whose full title is *Who will benefit most from a personal electronic health record? Analysing Tasmanian data about disadvantage, public hospital use and barriers to the adoption and use of personal health records*), is currently in review. It summarises the key findings of the data analysis which was undertaken in order to provide empirical evidence of the association between socioeconomic disadvantage, public hospital use and proxy measures for barriers to the use of personal electronic health records. The investigation was conducted in order to address the additional research question:

RQ2b   Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

Because of publisher-imposed word limits for publications, some of the complex decisions about data preparation and analysis, and the justifications for those decisions, are either missing from this publication or described in summary form. Section 9.2 provides more detail about the preparation

of data for analysis, with further details included in Appendix 2. A more comprehensive report of the results of this analysis is included in Appendix 5.

9.2 Preamble

This section provides additional details of the preliminary processing of DHHS data, including data evaluation and record filtering, and the calculation of the Index of Concentration at the Extremes for census data used as proxies for PHR barriers. More details are provided in Appendix 2.

Calculating ICE scores

Massey's Index of Concentration at the Extremes (ICE) (Massey, 2001) was used to derive a single measure for each SA2 region for years of education, qualifications, household income, and internet access. ICE scores were structured in a manner comparable to SEIFA indexes, with a higher ICE score identifying an SA2 which is relatively better off (more privileged).

For education, the number of individuals aged 15 or over was used as the denominator; the numerator counted those in the 'Year 8 or below' and 'Did not go to school' groups as "disadvantaged", and those who completed Year 12 as "privileged". For qualifications, the denominator was calculated as the total number of individuals 20 years and over, with 'Level of education inadequately described', 'Level of education not stated', and 'Not applicable' as "disadvantaged", and those with an Associate Degree or higher qualification as "privileged". For Internet access, the number of dwellings was used as the denominator, with those having no Internet access classed as "disadvantaged", and those with broadband Internet access as "privileged".

Allocating SA2 codes to records

Relevant Statistical Area Level 2 (SA2) codes were assigned to each patient record, based on post code and suburb, using a manually derived reference list including each of the 12,863 unique combinations within the data and their associated SA2 codes. Variant spellings within the data were not corrected; instead, an reference entry was created for each mis-spelled suburb.

Data evaluation and filtering

Data received from DHHS included three files, for admitted care separations (887,992 records, 413 MB), ICD and DRG coding (893,431 records, 232.2 MB) and emergency department (1,593,515 records, 547.6 MB).

Records were filtered to remove a number of anomalies which were apparent from initial inspection. These included:

- Patients receiving long term residential care who were recorded as hospital patients;
- Records with a hospital discharge date some time after the patient's data of death;
- Invalid or missing address data
- Incomplete records (at the start and end of the collection);
- Care types (such as 'Boarder', 'Nursing Home Type' and 'Social') which were not appropriate for inclusion in the analysis; and
- Normal (well) newborns incorrectly recorded as receiving acute care.

Records for patients receiving regular renal dialysis were removed, and analysed separately.

Emergency department (ED) data for one hospital showed 75,662 attendances for 18,609 individuals over eight years from an SA2 region with a population of only 3,800. There was also a significant variation in the rate of ED attendance between hospitals, from 3,418 per 1,000 in the North West to 1,465 per 1,000 in the South, with far fewer patients in the North West assigned to triage categories 1, 2 and 3. These anomalies led to a decision to conduct separate analyses of ED activity in the South and North, and to not further examine ED activity in the North West. Analysis of attendance data for each ED focused on patients from that ED's 'catchment' SA2s – those where more than 90% of the attendances were to that particular ED.

All data analysis reported in the publication was conducted on summaries of data at the level of an SA2. Additional analyses used data summarised to the level of an individual patient, using the

proxy patient identifier provided by DHHS. However, these analyses showed a high degree of skew and kurtosis, making the data unsuitable for cluster analysis.

9.3 Paper as submitted (in review)

Publication details

Abstract

Objective

Personal health records (PHRs) offer benefits for healthcare systems and patients. However, socioeconomically disadvantaged patients face barriers which limit adoption and use, as well as a range of health related problems. This study explores a concern that PHR benefits may not be equitably distributed.

Materials and Methods

This research employs cluster analysis of data about 800,000 inpatient episodes and 1,300,000 emergency department attendances in Tasmania, combined with census data about socioeconomic disadvantage and barriers to the uptake and continued use of personal health records.

Results

The results identify a cluster of neighbourhoods with significant levels of socioeconomic disadvantage, significant public hospital use, and proxy measures suggesting barriers to PHR use. This cluster was also apparent in maps of neighbourhood.

Discussion

The results (about neighbourhoods, not individuals) suggest that disadvantaged communities make greater use of public hospitals, face barriers to the adoption and use of PHRs and are thus less likely to benefit. The literature on personal health records is relatively silent about the particular needs of disadvantaged patients, who seem to have acquired a degree of invisibility. These results suggest a need for more detailed research into how PHR implementations can engage disadvantaged patients, and how PHR supported healthcare can meet the needs of low capability users.

Conclusion

If PHRs provide fewer benefits than was expected for profoundly disadvantaged patients, alleviation of pressure on publicly funded hospital services will be less than if benefits were more equitably distributed, and the eHealth divide is unlikely to diminish.

Background and significance

The burden of ill health and diminished wellbeing tends to fall disproportionately on those at a socioeconomic disadvantage. The adverse impacts of disadvantage include worse access to healthcare (Adler & Newman, 2002; Tudor Hart, 1971), reduced life expectancy (Olshansky et al., 2012; Rowlingson, 2011), and earlier onset of multimorbidity (the presence of multiple chronic conditions) (Barnett et al., 2012), which has been identified as a significant contributor to worse quality of life and increased healthcare costs (Kuo & Lai, 2013; Marengoni et al., 2011).

Informaticians in much of the developed world are working to develop and implement personal electronic health records (PHRs). These may be tethered to or integrated with a provider's electronic health record system or operate independently, and may import or integrate records from other systems (Detmer et al., 2008). A range of benefits have been identified for PHRs, both from the providers' perspective (improvements in resource use (NEHTA, 2011), population health (Horan et al., 2010), record accuracy (Pagliari et al., 2007)) and for patients (better communication with providers, more active participation in care (Tang et al., 2006)). The healthcare recipients who

are expected to derive benefits in the latter category are typically described in homogeneous terms "individuals and society" (Detmer et al., 2008), "patients" (Tang et al., 2006), "for all" (Pearce & Bainbridge, 2014) with no recognition of disadvantage.

Concerns have been expressed previously that personal health records tend to involve some degree of exclusion for ordinary citizens, through the use of expert language (Showell et al., 2010), and through a restrictive approach to the development of ehealth policy (Showell, 2011). Of even greater concern is the exclusion of patients at a socioeconomic disadvantage, who experience an ehealth divide (Lustria et al., 2011), face barriers to the uptake and continued use of personal electronic health records (PHR barriers), and may obtain fewer of the associated health benefits (Showell & Turner, 2013a, 2013b) .

Recent reports such as that by Pearce and Bainbridge in this journal (Pearce & Bainbridge, 2014) describing progress with Australia's personally controlled electronic health record (PCEHR) have done little to allay these concerns. Although the authors refer to 'extensive consultation with consumers' as part of the system development (Pearce & Bainbridge, 2014, p. e1), it appears that most of the consultations have been with stakeholder organisations, with little evidence of direct involvement of citizens or patients, and no explicit focus on the needs of disadvantaged users.

Successful implementations of personal health record systems must address barriers to effective and continued use, for organisations (Tang et al., 2006), for healthcare providers (Witry, Doucette, Daly, Levy, & Chrischilles, 2010), and for patients (Kim et al., 2009; Lober et al., 2006; Yamin et al., 2011). Most barriers for patient users are related to usage intention (attitudes, expectations, incentives), to demographic characteristics (such as age, gender, race/ethnicity, income or disability) or to capability factors (knowledge and skills, text literacy, technical literacy and health literacy); limited access to the Internet and to a computer may also act as barriers (Logue & Effken, 2012). This research focuses specifically on capability barriers for patients, and in particular the low levels

of text, technical and health literacy (J. S. Kahn et al., 2009; Lober et al., 2006) which may be associated with socioeconomic disadvantage.

It should be noted that research into patient use of health related information technology may actively exclude subjects who are unable to read English (Kruse et al., 2012; Patel et al., 2012; Zarcadoolas et al., 2013) or who are unable to use a computer (Chrischilles et al., 2014; Fuji et al., 2014; Nijland et al., 2011). As a result, the literature probably underestimates the significance of capability barriers associated with disadvantage.

Objective

The concerns that disadvantaged patients are less likely to benefit from PHRs are based on deductive analysis of relevant literature, rather than evidence, and a possibility remains that individuals with low socioeconomic status facing PHR barriers do not constitute a recognisable group. The objective of this research was to explore this general problem using empirical analysis of data in a Tasmanian setting, to determine whether an identifiable association exists between disadvantage, healthcare use, and higher barriers to the adoption and use of personal electronic health records.

A number of analytical approaches were considered. A direct evaluation of PHR uptake and use was deemed unlikely to be helpful; implementation of Australia's PCEHR is still in its early stages, and Rogers' 'early adopters' (Rogers, 1983, p. 246, p246) are likely to be over-represented amongst current users. Studying disadvantaged patients who were in a position to use a PHR, but had not taken up the option would be difficult, since these subjects might be difficult to identify or to engage. The third option considered, and the one that was pursued, was to analyse episode level data about use of public hospital services alongside area level data about disadvantage and PHR barriers, at the lowest available level of granularity.

Materials and Methods

The research strategy involved accessing and analysing census data and hospital records using cluster analysis techniques to produce relevant clusters, with choropleth maps used for visualisation. The hospital data included deidentified records for all inpatient episodes and emergency department attendances in Tasmania (2011 population 495,354; area 68,401 sq km) over an eight year period. This was combined with census data about socioeconomic disadvantage. Census data about years of schooling, Internet use and post secondary qualification were used as proxy measures for text, technical and health literacy, factors identified as barriers to the uptake and continued use of personal health records. Cluster analysis can be used to test a developed theory, to develop an understanding of the underlying data, or to explore a data set to highlight interesting features within in it; in this case it was used to gain an understanding of the data.

The Tasmanian Department of Health and Human Services (DHHS), which delivers health services at four major public hospitals and 18 smaller facilities, provided deidentified administrative records for some 800,000 inpatient admitted care episodes (including dialysis) from 1 July 2006 to 30 June 2013, and around 1,300,000 attendances at emergency departments (located in the four major hospitals) from 1 January 2005 to 30 October 2013. Inpatient records included procedure and diagnosis codes from the International Classification of Diseases – Australian Modification, version 6 (ICD10), and an assigned category from the Australian Refined Diagnosis Related Group version 6.0 (DRG).

The 'sample size effect' means that analysis of area data at a lower level of detail (summarising data for larger areas) underestimates the degree of variation within a population. In order to minimise this effect, data about disadvantage and PHR barriers was sought for relatively small geographic areas, limiting the range of data sources which were available for the study. The lowest level of aggregation for which the Australian Bureau of Statistics (ABS) data is published is for 2,214 level 2 Statistical Areas (SA2s), which are designed to represent neighbourhoods (suburbs and

localities) with around 10,000 residents (range 2,000 to 25,000). Tasmania includes 99 SA2s (including three with no population, and two with no geographic location).

ABS collects census data from all Australian households every five years, most recently in 2011. ABS uses this data to derive relative measures of socio-economic advantage and disadvantage (Socio-Economic Indexes for Areas – SEIFAs) (Australian Bureau of Statistics, 2013a, p. 1). Three of the SEIFAs for 2011 were used in this study: the *Index of Relative Socio-economic Advantage and Disadvantage* (IRSAD) which measures relative disadvantage and advantage, the *Index of Education and Occupation* (IEO) which aggregates indicators of the skills and qualifications associated with different occupations, and the *Index of Economic Resources* (IER), an indicator of income and wealth (Australian Bureau of Statistics, 2013b).

This study examined three capability related PHR barriers – text, technical and health literacy. In Australia, measures for these parameters are only published for states or major regions; as an alternative census data on education, Internet access and qualifications were used as proxy measures. Proxies provide a less direct assessment of PHR barriers, but give a more granular indicator for those barriers within a population.

Because data for potential proxies are reported in multiple categories, rather than as a single measure, Massey's 'Index of Concentration at the Extremes' (ICE) (Massey, 2001), which calculates a measure of a neighbourhood's position along a continuum between privilege and disadvantage, was used as a comparator. ICE is calculated as:

$$ICE_i = \frac{P_i - D_i}{T_i}$$

where P¡ is the number of cases in the privileged group, D¡ is the number of cases in the disadvantaged group, and T¡ is the total number of cases in the neighbourhood. Values for ICE can range from +1.0 (an all-privileged neighbourhood) to −1.0 (all disadvantaged); an ICE value of 0.0 indicates a balance between privilege and disadvantage. Note that for the proxy measures described below, lower ICE values indicate greater barriers.

Text literacy is related to years of schooling; the ABS reports "adequate or better" literacy for 71% completing year 12, 56% completing year 11, and only 10% of those finishing school at year 8 or below (Australian Bureau of Statistics, 2008, p. 2). Based on these observations level of education was used as a proxy for text literacy. ICE for Education was calculated from the number of those completing Year 12 (as privileged) and those finishing school at Year 8 or below (disadvantaged) with the population aged 15 or over as the denominator.

Technical literacy is seen to reflect "...a capacity to understand the broader technological world rather than an ability to work with specific pieces of it" (Pearson & Young, 2002, p. 21), and the pervasive nature of the Internet establishes some degree of association between home Internet use and technical literacy (Howard, Busch, & Sheets, 2010; Miller & West, 2009), although the relationship has not been widely studied. For the purposes of this analysis, Internet connections to households were used as a proxy for technical literacy, while also reflecting PHR barriers related to computer and Internet access. ICE for Internet counted dwellings with broadband Internet access as privileged, those with no Internet access as disadvantaged and used the total number of dwellings as the denominator.

Definitions of health literacy now focus on more than the ability to read health related text. The Australian 2006 Adult Literacy and Life Skills Survey (Australian Bureau of Statistics, 2008) defined health literacy as "...the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy" (ABS, 2008a, p. 5). Data from this

Survey showed a clear relationship between post secondary qualifications and health literacy. Of those with a Bachelor's degree or higher qualification, 3.7% were at Health Literacy Level 1, and 15.4% at Level 4 or 5; for those without non-school qualifications, 29.8% were at level 1, but only 2.9% at Level 4/5. Based on these results, and in the absence of a more accurate measure at SA2 level, post-secondary qualifications were used as a proxy for health literacy. ICE for Qualifications included those with an Associate Degree or higher as privileged, and those with qualifications inadequately described, not stated or not applicable as disadvantaged, and the population 20 years or over as denominator.

Data was processed using R (R Core Team, 2014), geographic shapefiles were edited using QGIS ("QGIS project," n.d.) and maps were produced with TileMill ("TileMill," n.d.). Records were filtered to remove a small number with unusually protracted inpatient episodes or care types suggesting residential and long term care; all records for normal neonates (DRG P67D) were also removed. Haemodialysis episodes (with a DRG of L617) were extracted from the dataset and analysed separately. Details of suburb and post code were used to assign an SA2 code to each record. Anomalies in the data from two hospitals suggested issues with the reliability of location data, and their EDs showed significantly higher attendance rates. For these reasons, data was analysed for individual hospitals, rather than for the state as a whole.

Patients with multiple instances of 19 identified chronic diseases were identified from ICD10 codes (aggregated for all admitted episodes) by applying the method described by Charlson in 1987 (Charlson et al., 1987), and updated to use ICD10 coding (Sundararajan et al., 2004; Thygesen et al., 2011). All assigned ICD10 codes for each patient were aggregated, and processed to flag each chronic disease, and to calculate a total.

Data was summarised by SA2 code, and calculated as rates per 1,000 population. Rates were calculated (over the eight year period studied) for total bed days, total number of episodes, haemodialysis episodes, and dialysis patients for admitted care episodes; total chronic diseases identified and

number of patients with three or more chronic diseases for diagnosis data; and total ED attendances and aggregate time spent in ED for ED attendances. Measures for the number of general practices per 10,000 population and the distance of the SA2's centroid from the hospital were also included in the analysis.

Partitional techniques such as k-means cluster analysis can produce any desired number of clusters, from one (all items clustered together) to the number of items in the study (each item in its own cluster). The k-means algorithm was used with a range of 'seed' values between five and seven; results for clustering around six centres are presented here. Cluster analysis used the *kmeans* function from the R *stats* package; the cluster plot was produced using *vegan.*

Summary measures for each SA2 region were used to produce choropleth maps, with data segmented in similarly sized groups using a 'quantile' method (Brewer & Pickle, 2002), facilitating direct visual comparison. It should be remembered that "…a single map is but one of an indefinitely large number of maps that might be produced for the same situation or from the same data" (Monmonier & Blij, 1996, p. 2, p2).

This research was approved by the Health and Medical Human Research Ethics Committee (Tasmania) Network on 28 February 2013 (Reference Number H0013013).

Results

Data for each hospital was analysed separately, for the reasons noted above. Results of k-means cluster analysis for the largest hospital, which provides services for the largest number of SA2s (42 of 94), are shown graphically in Figure 1.
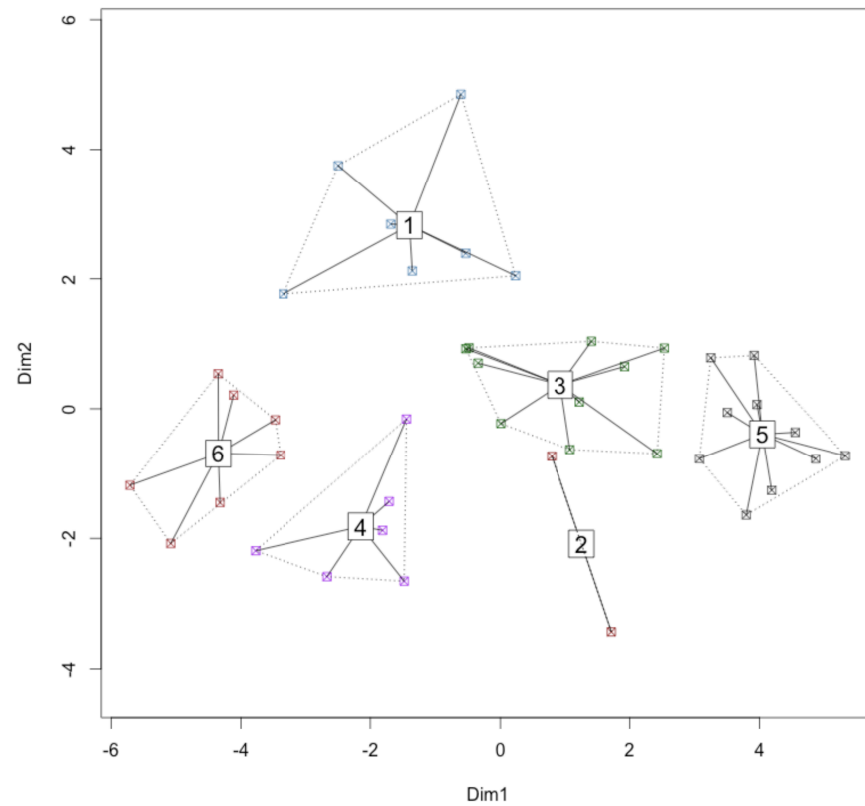
Figure 12: kMeans clusters of SA2s

Figure 1 shows five clearly differentiated groupings of SA2s; a sixth cluster (Cluster 2) combines two SA2s which are poorly matched . Cluster 6 (on the left of the diagram) has the lowest averages for the three SEIFA indexes, and for proxy measures for PHR barriers, and has the highest average rates for inpatient episodes, bed days, chronic diseases and ED visits. These characteristics contrast with Cluster 5 (on the right of the diagram) which has the highest averages for the three SEIFAs, and for proxy measures for PHR barriers, and the lowest average rates for inpatient episodes, bed days, chronic diseases and ED visits. Note that lower PHR barrier proxy values indicate greater barriers. Cluster 1, at the top of the diagram, includes SA2s with centroids further from the hos-

pital (average 63.4 km, range 36.5 − 96.7 km). This cluster has the lowest average rate of dialysis patients, and a longer average time spent in ED.

Cluster averages for each of the measures are shown in Table 7

Table 7: k-Means cluster analysis - average of measures for each cluster

Cluster average of:	Cluster Number:					
	6	4	1	3	2	5
Index of Relative Socio-Economic Advantage and Disadvantage	830	921	912	994	1,020	1,055
Index of Economic Resources	874	921	965	1,015	951	1,025
Index of Education and Occupation	832	939	920	972	1,081	1,092
Index of Concentration at the Extremes for Education	0.19	0.32	0.24	0.35	0.56	0.58
Index of Concentration at the Extremes for Qualifications	-0.45	-0.30	-0.36	-0.24	-0.09	0.00
Index of Concentration at the Extremes for Internet	0.11	0.17	0.15	0.27	0.26	0.33
Distance of SA2 centroid from hospital (km)	14.2	7.5	63.4	21.7	2.7	9.7
General practices per 10,000 population	2.4	2.7	5.7	1.7	14.1	2.5
Admitted episodes per 1,000 population	1,650	1,352	1,279	1,113	1,058	820
Bed days per 1,000 population	5,350	4,675	4,164	3,295	3,747	2,431
Dialysis episodes per 1,000 population	343	511	53	221	358	169
Dialysis patients per 1,000 population	1.1	1.6	0.7	1.0	1.5	0.8
Patients with multiple chronic diseases per 1,000 population	463	392	367	321	305	236
Total chronic diseases per 1,000 population	219	196	164	140	146	97
Emergency Department attendances per 1,000 population	229	196	110	130	186	105
Time spent in Emergency Department per 1,000 population (min)	294	295	325	289	278	263

A map identifying the six clusters in shown in Figure 13.
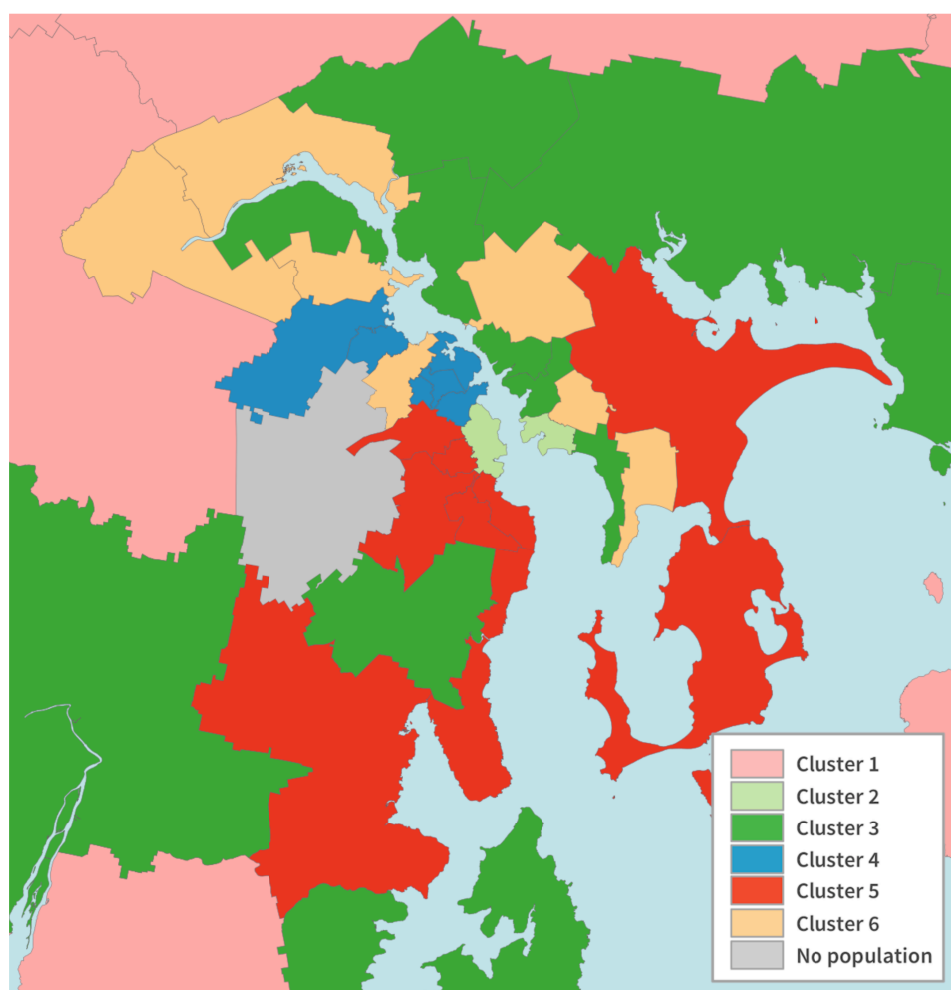
Figure 13: Geographic distribution of SA2 clusters

Choropleth maps of selected measures (IRSAD, ICE for Internet, admitted episodes per 1,000 population, and ED attendances per 1,000) are shown in Figure 14, with values for each measure shown in Table 8.
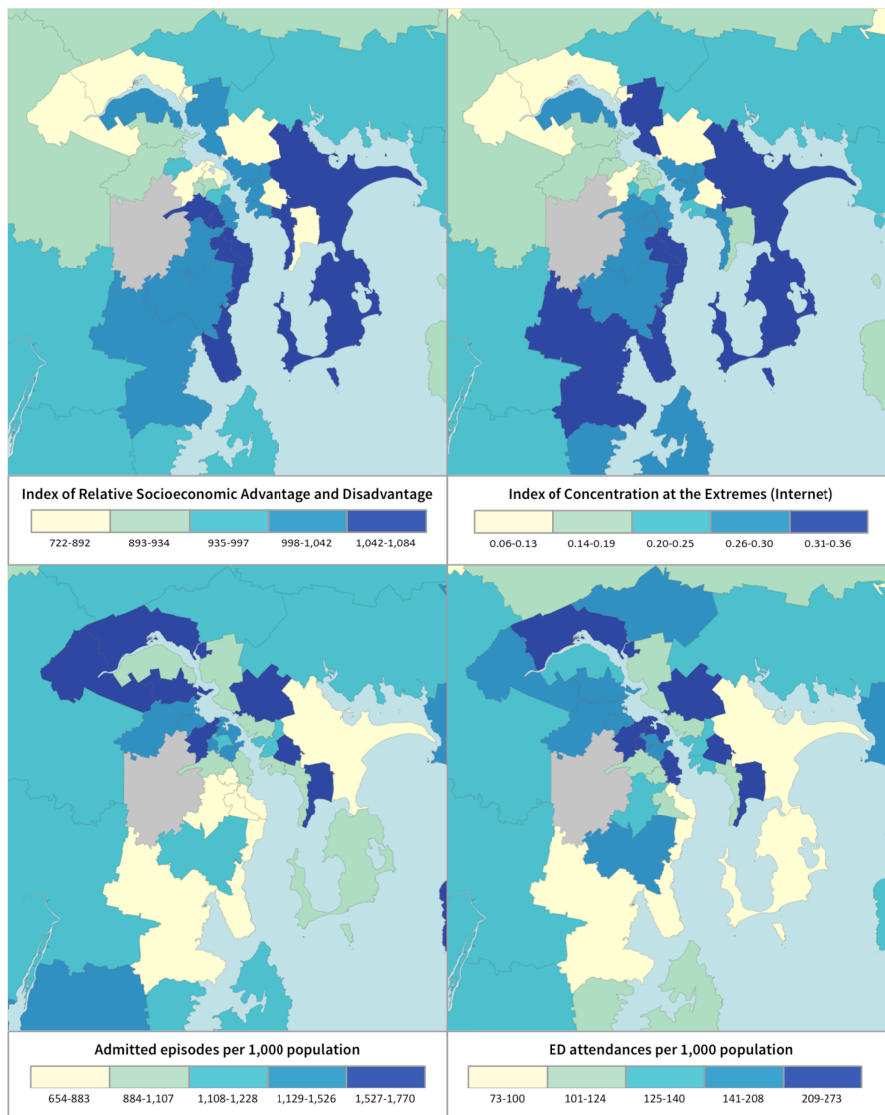
Figure 14: Geographic distribution of selected measures of disadvantage, PHR barriers, and public hospital use.

Table 8: Selected measures for clusters

	Cluster Number:					
Cluster average of:	6	4	1	3	2	5
Index of Relative Socio-Economic Advantage and Disadvantage	830	921	912	994	1,020	1,055
Index of Concentration at the Extremes for Internet	0.11	0.17	0.15	0.27	0.26	0.33
Admitted episodes per 1,000 population	1,650	13,52	1,279	1,113	1,058	820
Emergency Department attendances per 1,000 population	229	196	110	130	186	105

The maps confirm that the areas with low IRSAD and ICE for Internet (lighter shades) display high rates for inpatient episodes and ED attendances (darker shades), while areas with high IRSAD and ICE for Internet display low rates for inpatient episodes and ED attendances. Comparison with the map in Figure 2 confirms the overlap between these extremes and SA2s within Clusters 6 and 5 respectively..

Analysis of data for the other three large hospitals showed similar clustering behaviour but this was less clear cut. This is probably because of the smaller number of SA2 regions, a smaller range of values within measures of disadvantage and PHR barriers, and some misallocation of records between neighbouring SA2s.

Discussion

This research in a Tasmanian setting has identified a distinct cluster of neighbourhoods (SA2s) with measures which indicate significant levels of socioeconomic disadvantage, significant use of public hospital services, and proxy measures suggestive of barriers to the uptake and continued use of PHRs. This identifiable cluster was also apparent in maps of the areas analysed.

Some caution is required in interpreting these results. The use of proxies for PHR barrier factors inevitably gives a less reliable indication than direct measures of barrier factors, although with better granularity. Only public hospital data was analysed, with no allowance made for health services provided by the private sector, or by non-hospital service providers. Nationally, rates of private

health insurance are higher in the most privileged quintile, compared with the least privileged (75% vs 28%) (Australian Bureau of Statistics, 2010), suggesting relatively greater use of private hospitals by neighbourhoods with higher socioeconomic status. However, the absence of a private renal dialysis service means that this analysis includes all dialysis activity in Tasmania. The measures of public hospital service use, socioeconomic status and proxies for PHR barriers relate to SA2 areas, not individuals. In order to avoid the ecological fallacy (Robinson, 1950) interpretation of these results cannot assign characteristics to individuals within SA2s based on these measures; these results identify groups (of neighbourhoods) but say nothing about any individual within a group.

Despite these reservations, the study has used a large collection of patient level data (over an extended period), describing a significant proportion of public hospital activity for the Tasmanian population, with measures of socioeconomic status at the lowest level of detail available for the populations studied, providing a relatively high level of granularity. A careful search of the literature has found no previous analysis of this type comparing hospital activity with socioeconomic status and PHR barrier factors, suggesting that this is a novel approach to the evaluation of PHR barriers and socioeconomic status.

Conclusion

The identification of a cluster of neighbourhoods with significant socioeconomic disadvantage, significant use of hospital services and PHR barriers raises the possibility that, for the population studied studied, the likelihood of PHR adoption, use and differential benefit varies with socioeconomic status.

This raises a question about whether resources allocated to the implementation of PHRs will provide equitable health benefits. If benefits for profoundly disadvantaged patients are less than was expected, any alleviation of pressure on publicly funded hospital services will be more modest than might be the case if health benefits were more equitably distributed across the socioeconomic spectrum, and the eHealth divide is unlikely to diminish.

Although these results are specific to one state in Australia, they may well have wider significance. Relative socioeconomic disadvantage is present in every community and society, and PHR barriers are not specific to Tasmania. However, any generalisation of these results to other countries should recognise the wide variations in national systems of health delivery, as well as differing associations between disadvantage and PHR barriers. These results should not be uncritically applied to other countries without careful consideration of those differences.

The findings suggest two far reaching implications: firstly, that PHRs as they are currently being implemented may accentuate existing inequity and exclusion for some sections of society unless that possibility is actively managed, and secondly, that any integration of PHRs into routine health-care delivery should include appropriate alternatives for low capability disadvantaged patients.

These implications prompt a number of questions:

- Should PHR implementations routinely take note of potential users who are disadvantaged, and of the capability barriers which they face?
- How effective is patient education within a PHR implementation in mitigating barriers to use (bearing on mind that previous educational achievements for the most disadvantaged users may have been modest)?
  - Is there a need for new PHRs (or modifications to existing PHRs) which cater specifically for the needs and abilities of disadvantaged users?
  - Do PHR supported healthcare processes need to be adapted for disadvantaged patients (for example, by having a trusted health professional act as a proxy user)?

There is relative silence in the literature about the particular needs of disadvantaged PHR users, who seem to have acquired a degree of invisibility. Despite advice that "PHR systems in under-served communities need to be explicitly attuned to limited levels of literacy, computer skills, and health information knowledge" (Horan et al., 2010) there is little evidence that this advice is

heeded in practice (Showell & Turner, 2013a), and evaluations of PHRs frequently ignore or avoid capability barriers. Why has it become common practice to ignore or discount disadvantaged users? It seems likely that the distribution of benefits from PHRs will not be equitable – disadvantaged patients will be less likely to take advantage of PHRs.

There is also a wider question, no less important, which this research has not attempted to answer: will widespread efforts to implement PHRs produce benefits for patients commensurate with the resources expended? Or any realistic benefits at all? After 18 months, only 5.1% of Australia's population had registered for the personally controlled electronic health record (PCEHR), and fewer than 1% of those access the system in any week (Royle, Hambleton, & Walduck, 2013); evidence of benefits is yet to emerge.

Further work

Although this study has provided sound evidence, it invites further research in other settings to confirm or refute the relationship between healthcare need, disadvantage and PHR barriers. There is also a need for research (in the context of system evaluations) focused on the uptake and continued use of PHRs by disadvantaged patients. This work should take care to identify and follow up 'non-adopters' and those who initially register, but subsequently abandon PHRs, with particular attention to their demographic characteristics. Evaluation is also needed of the benefits provided by PHRs, particularly in terms of improvements in health outcomes for patients, taking note of the distribution of benefits between different socioeconomic groups.

In an Australian setting, research might include a review of registrants and continued users of the PCEHR, using an SA2-based categorisation similar to that applied in this study, and Medicare data about the utilisation of private health services.

However, the implementation of PHRs will continue while that research is under way. This paper has identified a problem of global significance with implications for continuing investments in

eHealth. and for investments in PHRs in particular. Based on the problem identified here, a continuation of current ehealth investment trends means that the eHealth divide will widen.

9.4 Commentary

Cluster analysis showed two subgroups of SA2s with disadvantaged, low capability users who were higher consumers of public hospital care, in contrast to a privileged capable subgroup using much less care. Choropleth maps of SA2 summary data confirmed the dichotomy between these clusters. Additional results are shown in the Appendix.

9.4.1 Results of SA2 summary analysis

Analysis of the data sets at the level of SA2 region summaries provided clear evidence of an association between measures of socioeconomic status (both SEIFA indexes and ICE scores) and the use of public hospital services. As noted in Chapter 7, the magnitude of any area based discrepancy is likely to increase with increased granularity of measurement. If this association is evident at the level an SA2 region, it is likely to be more pronounced at the level of an SA1, and more so in mesh blocks or even families.

9.4.2 Granularity

The study has been conducted at a reasonably fine level of granularity, and has the capacity to identify trends in small population groups which may be moderated or completely masked in data analyses conducted at a less granular level.

9.4.3 Concerns

The empirical analysis has raised some issues about the level of data available for the analysis, resulting in a number of choices about the design of the empirical research phase.

Given that limited nature of the resources available for data collection and analysis (the researcher's own time, and essentially no funding) the first dichotomy was between the use of a small

data set with intimate details about socioeconomic status and barriers to personal health record use, or a much large data set with a lower level of detail.

Area level measures of socioeconomic status from the Australian Bureau of Statistics provided provided meso-level data about average values for neighbourhoods (SA2 regions), but gave no insight into the status of individuals or families. The same issue applied to measures used to infer the extent of barriers to personal health record uptake and continued use, with the additional complication that use of proxy measures for text literacy, technical literacy and health literacy was likely to attenuate any identifiable effect.

Micro-level data about healthcare utilisation at the level of individual patients, and individual episodes, was available from public hospitals, but was not readily accessible from private hospitals, general practitioners or private medical specialists.

These concerns may serve to dilute the strength of the findings from the empirical analysis. However, the practical challenges inherent in attempting to collect a representative person-level data set about socioeconomic status, healthcare service use and outcomes, and the initial uptake and continued use of personal health records mean that the conduct of more comprehensive research is unlikely.

Chapter 10: Discussion and conclusion

> "Explanations exist: they have existed for all times, for
> there is always an easy solution to every problem — neat,
> plausible and wrong."
>
> — HL Mencken, "Divine Afflatus"

> "Why is this thus? What is the reason for this thusness?"
>
> — Artemus Ward

10.1 Introduction

This concluding chapter begins with a brief summary of the initial Research Question, and the responses to the additional Research Questions which were presented in Chapter 8 (literature review) and Chapter 9 (empirical data analysis). This summary provides a background for the section which follows, a critical reflection on the implications of the overall results, and some personal reflections of the researcher which, while not fully supported by evidence, are guided by experience and intuition (and, without a doubt, personal prejudice). The chapter continues by elaborating the unresolved questions which have arisen from the thesis, and identifies some opportunities for further research which might help to address those questions. The chapter ends with concluding remarks about the thesis overall.

10.2 Summary of research

10.2.1 Research Question 1

The findings of Phase 1 of the research were reviewed in some detail in Section 7.2 on page 118.; this section section provides a brief summation. The thesis started with an expression of concern

about the gap between the promised benefits of technology and the often more limited reality of the benefits which that technology delivers. This generalised concern was seen to have particular relevance to personal health records, particularly for disadvantaged individuals, who may struggle with literacy and the use of technology. It seemed that there was a risk that a lack of skills among those at a socioeconomic disadvantage would inhibit or limit their ability to benefit from the use of a personal health record (PHR). This research set out to explore the extent of those inhibitors and limitations through a critical examination of relevant literature, and to provide evidence addressing the Research Question:

RQ1:   What is the relationship between socioeconomic disadvantage and personal health records?

The background material provided in Chapter 2 reviewed the nature of disadvantage, and highlighted the links between disadvantage and health, as well as the various divides which separate disadvantaged and privileged individuals. Concerns were also raised about the potential invisibility of disadvantaged groups.

Phase 1 of the research used exploratory investigations to develop publications which delineated, tested and validated a number of ideas and concepts related to the research question, and in the process exposed them to critical consideration by peers involved in health informatics research. The publications presented in Chapters 3, 4, 5 and 6 highlighted several aspects of personal electronic health record systems which could limit their usability, and in particular their suitability for those with limited capabilities.

The first publication, *Language Games and Patient-centred eHealth* (Showell et al., 2010), highlighted that the use of the Systematic Nomenclature of Medicine (SNOMED-CT) in personal health record systems could limit their use by those not familiar with specialised medical language, and called for a more flexible approach to the use of terminology within such systems. The second publication,

Citizens, patients and policy: a challenge for Australia's national electronic health record (Showell, 2011), explored the process of developing the policy framework surrounding Australia's Personally Controlled Electronic Health Record (PCEHR). It found little direct engagement of citizens and patients in setting policy directions for PHRs in Australia, with the likely result that the expectations, needs and capabilities of patients were under-represented in the policy and in the design process, which could result in a low level of trust in the system. Taken together, these two publications helped to crystallise concerns about the exclusionary nature of PHRs, even for ordinary citizens, through the use of specialised language, and limited engagement in ehealth policy development.

The next publication, *The PLU problem: are we designing personal ehealth for People Like Us?* (Showell & Turner, 2013b), made the case that personal electronic health records were unlikely to provide significant benefit for those at a socioeconomic disadvantage, and might result in worse care for disadvantaged patients. This paper identified the risk of 'People Like Us" (PLUs) having a narrowed perspective, and introduced the concept of a group within society who are "disempowered, disengaged and disconnected" (DDDs). The final publication from Phase 1, *Personal Health Records are designed for People Like Us* (Showell & Turner, 2013a), used a literature review to determine whether disadvantaged low capability users were considered during the design and implementation of personal electronic health records; in most cases they were not.

The exploratory research in the first four publications identified a complex web of related interactions between socioeconomic disadvantage and PHRs, making it difficult for disadvantaged patients to obtain a benefit. The results were suggestive of a group of potential PHR users with low socioeconomic status and limited capabilities, including text, technical and health literacy, facing barriers to PHR adoption and continued use, and as a result less likely to derive a benefit. The publications also suggested a tendency for the design and implementation of PHRs to disregard the needs of disadvantaged users, effectively leaving them invisible. This invisibility could lead to disadvantaged patients receiving less equitable healthcare as a result.

These four publications from Phase 1 did not address in any substantive detail the nature of the barriers to personal electronic health record use that exist for disadvantaged and low capability users. Neither did those publications identify whether these disadvantaged individuals existed as an identifiable group within a local population. These gaps in the evidence then prompted two additional research questions:

RQ2a: What is the current evidence about barriers to the uptake and continued use of personal electronic health records?

RQ2b   Is it possible to identify a group of disadvantaged healthcare users in Australia likely to face higher barriers to the adoption and use of personal electronic health records?

10.2.2 Research Question 2a

A literature review was used to address Research Question 2a. Searches in PubMed, Embase, CINAHL and ProQuest databases retrieved 40 relevant publications, which provided evidence of 21 individual barriers to patient adoption and continued use of PHRs, grouped as Individual, Demographic, Capability, Health-related, PHR or Attitudinal factors; twelve of these barriers were identified as being associated with socioeconomic disadvantage. The literature review did not identify any previous publication which provided a comprehensive enumeration of patient level barriers top PHR adoptions and continued use.

This literature review was not intended to provide a canonical statement about what barriers exist (and by inference what factors would not be barriers). Rather it was intended to give some immediate guidance about limitations which might prevent patients from adopting or continuing to use a PHR, and therefore contribute to adoption rates which are lower than desired or expected. The review also served as a basis for the identification and characterisation of PHR barriers to support the empirical analysis.

10.2.3 Research Question 2b

Research Question 2b was addressed by applying empirical research using measures of socioeconomic disadvantage, local data on 800,000 public hospital admissions and 1.3 million emergency department attendance, and proxies for barriers to the adoption and continued use of PHRs. Cluster analysis was used to determine whether there were identifiable groups of SA2 regions with a higher proportion of disadvantaged patients, more use of healthcare services, and proxy measures suggesting greater barriers to PHR adoption and use.

The results showed that two such clusters existed, with a higher proportion of residents experiencing socioeconomic disadvantage, using public hospital services (such as inpatient admissions, renal dialysis and emergency departments) at a higher rate, having a higher incidence of chronic disease, and showing proxy measure for barriers to PHR adoption and use. A cluster at the other extreme displayed contrasting measures for all characteristics. Displaying these results as choropleth maps confirmed these findings.

The ecological fallacy makes it unwise to attribute these characteristics of disadvantage to any individual residing within a cluster. However, it can be said that those living in SA2s within these clusters are more likely to be individuals whose use of public health services is marked by more days in hospital and longer stays, more emergency department visits, and a higher incidence of chronic disease. They are also likely to have lower school achievement, qualifications and broadband use, proxies for barriers which will interfere with or prevent their ability to benefit from personal health records.

10.3 Critical reflections

10.3.1 Limitations of the research

There are some aspects of the empirical research reported in Chapter 9 which might limit either its validity, or its generalised applicability to the issues being studied.

Granularity

Sensitivity of geospatial analysis increases with increasing granularity and is improved by the use of smaller units of data collections. Although the analysis has used measures of disadvantage and proxies for PHR barriers at the lowest available level of granularity, repeating the study at a finer level of granularity, by using data at the level of Statistical Area 1 (SA1) or Mesh Block would almost certainly increase the strength of the findings. However, there was no feasible option to assign SA1 or Mesh Block codes to patient records within the health data set, and census data at these levels was not easily available.

Time series issues

The patient's domicile (and the associated SEIFA and ICE values) were assigned based on the SA2 for the individual's most recent address. This may have introduced errors where individuals have moved to another SA2 region during the period of the study, or where the socioeconomic characteristics of the SA2 region have changed significantly overt time.

Demographic scope

Not all health service use by individuals who arrived in or departed from Tasmania during the study has been captured.

Private sector and non-hospital services

The health data used for the analysis was sourced entirely from public hospitals, and no allowance has been made for health services obtained from the private sector, or from non-hospital service providers.

Despite the omission of patients' use of private health services in this analysis, the results are relevant in understanding the role of government in providing health services. It should be noted that the absence of a private renal dialysis service in Tasmania means that the subset of dialysis episodes represents all of the dialysis activity in Tasmania.

Insensitive measure

The level of utilisation of public hospital services may not be a reliable measure of healthcare needs. Indeed, a high level of hospital use may be for other reasons:

- As a substitute for services from general practitioners and private specialists;
- Some groups may be more prone to seek or receive 'overservicing'; or
- Some groups may be less adept at taking advantage of other services (such as public health, community nursing, and disease prevention).

Locally based study

This analysis has been conducted in a small state in Australia. Because of the relatively homogeneous nature of Australian society and Australian healthcare services, the results may be transferrable by inference to many other locations in Australia. It would be wise to exercise caution when applying the results to other developed countries, and the results should not be applied to less developed countries without further analysis.

10.3.2 Strengths of the research

There are a number of aspects of the research which add weight to the findings.

Size

The empirical study used an analysis of local Tasmanian data on 800,000 public hospital admissions and 1.3 million emergency department attendances over eight years. Despite the selective removal of records as a result of the data evaluation and filtering described in Section 9.2, the large number of records included in the analysis add weight and value to the findings of this research.

Originality

The overall approach used in this research, applying an initial exploratory phase to explore the research question, followed by empirical analysis to address emerging research questions, is not particularly innovative. However, the empirical analysis itself, matching deidentified person level data

with small area measures of socioeconomic status and proxies for PHR barriers has not been identified in the literature.

Broad scope

The intertwined issues of the digital divide, the ehealth divide, socioeconomic disadvantage, the social determinants of health, and barriers to the adoption and continued use of personal health records are well described, and well understood. However, the combination of related findings based on empirical research, presented as a holistic and integrated argument have not previously been elaborated. It is true that in each of the fields which these findings traverse – health social research, social determinants of health, demography, patterns of socioeconomic disadvantage, PHR barriers – the individual findings are generally known and accepted, at least at an intellectual level. However, the systemic, holistic reality and its broad implications about what is needed for the equitable delivery of healthcare services have not previously been published, or widely discussed.

10.3.3 Implications

The implications of this research for government policy regarding PHRs are significant. When governments commit expenditure to the implementation of a particular initiative, questions inevitably arise about whether the benefits which the initiative provides for citizens are equitably distributed. There does not appear to have been widespread concern about equity relating to PHRs, in Australia or elsewhere. Furthermore, as healthcare increasingly includes Internet mediated services within the overall mix, it is likely to become apparent that not all patients will find online services appropriate for their particular needs.

In the specific case of Australia's PCEHR, both the government and healthcare providers may need to revisit the project's original assumptions, including those laid out in the business case. The results of this research suggest that there may be a mismatch between healthcare needs and the benefits which patients could obtain from a PHR. After significant expenditure, Australia has a PHR system whose adoption has been slow, and an early independent evaluation (by Navy Design) sug-

gests that the system will be difficult to use. Although detailed user level data about adoption is not widely available, it is likely that initial uptake has been selective, with patients from the most disadvantaged SA2s being the least likely to enrol, or use the system, or to benefit. Research access to this demographic data would be welcomed, and its careful analysis should be incorporated as a significant part of any PCEHR evaluation which is to be undertaken.

The findings of this research also have implications for the practice of health informatics as it applies to personal health records. Any PHR implementation which includes disadvantaged patients among its potential users should take into account the barriers and limitations identified by this research.

10.3.4 Future research

A number of opportunities for further research in this field are apparent. These opportunities may be broadly categorised as those which would involve additional analysis on the same of a similar data set.; those targeting the design of PHRs in a way that reduces barriers for disadvantaged and lower capability users; and those which explore the issue of disadvantage in the context of PHR implementations and evaluations.

Additional analysis using the same data

A number of possible options for analysis of the data set were considered, but set aside in order to maintain a manageable scope for the analysis. These include:

- Segmenting the data to investigate the incidence of chronic disease for males and females of different age groups;
- Evaluating a healthcare use by patients in ten last year or two preceding death; and
- Investigating factors socioeconomic factors associated with unplanned readmissions to hospital within 28 days.

Similar investigations in other settings

- Is it possible to reproduces these findings in other locations?

- Does the nature of the association between socioeconomic disadvantage, use of health services and barriers to the adoption and use of a PHR vary between countries?

Implementation and evaluation of PHRs

- What is the relative impact of the various identified barriers on different groups of potential PHR users?

- How do those living with disadvantage perceive the use of a PHR? Does that perception change when they actually use a PHR?

- Does the apparent invisibility of disadvantaged individuals and communities affect research in other disciplines, and practice in other areas of healthcare?

10.4 Personal reflections: Obviousness and the Invisibility Cloak

The development of this thesis has involved a significant amount of effort over an extended period, examining personal health records and their design and implementation, and the challenges which they present for patients who experience socioeconomic disadvantage. In reflecting on the work that has been done and the results that have been produced, a question arises for the author about whether the research findings and their implications are of sufficient importance to justify the use of time, and whether the insights which have become apparent are worth sharing.

The next logical step in this process would be to consolidate and distil the research findings, and to provide advice and recommendations for those who envision, commission, design and implement PHRs. This advice would highlight those features of PHRs which make them harder to use, and suggest opportunities for improvements. One might envisage a new, more efficient system, supported by the work of empowered, engaged patients, which becomes the norm for the delivery of care for patients living with chronic disease. What would then be the level of care services which would be provided for patients who were not empowered, not engaged, and excluded from participation because of low levels of textual, technical and health literacy? They would probably be more costly

to care for than their engaged and empowered neighbours, and that additional cost would need to be managed.

But as the US journalist HL Mencken is often misquoted as saying: "There is always an easy solution to every human problem – neat, plausible, and wrong."

This reflection offers no easy answers (or even difficult ones) to specific problems associated with PLU friendly PHRs. Instead, it provides a summary of the thoughts, insights and opinions which interest the researcher as this phase of the thesis approaches its conclusion.

10.4.1 Obviousness

After reviewing a range of background material, much of which appears in Chapter 2, the challenges facing disadvantaged patients attempting to use a PHR appeared obvious. The use of an ehealth system requires a degree of technical capability in order to be able to navigate the system effectively, but perhaps more important is the need to navigate the syntactic and lexical landscape embedded in the design. However, the obvious nature of these challenges seemed not to surface in the literature about PHR design and implementation. Perhaps there was a problem to be explored.

By the end of Phase 1 of the research, the concern was so clearly apparent to the author that it seemed obvious, almost trite. But why was this concern not more widely discussed? The association between socioeconomic disadvantage and poor health outcomes is so well accepted as to be viewed as a commonplace observation. Similarly, the existence of a 'digital divide' is well reported and understood, as is the ehealth divide which reduces the likelihood of PHR use by certain disadvantaged groups. Given that these separate (but related) factors are generally known and accepted, why then do PHR developments continue to provide systems which disadvantaged patients either find harder to use, or avoid altogether; and why is there so little interest within the health informatics community in addressing this significant example of inequity in resource allocation and service provision?

Indeed, an early review of the material presented in Chapter 9 suggested that the findings were so unsurprising and commonplace that the observation that disadvantage, healthcare service use and PHR barrier proxies were closely associated, and linked geographically was not sufficiently novel to warrant publication, even though this result does not appear to have been published previously.

10.4.2 The Invisibility Cloak of Disadvantage

Why has the professional response to the 'obvious' issues which are discussed in the section above, been so weak or absent?

The background provided in Section 2.7 on page 59 raised the issue of the relative invisibility of disadvantaged individuals and groups within society. In particular, the disadvantaged are apparently invisible to People Like Us, absent from our field of view. It is as if they are covered by JK Rowling's (or Harry Potter's) magic Invisibility Cloak (Rowling, 2001), hidden from our gaze. Nothing that has emerged from the research in Phase 1 and Phase 2 reduces the significance of this invisibility, or the impact that it is likely to have on PHR developments.

How does this cloak work its magic?

Statistical smoothing

The sample size effect introduce in Section 7.4 means that a statistical measure for a group will mask the extremes of that measure which apply to individuals, and this masking is greater for larger groups.

Even in the most disadvantaged SA2 regions, the number of DDDs in the community is likely to be small. This means that any 'average' measure of disadvantage will understate the extent and severity of the problem for those who are directly affected – our DDDs remain invisible, or fade into the landscape.

It was suggested in the publication in Chapter 5 that the design and implementation of PHRs is constrained by a 'PLU problem' - a tendency to envision technology which is suitable for our own use. This same restricted gaze may extend to sociodemographic variability: we rely on group statistics which mask the extremes, and the sample size effect hides from our view the most extreme examples of privilege and of disadvantage.

Measures of socioeconomic disadvantage are presented as continuous variables, and much of the research into personal health records assumes a continuum of adoption, moving progressively through Rogers' Innovators, Early Adopters, Early Majority, Late Majority and Laggards (Rogers, 1983). However, there is no continuity between those who can read and those who are functionally illiterate; between the technically literate and those unable to use the Internet; between patients with a degree of health literacy and those unable to manage or participate in their own care.

Although there are exceptions, the reality for many studies of PHR adoption is that subjects are selected (or self-select) from among a 'cohort who can'; the 'cohort who cannot' – the DDDs – are passed over, neglected, ignored and forgotten.

Lack of voice

Engaging disadvantaged participants in a design process is likely to be challenging. As noted in Section 2.4 on page 36, poor text literacy can act as an impediment to effective verbal communication. If participants are not carefully selected and carefully managed, disadvantaged subjects are likely to be overawed by the confident, verbally adept 'experts' that they encounter They may well feel that they are being 'tested' - asked to provide the 'correct' answer – and respond by being unwilling to venture an opinion of their own, or saying what they think is expected. The invisibility cloak also leads to the more widespread avoidance of DDDs as members of working groups, steering committees and reference groups, as research subjects, as contributors to design, as beta testers, and as adopters and users of PHRs.

Isolated communities

As noted in Section 2.6.3 on page 56, disadvantaged individuals are subject to a geospatial divide. Geographic segmentation of society is also effectively a socioeconomic segmentation, and it is unusual for adjoining neighbours to have markedly differing socioeconomic status. The way in which this study used area measures of disadvantage within SA2 regions to infer person level disadvantage means that family, friends and neighbours are within the same cohort with respect to area level disadvantage. This suggests that, for the purposes of this analysis, asking grandchildren or neighbours to help with the use of a PHR is unlikely to be a sufficient solution in many cases. Despite the popularity of social media, society remains segmented; we rarely interact in any substantive way with those whose background and social circumstances vary widely from our own. This can lead us to overestimate the extent to which our own experience and capabilities represents the experience and capabilities of society as a whole. Most of us live almost entirely within a comfort zone, a protective bubble which shields us from the rest of the world. The particular *weltanschauung* of People Like Us, cocooned in technological comfort, filtered by screens and social media, reflected back at us in the 'Black Mirror' (Brooker, 2011) of our smart devices, prevents us from seeing beneath the invisibility cloak.

10.4.3 eHealth: Kill or cure?

A challenge for all health informaticians and healthcare professionals working with or considering a PHR – take a look under the invisibility cloak of disadvantage, take stock of what (and who) you find there, and build a system that will include the disadvantaged. Remember that self-actualisation may be missing, and rewards and penalties may be needed. Rewards are likely to work better than penalties.

And how can that cloak be lifted or removed? Will more, better, stronger evidence about PHRs and disadvantage, about this invisibility, change our behaviour?

This thesis and the analysis within it has been predicated on the assumption that our society has a responsibility to provide assistance to those who are most in need, and to do that in an effective way, without wasting resources by providing a solution to those for whom the problem is not great.

Any attempt to improve health outcomes which is driven by a strong sense of equity – shaped to ensure equitable access for all to the newly established or redesigned services and resources – will be of benefit to those demonstrably not in need, as well as to the disadvantaged. Indeed, there is a risk that much of the activity in the 'improved' model will be for PLUs.

I am aware that there may be a countervailing neoliberal view that it is entirely appropriate for the elites to expropriate for themselves the resources that they desire to improve their own health, without undue concern for those whose need may be greater. These neoliberals wish to see a role for governments which is as as small as possible. If it is appropriate for that view to underpin PHR developments, then let us be explicit about making the statement. But if that is the case, then it represents middle class and upper class welfare, and should be provided by the markets, not provided (or subsidised) by governments.

10.5 Further work

10.5.1 Unresolved questions

There are a number of questions which this research leaves unanswered. Some were apparent early on, but have not been satisfactorily addressed; others have arisen as a result of the findings of the research; a few additional questions emerge as philosophical considerations, and are probably more useful as thinking cues than as questions.

Initial questions

- Is there a need for new PHRs (or modifications to existing PHRs) which cater specifically for the needs and abilities of disadvantaged users?

- Is the increasing use of PHRs likely to displace more conventional options for providing care? If this is the case, what risks are there for patients who are less likely to become PHR users?

- If there are savings possible through an ehealth intervention such as a PHR, then how will those efficiencies be realised?

Emerging questions

- How effective is patient education within a PHR implementation in mitigating barriers to use (bearing on mind that previous educational achievements for the most disadvantaged users may have been modest)?

- What does a PHR designed specifically for 'low functional literacy' users look like, and what assistive options within a PHR could help to reduce the negative impact of poor health literacy?

- How should those implementing PHRs deal with options for addressing the lower level needs in Maslow's hierarchy? 'Social media' functionality may satisfy Maslow's 'social needs' for example, but use of technology may still be a problem.

Philosophical considerations

- Is there a realistic prospect of attaining PHR use by a vast majority of patients (say, more than 95%)?

- To what extent can PHR systems really provide the benefits that have been promised? How many of these problems are functions of healthcare systems rather than poor scheduling, planning and communication?

- Are the PHR barriers which disadvantaged individuals face really about the PHR itself, or are they also (or only) about those individuals?

Answering these questions is unlikely to be simple or straightforward. While a number of the answers will rely on a better understanding of the design and use of PHRs, others will require an understanding of issues related to patient motivation and self actualisation.

10.6 Concluding remarks

This thesis began by exploring the possibility that ehealth systems might serve to selectively exclude those in greatest need of improved health services. The data is not overwhelmingly conclusive, but the conclusion cannot be ruled out, and the results suggest that the problem is likely to be a real one. It is possible to make a number of observations about the evidence produced by the research, and its implications.

It has become apparent through the work undertaken for this thesis that current approaches to research on personal electronic health records leaves socially disadvantaged groups and individuals invisible. They are often discounted as 'non-adopters', or as 'not qualifying' for a study. Without special attention, personal electronic health record systems will continue to ignore the 'disempowered, disengaged and disconnected'.

This research has shown that patients from disadvantaged neighbourhoods in Tasmania use public hospital services to a greater extent than those from privileged neighbourhoods. In addition, they display characteristics which are indicative of barriers to personal health record use.

These results suggest a risk that focusing on personal electronic health records as they are currently realised could lead to disadvantaged patients receiving worse healthcare than they do currently. Continued implementation of personal health records could divert health resources – human, financial and physical – away from existing models of service delivery, resulting in an increased inequity in healthcare outcomes.

Greater use of user centred design may help to provide personal health records which are more suitable for disadvantaged users. However, this will require the participation of a truly representative group of potential users, including the disadvantaged.

So where does the potential interest (and excitement) in these findings lie? Where in this research is there a finding which might spark interest for health informaticians?

Surely it is in the exceptional degree of apparent blindness and inattention among the proponents, developers and implementers of personal health records to that which is 'hidden in plain sight' - that those whose healthcare is most in need of improvement are the least likely to benefit from having (at least theoretical) access to a PHR.

The interest emerges from the realisation/knowledge that these ('obvious') findings are probably known and understood by many who work in informatics in healthcare, and who work in healthcare using information systems.

What work needs to be undertaken to deal with this distorted vision?

There is a cognitive gap, a 'blindness', between the evidence about disadvantage and PHR adoption and use and the pragmatic realities of what happens in practice. A cloak of invisibility hides these disadvantaged PHR (non-) users from view. Translational research has the laudable aim of making sure that what is known about effective care is applied in routine practice. In the context of safe healthcare, Lucien Leape and Don Berwick observed: "...[t]hough clearly we have much more to learn about how to make our systems safe, we already know far more than we put into practice." (Leape & Berwick, 2000, p. 725)

The same need is evident to the author regarding the equitable implementation of PHRs. There is already sufficient data, information and knowledge about PHR barriers which affect disadvantaged patients to allow action to occur. In the opinion of this researcher, it seems that the necessary wisdom and insight has not yet become widespread.

In conclusion, policymakers, informaticians, health service managers and healthcare providers should look carefully behind the cloak of invisibility which hides the disadvantaged, and ensure that any benefits generated by ehealth innovation are being shared equitably.

Must the slow progress of PHR adoption proceed to a stage where the low percentage of disadvantaged high needs patients among regular PHR users becomes a cause for embarrassment and concern before we notice?

I hope not.

In the meantime, this thesis, the publications within it, and the further publications which may appear as a result are my contribution to raising the invisibility cloak of disadvantage and promoting a broader consideration of the particular needs of disadvantaged users when patient focused ehealth system such as PHRs are being considered. I look forward to a future in which these disadvantaged users are no longer hidden in plain sight.

Glossary

DDD   A term used in this thesis to describe individuals and groups who are 'dis-empowered, disengaged and disconnected'. The DDDs experience socioeconomic disadvantage, and a wide range of associated limitations such as poor text, technical and health literacy, as well as poor health.

DHHS   In this thesis, this abbreviation refers to the Tasmanian Department of Health and Human Services.

ED   Emergency department.

EHR   Electronic health record.

GP   General practitioner.

ICD9   International Classification of Diseases, version 9.

ICD10   International Classification of Diseases, version 10, Australian Modification.

ICT   Information and communication technology.

IS   Information system.

PCEHR   Personally controlled electronic health record – the patient facing component of Australia's National Electronic Health Records Service.

PHR   Personal health record. Although this term can also apply to physical records, its use in this thesis generally refers to electronic versions (also referred to as personal electronic health records).

PLU   A term used in this thesis to describe this who are well off, tertiary educated, and familiar with the use of everyday technology – 'People Like Us'.

SNOMED   Systematic Nomenclature of Medicine – Clinical Terms
(also SNOMED-CT)

References

"After all, all he did was string together a lot of old, well-known quotations."

- H. L. Mencken (on Shakespeare)

"Cave ab homine unius libri"

- Latin proverb

This list of references includes all works which have been referred to in the thesis, including those cited in the author's own publications (which appear as Chapters 3 – 6, 8 and 9).

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Nunc est bibendum, nunc pede libero pulsanda tellus

Horace, Odes