

**‘I’d Like to Think You Could Trust the Government, but I Don’t Really Think We Can’:  
Australian Women’s Attitudes to and Experiences of My Health Record**

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**Abstract**

The Australian government’s Australian Digital Health Agency is working towards its goal of enrolling every Australian in My Health Record, its national electronic health record system. This article reports findings from a qualitative project involving interviews and focus groups with Australian women about their use of digital health across the range of technologies available to them, including their attitudes to and experiences of My Health Record. A new materialism theoretical perspective informed the project. The study identified many barriers to the participants’ successful registration and use of the system. Even among this group of participants, who were experienced and active in finding and engaging with health information online, uncertainty, a lack of awareness of and interest in My Health Record was evident among many. Technical difficulties were major barriers to enrolling and using the system successfully. No participants had yet found any benefit or use for it. My Health Record was viewed more as a repository for the use of healthcare professionals than for women’s own active use as contributors and users of their data. Lack of trust and faith in the Australian government’s general technological expertise and concerns about data privacy and security were also key in many participants’ accounts. These findings highlight the complex sociomaterial dimensions of publics’ engagements with national electronic health records. People’s personal experiences, the actions of others such as the agencies and providers responsible for system implementation and function and broader social, cultural and political factors are important in shaping publics’ knowledge and practices.

## Introduction

National patient electronic health records (EHRs) have long been promoted by governments and healthcare systems as a way of preserving patients' health and medical information and maintaining their data in a central facility that ideally can be shared between different healthcare providers. National EHR systems potentially offer efficiencies in collecting and storing patient information, contributing to continuity of care and alleviating problems such as misdiagnosis or prescription errors. They can also offer citizens better opportunities to view or add information to their health records and exert control over who can access their information (Pearce and Bainbridge, 2014; Roehrs et al., 2017; Greenhalgh et al., 2013).

However, many difficulties have been experienced in implementing large-scale EHR systems (Evans, 2016; Greenhalgh et al., 2013). The quality of information captured and its management can be very variable (Allen-Graham et al., 2018). Health data privacy and security risks also have profound impacts on the success of EHR systems. There are a range of potential risks and harms that must be identified and negotiated. This includes the privacy and security of digitised health and medical data, which are often subjected to leaking and breaches, sale to third parties for commercial gain, hacking or illegal access for criminal activities such as insurance fraud (Huckvale et al., 2015; Wicks and Chiauzzi, 2015). De-anonymising medical data and detailed profiling of individuals for commercial purposes are also relatively easy once several digital datasets can be combined (Zivanovic, 2014). Release of health and medical data and loss of anonymity can potentially lead to stigmatisation and discrimination against people with conditions such as HIV/AIDS or mental illness (Rosenblat et al., 2014).

Given the sensitivities and highly personal nature of health and medical information, there are manifold ethical and human rights issues involved in the establishment and adoption of EHRs. It is important to ensure that patients give their informed consent to signing up to an EHR and are able to understand how their personal health data may be used by providers and third parties (Bratan et al., 2010; Fry et al., 2014; Spriggs et al., 2012). High levels of digital literacy are required from both patients and practitioners to successfully navigate and benefit from EHRs (Hemsley et al., 2018). Ensuring access for marginalised or disadvantaged groups, including those with disabilities, requires considered attention (Hemsley et al., 2017; Newman et al., 2012).

The Australian government is currently seeking to expand citizens' use of its EHR system, My Health Record, by introducing an approach that will enrol every Australian into the system unless they take steps to opt-out. Little research has been conducted on Australian publics' understandings and engagements with the current iteration of My Health Record. In this article, I discuss some findings from a study that sought to investigate Australian women's experiences with digital health technologies, using semi-structured interviews and focus groups. The Australian Women and Digital Project is the first study to include women from a range of age groups and locations and to investigate their use of digital health technologies across the full spectrum available to them. Qualitative methods were chosen to enable detailed exploration of the social and biographical factors contextualising women's use of digital health technologies. During the interviews or focus groups, participants were asked whether they had signed up to My Health Record and to explain their reasons for doing so or for not signing up.

It is important to note that the interviews and focus groups took place during the period from late 2016 to mid-2017, a time in which there had been widespread media coverage of various controversial events concerning the misuse or breaching of Australians' medical and other personal digital data and of government digital systems dramatically failing. In August 2016, the national census, offered to Australians to complete online for the first time, was disrupted by the website crashing and refusing access to people trying to upload their details. Another highly publicised event involved Australian citizens' personal data from the MyGov website. The so-called 'robo-debt' event occurred just before Christmas 2016. Tens of thousands of recipients of social security payments were threatened with having to repay sums that a new algorithmic system had in many cases erroneously

calculated they owed to the government agency Centrelink. A third scandal erupted in mid-2017, when it was revealed that Australians' personal Medicare details were available for sale on the dark web.

The theoretical approach informing the Australian Women and Digital Health Project is new materialism. This approach takes a broad view of the assemblages of human and nonhuman actors that come together when new technologies such as EHR systems are developed, configured, implemented and promoted. Recognition of the sociocultural and political contexts in which EHRs are introduced and experienced is important in this perspective, but so too is identifying the understandings and lived experiences of people with the systems. Humans and nonhumans (in this case, digital technologies) are viewed as working together to generate agential capacities, a term used in feminist materialist theory to denote the ways in which people create action and meaning with and through things (Barad, 2007; Braidotti, 2016). This theoretical approach recognises and emphasises the relational engagements of people with technologies as well as with other people, and the dynamic nature of these engagements (Fullagar et al., 2017; Lupton, in press). Discourses operate with embodied experiences and practices to open up or close off the agencies and capacities offered by the affordances of software systems such as My Health Record and the personal data they archive (Lupton, 2014; Lupton, 2018).

In what follows, I first provide the background to My Health Record and an overview of the findings of previous studies investigating healthcare consumers' attitudes to EHRs, including research conducted with Australians. The Australian Women and Digital Health Project is then described, followed by findings from the project. The findings are structured into four main sections. The first part provides a brief overview of the participants' use of digital health across the range available to them, providing the broader technological context in which the participants were engaging with My Health Record. Then follows discussion of the participants' awareness of My Health Record and the benefits and barriers related to My Health Record emerging in the women's accounts.

### ***My Health Record***

The Australian government's My Health Record system is a national-scale EHR linked to the government-funded Medicare health insurance scheme. Registration for My Health Record takes place via the MyGov platform, which hosts a range of other government services, including Medicare and other health agencies, social security agencies such as Centrelink, and the Australian Tax Office. My Health Record was announced in May 2010 with the initial title of the Personally Controlled Electronic Health Record (PCEHR). The National E-Health Transition Authority (now titled the Australian Digital Health Agency) was charged with overseeing its implementation. As this title suggests, from the inception of the PCEHR the Australian government placed emphasis on patients having access to and control of their health records as well as healthcare providers. Stakeholders, including healthcare consumers, were involved in consulting on the design of the system (Pearce and Bainbridge, 2014; Van Kasteren et al., 2017).

The system was rebranded with the more user-friendly title My Health Record in 2016, and relaunched, with the Australian Digital Health Agency embarking on a series of promotional and consultation activities to increase public awareness and encourage adoption by publics and industry. On the current My Health Record website, patients are told that they can share their medical information 'with doctors, hospitals and other healthcare providers from anywhere, any time'. They are informed that 'You control what goes into your record, and who is allowed to access it'. Healthcare providers are told that 'Through the My Health Record system you will access timely information about your patients' (Australian Digital Health Agency, 2018b). This promotional portrayal of My Health Record's affordance works to gloss over the kinds of complexities referred to earlier. The system is represented as seamlessly and readily operable and usable by patients and practitioners alike.

The troubled history of My Health Record challenges this idealised vision. Consumer uptake of My Health Record has been low. By June 2018, only 5.8 million Australians (one in five) had registered for a record (Australian Digital Health Agency, 2018b). In its efforts to enrol as many Australian citizens as possible, the Australian Digital Health Agency decided to introduce an opt-out approach, in which all Australians would be automatically provided with a record by the end of 2018 unless they informed the Agency that they wished to opt out. Australians were given a three-month opt-out period (16 July to 15 October 2018) (Australian Digital Health Agency, 2018a). This move has been subjected to trenchant criticism by civil and digital rights advocacy groups in Australia, who have urged Australians to take the opt-out option and called on the Agency to better publicise the option. These groups have raised concerns about patient consent being properly obtained and the risks of breaches, hacks or non-consensual secondary use of citizens' personal data (Sadler, 2018). In response, in a public speech the CEO of the Australian Digital Health Agency was forced to deny that there was intention to use My Health Record to conduct 'Big Brother'-like surveillance of Australian citizens or that there was a 'conspiracy' to deny them information about the opt-out process (Nott, 2018). As this suggests, the introduction of a national EHR system is not merely a technical problem to be solved but can be a fraught political process.

The Australian Digital Health Agency is relying on public information campaigns to ensure that Australians are aware of the opt-out process. However, research in the English context has demonstrated that such campaigns are often ineffective in adequately informing publics (Bratan et al., 2010). A content analysis of the information provided to Australians about My Health Record demonstrated that its readability was too high for the general Australian population, few resources existed for people with limited literacy or English fluency and limited information was provided about how healthcare consumers could best use their record (Walsh et al., 2017b; Walsh et al., 2017a). Furthermore, as noted by van Kasteren and colleagues (Van Kasteren et al., 2017), even if Australians are automatically enrolled into My Health Record, if they lack awareness, knowledge, interest and motivation to use the system, one of its stated key purposes – to facilitate patient engagement with and access to their health information – will not be realised. Those patient groups with the highest needs for a functioning EHR system, such as people with chronic health conditions, those from socioeconomically disadvantaged backgrounds or the elderly, will continue to be disadvantaged if they are not better informed about what My Health Record can offer them and provided with support to navigate the system (Van Kasteren et al., 2017).

#### *Previous research on patients' attitudes to and use of EHRs*

Systematic literature reviews have identified that most studies on EHR users have focused on healthcare providers and health service employees in North America and Europe (McGinn et al., 2011). Studies on healthcare consumers' attitudes to and experiences of EHRs have demonstrated that while they often recognise potential benefits such as patient convenience and better communication with healthcare providers, barriers to use include low digital literacy skills, fear of new digital technologies, data privacy concerns, scepticism about usefulness and difficulties with access and functionality of the systems (de Lusignan et al., 2014; Hawthorne and Richards, 2017).

Most of this research has relied on quantitative surveys. Few previous studies have adopted in-depth sociological analyses of healthcare consumers' experiences of national EHR systems that acknowledge their broader social and political contexts. One example of a multi-site and mixed-methods project that did incorporate attention to these elements is Greenhalgh and colleagues' analysis of consumer and provider engagement with the Summary Care Record that was offered on the HealthSpace platform in England (Greenhalgh et al., 2010; Greenhalgh et al., 2008b; Greenhalgh et al., 2008a). This project involved research at four early-adopter sites for this central ECR system in 2007–2008, eliciting the views of members of the public using interviews and focus groups (Greenhalgh et al., 2008b). This research found that most participants were unaware of the Summary Health Record or how to access it online. Key factors shaping their attitudes included the nature of illnesses they had experienced, their past and present experience of healthcare and government surveillance, levels of digital literacy and engagement and their trust and confidence in the primary

healthcare team and the National Health Service. People who had personally experienced disadvantage due to lack of sharing of their health records across services were more likely to see the value of the EHR. However, most people could not see the point of having their health records available online and were concerned about their data security. The same research team published findings from a related study, including interviews and ethnographic observations of patients and carers (Greenhalgh et al., 2010). This study demonstrated that patients found HealthSpace difficult to use and it was not viewed as aligning with their personal health management practices. Based on their research, this team predicted that HealthSpace would fail, and this did indeed eventuate. HealthSpace was abandoned in 2012 because of extremely low uptake (Greenhalgh et al., 2013).

Only a small number of studies have researched Australian health consumers’ perspectives on and experiences with My Health Record, and most of these relate to its earlier iteration, the PCEHR (Van Kasteren et al., 2017). An early interview-based study found that Australian healthcare consumers were uninformed about the PCEHR and were unsure about how information would be shared with their healthcare providers. They also voiced concerns about how their health data privacy would be protected and about the accuracy of these data (Lehnbom et al., 2012). Surveys of Australians have continued to demonstrate low awareness of the PCEHR/My Health Record, reluctance to register and privacy concerns, even though many do recognise the potential value of the system (Lehnbom et al., 2014; Kerai et al., 2014; Andrews et al., 2014; Armani et al., 2016). A small-scale qualitative study conducted in 2012, involving interviews with 12 patients who had experience of a PCEHR, showed that the participants saw two main interdependent advantages of PCEHRs: improved quality of healthcare due to better sharing of information and enhanced capacity for people to self-manage their health by being able to monitor and review their records. Drawing on their experiences of using PCEHRs, they identified two main conditions for optimal use and effectiveness: widespread awareness, integration and use of the PCEHR and a user-friendly interface (Hanna et al., 2016). Other researchers have identified the many literacy demands posed by the PCEHR/My Health Record for both patients and health service providers (Hemsley et al., 2018), including challenges for people with communication disabilities (Hemsley et al., 2017) and intellectual disabilities (Van Dooren et al., 2013).

## **The Australian Women and Digital Health Project**

### *Methods*

The Australian Women’s Digital Health Project provided an opportunity to identify more recent attitudes to and use of My Health Record. The overall project was designed to investigate the following research questions: What digital technologies do women use regularly for health-related purposes, both for themselves and for any others (family members or friends)? Which do they find most and least helpful and useful? What kinds of digital health technologies would they like to see developed in the future?

The project was comprised of two separate studies. A total of 66 women participants across the two studies were involved in either interviews or focus groups about their use of digital health technologies (Table 1).

*Table 1*

Study 1 (Canberra)	<ul style="list-style-type: none"> <li>• community forum (2 groups): 11 participants, age range 28—65</li> <li>• face-to-face interviews: 12 participants, age range 21—63</li> <li>• focus groups (3 groups): 13 participants, age range 25—58</li> </ul>
Study 2 (Australia-wide)	<ul style="list-style-type: none"> <li>• telephone interviews: 30 participants, age range 22—73</li> </ul>

The same semi-structured interview schedule was used with all participants. They were asked which digital technologies they used and found valuable or useful for their everyday engagements and practices related to health and wellbeing. The participants were also asked to reflect on what type of digital technology they would like to see invented that would fit their needs: in effect, to articulate their own imaginaries about the potential of digital health. These questions provided the basis of the interviews and group discussions, but interviewers also probed participants for further comments and explanations of their responses, allowing for free-ranging conversations.

### *Ethics approval*

Ethics approval to conduct this research was granted by the University of Canberra's human ethics research committee. All participants were provided with project information and gave their consent to participate. They were all given pseudonyms to protect their anonymity.

### *Participant characteristics*

*Study 1* involved three sets of women living in Canberra, totalling 36 participants. The first set included a total of eleven women who attended an initial community forum which was advertised among women's community health groups by the Women's Centre for Health Matters, a community-based not-for-profit organisation that works in Canberra and surrounding regions to improve women's health. The participants who attended the forum were divided into two focus groups, one of which was led by the second author and the other by a staff member from the community centre. Their ages ranged from 28 to 65 years. Following this forum, another twelve participants (aged from 21 to 63) were recruited to take part in individual face-to-face interviews. Three further focus groups with a total of 13 women were also conducted. One focus group consisted of six women with young children (aged from 25 to 33), the second included four women with young children who were part of a support group for mothers living with mental health conditions (aged from 25 to 30) and the third focus group included three women aged in their mid-to-late 50s. Of the total of 36 women involved across these Canberra participant groups, 28 identified their ancestry as Anglo-Celtic and eight as Asian. Twenty-two participants reported university-level education, while fourteen had high school or technical qualifications.

These interviews and focus groups were conducted by two research assistants employed on the project. The participants were recruited using the Women's Centre for Health Matter's networks, personal contacts, advertising on relevant Facebook pages (such as those for mothers, people with disabilities and women's fitness and sporting groups in Canberra) and posters in public places around the city. They took place in a range of locations, including places where the focus group participants usually met, homes and cafes.

*Study 2* involved telephone interviews with 30 women living in various locations around Australia. A market research company was commissioned to recruit the participants and conduct the interviews. Participant information and consent were provided online before the interviews were conducted. This group of participants were recruited using sub-quotas based on age, to ensure a good spread of ages: 10 aged 18 to 40, 10 aged 41 to 60, 10 aged 61 and over. These participants ranged in age from 22 to 74. Two-thirds lived in major cities or towns, one third lived in rural Australia. Twenty participants lived in the state of New South Wales, four in Queensland, five in Victoria and one in Western Australia. Twenty-four participants described themselves as having Anglo-Celtic ancestry, one as western European, two as southern European, two as Asian and one as middle Eastern. Of this group, 14 reported university qualifications, and the remaining 16 participants had high school or technical qualifications.

## *Analysis*

All the group discussions were audio-taped and transcribed by a professional transcription company. I analysed the transcripts using inductive thematic analysis (Ezzy, 2013) informed by new materialist theoretical approaches (Lupton, 2018). This involved identifying recurring themes within and across each group discussion by reading and re-reading the parts in the transcripts where the participants talked about My Health Record, and considering what experiences and practices they referred to, the relational dimensions (with other people and with the platform) emerging as important in their accounts, and the affects, capacities and agencies that participants described. Verbatim quotations from the discussions were chosen to provide support for the thematic analysis.

## **Findings**

### ***Broader digital health use***

The findings of the Australian Women and Digital Health Project identified the highly active digital engagement of the participants. Regardless of their age, ethnicity or geographical location, all the women in the study were regular users of online technologies to search for information about health and medical topics. They referred to ‘googling’ or consulting ‘Dr Google’ when describing this practice. Health and fitness apps were used by about half of the participants. Social media were used less frequently (a third of participants), with Facebook groups most often mentioned as sources of information about health. About a quarter of participants were currently using a wearable device for health-related purposes, with Fitbit fitness trackers and Apple Watches the most popular.

For the most part, traditional media forms, such as television, radio, newspapers or books were rarely mentioned as important sources of information. Websites were considered more up to date than traditional media, and the internet presented the vast array of options for women to find the information they needed. Hard-copy pamphlets, however, did remain influential sources for about half the women, as they were available when they were waiting at doctors’ surgeries for appointments. Despite their regular recourse to online sources of information, all the women still referred to the importance of seeking advice from healthcare practitioners. They were engaging actively, creatively and critically with online information, using it in a number of different ways to complement rather than supplement medical advice. They often went online as a first step to decide whether they needed to seek medical attention, for example.

### ***Awareness of My Health Record***

Despite their generally highly engaged use of online health and medical sources, awareness and use of My Health Record was quite low among the participants. When asked if they had signed up to My Health Record, only a third (24 out of the 66 participants) answered that they definitely had enrolled themselves. Nine women said they weren’t sure or couldn’t remember if they had registered, while the remaining 33 women responded either that they had not heard of My Health Record or they had decided not to sign up.

### ***Benefits of My Health Record***

#### ***Being able to share information***

The women who had registered for My Health Record said that they had done so because of the benefits they could see of being able to have a digital health record that could be shared across providers. They mentioned situations such as moving to a different location or different healthcare provider, or not having a regular GP as reasons for enrolling in My Health Record:

It’s harder and harder to source an appointment with a doctor when you want to go to a doctor, so if you had the capacity to just go to any doctor and you don’t have to sit there and

tell your story over and over and over again, I think that's a wonderful thing really. (Sandra, 55 years)

I thought it would be a good way to store all my records, especially for things like when I move, it would be easier to access. In case of emergencies and things like that, it's easily accessible to whoever needs to view it. I think that would be my main reason. (Amelia, 24 years)

I thought it was a good idea because sometimes you can become incapacitated or you can be somewhere else and from what I've gathered a doctor can access that and, if you're unconscious they can see your past history. (Rose, 73 years)

None of the women who had registered for My Health Record made any reference to the opportunity to be able to view their health records themselves or add to them. As this suggests, there was little awareness among the participants that My Health Record had been initially designed as a patient engagement tool as well as a platform for storing their medical information and sharing it with their healthcare professionals.

### *Better data for planning and policy*

A small number of women identified the secondary benefits for society of the My Health Record system, raising such issues as better provision of health and medical data for government planning, budgeting and service provision. Two of the participants who referred to these benefits worked in the health services sector and could readily envisage these applications of My Health Record data. Sally, 41, works in the Department of Health and noted that her work experiences highlighted the importance of better health data:

The more the government actually knows about how people are using the health system – even if they don't need to know about you personally, just generally what people are doing – the more they can actually figure out where the money should go. Because from the side of being in the Department of Health and just going well, the research all says we don't have good data. We'd love to answer this question, we don't have good data. My Health Record and that sort of thing would be really useful, once it's adopted and kicking along, but it'll take a while.

Erica, 55, is a nurse, and noted that she has been interested in digital health for some time, including recognising the value of EHRs for continuity of care purposes:

Especially here in Australia, because we're a federated organisation, you don't have consistent notes from one hospital to the next, let alone one state to the next. Having one electronic version, I think is incredibly helpful, especially if it's started from the day you were born

## **Barriers to using My Health Record**

### *Difficult to use*

Some women said that they were interested in signing up to My Health Record and but had not got around to organising it yet or simply did not know how to do it. One example is Priscilla, 67, who said that she was in favour of eventually registering but had not done so:

Probably because I don't know enough about it. I'm not sure how to go about it and I'm not sure what it is they would need to know and how much time it would take.

There was some confusion expressed by participants about how the system worked and how to participate in it, or observations made about the complexities of enrolling. As Sharon, 55, commented:

I have registered, but I when I go on it – I would consider myself fairly computer literate for my age and stage of life – but I haven't quite worked out how you get all of that information about yourself put on to the record, if you know what I mean? I signed up for it a long time ago, it's part of the MyGov account, but I really don't know how it works.

The problem was not just My Health Record itself, but the MyGov platform on which it was hosted. Several women made reference to other services on MyGov being difficult to access and use:

Yes, I have registered. I think I had to do it last year. I mean, I find the government departments of Centrelink and Medicare just the most difficult to use. Even when you call them it's just the most difficult place to access. So I really don't know. I know I'm signed up for it but that's it. (Julie, 51 years)

#### *System is not functional yet*

A common observation among women who had signed up to My Health Record was that the system was still not functioning adequately. Katrina, 38, has experience in medical records in her job and commented that her knowledge from her work has highlighted the deficiencies in the system. She hasn't registered yet because she wants to wait until My Health Record is working effectively:

I just kind of want them to get it sorted before I do. I just don't feel like they've got it right yet and I just don't feel like it's at a point where it's actually useful. I don't feel like it's at a point where I could actually go in there and look at the things I want to look at.

Justine, 38, said that she registered a while ago, but has not found that any information has been uploaded to it and has given up bothering to check:

I haven't logged in to check any of that for ages. When I did, there was no information for me to read off it from my doctors. I don't know if I was meant to be able to have access to my records or not, but there was nothing, only my details that I've put in. It was just like a system created that did nothing.

Several participants said that they regularly had to remind their doctors that they had a My Health Record, only to find that the doctors were not using the system or uploading information:

Recently I had something happen with my health where I was being contacted by a few different doctors because it was over the long weekend and so there were only certain places were open at certain times. So, I saw three or four different doctors for this one problem and they were like, really struggled to communicate with one another. Which is weird, because I'm on the My Health thing so surely it couldn't have been that hard. (Jessica, 24 years)

Colleen, 58, said that her doctor sought to dissuade her from using My Health Record. She had registered, and had talked to her doctor about using it:

His reaction was well, that's a waste of time because we as doctors don't even want to share that information – so why are you dialling in to do it if we're not going to sign up to it? It's not going to be shared, and you've just gone and done something that there's resistance within the medical profession to share.

Kate, 35, noted that her doctors held a proprietary approach to her medical data and were unwilling to upload her details to her record or share them with other healthcare professionals or herself:

There seems to be this funny thing where some of the doctors almost seem to view the information they get about My Health from me visiting them is their information, not something for them to share. It's not actually doing anything for me.

*Disillusionment with the healthcare system and government services*

A small number of women had made the choice not to register because of their general feelings of disillusionment with the healthcare system or other government services. These were women who were living with chronic health conditions for which they had struggled to find orthodox medical support or effective treatment. One of these participants is Megan, 48. After years of attempting to access good medical care, and finally resorting to online information and peer support groups, her general cynicism towards and distrust of medical practitioners have shaped her perspectives on My Health Record. For Megan it is simply just another part of a healthcare system that has failed her:

I signed up for it, but it seems useless to me. I was coaxed into signing up, one day, in a Medicare office. But I've been given no further information about it. I don't know what to do with it. I don't know who's putting my stuff in. Now because I'm a bit cheesed off with the healthcare system, and its utter bloody neglect, I can't see any point in that. I think a lot of the medical profession don't know what the hell they're doing ... So I don't have any faith in My Health Record at all. I can't see how it would help me now. I'm helping myself.

Sally said that she supports the idea of My Health Record, but hasn't yet signed up because she is not necessarily convinced that it will help her when she is seeking medical care for her pain condition:

I have been planning to sign up. I guess feedback from the other people in the pain support group, is that yes, it's kind of good, but it's not really hinged around pain stuff. It's not going to help you if you rock up in emergency with pain that you needed meds for, because they can't access that information for My Health Record yet. Even if you put it in, it's not accessible to them. So no, I haven't signed up yet. The problem, the linkage between primary care and the hospitals and your GP is just terrible. Or if you move around to different GPs. I mean this information just for you personally, it's not transferred very well between all these places, often your GP doesn't even know you went to hospital. The hospital doesn't know what meds you're on. Any of that.

Justine thought that the government doesn't care enough to properly implement My Health Record:

I really don't think they care. If it's benefiting us, they just need to spend money because the budget comes around each year. They need to go, look, we've spent this amount of money in our budget and we've made this. If they did an audit on all these services that are actually working, it's just going nowhere. There's not one service that has streamlined the care of the Australian people that's effective. Not one works.

*No need for it*

Some women noted that they were in favour of My Health Record, but not registered because they did not see the relevance of it. One example is Frances, 66, who was not sure if she had ever registered. She noted that in any case she did not see the point in having a My Health Record, as she always sees the same doctor:

I'd have to say, one of the reasons perhaps that I haven't even really thought about this is that basically I've been going to the same practice for 40 odd years and they've got the files there. If I see a specialist the stuff goes back to the doctor.

Another example is Erica, who commented that because she rarely saw a doctor, she currently had no need to register:

I'm not against it in a philosophical way, far from it. But just touch wood, I've been reasonably healthy and haven't needed to engage with it in any way.

### *Data privacy and security concerns*

In the accounts of those women who had chosen not to sign up to My Health Record, there was a strong current of distrust in the government to adequately protect the health and medical information stored in the system. This distrust tended to relate to the women's views that the government was ill-equipped to protect people's data adequately, rather than concerns that it would deliberately exploit their data by selling them to third parties. As noted earlier, at the time of the interviews and focus groups some well-publicised personal data breaches, disruptions and hacks, including of Australian government-held information, had occurred. Several women referred to these when recounting their caution and noted that they had difficulty trusting the government to protect their medical data.

I don't want everybody knowing stuff about me and I don't think it's safe ... Well they hacked the government census website and I don't want my personal information, like my name, my age, my address, what diseases I have, just to be public knowledge. (Kylie, 38 years)

I personally don't think the government would do a great job of securing that sort of information. They haven't done a great job on some other things, so can't imagine them doing a great job with that either. (Naomi, 53 years)

Louisa, 30, said that she views government workers as lacking the skills and knowledge to adequately protect people's data:

In some ways I'd like to think you could trust the government, but I don't really think we can. The fact that most people in the government are flat out even turning on computers concerns me pretty greatly. Like I would prefer in some ways a private business that uses really good IT security group because I know hackers, like if it was run by them, I'd be like, well if they're running it, they probably know what they're doing, it's secure as possible. They're going to employ people to test it to see if anyone can get into it sort of thing, whereas the government is just – they just don't know what they're doing.

Women who were employed in professions involving dealing with personal medical data or digital technology systems drew on their professional knowledge in evaluating My Health Record.

I'd like to know a little bit more about how the data is being protected and who's going to have access to it. I think it's a good idea, especially for people who are going to the doctor all the time and are getting prescriptions and things. The trouble is there's a certain amount of – I work in IT – so there's a certain amount of [trust] where people say 'Well, everything is basically protected.' Well no, it's not. (Tracy, 56 years)

Chelsea, 28, works in genetic research and is aware of the possible privacy implications of collecting people's genetic data, even if they have consented as part of a research study. Chelsea commented that she had chosen not to sign up to My Health Record because of her concerns that her data will not be adequately protected by the government. She noted that based on her experience in working in the medical and health research sector:

People are very well meaning but their idea of data security isn't actually data security. So I completely trust their intent. I do not trust the implementation.

### **Discussion**

Adopting a sociomaterial approach, the study identified many barriers to the participants' successful registration and use of the system. Even though all the participants were active users of online sources of health and medical information, they evinced a lack of awareness of and interest in My Health Record, suggesting that attempts by the Australian Digital Health Agency to publicise and promote the system have not been effective. Technical difficulties were identified by some women who were aware of My Health Record and favourably disposed to it. They recounted experiencing difficulties in understanding how to register or what to do once they had signed up. These barriers were identified in previous research on Australians' engagements with earlier versions of My Health Record (reviewed earlier), suggesting that little has changed in terms of the Australian public's views on their national EHR system.

The study was also able to identify that factors such as health status, previous experiences in dealing with the healthcare system, doctors' attitudes and women's work-related experiences could also contribute to their views on My Health Record. Even among those women who were certain that they had registered, none had yet found any benefit or use for it. They lacked knowledge in what they needed to do to access their information. Some women mentioned that their doctors were not yet using My Health Record. Furthermore, despite the focus placed on patient engagement in promotional material about My Health Record, few participants discussed the opportunities offered by the system to view or add to their own medical information. Those who discussed the benefits of My Health Record described these as relating to their healthcare providers being able to see all of the information in one place. There was little awareness that patients are able to control what information goes into the online summary or who could access it. Indeed, those participants who expressed highly negative views about My Health Record tended to raise issues such as lack of control over their medical data as a key concern.

As in previous studies in Australia and elsewhere, concerns about data privacy were key in many participants' accounts. Not only have these concerns persisted since the introduction of the early version of My Health Record, recent publicity in relation to the Australian government's misuse or lack of protection of citizens' personal data have led to the participants demonstrating low levels of faith in the government's capability to adequately manage My Health Record. Many participants also referred to their distrust in the Australian government to protect their medical information adequately. Government agencies were represented as incompetent rather than malicious, lacking the knowledge and skills to establish and maintain a national EHR system that was secure and effective enough to give them enough confidence or motivation to register and use it.

Several researchers have drawn attention to the ethical issues of personal health data privacy and security related to EHR systems (Bratan et al., 2010; Fry et al., 2014; Spriggs et al., 2012). The Australian Government's move towards an opt-out rather than opt-in approach to enrolling Australians into My Health Record flouts these researchers' calls for ensuring that citizens can exert informed consent. The participants in the Australian Women and Digital Health Project had a mixture of levels of educational attainment, including a high proportion with university-level qualifications. It was often those with university education and in professions related to medical data, healthcare or administration who were the most critical of My Health Record, particularly in relation to what they perceived to be the government's deficiencies in the management of it. Their high levels of digital and data literacy led them to conclude that the system was substandard. Socioeconomically-disadvantaged groups are likely to require greater support in understanding the potential threat to their health and medical data in a system like My Health Record, the implications of sensitive medical information being accessed by third parties (including the potential for stigmatisation and exacerbation of marginalisation using their data) and negotiating consent concerning who can access their data.

As these findings suggest, people's personal experiences, the actions of others such as the agencies responsible for system implementation and function, their healthcare providers and broader social, cultural and political factors are important in shaping their knowledge, interest in and acceptance of an electronic health record system. In summary, these findings suggest that the Australian government needs to provide adequate and appropriate information to the Australian public about My Health

Record, and particularly the opt-out process and negotiating consent to data sharing. It so doing, it will have to address wider problems of the Australian public's lack of trust in the ways in which government agencies collect, share, protect or exploit their personal data.

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## References

- Allen-Graham J, Mitchell L, Heriot N, et al. (2018) Electronic health records and online medical records: an asset or a liability under current conditions? *Australian Health Review* 42: 59-65.
- Andrews L, Gajanayake R and Sahama T. (2014) The Australian general public's perceptions of having a personally controlled electronic health record (PCEHR). *International Journal of Medical Informatics* 83: 889-900.
- Armani R, Mitchell LE, Allen-Graham J, et al. (2016) Current patient and healthcare worker attitudes to eHealth and the personally controlled electronic health record in major hospitals. *Internal Medicine Journal* 46: 717-722.
- Australian Digital Health Agency. (2018a) *Find out more about opt-out*. Available at: <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/opt-out>.
- Australian Digital Health Agency. (2018b) *My Health Record*. Available at: <https://www.myhealthrecord.gov.au/>.
- Barad K. (2007) *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*, Durham: Duke University Press.
- Braidotti R. (2016) Posthuman critical theory. In: Banerji D and Paranjape M (eds) *Critical Posthumanism and Planetary Futures*. Berlin: Springer, 13-32.
- Bratan T, Stramer K and Greenhalgh T. (2010) 'Never heard of it' – Understanding the public's lack of awareness of a new electronic patient record. *Health Expectations* 13: 379-391.
- de Lusignan S, Mold F, Sheikh A, et al. (2014) Patients' online access to their electronic health records and linked online services: a systematic interpretative review. *BMJ Open*, 4. (accessed 12 June 2018).
- Evans RS. (2016) Electronic health records: then, now, and in the future. *Yearbook of medical informatics*, Suppl 1. (accessed 13 June 2018).
- Ezzy D. (2013) *Qualitative Analysis*, London: Routledge.
- Fry CL, Spriggs M, Arnold M, et al. (2014) Unresolved ethical challenges for the Australian Personally Controlled Electronic Health Record (PCEHR) System: key informant interview findings. *AJOB Empirical Bioethics* 5: 30-36.
- Fullagar S, Rich E, Francombe-Webb J, et al. (2017) Digital ecologies of youth mental health: apps, therapeutic publics and pedagogy as affective arrangements. *Social Sciences*, 6. (accessed 14 November 2017).
- Greenhalgh T, Hinder S, Stramer K, et al. (2010) Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. *British Medical Journal*, 341. (accessed 12 July 2017).
- Greenhalgh T, Morris L, Wyatt JC, et al. (2013) Introducing a nationally shared electronic patient record: case study comparison of Scotland, England, Wales and Northern Ireland. *International Journal of Medical Informatics*, 82. (accessed 15 June 2018).
- Greenhalgh T, Stramer K, Bratan T, et al. (2008a) Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. *British Medical Journal* 337: 1040-1044.

- Greenhalgh T, Wood GW, Bratan T, et al. (2008b) Patients' attitudes to the summary care record and HealthSpace: qualitative study. *British Medical Journal*, 336. (accessed 12 June 2018).
- Hanna L, Gill SD, Newstead L, et al. (2016) Patient perspectives on a personally controlled electronic health record used in regional Australia: 'I can be like my own doctor'. *Health Information Management Journal* 46: 42-48.
- Hawthorne KH and Richards L. (2017) Personal health records: a new type of electronic medical record. *Records Management Journal* 27: 286-301.
- Hemsley B, McCarthy S, Adams N, et al. (2017) Legal, ethical, and rights issues in the adoption and use of the "My Health Record" by people with communication disability in Australia. *Journal of Intellectual & Developmental Disability* online ahead of print.
- Hemsley B, Rollo M, Georgiou A, et al. (2018) The health literacy demands of electronic personal health records (e-PHRs): an integrative review to inform future inclusive research. *Patient Education and Counseling* 101: 2-15.
- Huckvale K, Prieto J, Tilney M, et al. (2015) Unaddressed privacy risks in accredited health and wellness apps: a cross-sectional systematic assessment. *BMC medicine*, 13. (accessed 26 September 2015).
- Kerai P, Wood P and Martin M. (2014) A pilot study on the views of elderly regional Australians of personally controlled electronic health records. *International Journal of Medical Informatics* 83: 201-209.
- Lehnbom EC, Brien J-AE and McLachlan AJ. (2014) Knowledge and attitudes regarding the personally controlled electronic health record: an Australian national survey. *Internal Medicine Journal* 44: 406-409.
- Lehnbom EC, McLachlan AJ and Brien J-a, E. (2012) A qualitative study of Australians' opinions about personally controlled electronic health records. In: Maeder AJ and Martin-Sanchez FJ (eds) *Health Informatics: Building a Healthcare Future Through Trusted Information*. Amsterdam: IOS Press, 105-110.
- Lupton D. (2014) Critical perspectives on digital health technologies. *Sociology Compass* 8: 1344-1359.
- Lupton D. (2018) 'I just want it to be done, done, done!' Food tracking apps, affects, and agential capacities. *Multimodal Technologies and Interaction*, 2. (accessed 23 May 2018).
- Lupton D. (in press) Wearable devices: sociotechnical imaginaries and agential capacities. In: Pedersen I and Iliadis A (eds) *Embodied Technology: Wearables, Implantables, Embeddables, Ingestibles*. Massachusetts: The MIT Press.
- McGinn CA, Grenier S, Duplantie J, et al. (2011) Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. *BMC medicine*, 9. (accessed 12 June 2018).
- Newman L, Biedrzycki K and Baum F. (2012) Digital technology use among disadvantaged Australians: implications for equitable consumer participation in digitally-mediated communication and information exchange with health services. *Australian Health Review* 36: 125-129.
- Nott G. (2018) Digital Health Agency: 'No conspiracy' to keep My Health Record opt-out quiet. *ComputerWorld*. (accessed 15 June 2018).
- Pearce C and Bainbridge M. (2014) A personally controlled electronic health record for Australia. *Journal of the American Medical Informatics Association* 21: 707-713.
- Roehrs A, da Costa AC, Righi RRd, et al. (2017) Personal health records: a systematic literature review. *Journal of Medical Internet Research*, 19. (accessed 15 June 2018).
- Rosenblat A, Wikelius K, boyd d, et al. (2014) Data & civil rights: health primer. *Data & Society Research Institute*. (accessed 16 December 2014).
- Sadler D. (2018) My Health Record an 'abuse of trust'. *InnovationAus.com*. (accessed 15 June 2018).
- Spriggs M, Arnold MV, Pearce CM, et al. (2012) Ethical questions must be considered for electronic health records. *Journal of Medical Ethics* 38: 535-539.
- Van Dooren K, Lennox N and Stewart M. (2013) Improving access to electronic health records for people with intellectual disability: a qualitative study. *Australian Journal of Primary Health* 19: 336-342.

- Van Kasteren Y, Maeder A, Williams P, et al. (2017) Consumer perspectives on MyHealth Record: a review. *Studies in health technology and informatics* 239: 146-152.
- Walsh L, Hemsley B, Allan M, et al. (2017a) The e-health literacy demands of Australia's My Health Record: a heuristic evaluation of usability. *Perspectives in health information management*, 14. (accessed 13 June 2018).
- Walsh L, Hill S, Allan M, et al. (2017b) A content analysis of the consumer-facing online information about My Health Record: Implications for increasing knowledge and awareness to facilitate uptake and use. *Health Information Management Journal* online ahead of print.
- Wicks P and Chiauzzi E. (2015) 'Trust but verify' - five approaches to ensure safe medical apps. *BMC medicine*, 13. (accessed 8 October 2015).
- Zivanovic NN. (2014) Medical information as a hot commodity: the need for stronger protection of patient health information. *Intellectual Property Law Bulletin*, 19. (accessed 14 June 2018).