

# Consumer Perspectives on MyHealth Record: A Review

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**Abstract.** The vision for Australia's national electronic health record system included empowering consumers to become active participants in their own health care. This paper aims to critically review the literature on consumer perspectives of Australia's My Health Record (formerly PCEHR). The review is based on a subset of articles (n=12) identified in the Australian EHR Repository (N=143), a repository of metadata of Australian Research on EHR located at Flinders University. Results show low levels of awareness and concerns about sharing records and equity of access for all Australians, which in view of the change from opt in to opt out raises concerns about explicit consent. Improved promotion and support, along with different models of access might lead to higher consumer engagement with, and use, of My Health Record, especially for populations at risk of digital exclusion.

**Keywords.** PCEHR, My Health Record, consumer, adoption, opt-out

## Introduction

Research into consumer perspectives of electronic health records (EHRs) in Australia is still in its early days. The first national electronic health record system was launched in 2012[1]. The vision for the Personally Controlled Electronic Health Record (PCEHR), now known as My Health Record (MyHR), was twofold: to improve the delivery of healthcare through increased consumer engagement and to improve healthcare outcomes through sharing of health records (health summaries only) across healthcare providers[2]. The central premise of the Australian implementation was that consumers would control who can access their EHR. Consistent with this consumer focus, Australia also chose an opt-in system [2].

Low uptake by consumers and healthcare practitioners alike resulted in an official review and an extensive public consultation process in 2013 which was released in 2014[3]. The review recommended improving promotion and consumer awareness as well as shift to opt-out model of consent to achieve the critical mass of consumer participation necessary to galvanise healthcare provider engagement. The PCEHR was rebranded as MyHR and relaunched in March 2016. Since the relaunch of MyHR, uptake has increase to 17% of all Australians, however, this includes a million plus people who were automatically registered as part of an opt-out trial [4]. Following the end of the opt out trials, and with the support of the Council of Australian Government, the federal government is preparing to implement the opt out policy with \$374.2 million allocated to the expansion of MyHR in the 2017-2018 budget [5]. The change

in government position from Opt in to Opt out, provides a timely opportunity to critically review consumer perspectives of EHRs.

## 1. Methods

Papers selected for this review are a subset of papers from the EHR repository: <http://www.flinders.edu.au/digitalhealth/>, a collection of peer reviewed academic research (metadata) on EHR in Australia. The process for the selection of papers for this review is in two stages. First, selection process for inclusion into the repository and second, the selection for inclusion in the review.

### 1.1. Stage 1 The Repository

The essential criteria for inclusion in the repository is that the research focus is on EHRs in Australia, defined as “a system for making health information about a healthcare recipient available for the purposes of providing healthcare to the recipient”[6]. Three different search strategies were used: 1) a targeted search of papers in the publications repositories of Australian eHealth Research Centres, 2) an iterative search of Google Scholar and 3) structured searches of Scopus, PubMed and Informat databases. Search words/phrases are summarised in Table 1.

**Table 1.** Search terms (abbreviated and plurals of search terms were also included).

EHR search terms	Australian identifiers
electronic health record, personally controlled electronic health record, personal health record, electronic health data, personal health data, e-health, e-health, electronic medical record, my health record, health level 7, Snomed CT AU, health information exchange, clinical document architecture.	Australia, Australian, National eHealth Transition Authority, HealthConnect, Australian Digital Health Agency. Also names of Australian states, state capitals and university towns.

Searches identified 701 references after deduplication. There was a three tier review process: 1) The first-named researcher excluded 348 papers that did not use Australian data, medical papers using electronic records as a data source, papers that were historical, journalistic or editorial. 2) The second and third named co-authors excluded 141 papers and 3) a fourth reviewer, an independent senior academic in the field of e-health excluded a further 69 leaving a total of 143 papers for inclusion in the repository. The exclusion criteria for stages two and three included research on: data linkage not related to EHR, personal health data or medical data collected at home not linked to health records or EHR holders, e-pharmacy and genomics.

### 1.2. Stage 2 The Review

All the papers on consumer perspectives of EHR in the Repository were included in this review (n=12).

## 2. Results

Of the eleven papers on consumer perspectives of EHR, data for three papers was collected prior to the launch of PCEHR, seven papers post launch and one since the launch of the revised MyHR. Five of the eleven papers focussed on the viewpoint of non-mainstream groups who may be digitally excluded [7]; the elderly (n=1), people with disability (n=2), low socio economic consumers (n=1), and people with complex chronic conditions/rural (n=1). Five papers were qualitative papers and six papers were quantitative analyses of surveys. Results identified a number of themes including low levels of adoption, concerns about privacy and misuse of records, issues of equitable access and willingness of consumers to share records.

### 2.1. Adoption

Consistent with national statistics which showed that in Feb 2016 11% of Australians registered for PCEHR [8] uptake from surveys reflected similar results. Andrews et al [9] identified perceived value as the strongest predictor of PCEHR adoption.

### 2.2. Awareness, Promotion and Engagement

Uptake is likely associated with the low levels of awareness. Knowledge of PCEHR is also low. Lehnbohm, Brien, & McLachlan [10] found most respondents answered unsure to a series of six statements to test knowledge of PCEHR, with only one of 203 participants able to answer all questions correctly. Low levels of awareness and knowledge may be in part attributable to poor engagement with and promotion of the PCEHR by healthcare providers and services. Research reported low awareness amongst healthcare providers [11-13] as well as concerns that time constraints might also prevent healthcare providers engaging patients [14, 15]. Respondents felt that GPs were best positioned to promote e-health records [9, 12, 15, 16]. For digitally excluded populations active engagement by service providers was important [13], however this was balanced by concerns that “pressuring unprepared or unwilling consumers... might further undermine health by creating stigma trust and feeling of losing control” [17].

### 2.3. Concerns Mediate Attitude

Perceived risk was found to be a strong predictor of attitude towards PCEHR moderated by trust and perceived security [9]. Key concerns about the PCEHR include privacy and security of the data with the associated risks and fears of misuse. There are privacy risks with any health records whether they are paper or computer based. The key concern was privacy [16, 18] though overall concerns about privacy and security were moderate [9]. Risk perceptions of paper versus electronic records were at similar levels. The earlier Bomba survey [19] found that Australians had slightly more confidence in the privacy and security of computer records than paper records, the 2010 Lehnbohm survey [10] showed that 46% of respondents felt the risk to privacy is higher with electronic records. The risks associated with breaches of privacy included discrimination or denial of service by healthcare providers or the police and misuse of data by corporate bodies including insurance companies and employers [10, 16, 18, 20]. The risk associated with data quality were discussed only in the survey of elderly rural

patients [16], where a third of respondents had concerns about the correctness of the data. Perceived risks were mediated by trust [9]. Trust in the government's ability to ensure the privacy of health records was moderate [9, 10, 19]. Only the low socio economic and disadvantaged population expressed low levels of trust in the government [17].

#### *2.4. Digital Divide: The Views of the Digitally Excluded*

It is important for all Australians to be included in the rollout of a national health scheme. A qualitative research project (n=80) conducted in South Australia in 2008-2009, prior to the introduction of the PCEHR, focussed on barriers to participation in e-health for people with low income and disadvantaged backgrounds (n=80) [17]. Three key concerns emerged 1) access to resources including computers and internet; 2) skills/education including language (even for non CALD communities) and computer literacy; and 3) personal attributes including trust, confidence or perceived need. The paper identified the need for skills support, assistance with affordability of technology and internet access.

People with disabilities are another group that may be excluded through poor engagement. Two studies looked at consumer perspectives of PCEHR for people with intellectual and communication disabilities. Qualitative data collected in 2012 from people with intellectual (n=9) [15] and communication disabilities (n=21) [14] highlighted the need for themselves and/or their family and carers, to track extensive medical information, usually managed manually, and coordinate appointments with numerous health professionals. These groups are not homogenous in need, as there is a diverse range of ability and capacity to understand and manage health information, and a differing desire, need or requirement for involvement of family or carers to participate in managing their healthcare. Only one of the 12 participants with communication disabilities had signed up for PCEHR, however all of them wanted further information from disability service providers [14]. The research highlighted the importance of a sense of control and ownership of their records.

The elderly are another group potentially excluded from participation in e-health [21]. A survey of 80 elderly (<60 years old) Australians from regional Victoria [16], showed that respondents believed electronic records were a good thing (85%). Consistent with lower levels of digital literacy in the elderly [22] respondents preferred to print the records out rather than view them on the computer (60%). Lastly, a recent community based participatory project for people with complex chronic conditions (CCC) living in rural or remote areas (n=19) [13], showed how community engagement can be effective in improving uptake of EHRs. Participants in this research had heard of the MyHR yet none had registered. By the end of the intervention, participants were very actively engaging with their own health records and could see the benefit of the use of MyHR in their self-management of their CCCs.

#### *2.5. Sharing – Not So Much*

The PCEHR allows consumers to selectively grant access to their MyHR. In a national survey 82% of respondents preferred having control over with whom they would share their record (82%). Only 66% agreed to share their records with all their healthcare providers. Consumers were most willing to share their records with their GPs (97%) and specialists (91%). They were most reluctant to share with their pharmacists (49%)

[10]. Elderly respondents also had reservations about sharing their records with all their health providers/relations/carers [11, 16]. Only between 85% and 78% of the elderly surveyed by Kerai et al [16] were willing to grant access to, in order of preference: their GP, specialists, hospital clinicians and emergency services personnel. Only 44% willing to share with their pharmacist, just over half (53%) were willing to share with family members and less than a third (29%) would share with carers. In addition to concerns about sharing records with different kinds of healthcare providers, there were also concerns (25%) about sharing certain types of information including sensitive or embarrassing information [10, 18].

### 3. Discussion

Almost five years after the introduction of a national EHR, MyHR still has low rates of adoption with only 17% of Australians registered [8]. The implementation of a national health record system is as much of a challenge in social change management as it is a technical challenge [23]. While engagement of health care providers is likely to increase with the change to an opt out system, it is still essential to engage the general public [19] for the full benefits of increased consumer engagement in health through MyHR to be realised, even in an opt out system.

This review reflects that while consumers have concerns about privacy and security, there is sufficient trust in the government to put the systems in place to ensure privacy and security. Increasing awareness of MyHR is critical to success in the roll out of national health records system [24]. The low sign up rates under the opt-in PCEHR are in part attributable to the low levels of consumer awareness of, and engagement with, the national health records system.

Consumer engagement is particularly important for populations identified as most likely to benefit from engagement with MyHR, in particular for consumers with complex needs which require coordination of care across a number of providers [2]. Worryingly, chronic disease and multiple chronic disease is more prevalent in the elderly, and people living in low socioeconomic and remote and rural communities [25], populations that are more likely to be digitally excluded. Without substantial engagement and support, and consideration of different models of access and delivery, these populations may continue to be excluded. The switch to an opt-out model will increase registrations and by default build the critical mass of consumers needed to engage healthcare providers, however, in order to realise the promise of benefits to consumer understanding the consumer perspective is more important than ever [1].

The risk with opt-out is that, given the ongoing low awareness of MyHR and the concerns expressed by consumers about with whom they are willing to share their records, opt-out will result in default registration without explicit consent as to who accesses their records or a proper understanding of the uses, unconnected to healthcare delivery, that data from MyHR may include [26]. This is of particular concerns for those populations who are digitally excluded because they face additional challenges in accessing e-health to opt-out [12].

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