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Final Report

August 2018

The Impact of My Health Record Use in Primary Care: a mixed methods study

Reference No: DH0562

for The Australian Digital Health Agency

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Executive summary

The Impact of My Health Record Use in Primary Care in Western Sydney: a mixed methods study

Research team

The chief investigators on this project were Dr. Kate McBride [1] and Ms. Patricia Cornell [2] and The MHR Impact Investigating Team[3]

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Table of Contents

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Executive summary

1   Background

This executive summary describes the key triangulated mixed methods findings from the quantitative NSW GP Data Linkage Pilot Project: My Health Record sub-study and The Impact of My Health Record use in Primary Care in the Western Sydney Primary Health Network Region: qualitative sub-study. The methodology and findings from each of these studies is described in detail in the summary reports for each of the projects. The purpose of the mixed methods executive summary is to provide an overview of where the findings of each of these projects support each other within the context of the overarching aim of evaluating the benefits My Health Record (MHR) use in Primary Care in the Western Sydney Primary Health Network Region.

MHR is designed to be an effective digital system of shared and connected patient information to support improved health care, with key health information located on the system, which has been designed to be a central repository of an individual uploaded electronically in summary form. When using health services, a patient who has a MHR can grant the provider access to this summary information to inform their health care management. Currently MHR is an 'opt-in' system requiring patients and healthcare providers to register to participate, with the full roll-out of MHR in Australia ongoing. The system has been available for opt-in for some time, however recently, there have also been opt-out trials of my Health Record in selected regions. Western Sydney, the site of this project GP Data Linkage Pilot Project, is currently still an opt-in region of NSW for MHR.

Expectations of findings varied between the qualitative and quantitative research teams. The qualitative research team had no expectations of findings given they were based outside of the health care system at Western Sydney University. This adds to the strength of the qualitative findings as that research team had no pre-conceived ideas that could bias the data collection and

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analysis. The quantitative sub-study sought to explore hypotheses based on previous research that shared patient records could improve medication safety and management through:

- Reduced incidence of medication errors and/or adverse drug events
- Reduced hospital admissions and/or cost of treatment and/or length of stay, ED and/or GP visits

2   Aim

To triangulate the quantitative findings from the GP Data Linkage Project: My Health Record sub-study with the qualitative findings of The Impact of My Health Record use in Primary Care in the Western Sydney Primary Health Network Region: qualitative sub-study, to examine benefits and impact of My Health Record in the Region.

3   Methods

The methods for each sub-study have been described in detail elsewhere (1, 2). For this overarching mixed methods study, a concurrent triangulation mixed methods approach was to be used, where quantitative and qualitative data were collected at the same time (3). Studies with a concurrent triangulation design prioritise both quantitative and qualitative methods, however results are separated for analyses, then integrated, or triangulated, during interpretation (4). The data collected in the qualitative evaluation was therefore initially analysed independently of the quantitative data before the findings were subsequently triangulated with the results of that analysis.

4   Findings

4.1   Key Findings of the NSW GP Data Linkage Project: My Health Record sub-study

The sub-study of the Pilot Project compared the characteristics and outcomes such as hospital admissions and emergency department presentations, duplication of services, and adverse events,

among patients who had a My Health Record (MHR) (n=9,154), with those who did not have a MHR (n= 116,515).

Approximately 7% of patients were identified in the participating Western Sydney general practices as having a MHR. However, this varied from around 2% to 20% depending on the type of source clinical information system used in each general practice. Compared to all other patients, patients with a MHR tended to be older, have more chronic conditions, use more medications and have more hospital admissions and ED presentations. From these findings, it appears that early adopters of MHR in Western Sydney were predominantly those patients who have poorer health.

4.2 Key Findings of The Impact of My Health Record use in Primary Care in the Western Sydney Primary Health Network Region: Qualitative sub-study

A total of 35 primary care practitioners and practice staff participated in the qualitative sub study between February 2018 and June 2018. Purposive sampling was used to recruit higher MHR use primary care participants in the Western Sydney PHN region (with a further 4 participants from the 'Opt Out' Nepean Blue Mountains Region).

Findings from this research revealed several insights into the primary care experience, in the Western Sydney Primary Health Network region, around satisfaction and impact of MHR on daily practice. The most promising finding of this sub-study were the positive perceptions of MHR among these primary care providers, despite current low usage of MHR in the context of some limitations and challenges to use. MHR was especially viewed as being beneficial in acute care settings and in the care of complex patients, for example patients with chronic conditions as well as the elderly and culturally and linguistically diverse (CALD) individuals, with these patients being encouraged to opt in as a priority. This research also found that the system needed to be populated with comprehensive high-quality data, presented in a user-friendly manner, in order for the use of MHR to improve. This is because some of the factors affecting motivation to use MHR are the limited availability of viewable data, data quality, low interaction with other health care providers and the lack of current clinical outcome improvements.

4.3 Mixed Methods Findings

Comparison of the qualitative findings with the quantitative findings revealed a number of consistencies, particularly in the characteristics of patients registering for MHR. For example, the quantitative study found patients in the MHR group tended to have higher proportions in the ages 55-75 years and less aged 25-45 years compared to patients in the No MHR group. Patients in the MHR group also tended to have a higher proportion of each of the selected chronic diseases than those in the No MHR group, with fewer patients (51%) in the MHR group having no identified chronic conditions compared to patients in the No MHR group (70%). These findings are reflected by the qualitative sub study primary care practitioner descriptions of the type of patients being registered for MHR as a priority at their practices. These patients were typically elderly, more complex patients with chronic conditions and co-morbidities as well as patients who were from CALD backgrounds. These patients were qualitatively perceived by primary care practitioners in the Western Sydney PHN region as those in the highest need of MHR, and who would benefit most from clinicians other than their general practitioner having ready access to their health information.

Primary care practitioners also reported multiple medication use in this priority group, which supports the quantitative findings showing a higher proportion of patients in the MHR group recorded as being prescribed selected medications than those in the No MHR group. Furthermore, a higher proportion of patients in the MHR group experienced hospital admissions (nearly 10% higher), and increased emergency department presentations when compared to the No MHR group. Again, this was consistent with qualitative interviewee accounts of the characteristics of the patients they encouraged to register with MHR, that is, those more likely to be experiencing poorer health. Significantly, this was reported by qualitative interviewees as the group of patients they could see MHR being of most benefit in terms of medication management and continuity of care.

The quantitative sub-study found there was an increased proportion of patients in the MHR group who were admitted to hospital for adverse drug events as compared to the No MHR group (10.7% and 6.6% respectively). This is also consistent with the qualitative primary care perspectives on the heightened need for MHR among the priority patients they identified, due to their greater risk of adverse drug events.

5   Future research

There is a need for ongoing enquiry in these areas. Specifically, mixed methods research examining case studies of individuals with chronic conditions as they navigate through the health system could add an important perspective to benefits and limitations of MHR to patients and clinicians. This could also highlight repetitions, such as duplication of pathology, experienced by patients during their healthcare journeys and help to reduce unnecessary servicing in the system. As experience and duration of MHR evolves, detection of the impacts of MHR will become more viable in quantitative and qualitative studies such as those presented here. Therefore these mixed methods approaches should be revisited as MHR becomes more established in Australia. Further, closer mixed methods scrutiny of uptake among the broader range of sectors of the healthcare system will be warranted.

6   References

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The impact of My Health Record use in primary care in the Western Sydney Primary Health Network region: Qualitative evaluation August 2018

Research team

The chief investigators on this project were Dr Kate McBride [1], Prof Andrew Page [1] and Dr Shahana Ferdousi [2] with Ms. Sandra Sonego [1] as associate investigator.

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Contents

List of Figures and tables

7   Executive Summary

This report presents the findings of a qualitative evaluation of My Health Record (MHR) use among primary care practices in the Western Sydney Primary Health Network, who have been part of the Western Sydney General Practice Data Linkage Pilot Project (currently still an opt-in region of NSW for MHR). MHR is designed to be an effective digital system of shared and connected patient information to support improved health care with the introduction giving healthcare organisations the opportunity for faster, easier access to important summary health information for their patients. While there is some evidence that MHR improves the efficiency and effectiveness of the Australian health system, a consistent improvement of quality care has not yet been demonstrated and potentially may also be increasing healthcare provider workload.

The present study aimed to qualitatively examine how MHR may impact on clinicians and consumers by potentially improving work efficiency, reducing time spent on communication with other clinicians, improving medication safety, and reducing duplicative diagnostic imaging and pathology testing.

Findings from this research reveal several insights into the primary care experience, in the Western Sydney Primary Health Network region, around satisfaction and impact of MHR on daily practice. The most promising finding is the positive perceptions of MHR among these primary care providers, despite current low usage coupled with the limitations and challenges outlined in this study. For frequency of use of MHR to improve, however, population of the system with comprehensive high-quality data, presented in a manner that is user friendly and efficient to use is much needed as factors strongly affecting motivation to use MHR are the limited availability of viewable data, data quality, low interaction with other health care providers and the lack of current clinical outcome improvements. As one GP reported "I'd use it all the time if I could easily access everything on there, why wouldn't I?"

7.1   Key messages

MHR is positively viewed by primary care practices in Western Sydney

Almost unanimously, interviewees were able to see to see the future potential benefits of MHR to both their practice, in terms of streamlining communication and reducing unnecessary tests as well as the optimising care of their patients and reduction of adverse medical events.

MHR can optimise patient care among particular patient groups

MHR was especially viewed as highly beneficial in acute care settings and for their complex patients, the elderly and CALD individuals. It should be noted, however, that while some actual accounts provided by interviewees of proven benefits for patients, the perceived benefits for the majority of those interviewed were largely theoretical and based on such a time that adequate information was being uploaded into MHR across all clinical areas.

Positive attitudes found in primary care need to be fostered and utilised

The positive attitudes about the potential benefits of MHR presently held by primary care practitioners in the Western Sydney Primary Health Network region need to be harnessed. Healthcare practitioners require further encouragement, support and continual communication, including updates, incentives and reminders of MHR's benefits to maintain these attitudes. Should these positive attitudes not be supported, they may diminish in the currently minimal actual benefits being seen.

Evidence of MHR success can motivate use

To address concerns around the current lack of tangible benefits in clinical outcomes, further studies are suggested. Practitioners also need to see evidence that MHR is making a difference in patient care, and this could be communicated through individual patient cases that illustrate MHR successes, serving as motivation for consistent use of MHR.

Further promotion of the potential positive benefits to the clinicians and consumers is needed

Awareness building and encouragement needs to be delivered to both clinicians and patients to maximise MHR use. Specifically, the benefits outlined in this study, such as MHR being beneficial in emergency hospital settings, being helpful with older patients, CALD individuals and people with chronic conditions, need to be highlighted and better communicated to clinical users and consumers in a meaningful way. Clinicians also need to be equipped with tools to help them address patient concerns around security and confidentiality.

Early adopters of MHR could be peer champions

Identification of clinicians who are early adopters, and are skilled high frequency users can encourage other clinicians to increase their use of MHR. They could act as facilitators, role models, peer supporters, and ambassadors, helping to foster acceptance of change.

Wider implementation of MHR in different healthcare settings is needed

An important motivator for primary care use appears to be uptake and use by specialists and hospital based clinicians. Broader use of MHR among these other healthcare providers would be one of the important strategies to increase MHR use by addressing the lack of viewable data available, as well as providing the incentive of interdisciplinary teamwork leading to better management of patients. This uptake is seen as being essential to truly see an improvement in communication efficiency.

7.2   Key recommendations

- Development of an easy to follow checklist for clinicians to improve completeness of medication records, including reasons for medication changes, and to strengthen trust in MHR, in clinical care decision making

- Clear guidelines for clinicians on timelines for entering data to support currency of MHR information

- Improved presentation of the medicines information view to allow more efficient medication reconciliation activities, including classification and linking of medication listings, and incorporation of efficient and easy to use search functions

- Regular updates for primary healthcare providers on newly added features to MHR, such as private pathology and diagnostic imaging reports

- Increased compatibility between existing practice software and MHR as well as greater integration of information, to minimise duplication of medical reports received in GP software and MHR

- Improvement of navigation and data view of pathology and diagnostic imaging reports to include a summary of results overview page (request and summary of results) and addition of search functions

- Targeted education and awareness raising of MHR among hospital clinicians focussed on the benefits of MHR to improve continuity of patient care on admission to hospital and following discharge

- Development of an easy to follow tailored checklist for hospital based clinicians to improve completeness of medication records, including reasons for medication changes

- Provision of support and incentives to accelerate the connection of private hospitals to MHR

- Consultation and/or research to investigate the barriers to MHR use among specialists and hospital clinicians

- Leveraging early adopters of MHR to be peer champions of MHR to encourage use among their peers

- Creation of a simple visual prompt for GPs consultation rooms to encourage, remind and explain step-wise the MHR data entry processes as well as security of data, during consultation with patients

- Automated built-in reminder systems that delivers prompts to upload to MHR on GP software

- Introduction of MHR in medical curriculums

- Development of features on MHR that generate greater interactivity between clinicians, for example, a communication screen that could be used with patients under the care of multiple clinicians

- Investigation into an update function for records that may need to be amended, for example, care plans

- Consultation with clinicians on their workloads to determine how MHR can be better integrated into the existing daily workflow and become a routinely used system

- Assistance provided to practices to get patient data uploaded into MHR

- Attachment of CPD points to the MHR training to increase the uptake of this training

7.3 Study limitations

Some of the limitations of this study include the small sample size and restriction to practices in the Western Sydney region, that may affect generalisability of the findings. A further limitation of this study is that despite 'high MHR users' being targeted as participants, in reality usage in general was much lower than anticipated. Due to this overall low usage of MHR, some of the interview questions were unable to be answered by interviewees, as they had not yet accessed certain functions or were unaware of their availability. Consequently, while still valuable in being able to highlight possible future benefits of MHR, responses from interviewees on certain topics were largely hypothetical.

8   Background

The prevalence of medication use in the Australian general population is approximately 60% with the proportion of the population using prescription medications increasing with age, as does the number of medications used per person[1,2]. Approximately 2% to 3% of hospital admissions in Australia are caused by avoidable medication errors[3,4]. Medication errors are associated with considerable healthcare costs[5]. Further, it has been estimated that 13% of patients have experienced an adverse drug reaction after taking prescription drug medication prescribed by their primary care provider[6] It is also estimated that approximately 14% of pathology tests are duplicated as a result of doctors' lack of access to prior test results[7]. Electronic health records have been proposed as an important means to improve quality of patient care, reduce medical costs and improve safety[2,8].

My Health Record (MHR) is designed to be an effective digital system of shared and connected patient information to support improved health care and is a key element of the National Health Reform agenda. The introduction of MHR has given healthcare organisations the opportunity for faster, easier access to important summary health information for their patients, with an overall aim of creating a more efficient health system. Currently MHR is an 'opt-in' system requiring patients and healthcare providers to register to participate. In October 2016, the Australian Government trialled 'opt-out' sites in Northern Queensland and the Nepean Blue Mountains of New South Wales to assess the public response to different participation arrangements and guide strategies to improve MHR use. The 'opt-out' arrangement involves the automatic creation of a MHR unless individuals choose not to have one. Recommendations from a recent evaluation[9] have led to the MHR National 'opt-out', scheduled to roll-out later this year. This should accelerate improvements in continuity of care, reduced adverse events due to medication errors, reduced hospital admissions and improved medication management, particularly for chronic conditions[10-12].

While there is some evidence that MHR improves the efficiency and effectiveness of the Australian health system, a consistent improvement of quality care has not yet been demonstrated and potentially may also be increasing healthcare provider workload. The present study aims to qualitatively examine how MHR may impact on clinicians and consumers by potentially improving work efficiency, reducing time spent on communication with other clinicians, improving medication safety, and reducing duplicative diagnostic imaging and pathology testing. By gaining a better understanding of the impact of MHR on clinical practice, recommendations to guide and improve MHR adoption could be developed, and areas identified where current systems can be improved.

9   The Research Study

The aims of this study were to qualitatively explore GP and practice staff experiences of, and satisfaction with, using MHR in primary care in the 'opt in' site of Western Sydney Primary Health Network (PHN). This included the impact of MHR use on the improvement of medication safety and reduction of pathology and diagnostic imaging test duplication. A small sample of interviewees from the Nepean Blue Mountains (NBM) PHN were also included to examine any variance in MHR experiences and satisfaction of MHR due to NBM PHN's status as an 'opt out' site. These findings will be triangulated with quantitative findings from the NSW Ministry of Health led GP Data Linkage Project. It is anticipated that this study will contribute to the continual quality improvement of MHR, as well as highlight gaps in usage by primary care providers in the Western Sydney PHN. Identification of issues and gaps in usage will inform potential improvements that may in turn lead to an increase in quality patient care, enhanced medication safety and reductions in duplicative diagnostic imaging and pathology test requests.

This report presents the views of GP and practice staff experiences on the satisfaction and impact of MHR in daily practice, as well as their perspectives on the utility of MHR in being able to reduce adverse medical events as well as duplicate pathology and diagnostic imaging requests.

9.1   Research Methodology

A total of 39 primary care practitioners and practice staff participated in the study between February 2018 and June 2018. Purposive sampling was used to recruit high MHR use primary care participants in the Western Sydney PHN region. Potential participants were first identified and approached by Western Sydney PHN through existing communication channels. A list of select practices with known higher use of MHR was generated by Western Sydney PHN and provided to the Western Sydney University research team who contacted practices from the list to further explain the project, confirm participation and organise consent and interviews. Thirty-five interviewees were from primary care practices in the Western Sydney PHN region with an additional 4 interviewees from the Nepean Blue Mountains PHN region. Interviewees included 23 GPs, 5 practice managers, 8 practice nurses and 3 administrative staff (Table 1). Data was collected via one-on-one interviews and focus groups using a semi-structured interview schedule (Appendix 1).

9.1.1 Interviews

Trained interviewers from the Western Sydney University team conducted the interviews. Interviews and focus groups took place at the interviewees' place of work. In the few cases where it was not possible to conduct the interview at their practice, phone interviews were arranged. Primary care interviewees gave informed consent with all interviews and focus groups digitally recorded with permission. Reflective notes were also taken by the researcher conducting the sessions and interviewees were able to withdraw at any time without penalty. Topic areas focussed on the feasibility of MHR in being able to reduce adverse medical events, duplicate pathology requests and diagnostic imaging requests as well as satisfaction, impact and usability of MHR and recommendations to improve the use of MHR.

9.1.2 Data Analysis

All interviews and focus group content were transcribed verbatim by a professional transcription service. Interviewee contributions were de-identified as they were converted to transcribed text with names replaced by interviewee numbers. Transcripts were analysed by thematic (inductive) analysis [13], a qualitative method for identifying, reporting and interpreting patterns within interview data, informed by grounded theory methodology.

Table 1. Characteristics of primary care interviewees

Primary care role	Number of participants
Western Sydney region:	
General practitioner	22
Practice manager	5
Practice nurse	5
Administrative staff	3
Nepean Blue Mountains region:	
General practitioner	1
Practice nurse	3

10 Findings

10.1 General characteristics of MHR Use

10.1.1 There are positive perceptions of the potential benefits of MHR

In general, interviewees had a positive perception of MHR, speaking favourably about its potential to increase the efficiency of health services and deliver better quality of care to patients. Although interviewees indicated overall satisfaction with the use of MHR and could see its value as a tool for enhanced data sharing, interviewees reported that the clinical benefits of MHR were not yet being realised. Concrete examples of MHR's benefits are lacking, at this stage, in daily practice as the majority of clinicians could only speak about future hypothetical digital health benefits, rather than being able to provide real accounts of benefits actually being experienced. This is interesting given that MHR (previously named Personally Controlled Electronic Health Record) has been active since 2012, yet the interviewees in this study still viewed MHR as a 'new' system in the preliminary stages of adoption, believing it would take some further time to see the full benefits of the system. It is possible that the general low uptake of MHR among practitioners and the resultant limited availability of data on MHR contributed to this perception.

10.1.2 Patients with poorer health are being registered for MHR as a priority

MHR registration was considered to be a straight-forward and easy process, mostly without issue. Registration was primarily conducted by practice nurses. Only a few difficulties were cited with patients that had minimal or no technical ability, in particular elderly CALD individuals with language barriers. Other issues specified in the creation of MHR included mismatches with patient names, date of births, registration of newborns and patients with certain visa status. Of note, the majority of practices identified priority registration groups such as the elderly, those with chronic diseases and CALD individuals, consistent with the MHR patient characteristics identified in the Western Sydney General Practice Data Linkage Pilot Project.

10.1.3 Existing low frequency of MHR use

No interviewees considered themselves high users of MHR, with most classifying themselves as low to medium frequency users. High frequency use was defined by interviewees as routinely accessing and uploading data on MHR for the majority of patients as an integral part of daily practice. A number of interviewees described an initial increased frequency of use when MHR was introduced at their practices. This was followed by a decrease in frequency of use over time, when they found limited perceptible benefits (largely due to lack of content on MHR). The majority of practitioners who we

spoke to indicated they regularly uploaded health summaries to MHR, though several indicated this was largely due to the need to meet their 'quota' of uploads as required by the PHN, with several interviewees estimating the proportion of patients registered with MHR at their practices to be around 10%, which appears to be consistent with this quota fulfilling. Few reported consulting MHR routinely when seeing patients. Taken together with the low proportion of patients registered with MHR, high frequency use is not apparent among our interviewees.

10.1.4 Functions most commonly used on MHR

The most commonly reported functions accessed in MHR were the shared health summary, event summary, hospital discharge summaries, medicines information view, PBS data, MBS data, immunisation data and advanced care planning documents. Interviewees indicated infrequent utilisation of other features such as e-referral letters, pathology reports and diagnostic imaging, specialist letters, child development information and any patient-entered data. As GPs access MHR through their various clinical information systems (CIS), it is anticipated that function use may be affected by differences in each CIS, however it should be noted that number the interviewees we spoke to had limited knowledge around information technology (IT).

10.1.5 MHR is easy to use with regular use

Interviewees on the whole described MHR as being easy to use and navigate, though there were some issues with specific areas of MHR. While MHR was considered easy to use, the low frequency of use meant that building familiarity and confidence through the routine practice of accessing MHR was difficult to achieve. There was one case of a completely paper-based GP that was entirely unfamiliar with MHR. Although this GP may represent a small minority it is expected that competency in dealing with technology would affect MHR's perceived ease of use. Other specific issues related to usability are discussed further in the relevant sections.

10.1.6 In general, patients are positive and receptive to MHR

Interviewees viewed their patients as positive and receptive to MHR once the benefits to their health outcomes were clearly explained to them, such as improving the patients' critical safety when they are not in the vicinity of their practice.

> *All are quite accepting, especially when you really talk about the positive factors, like nobody is confused about your medications, nobody is going to forget about your allergies and this is a medical record that you can take wherever you go (General Practitioner, P03)*

Without explanation and encouragement to their patients, interviewees perceived the awareness and priority of MHR among these patients to be low. Some patients assumed an advanced level of data upload to MHR, often asking healthcare providers to "look up their file", believing all their past medical records were readily accessible. Interviewees indicated that only a very small group of patients had concerns about privacy and data security. This, however, may be due to the specific characteristics of the patients currently enrolled in MHR. It is likely they have considerable health concerns, given the priority enrolment of patients with complex and chronic conditions, with these health concerns outweighing any privacy and data security concerns.

Of note, however, interviewees in this study reported they were unclear on how to address the patients' concerns, as they were not experts in IT, with one interviewee expressing it was unfair to place the responsibility on GPs of explaining this type of information (around security and confidentiality) to patients. If clinicians are unable to adequately deal with patient's privacy and data security concerns it may potentially represent a barrier to consumer uptake of MHR for the general population.

> *I'm not an IT person. Any security – If they can hack the American Government, they can hack anyone. I don't know. This is not my area (General Practitioner, P29)*

> *It's impossible. And to shove this to me and make me responsible for it and I have to convince the patient and teach the patient all that kind of stuff. It's really unfair, totally unfair, 'cause the government haven't done their homework, they haven't advertised it, they haven't explained it to patients what it's all about, and most of them, the people have some kind of worries about this – who's gonna know what and when? It might affect my WorkCover cases, it might affect my ex-wife, whatever it is. So there's issue of privacy which really hasn't been explained properly which I understand for the patient. (General Practitioner, P06)*

Recommendations:

- **Provision of clear explanatory materials for GPs to use to address patient concerns around security and confidentiality of data on MHR**
- **Broader marketing strategy of MHR potential benefits e.g. for patients with complex conditions, to the general public**
- **Distribution of clear guidelines on who can access MHR data to reduce public confusion around safety and visibility of their medical records**

10.2 Medicines information view and medication safety

10.2.1 Primary care providers see themselves as having a key role in medication safety

The medicines information view was stated by interviewees as being an increasingly common function used within MHR. Most interviewees were satisfied with this aspect of MHR and expressed optimism regarding its benefits, praising the ability to access and update patient medication data efficiently. The majority of our interviewees were optimistic about the contribution this function of MHR could make towards reducing medication errors in the future. Medication tracking on MHR was believed to provide the opportunity for increased transparency and improved quality of care for their patients. GPs clearly identified themselves as holding the primary responsibility for providing and maintaining accurate medication information for their patients and recognised their central role in medication safety. Though some physicians could at times feel overburdened by meeting MHR upload quotas, ensuring and improving the safety of their patients was a strong motivator to continue uploading data to MHR.

10.2.2 MHR has the potential to improve patient care

The MHR medicines information view was seen as being able to provide direct benefits to patients as well as having the potential to reduce medication errors and adverse drug events. These benefits were perceived to be especially accentuated in acute health settings where patients were suddenly admitted to hospital, had limited English language skills or were unconscious. Rather than needing to call GP surgeries to obtain medication information or if the emergency event occurred after-hours, the immediate access to the patient's most updated medication data could facilitate and improve the quality of care provided in these crisis situations and could save lives in time-critical conditions, if the information was being accessed by other clinicians. Interviewees reported that the anxiousness often experienced by patients and their families during an emergency could affect their recall of medication details and this feature of MHR could greatly alleviate stress and worry, overcoming obstacles to optimal care. However, it was reported that GPs still received calls from emergency departments who failed to access relevant information on MHR, indicative that routine use of MHR is still sub-optimal in other healthcare settings.

Interviewees also believed that the availability of medication data on MHR was especially valuable in managing their complex patients, such as those with multiple chronic conditions. Complex patients are typically on numerous medications and the opportunity to enhance the tracking of their medications was well regarded, and could be seen to reduce the potential risks of medication errors

in this group. Primary care providers expressed great satisfaction at being able to re-assure their complex patients that their records would be accessible in any healthcare setting, including overseas.

> *I have lots of complex patients so I can see the value to my complex patients of having an accurate health record so that when they do go somewhere else, whoever is treating them has access to accurate information. (General Practitioner, P29)*

Elderly patients, especially those that frequently travel ('grey nomads') were mentioned on several occasions as being excellent candidates for MHR. Other specific groups that were described as gaining most benefit were culturally and linguistically diverse (CALD) patients, where MHR could overcome language barriers, and patients who have memory issues or intellectual disabilities.

> *Like I said, the different groups of people, like our seniors who travel a lot who are on multiple medications, or culturally and linguistically diverse population where English is a barrier for them to explain what exactly is happening, so they don't have to go a whole a lot and explaining, even for other patients who have certain problems that when they meet somebody new, they need to explain that with them, so everything is there. (General Practitioner, P03)*

Furthermore, there were both perceived and actual advantages identified for new patients coming to their practices or patients moving to another location. Although patients can often list their medications from memory, they may forget doses or confuse medication names. Accessibility to an up-to-date MHR medications view in these cases was seen to save time, without having to re-gather clinical information or request records from other medical practices. Instead that time was used for the actual consultation. In two of the practices within the sample, this benefit had already been experienced.

> *That's been so helpful. It's happened a few times. I'm like, "Oh, that's good," 'cause they were out of area and they were travellers or new to the practice. And then looking again at their medical history, so then we know what we're dealing with or like why they're – they might be on Warfarin and, "Why are you on Warfarin?" We have no idea why they're on Warfarin. And you have a look. Oh, it's because they've had a DVT. (General Practitioner, P35)*

Regarding the transition of patient care, the ability to access any changes to medications upon discharge from hospital was also highly valued and deemed helpful in clarifying the patient's continued care and preventing possible medication misadventures. One criticism of the electronic discharge summaries however was that sometimes when medications were changed during hospital visits, the explanation for the changes were lacking, with GPs stressing the importance of providing

complete medicines information. This concern is consistent with previous research comparing electronic and paper-based discharge summaries [14].

> *I don't know that I've used it at all for the moment. I mean, 'cause you've got to have data up there, you've got to have something to download. And I think when it comes to medication safety, the potential is I've got my accurate – this is what they're on and so when they go to the hospital, they know. But the question is how good are the quality of data that I get back from them because if they change their medications, I not only need to know what they've been discharged on but why.*
> *(General Practitioner, P29)*

An additional benefit of medicine record management on MHR was its promotion of continuous 'data cleaning' to keep records updated. This increased monitoring and added incentive to keep medication records frequently updated was a welcomed tool for continuous improvement and increased level of medication safety.

Although there were some actual accounts provided by interviewees of proven benefits for patients, the perceived benefits for the majority of those interviewed were largely theoretical and based on such a time that adequate information was being uploaded into MHR across all clinical areas. Currently, an observed low use of MHR in the broader medical population was reported, with the exception of medication updates from discharge summaries, GPs were primarily viewing their own uploaded information. Quantifiable improvements in medication safety could not yet be detected by interviewees, however they remained positive about the future of medication safety with the use of MHR and expressed that in order to reap the full benefits it could only work if all healthcare providers including hospital clinicians and specialists were all on board and contributing.

10.2.3 There is a concern in accuracy of medication information on MHR

A common concern expressed by interviewees was about the accuracy of medication information and its timeliness. Although the medicines information view is intended as a decision-making support tool, there was low confidence and trust that the record is a complete picture of the patient's medication history. Some of the reasons cited were that the accuracy of the records was highly dependent on whether the patients were granting access to their MHR when visiting other healthcare providers. Among our interviewees, there was both scepticism and curiosity about whether other healthcare providers were uploading medication data in a timely manner or whether any medication reconciliation was being conducted. The prospect of incomplete medication records appeared to

reduce the perceived reliability of the MHR medicines view and could present some challenges in clinical care decision making.

10.2.4 There is low confidence in MHR's ability to reduce 'doctor shopping'

Most practices did not report a high volume of 'doctor shopper' type of patients, such as those with opioid dependencies. However, interviewees did not feel confident that medication monitoring through MHR could result in a reduction of doctor-shopping, believing that patients would either choose to opt-out or restrict access to their record, rendering MHR inadequate for tracking medication use for this purpose. Interviewees felt limited in being able stop it, with some suggesting compulsory real-time prescription monitoring as a possible solution to the problem.

10.2.5 Issues exist with the usability and display of medication data

A number of interviewees discussed issues with the display of the medication data on the MHR medicines view. It is unclear whether this was dependent on the type of CIS used. In cases where patients were on multiple medications and had a high frequency of prescription and dispensing records, the medication items listing could be too numerous and overwhelming to view, which could cause confusion for healthcare practitioners and an increased risk of prescribing errors. Additionally, this presentation of medicines information could be time consuming to view. Some interviewees suggested the linking of medication items and enhanced search features to improve this medicines display issue.

Recommendations:

- **Development of easy to follow checklist for clinicians to improve completeness of medication records, including reasons for medication changes, and to strengthen trust in MHR, in clinical care decision making**
- **Clear guidelines for clinicians on timelines for entering data to support currency of MHR information**
- **Improved presentation of the medicines information view to allow more efficient medication reconciliation activities, including classification and linking of medication listings, and incorporation of efficient and easy to use search functions**

10.3 Pathology reports and diagnostic imaging

10.3.1 Viewing rates of pathology and diagnostic reports are currently low

There was low awareness and access of pathology reports and diagnostic imaging by interviewees on MHR, with only a small number of interviewees reporting use of the pathology reports function, and fewer having accessed diagnostic imaging due to the limited availability on MHR. Access to pathology and diagnostic imaging reports from public hospitals has been in place since April 2017, with private pathology and diagnostic imaging laboratories in the process of connecting to MHR at the time of this study. The limited use of these functions by interviewees is consistent with the low number pathology reports being uploading at the time of interview. Nonetheless, all interviewees could identify the substantial future theoretical benefits in the reduction of test duplications, cost and time savings, all which could lead to an increased quality of care for their patients. It is promising that despite not yet being able to fully benefit from these features, interviewees maintained a positive outlook about its use and looked forward to seeing the wider availability and use of these functions, indicating that primary care providers are no longer questioning the introduction and use of MHR in their practice.

As a more recently added function of MHR, limited use and viewing of the pathology reports and diagnostic imaging features were attributed to low awareness of their availability and reduced familiarity. Furthermore, interviewees reported a lack of available reports to view, with very few having encountered any uploaded pathology reports or diagnostic imaging as yet.

> *I don't think that the rest of it, the ancillary parts, have been used much at all because the pathology and imaging is so new to be added to the My Health Record. I don't think that our providers here would have had much experience with that yet. (Practice Manager, P28)*

10.3.2 Immediate access to pathology and diagnostic imaging reports through MHR can optimise continuity of care

Most interviewees recognised the potential benefits of secure digital access to pathology and diagnostic imaging reports that could lead to timely viewing of reports and follow-ups, improved patient monitoring and minimisation of unnecessary duplication of tests. Among interviewees that had the opportunity to view pathology and imaging reports, GPs described the very satisfying experience of promptly and easily accessing pathology reports (where available), including being able to see follow up details clearly, saving time and receiving positive responses from their patients.

> *Yeah, because like I said, I haven't – actually, radiology, I have not had the opportunity to have a look as yet, but pathology definitely, because it's so much –my patients, they feel much more relieved because we have the time to sit down with them and then go through all the results with them like what we do here on an everyday basis, and explain to them what each of these results mean. Some results might be actually very comforting or would be a positive and that really helps them, so, yeah, definitely.*
> *(General Practitioner, P03)*

Interviewees also mentioned the benefits in emergency situations when patients go to hospital out of hours, saving the need to re-do tests and providing clinicians with critical clinical information that could improve the patient's outcome. Similarly, upon being discharged from hospital it was considered potentially very valuable and efficient to have immediate access to the pathology and diagnostic imaging reports conducted while in hospital, reducing the time spent requesting copies of results.

Due to the very limited use of the pathology and diagnostic imaging reports on MHR, interviewee views on its advantages were mostly restricted to their envisaged potential benefits rather than current benefits being experienced. Some GPs stated that all patients' past pathologies and diagnostic imaging records would need to be available in order for these features to be truly useful, reduce duplicate testing and save costs.

10.3.3 Perceptions exist that MHR records may be incomplete, impacting on use

Some GPs indicated that the pathology reports and diagnostic imaging functions are currently somewhat limited and unreliable, and believed they would not represent a complete record of the patient's test history due to the patient being able to pick and choose what is uploaded and accessible. It is unclear whether this situation differs to patients providing selective verbal medical histories. It is possible it may indicate clinician expectations of higher standards for an electronic health system (perhaps due to the permanency and visibility by others of electronic records) compared to current practice. Additionally, interviewees mentioned that there did not appear to be many pathology laboratories or diagnostic imaging centres currently uploading reports to MHR, with only public pathology reports being available so far and none from private pathology companies.

> *I think pathology report as well, I think it's only from the hospital labs. I don't know if they are talking to the private pathology labs. I'm not sure whether that's come through and – radiology, I haven't had any patients so far, yet, but pathology yes. (General Practitioner, GP02)*

This was reflected in several interviewees reporting that while they had accessed the pathology and diagnostic imaging features on MHR, they had not yet seen any reports available for view. Encountering this lack of data seemed to act as a barrier to continued use.

> *So, this one I'm looking at, at the moment, hasn't got anything in here. And he's in, I know he's had lots, so I – there's nothing actually in there. There's no pathology in there for some reason.*
> *(Practice Nurse, P36)*

The combination of low data availability and low usage appeared to create a perception of limited current accessibility of pathology and diagnostic imaging records. Moreover, interviewees expressed the need for all healthcare providers to be contributing at the same level, with greater communication and collaboration in order to achieve the objectives of MHR.

> *Yeah, it's ridiculous the amount of waste that goes on just because people are too lazy to go and look and see if there's a result, or the patient doesn't remember or is sickly, just wanting to repeat everything because they don't trust the first result. So, if we had that information easily accessible, and at the moment, My Health Record is not easily accessible. (General Practitioner, P30)*

> *There's no doubt, but the problem is, the objective of this – actually to save the government money, communicate well, so no doubling of tests and you know what safety of these drugs. That's not achieving at this stage because all players has to be playing the same game and the same level.*
> *(General Practitioner, P06)*

10.3.4 Confusion around integration of existing CIS and ease of navigation in MHR is a barrier to MHR use

There were a few interviewees who indicated dissatisfaction with the navigation and data view of the pathology reports in their CIS, describing it as cumbersome, time consuming and laborious, requiring each test to be opened individually.

> *Yeah, as I said, I haven't seen any diagnostics but the pathology –and it was a hospital one, I think. It was very laborious to click, and save it in to your notes. There has to be an easy way to save things. I don't know, I'm not an IT but there has to be something that does not take – because, it's just – it wasn't worth my time. I looked at them but to actually save them into the file would have been very laborious.*
> *(General Practitioner, P29)*

Other interviewees seemed to be confused about the clinical software requirements to access pathology reports, highlighting a need for further support and training in these MHR functions.

> *Pathology report, we have to – we still have to save it. I don't know whether we know how to do it or I'm not sure– I was told that should be able to December, but last year – but still, I don't know how to get that pathology report integrated as a report. Yeah. I don't know. (General Practitioner, P34)*

In practices where pathology was already part of the GP clinical software, such as Medical Director, interviewees commented that there was an element of duplication, indicating that better integration of MHR and their practice software would be desirable. As non-IT specialists, GPs were unable to describe how this increased integration would work. In consideration of the current variability in practice CIS, one possible solution could be the standardisation of practice software, utilising one default CIS for MHR use.

Recommendations:

- **Regular updates for primary healthcare providers on newly added features to MHR, such as private pathology and diagnostic imaging reports**
- **Increased compatibility between existing practice software and MHR as well as greater integration of information, to minimise duplication of medical reports received in GP software and MHR**
- **Improvement of navigation and data view of pathology and diagnostic imaging reports to include a summary of results overview page (request and summary of results) and addition of search functions**

10.4 Availability of hospital discharge summaries increases use of MHR

One of the most favourably viewed and mentioned features of MHR were the hospital discharge summaries, which were a source of confidence in the potential benefits MHR could offer.

Interviewees identified several advantages of the electronic discharge summaries. One highly valued aspect was the improved legibility, providing greater ease in interpreting the document. Digital discharge summaries were also seen to facilitate the patient's transition of care, preventing any delays in the continuity of medical care and reducing any clinical information gaps. The discharge summaries were regarded as particularly useful in cases where patients forget or misplace their paper discharge summaries at follow up. Many patients may not know the precise names of surgeries, procedures, diagnosis or recall any alterations to their medications during their hospitalisations. The prompt access to this information allows the provision of quality, appropriate follow-up care by the GP, at the same level as when they were discharged.

Although the electronic discharge summaries were highly regarded, many interviewees had experienced delays and inconsistencies in their uploading. For example, one GP reported receiving a discharge summary four months after the patient's hospitalisation. Another GP told of a patient who had been hospitalised twice in the month, one discharge summary was uploaded while the other was not, highlighting inconsistent use among hospital clinicians. Additionally, interviewees stated they were not yet able to see discharge summaries from private hospitals.

Many of the interviewees emphasised the importance of complete, accurate and timely hospital discharge summaries (that could often be lacking), to ensure continuity of care among their patients.

> **Recommendations:**
>
> - **Targeted education and awareness raising of MHR among hospital clinicians focussed on the benefits of MHR to improve continuity of patient care on admission to hospital and following discharge**
> - **Development of easy to follow tailored checklist for hospital based clinicians to improve completeness of medication records, including reasons for medication changes**
> - **Provision of support and incentives to accelerate the connection of private hospitals to MHR**

10.5 Optimising MHR use among specialists and other healthcare providers could realise MHR's full potential

Very few of the interviewees reported encountering any information uploaded to MHR by specialists or other healthcare settings. Almost ubiquitously, the primary care providers we interviewed strongly believed that the full benefits of MHR would only be realised once specialists became active on MHR. Given their central role in coordinating the care of patients, GPs proposed that multi-disciplinary communication via MHR and more efficient communication would facilitate and enhance patient management.

> *And same with specialists, they play a big part in our management. If we don't have them on board as well, then that's a big gap 'cause we're focused so much on team management, multidisciplinary management with all the government sort of Medicare things like arrangements and management plans that we're coordinating. If we are seen as – GPs are coordinators of care for patients –how can we coordinate things if we don't have the information? So it's really hard for us to do*
> *(General Practitioner, P35).*

Currently, letters from specialists can take several weeks to arrive with the primary care provider, with patients typically following up with their GP before the letter arrives. This results in time being needed to chase up specialist letters or even an element of guesswork in follow-up treatment while waiting for the letter. Having the capability to access specialist letters on MHR was considered to be a key aspect in making use of MHR an integral part of everyday practice. According to most of our interviewees, higher availability of information from specialists and other healthcare providers was seen to be a key incentive to routine use MHR and could function as a powerful motivator to increase MHR use.

Recommendations:

- **Consultation and/or research to investigate the barriers to MHR use among specialists and hospital clinicians**
- **Incentives for specialists, private hospitals, pathology labs and diagnostic imaging company to upload results and communication to MHR in a timely manner**

10.6 Factors affecting consistent use of MHR

10.6.1 MHR is seen as an 'empty bag'

As one GP described, MHR commenced as an 'empty bag', with most 'bags' still waiting to be filled with patient information. The minimal amount of viewable clinical data was frequently cited by interviewees as a reason for the lack of motivation to routinely use MHR.

> *So, we have patients that come in as they're from interstate and they – "Oh, I've left my prescription. I need this. I need that." So I go in and check. It's always empty. So I do my part when the patient leaves, I upload it. So it's going to help the person that tries 'til next time, but it's always empty. Everything's empty. (General Practitioner, P06)*

Continually encountering empty records was discouraging to the primary care practitioners that we interviewed and deterred use of MHR. Our interviewees expressed that MHR generally did not currently offer new data to be viewed, with practitioners accessing their own entered data the majority of the time. This created difficulty maintaining the motivation to keep checking MHR and a persistent theme was the need for all healthcare providers to become active on MHR. For example, several of our interviewees reported feeling very deflated after they had spent time and effort uploading patient health summaries, only for a hospital clinician to call them requesting results. This

resulted in a further increase in their workload and made the information as well as the time they had spent entering the information into MHR redundant.

10.6.2 Quality of clinical data on MHR impacts usability

Several interviewees expressed concern about the quality and relevance of clinical data being entered on MHR. In addition to the low amount of data available to view on MHR, the usefulness of the data itself was reported as lacking due to poor documentation. For example, some clinicians mentioned coming across incomplete information, incorrect coding of medical history, and inaccurate and out-dated medicines data. The absence of explanations for medication changes done by other clinicians was reported as being common.

> *I think it has a great potential. It's just a matter of – and it's like any data, you've got to put quality there to have useful information (General Practitioner, P29).*

An important point highlighted by interviewees was that the use of electronic medical records did not necessarily imply better quality of information, and that healthcare practitioners were still required to include the same essential clinical data as paper-based records. Some interviewees feared that electronic records minimised clinical information. Establishing a criterion for the minimum required clinical data and routine data 'cleaning' were regarded as imperative to ensuring information on MHR was clinically useful and up to date.

> *It should be fabulous but it depends on the data being uploaded. So, I've had one patient who came from another practice transfer here, and her health summary had been uploaded with antibiotics. I know that she wasn't on anymore and never had been for a long time, it was as if it hadn't really been cleaned and, I don't know, that's useless. So, I think that as long as the quality of the information that goes up is good, it will be very useful but it needs to be constantly updated when there has been a change, and that's really important. (General Practitioner, P30)*

One interviewee also commented that there was insufficient information on shared health summaries for the management of chronic diseases such as COPD, where clinical details like traits of disease and flare-up frequency are usually lacking.

This decreased usefulness and clinical value of low quality data was seen as a significant factor discouraging the use of MHR further. Also, considering that the drive to utilise MHR may stem from

meeting minimum upload quotas, rather than confidence in the system and being invested in MHR, it is likely that this may also influence the quality of data uploaded.

10.6.3 Increased interactivity through MHR can motivate use

Another important issue identified by interviewees was the minimal level of interactivity offered by MHR - this was also associated with reduced motivation to use MHR. This limited interactivity referred to the low communication activity with other healthcare providers on MHR, creating a sense of isolation. Clinicians also envisaged the management of patients as a multi-disciplinary team on MHR and expressed frustration that this type of communication and coordination was not yet present. Other interactivity limitations included restrictions in the static nature of the MHR data collection system itself.

The majority of interviewees, particularly GPs, characterised their experience with MHR as uploading and viewing their own information, with very little data being accessed from other healthcare providers. This lack of interactivity with other healthcare practitioners dis-incentivised interviewees. There was also an assumption that other healthcare providers would not be accessing the information they themselves had uploaded, and that MHR was generally not being utilised very much by the wider medical community. For example, one physician remarked that they would use MHR more if they knew that someone else would be reading their information.

Given that hospital discharge summaries were one of the most popularly described current benefits of MHR suggests that improving communication and interaction with other healthcare providers is likely to increase the use of MHR. The reduced awareness of MHR in other healthcare settings, such as hospitals and among specialists, was a source of frustration for many interviewees. For instance, one GP spoke about an occasion where an elderly patient with an up-to-date MHR was admitted to hospital, however hospital staff failed to check whether the patient had a MHR and instead called the GP's surgery to request medical information. Hospital staff were reportedly not aware of the existence of MHR in this case, and had to ask the GP to explain how to access the record.

Other interviewees identified interactivity limitations inherent in the design of MHR, due to it being a clinical document repository instead of a 'live' system that is easily updated, searched and accessed. For example, one physician criticised the inability to easily update fields in care plans in 'real time', instead having to upload a new PDF each time details had to be updated.

> *Because that's been the biggest drawback about it right from the beginning, is that it's been static, dead, almost out of date by the time it's put up. Otherwise – you know, the fact that it's a static upload, that's really annoying. I should be able to put a care plan up that' s a dynamic thing that I can just cross out and change so that, as time goes on, I have some patients who have enormously long list of things that is unfolding (General Practitioner, P30).*

10.6.4 MHR impacts on workload

With few exceptions, the use of MHR was associated with increased workload, changed workflow and presented challenges to productivity that need to be resolved in the future. In many practices the practice nurse had the primary role of uploading health summaries, as GPs were either too busy seeing their patients, or were not as familiar or confident with using MHR. A number of practice nurses felt overburdened by the increased workload while others seemed able to integrate registrations and uploading into their work routine.

Some GPs mentioned the inability to upload during consultations due to time constraints, requiring them to stay back after work to complete the uploads for the day. In some instances, the uploading was completed the following day after the consultation. Uploading to MHR was also considered to have repetitiveness and duplication as information had already been uploaded on to the usually used practice software, for example Medical Director.

> *Shared health summary takes a bit of time. You've got to go through all the history, which one is active, what's not active, and then you go through all the medications and their presentations. It does take a lot of time because when I do it, I would like it to be accurate and I check which of these are current and which can be left out. (General Practitioner, P07)*

Other GPs however did not see MHR tasks as very time consuming and described uploading as quick and easy taking only a few minutes. These mixed responses may reflect varied levels of familiarity with MHR as well as access to training materials. Many GPs spoke about feeling under immense pressure and overloaded with competing tasks and multiple program requirements. The utilisation and minimum upload requirements of MHR were at times regarded as an added stress to this already high-volume workload.

10.6.5 Lack of tangible improvements in patient outcomes is a de-motivator in MHR use

One of the most potent factors affecting the current usage of MHR was the absence of any currently detectable improvements in the clinical outcomes of patients. Interviewees explained that maintaining motivation and confidence in the ongoing use of MHR without direct evidence of clinical benefits for their patients was challenging, despite future promise of such benefits. However,

perceived satisfaction with future MHR impact on patient outcomes was a facilitator to MHR adoption and continued use.

10.6.6 MHR affects patient-clinician interactions

There were a few GPs, who we interviewed, who were concerned MHR caused disruption to the physician-patient interaction. Viewing the time spent with their patient as most important, MHR was seen to take time away from the interpersonal and clinical aspects of the consultation.

10.6.7 Transparency of the information on MHR makes clinicians feel they may be under scrutiny

Another proposed factor reported by two of our interviewees that could potentially affect the uptake of MHR among healthcare providers is a vulnerability that practitioners may feel when uploading their clinical documentation. The enhanced transparency of shared digital health records opens clinicians' work to possible scrutiny or judgement by peers and may contribute to MHR uptake reluctance.

10.6.8 Clinicians lack awareness of existing training resources

There was low awareness of the availability of online MHR training, with moderate awareness of the availability of workshops conducted by the PHN. Most training occurred in the setup stage at their practices, delivered by Western Sydney PHN staff. Interviewees expressed great satisfaction in the MHR introduction, training and continued support provided by Western Sydney PHN. Among the few interviewees that had attended training workshops, most had completed these early on when MHR was introduced at their practice, however ongoing training appeared to be lacking. Some interviewees suggested the addition of CPD points as a possible incentive to increase the uptake of training.

Recommendations:

- **Leveraging early adopters of MHR to be peer champions of MHR to encourage use among their peers**
- **Creation of a simple visual prompt for GPs consultation rooms to encourage, remind and explain step-wise the MHR data entry processes as well as security of data, during consultation with patients**
- **Automated built-in reminder systems that delivers prompts to upload to MHR on GP software**
- **Introduction of MHR in medical curriculums**
- **Development of features on MHR that generate greater interactivity between clinicians, for example a communication screen that could be used with patients under the care of multiple clinicians**
- **Investigation into an update function for records that may need to be amended, for example, care plans**
- **Consultation with clinicians on their workloads to determine how MHR can be better integrated into the existing daily workflow and become a routinely used system**
- **Assistance provided to practices to get patient data uploaded into MHR**
- **Attachment of CPD points to the MHR training to increase the uptake of this training**

Figure 1. Low use of MHR promotes even lower use when coupled with functionality and data completeness issues

27
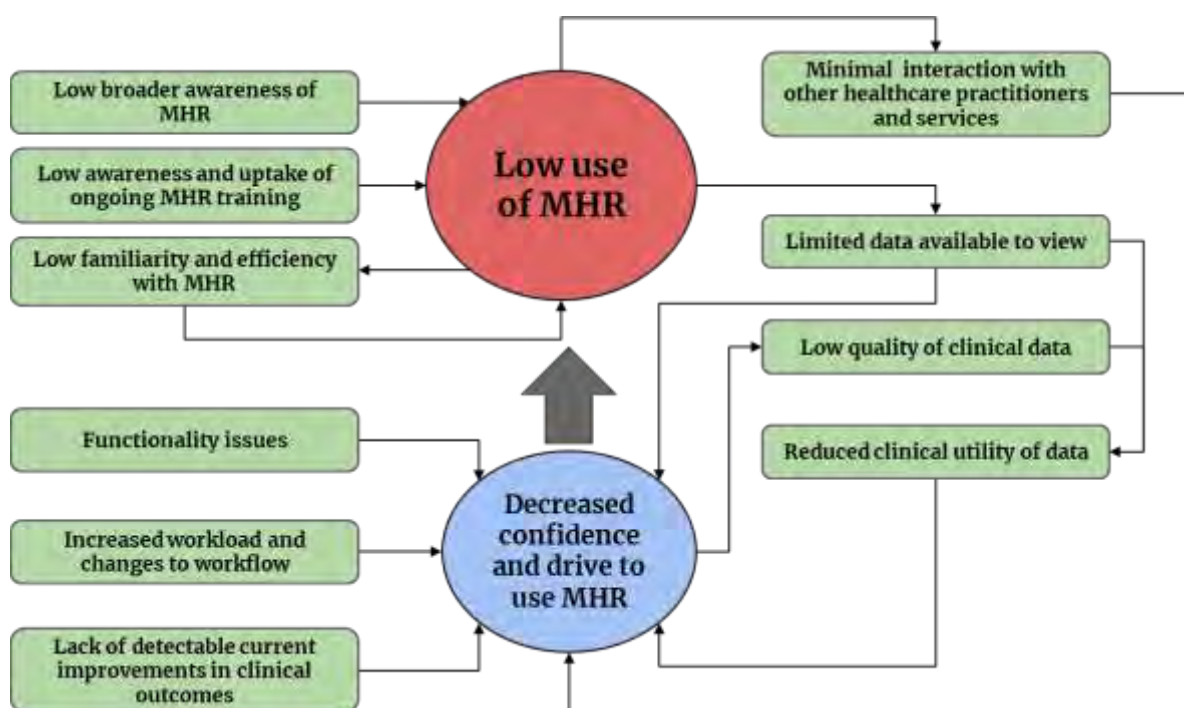
10.7 Perceptions of the upcoming opt-out and comparison with the Nepean Blue Mountains opt-out region

Most interviewees in the Western Sydney PHN region were optimistic about the upcoming opt-out, believing this move would eventually lead to the wider use of MHR. Compulsory use of MHR had been suggested by some GPs as a means to get the full potential from the system. When this idea of compulsory use of MHR was suggested to other interviewees, a surprising majority supported this as being an important strategy to maximise the potential benefit of MHR.

A comparison of data from the interviewees in the Western Sydney region to the interviewees interviewed from the NBM region (n=4) revealed no major differences in perspectives around current use and feasibility of MHR. While primary care interviewees from the NBM region reported that the opt-out had facilitated the opportunity to utilise MHR by eliminating the registration process for their patients and the associated workload, their use of MHR was still being affected by many of the factors raised by the Western Sydney PHN interviewees.

11 Commentary and next steps

Two distinct groups were identified among our interviewees: 1) early adopters who found no difficulty in the use of MHR who were using MHR frequently and 2) reluctant adopters who saw the whole system as being difficult and time consuming. Irrespective of group, however, almost unanimously, interviewees were able to see to see the future potential benefits of MHR to both their practice, in terms of streamlining communication and reducing unnecessary tests as well as the optimising care of their patients and reduction of adverse medical events. MHR was especially viewed as highly beneficial in acute care settings and for their complex patients, the elderly and CALD individuals.

For this to occur, however, frequency of use of MHR must improve, with comprehensive, high quality data, presented in a manner that is user friendly, and efficient to use combined with consideration of impact of MHR on workflow is also needed as it may negatively impact on efficiency and productivity, particularly around the duplication of tasks. Factors strongly affecting the drive to use MHR were the limited availability of viewable data, data quality, low interaction with other health care providers and the lack of current clinical outcome improvements with an important motivator for primary care use appearing to be uptake and use by hospital based clinicians and specialists. This uptake is seen as essential to truly see an improvement in communication efficiency as maintaining motivation and confidence in the ongoing use of MHR without direct evidence of clinical benefits for their patients was challenging for primary care practitioners, despite future promise of such benefits.

11.1 Key findings

- Primary care providers expressed satisfaction at being able to re-assure their complex patients that their records would be accessible in any healthcare setting, including overseas
- MHR could greatly alleviate stress and worry often experienced by patients and their families during an emergency and assist with recall of medications
- Primary care providers identified themselves as holding the chief responsibility for providing and maintaining accurate medication information
- Primary care providers still receive calls from emergency departments who have not accessed relevant information on MHR which undermines trust and confidence in MHR and leads to scepticism as to whether other healthcare providers are uploading medication data in a timely or accurate manner
- Interviewees are optimistic about the benefits of pathology reports and diagnostic imaging reports when they become more available on MHR

- In cases where pathology and imaging reports were available, primary care providers in this study were very satisfied with prompt and easy to access pathology reports, including being able to see follow up details clearly, which is saving time for them and is receiving positive responses from their patients

- Digital discharge summaries were highly regarded and are seen to facilitate transition of care, preventing any delays in the continuity of medical care and reducing clinical information gaps

- Primary care providers strongly believe that the full benefits of MHR will only be realised once specialists become active on MHR, as being able to access specialist letters on MHR was considered to be one key aspect in making use of MHR an integral part of everyday practice

- The limited availability of data on MHR was identified as a critical factor in the low uptake of MHR among interviewees in this study, and has implications for the future usability of the system

- Healthcare providers experienced some disillusionment in MHR, believing MHR was generally not being utilised very much by the wider medical population, as well as being associated with lower motivation to use MHR

- Many GPs mentioned feeling under immense pressure and overloaded with competing tasks and multiple program requirements

11.2 Next Steps

Further research exploring the barriers and facilitators to use among specialists and hospital based clinicians is much needed to establish how best to implement MHR beyond primary care and across the wider health system. Quantification of the impact of MHR on patient outcomes, such as better management of chronic disease as well as case studies on how MHR can maximise efficiency within daily practice also appear warranted, with this evidence disseminated widely to healthcare providers to encourage wider implementation and increased use of MHR.

Research focused on exploring and developing technical and organisational innovations on how MHR can be utilised to promote and support collaborative behaviours between healthcare providers to generate greater multi-disciplinary interaction and team-based care also appears warranted.

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13 Appendix – Interview Schedule

1. General awareness, understanding and use of MHR

- *What is your awareness and understanding of MHR?*
- *What are your general experiences of using MHR?*
- *What are your perceptions of MHR, i.e. the benefits and drawbacks and the circumstances where you would consider it to be most effective?*
- *What general issues, if any, have you experienced using MHR?*
- *What benefits do you think there could be for your patients?*
- *Do you use MHR yourself?*

2. Ease of use: Training

- *What training have you had around MHR?*

Prompts: training webinars, Australian Digital Health Agency training request, PHN training, other practice member e.g. practice manager, simulation of digital health functionality of software, self-paced learning modules, downloadable guides for healthcare providers, MHR Developer (customised guides and resources for integrating digital health products into their platforms)

- *How easy were these resources to access?*
- *If not had training – why not had training?*

3. Ease of use: registering patients

- *How easy has the process been gaining consent from patients*
- *Have you had any patients who have refused to register? If yes, approximately how large a proportion*
- *What concern, if any, did your patients express about their information being shared on MHR?*

4. If practitioner DOES NOT use MHR:

Have you ever used MHR, even very infrequently?

- *Which functions did you use?*
- *Why did you choose to use these functions?*
- *What has discouraged you from using my HR further/discourage you from using it further?*

Prompts: lack of access, do not use computer in my practice, not confident computer applications, not had training/training insufficient, patients expressed concern about confidentiality, lack trust in security and confidentiality of the system, too hard to register, limitations in practice IT system, concerns about at risk patients

- *What might encourage you to use MHR in future?*

Prompts: IT support, ePIPs, training, more information available e.g. diagnostic reports, patients want it, opt out scheme, medicine safety, pathology and/or diagnostic test ordering

- *Who else, if anyone, uses MHR in your practice?*
- *How do you communicate with clinicians from within and outside of your practice?*
- *How much time is spent communicating with other clinicians from within your practice when following up on your patients?*
- *How much time is spent communicating with other clinicians from outside your practice when following up on your patients?*
- *How do you think MHR could save time on communication with clinicians from both within and outside of your practice?*
- *What do you see as being your roles and responsibilities in medication safety?*
- *How do you perceive the feasibility and appropriateness of MHR in engaging in safe medication practice?*

Prompt: can patients' electronic health records be screened to identify potentially hazardous prescribing events?

- *How do you think MHR could assist you in identifying patients who may be at risk of adverse drug reactions (e.g. patients with chronic conditions) or patients who may be 'doctor shopping'*

Prompts: Would you able to clearly identify medication errors using MHR? How would being able to see previously prescribed medications assist you in managing your patients' medication regimes?

- *Overall, what benefits do you think MHR could introduce around medication safety?*

Prompts: reduce ED visits, reduce GP visits, improved medication management, reduced hospital admissions/ cost of treatment hospital/length of stay,

PROCEED TO SECTION 13 FOR NON-USERS IF INDIVIDUAL INTERVIEW

5. If practitioner USES MHR (Skip for non-users):

- *What has motivated you to use MHR?*

Prompts: encouragement by PHN/Digital health Agency, patients want it, desire/necessity to track patients e.g. with complex or chronic conditions, desire to save time on communicating with other practitioners, improved communication concerns over 'doctor shopping', overall improvement in practice, ePIPs, patient wanted to use it, able to access otherwise unknown information, gave confidence in clinical decision making,

- *What has enabled your use of my MHR?*

Prompts: training, support from PHN/ Digital health Agency, improved communication, assistance with IT issues, resources for patients

6. Ongoing use of MHR: confidence, issues and incentives (NB. ascertain frequency of use)

- *How often do you use my HR?*

Prompts: everyday, only for particular patients for example complex patients

- *What would you consider to be frequent or high use of MHR?*

- *Would you consider yourself to be a frequent, high user?*

- *How confident are you using MHR?*

- *How easy do you find it to navigate MHR?*

- *What issues (if any) have you had using MHR?*

Prompts: adds time to work, technical difficulties, information missing, information incorrect

- *What ongoing support do you receive to use MHR (prompt PHN, Digital Health Agency)*

- *What incentives are there e.g. ePIPS that encourage your use of MHR?*

7. Ongoing use of MHR: what used for

- *How do you use MHR/what functions do you use?*

Prompts: uploading documents only (e.g. event summaries), viewing only (e.g. hospital discharge or medication records), both

- *Which of the following have you created and/or uploaded on MHR?*

Prompts (for each ask frequency e.g. always, sometimes (e.g. for complex patients, never):

- *Shared health summary*

- *Event summary*

- *eReferral letters*

- *How easy is it for you to create each of these items?*

- *Which of the following have you viewed on MHR?*

Prompts (for each ask frequency e.g. always, sometimes, never and why they choose to use these views):

- *Hospital discharge summaries*

- *Medicines Information view*

- *Advanced care planning documents*

- *PBS data*

- *MBS data*

- *Immunisation data*

- *Pathology reports*

- *Diagnostic imaging reports*

- *Specialist letters*

- *Prescription and dispensing information*

- *Patient-entered personal health summaries*

- *Health notes entered by the patient*

- *Child development information*

- *How easy is it for you to view each of these items?*

- *What is easier, viewing these items on MHR or communicating with other practitioners (e.g. discharge summaries)*

We would now like to ask you more about three specific functions of MHR: Medicines information view, pathology reports and diagnostic imaging reports

8. Medicines Information view (and medication safety)

- *How easy is it to view or track medicines prescribed by yourself or others clinicians in MHR?*
- *How often do you use the medicines information view?*
- *What do you think about when you hear the words 'medication safety'?*
- *What do you see as being your role and responsibility in medication safety?*
- *How has your use of MHR provided easier access to prescription data or facilitated your ability to assess quality and safety of prescribing?*
- *How do you perceive the feasibility and appropriateness of MHR in engaging in safe medication practice?*

Prompt: can patients' electronic health records be screened to identify potentially hazardous prescribing events?

- *How does use of MHR assist you in identifying patients who may be at risk of adverse drug reactions (e.g. patients with chronic conditions) or patients who may be 'doctor shopping' (e.g. patients with opioid dependencies)*

Prompts: Are you able to clearly identify medication errors using MHR? How does being able to see previously prescribed medications assist you in managing your patients' medication regimes?

- *What, in your experience, is the effect of MHR on safe medication practices? Have you experienced fewer medication errors/fewer adverse events?*
- *Overall, what benefits do you think MHR could introduce around medication safety?*

Prompts: reduce ED visits, reduce GP visits, improved medication management, reduced hospital admissions/ cost of treatment hospital/length of stay,

9. Pathology tests

- *How easy is it to view or track pathology test reports for your patients on MHR?*
- *How often do you view pathology test reports on MHR?*
- *How do you perceive the feasibility of MHR in influencing the ordering of duplication of pathology tests in your patients?*
- *How has access to pathology test results available on MHR facilitated higher quality/prompter care for your patients?*
- *How has being able to access/view pathology results made your practice more efficient?*

Prompts: reduced your need to communicate with other clinicians, reduced need to create imaging request

10. Diagnostic imaging

- *How often do you view diagnostic imaging on MHR?*
- *How easy is it to view or track diagnostic imaging reports for your patients on MHR?*
- *How do you perceive the feasibility of MHR in influencing the ordering of or duplication of diagnostic imaging in your patients?*
- *How has access to diagnostic imaging results available on MHR facilitated higher quality/prompter care for your patients?*
- *How has being able to access/view diagnostic imaging made your practice more efficient?*

Prompts: reduced your need to communicate with other clinicians, reduced need to create imaging request

11. Ongoing general use of MHR: currency of information

- *How safe do you think it is to assume the information in a patient's My Health Record is a complete record of a patient's clinical history?*
- *What information do you think should be verified from other sources?*
- *Which other sources might you verify this information with?*

Prompts: with the patient, other health care providers

- *Overall, how does MHR facilitate data linkage?*

12. Ongoing use of MHR: tracking patients and communicating with other healthcare professionals

Prompt: Ascertain frequency of use

- *Can you tell us about a particular patient (either with or without chronic/complex disease) where MHR has been of benefit to them?*
- *What type of patient, if any, would make you more likely to use their MHR?*

Prompts: on multiple (5 or more) medications, has a chronic or complex condition, drug and/or alcohol issues, visits GP frequently, known to visits multiple practices, recent hospital discharge, mental health issues, patients you think may be 'doctor shopping', patient visiting after hours

- *Which patients, if any, would you be reluctant to use MHR with? Why?*
- *How many of your patients do you think visit multiple practices?*
- *How valuable is MHR for tracking patients who may visit multiple practices?*
- *How useful is MHR in caring for your patients who have chronic/complex conditions?*
- *What benefits do you think there may be to patients with chronic/complex conditions if you and other practitioners use MHR*
- *How much time is spent communicating with other clinicians from outside your practice when following up on your patients?*
- *How much time is spent communicating with other clinicians from within your practice when following up on your patients?*
- *Approximately much time do you think you have save on communication because of MHR?*

Prompts: Daily, weekly, overall

- *How can MHR help you care for your patients after hours?*
- *How much do you think MHR has improved communication around patients and helped to reduce your time spent on communication?*

13. Overall - users

- *How does MHR help you manage your workflow?*

Prompts: time saved communicating with other health professional, time wasted looking for information expect to be on there but it isn't there, no impact as rarely use

- *How much has your use of MHR increased since it was introduced?*
- *How valuable is MHR in your practice?*
- *How does MHR help facilitate negotiation of the complex nature of primary care?*
- *How capable is your IT system in being able to handle the higher volumes of information that can be uploaded and viewed?*

14. Overall - users and not users

- *What confidence do you have in the security and confidentiality of the MHR system?*
- *How helpful do you think MHR may increase your ability to assist your patients in future? Why?*
- *How would you feel if use of MHR was compulsory for all health practitioners?*
- *What could assist you to use MHR more?*
- *Any other general comments or questions?*

Impact of My Health Record

A sub-study of the Western Sydney General Practice Data Linkage Pilot Project

July 2018

NSW GOVERNMENT

Acknowledgements

Suggested citation

Contents

Figures and Tables

Executive Summary

This report presents the findings of a sub-study of the Western Sydney General Practice Data Linkage Pilot Project to evaluate the impact of My Health Record on patient outcomes.

My Health Record is a central repository of key health information for an individual uploaded electronically in summary form. When using health services, a patient who has a My Health Record can grant the provider access to this summary information to inform their health care management. The full roll-out of My Health Record in Australia is ongoing. The system has been available for opt-in for some time, however recently, there have also been opt-out trials of my Health Record in selected regions. Western Sydney, the site of the GP Data Linkage Pilot Project, is currently still an opt-in region of NSW for My Health Record.

The Western Sydney General Practice Data Linkage Pilot Project is a project overseen by NSW Ministry of Health that has linked patient clinical records from participating general practices to state health system hospital, emergency department and mortality records. The sub-study of the Pilot Project presented here, compares the characteristics and outcomes such as hospital admissions and emergency department presentations, duplication of services, and adverse events, among patients who have a My Health Record (n=9,154), with those who do not have a My Health Record (n= 116,515).

Approximately 7% of patients were identified in the participating western Sydney general practices as having a My Health Record. However this varied from around 2% to 20% depending on the type of source clinical information system used in each general practice.

Compared to all other patients, patients with a My Health Record tended to be older, have more chronic conditions, use more medications and have more hospital admissions and ED presentations. Therefore it appears that early adopters of My Health Record in Western Sydney were predominantly those patients who have poorer health.

Future investigation may repeat and build on these findings to investigate a broader range of outcomes and explore whether, with the currently available data, it is possible to detect differences in outcomes among patients who have a My Health Record. This report establishes a method for observing outcomes that may be concurrent with My Health Record in general practices that can be repeated over time.

Background

Internationally, electronic health record systems have been operating in some countries since approximately 2008. Countries where national electronic health record systems are being developed or have been implemented include (as well as Australia) Austria (ELGA, Dorda, et al), Canada (Infoway), Denmark (Kushniruk et al 2010), Estonia (ENHIS 2008), China (Gao et al 2013), India (Ministry of Health and Family Welfare, India, 2016), Jordan (Nassar et al 2013), Netherlands (Barjis 2010), Switzerland (Pietro et al 2018), United Arab Emirates (El-Hassan 2017), the United Kingdom (Houses of Parliament briefings 2016) and Singapore (Singapore Ministry of Health). In New Zealand, progress towards finalising a detailed business case for a national electronic health record is also nearing completion (New Zealand Ministry of Health 2018).

My Health Record exists as an electronic summary of key information pertaining to an individual. It pulls together information from other existing record systems and is designed to integrate into local clinical information systems. The aspired benefits of electronic summary health records like My Health Record include:

- Reduced need for patients to repeat their health history each time they visit a new clinician.
- Ensures a reliable and complete source of medical information that doesn't depend on accurate patient recollection.
- Provides a broader indication to clinicians about the range of other health professionals that their patients use.
- Provides a rich source of health service data that would inform health system policy, planning and decision making to guide the development of effective programs that target appropriate populations.

At the time of writing, approximately 5.5 million Australians (23%) had registered for a My Health Record, and 10,754 health care providers were connected ranging from GPs, allied health and pharmacies, to hospitals and aged care facilities (Australian Government Department of Health 2018).

The full roll-out of My Health Record in Australia is ongoing. Since 2012, it has been possible for Australians to opt-in to create a My Health Record that can be used as a repository of information about their health care. However recently, there have also been opt-out trials of my Health Record in selected regions including Nepean Blue Mountains Primary Health Network, whereby a My Health Record is created automatically unless individuals specifically opt-out. In this region, coverage of My Health Record reached approximately 98% and has been well received in the population (Nepean Blue Mountains PHN personal communication 22/05/2018).

In September 2017, the Australian Digital Health Agency (the Agency) issued a request for proposals to evaluate the impact of My Health Record on patient outcomes. In particular proposals were sought investigate whether My Health Record showed impacts on errors

and wastage in health. The Agency cited a number of statistics including: "*Approximately 2% to 3% of hospital admissions in Australia are caused by avoidable medication errors*". This had come from a literature review carried out by the Australian Commission on Safety and Quality in health Care (2013). A key source of these statistics came from research carried out at Monash Medical Centre using International Classification of Disease Version 10 Australian Modification (ICD-10-AM) codes to carry out surveillance of hospitalisations for adverse drug reactions (Hodgkinson et al 2009). They concluded that ICD-10-AM coding is an effective and efficient means of improving the reporting of adverse drug reactions using administrative data.

In response to the Agency's request, it was agreed that data from an existing project; the Western Sydney GP Data Linkage Pilot Project (the Pilot Project), would be modified to replicate the methods by Hodgkinson et al among GP patients using hospital diagnosis codes.

The Pilot Project is a highly productive collaboration between the western Sydney Primary Health Network, General Practices and Local Health Districts and the Ministry of Health and Pen CS Computing. It has delivered a proof of concept for the extraction and linkage of GP clinical information to health system data. With this achievement, the Pilot Project has been the first of its kind in Australia and has provided a rich source of patient clinical information across the care continuum. The data produced in the Pilot Project has already demonstrated its ability to provide unique information and insights around the patient journey across primary, acute and other healthcare services. It has also demonstrated the benefits of effective private-public partnerships, collaboration, policy formulation and resource allocation around an agreed, data-informed and comprehensive system-wide approach.

The instigation of a sub-study of the Pilot Project responding to the Agency's request, provided an opportunity to further test the real-world policy relevance of linked GP data. It afforded an ideal opportunity whereby the outcomes of patients with a My Health Record could be compared with those who do not have My Health record. This report provides the findings of this sub-study.

Methods

The Western Sydney GP Data Linkage Pilot Project (the Pilot Project) is a current activity of the Systems Information and Analytics Branch at NSW Ministry of Health in collaboration with the Western Sydney Primary Health Network and participating western Sydney general practices and enabled through Pen CS computing software. The Pilot Project has extracted and linked patient clinical records from general practices to state health system hospital, emergency department and mortality records.

Western Sydney, the site of the GP Data Linkage Pilot Project, is currently an opt-in region of NSW for My Health Record. In order to address the needs in the request by the Australian

Digital Health Agency (the Agency), a sub-study was approved by the NSW Population and Health Services Research Ethics Committee to add a flag for My Health Record to patient records extracted from the GP systems. This enabled examination of the differences in hospital events among patients with early adoption of My Health Record (MyHR group) and those remaining without a My Health Record (No MyHR group).

Aims

This sub-study aimed to generate evidence of the impacts of the My Health Record across primary and acute health care sectors. Specifically, the study investigated whether having a My Health Record influences medication safety by observing the incidence of hospital admissions for adverse drug events. The study also compared total number of hospital admissions and emergency department presentations among GP patients with and without a My Health Record.

Study population

The study population of the Pilot Project comprised all patients who attended participating general practices over the preceding five years (all ages). All patients in the cohort were linked to records from the NSW Health system including NSW emergency department (the Emergency Department Data Collection) and hospital admissions (the Admitted Patient Data Collection). The Pilot Project has been carried out in multiple tranches, with each building on those preceding. Since its commencement in 2016, the Pilot Project has successfully linked approximately 300,000 patients from 29 general practices over in three Tranches. The sub-study has only been incorporated into the third tranche of the Pilot Project whereby a My Health Record (MyHR) flag was added to identify case cohorts (MyHR group) and comparison cohorts (no MyHR group). The third tranche linked 125,669 patients from 17 practices, with inclusion of a MyHR flag.

Data linkage

Data linkage was carried out by the Centre for Health Records Linkage at NSW Ministry of Health using best practice techniques that have been documented in detail elsewhere (http://www.cherel.org.au/). Briefly however, linkage was carried out by using automated probabilistic techniques to match the identifying particulars of general practice patients within and across multiple data collections. A key feature of the linkage was that personally identifying information of patients was separated from their clinical content information at the time records were extracted from GP practices. This separation was maintained at all steps of the project. The result was the creation of de-identified clinical data that linked the patients' journeys across primary and other health service settings with a high degree of accuracy while adhering to stringent privacy standards that prevented the discovery of health information about an identified individual. Proposals are currently being considered to continue and expand GP data linkage, and if adopted, it will be possible to repeat the methodology described here in the future.

Statistical methods

For each linked dataset, the data were summarised to enumerate the proportion of individuals with GP, emergency department, and hospital episodes.

Initially, the likelihood of having a My Health Record was evaluated in relation to other characteristics such as age, sex, chronic disease and medications. A logistic regression model was developed to assess whether these characteristics were associated with having a My Health Record after adjusting for one another. Additional adjustments were made for the clinical information system of the source general practice. This was because different systems ascertained and flagged My Health Record in different ways which would potentially affect the attribution of My Health Record to an individual.

The impact of having a My Health Record was further evaluated, with adjustments for the previous characteristics, on the following outcomes:

- An adverse drug event (ADE) hospitalisation
- Hospital admissions
- Emergency department (ED) presentations
- Potentially preventable hospitalisations (PPH)
- Unplanned readmissions within 28 days of a previous admission

It is recognised that among patients with a My Health Record, their use of the Record, and therefore its ensuing impact, may vary considerably. Therefore among patients with a My Health Record, whether or not they also had a shared health summary uploaded was be used to create groups as a proxy of 'active' My Health Record vs 'inactive' use. The above list of outcomes was then compared in these two groups.

Findings

Of the 125,669 patients with My Health Record information in Tranche 3 of the Pilot Project, 58,275 (46.4%) presented to emergency departments, 59,252 (47.1%) were admitted to hospital, and 1617 (1.3%) died in NSW over the five years (Figure 1).

Figure 1: Tranche 3 Pilot Project overview, practices with My Health Record in the extraction, 2012-2017.

125,669 patients

47.1%
Patients Admitted to Hospital
19,270

All other patients
48,001

38,473   66

1,443

18,308   51   57

Patients with ED Presentations

Patients who have Died

46.4%   1.3%
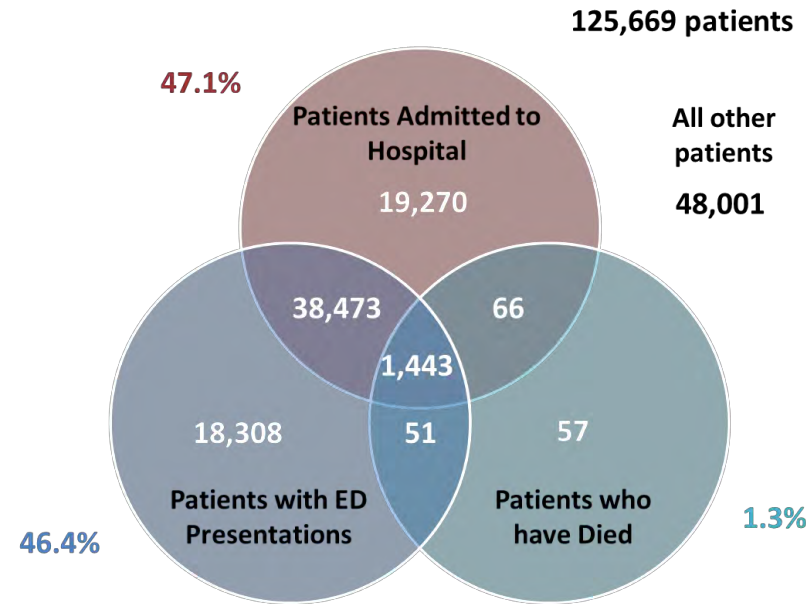
Among these, there were 9154 (7.3%) individual patients who were flagged as also having a My Health Record. Of these, 4,773 (52.1%) presented to emergency departments, 5481 (59.9%) were admitted to hospital, and 98 (1.1%) died in NSW in the preceding five years (Figure 2).

Figure 2 Tranche 3 Patients with a My Health Record Overview.

9,154 patients

59.9%
Patients Admitted to Hospital
1,786

All other patients
2,591

3,603   2

90

1,076   4   2

Patients with ED Presentations

Patients who have Died

52.1%   1.1%
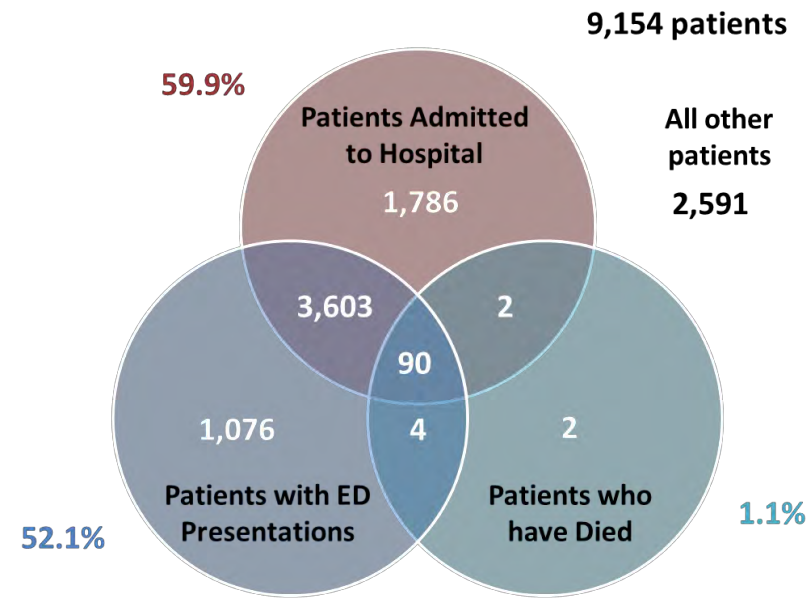
Characteristics of people who have a MyHR

The majority of patients (N= 116,515; 92.7% of total) did not have a My Health Record (No MyHR). Patients in the MyHR group tended to have higher proportions in the ages 55-75 years and less aged 25-45 years compared to patients in the No MyHR group. In both groups, there were more females than males (Figure 3).

Figure 3: Age and sex distribution – GP patients with (1) My Health Record (MyHR group, n=9154) and (2) with No My Health Record (No MyHR group, n=116,515)

MyHR

Age	Female	Male
85+	2.0%	2.0%
80-84	2.1%	2.8%
75-79	4.1%	4.2%
70-74	5.6%	6.0%
65-69	5.8%	6.9%
60-64	6.1%	5.6%
55-59	5.8%	5.8%
50-54	5.5%	5.3%
45-49	6.1%	5.8%
40-44	6.7%	5.6%
35-39	7.8%	6.3%
30-34	7.2%	4.9%
25-29	5.7%	3.5%
20-24	5.2%	3.3%
15-19	4.1%	4.4%
10-14	4.2%	5.9%
5-9	5.4%	7.5%
0-4	10.6%	14.0%

Male - 4,190   Female - 4,963

No MyHR

Age	Female	Male
85+	1.6%	0.9%
80-84	1.3%	1.0%
75-79	1.6%	1.5%
70-74	2.5%	2.2%
65-69	3.5%	3.2%
60-64	4.3%	3.6%
55-59	4.9%	4.5%
50-54	5.4%	5.3%
45-49	6.3%	6.3%
40-44	7.5%	7.8%
35-39	8.6%	9.0%
30-34	9.5%	8.8%
25-29	8.3%	7.9%
20-24	7.0%	7.0%
15-19	5.7%	5.9%
10-14	5.6%	6.3%
5-9	7.2%	8.3%
0-4	9.1%	10.2%

Male - 56,395   Female - 59,904

Patients in the MyHR group tended to have a higher proportion with the selected chronic diseases than those in the No MyHR group (Figure 4). Overall, fewer patients (51%) in the MyHR group had no identified chronic conditions compared to patients in the No MyHR group (70%).

Figure 4: Selected Chronic Conditions (proportion) among patients with and without My Health Record.
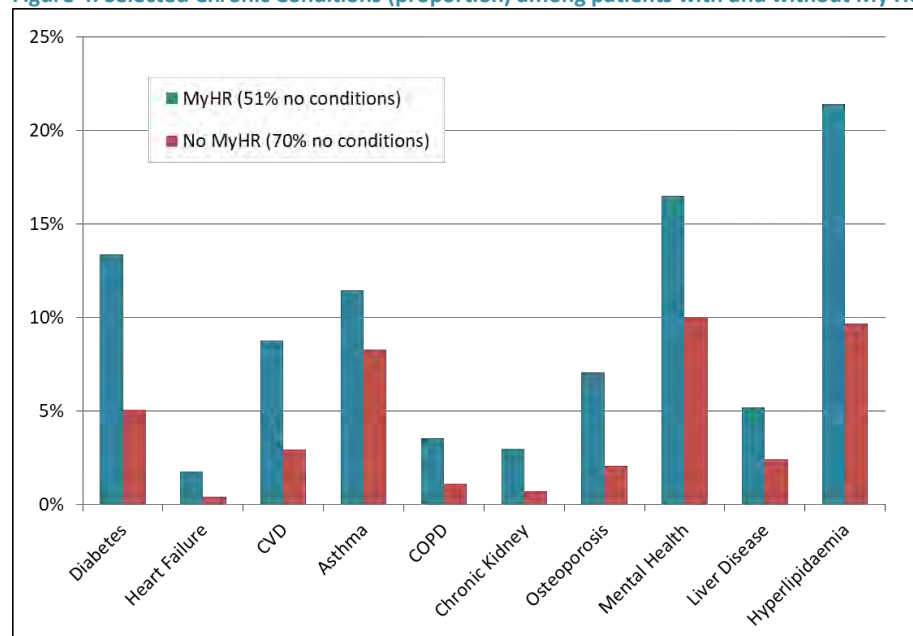
Higher proportions of patients in the MyHR group were also recorded as being prescribed selected medications than those in the No MyHR group (Figure 5). Overall, fewer patients (46%) in the MyHR group had none of the selected medications compared to 65% of patients in the No MyHR group.

Figure 5: Proportion of patients prescribed selected medication groups by whether or not they had a My Health Record.
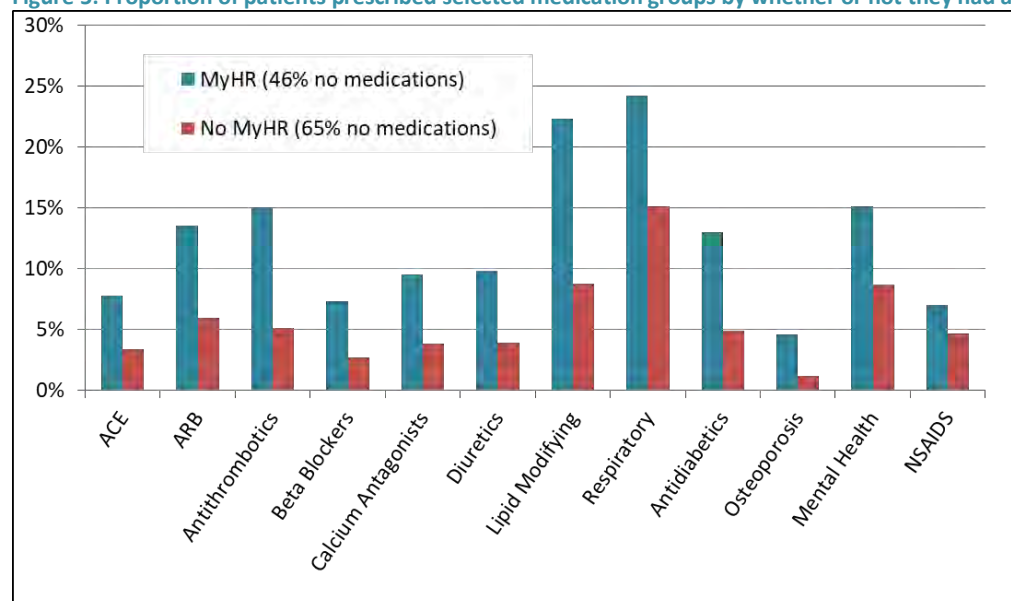
Adjusted analyses

Table 1 shows the unadjusted (crude) and adjusted effects of selected chronic conditions as odds ratios. The likelihood of having a My Health Record is slightly higher for most chronic conditions after accounting for differing age, gender and medications. Therefore, having a chronic disease could be a driver for having a My Health Record.

Table 1: Likelihood of having a MyHR among people with selected chronic diseases and after adjustment

Chronic condition flag	Crude Odds ratio of Having MyHR	95% CI OR	Adjusted Odds ratio* of Having MyHR	95% CI OR
Diabetes	2.90	(2.71 - 3.10)	1.27	(1.11 - 1.46)
Heart Failure	4.34	(3.60 - 5.21)	1.06	(0.84 - 1.34)
CVD	3.16	(2.91 - 3.43)	1.04	(0.92 - 1.18)
Asthma	1.43	(1.34 - 1.53)	1.28	(1.17 - 1.40)
COPD	3.37	(2.97 - 3.81)	1.30	(1.11 - 1.52)
Chronic Kidney	4.43	(3.84 - 5.10)	1.73	(1.45 - 2.06)
Osteoporosis	3.58	(3.27 - 3.92)	1.66	(1.44 - 1.93)
Mental Health	1.78	(1.68 - 1.88)	1.45	(1.33 - 1.57)

* Adjusted for age group, gender, clinical information system, and medication flags

Table 2 shows the effects of selected medications, after adjusting for other characteristics, as odds ratios. The likelihood of having a My Health Record is slightly higher for most of the medications even after accounting for differences in age, gender and chronic condition. Therefore, most of these medications also appear to remain as a residual driver of having a My Health Record.

Table 2: Likelihood of having a MyHR among people taking selected medications and after adjustment

Medication flag	Odds ratio of having MyHR	95% CI OR	Adjusted Odds ratio* of having MyHR	95% CI OR
ACE	2.40	(2.20 - 2.61)	1.38	(1.23 - 1.54)
ARB	2.45	(2.30 - 2.62)	1.19	(1.07 - 1.31)
Antithrombotics	3.25	(3.05 - 3.46)	1.21	(1.09 - 1.34)
Beta Blockers	2.82	(2.59 - 3.08)	1.12	(1.00 - 1.26)
Calcium Antagonists	2.66	(2.46 - 2.87)	1.16	(1.05 - 1.29)
Diuretics	2.68	(2.48 - 2.89)	1.09	(0.98 - 1.22)
Lipid Modifying	3.00	(2.84 - 3.16)	1.41	(1.28 - 1.55)
Respiratory	1.78	(1.70 - 1.88)	1.17	(1.09 - 1.26)
Antidiabetics	2.92	(2.73 - 3.12)	1.22	(1.07 - 1.40)
Medication Osteoporosis	3.91	(3.49 - 4.37)	1.46	(1.23 - 1.75)
Medication Mental Health	1.87	(1.76 - 1.99)	1.27	(1.17 - 1.38)
NSAIDS	1.53	(1.40 - 1.67)	1.15	(1.04 - 1.26)

* Adjusted for age group, gender, clinical information system, and chronic conditions

Impact of My Health Record on health related outcomes

Using diagnostic coding from ICD-10-AM in the Admitted Patient Data Collection, it was possible to identify hospital admissions where adverse drug events (ADEs) had occurred (based on methods in Hodgkinson et al 2009). The proportion of patients in the MyHR group who were admitted to hospital for ADEs in the last 12 months was higher than the proportion in the No MyHR group (3.0% and 1.4% respectively, Figure 6 and Table 3).

Figure 6: The proportion of patients with and without a MyHR by whether or not they also had a hospital admission with an adverse drug event (ADE) over the preceding year.
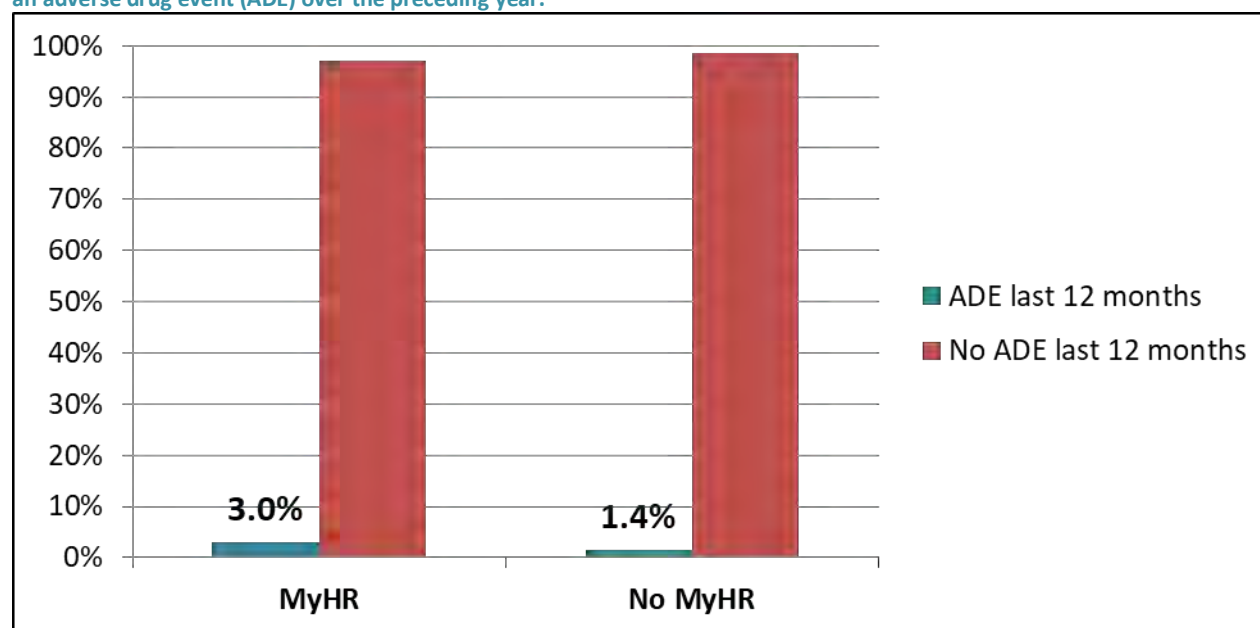
Table 3: The proportion of patients with or without a MyHR by whether or not they also had a hospital admission with an adverse drug event (ADE) and for all Tranche 3 patients over the preceding year.

	ADE last 12 months	No ADE last 12 months	Total
My HR	272 (3.0%)	8,882 (97%)	9,154
No My HR	1,667 (1.4%)	114,848 (99%)	116,515
All GP Patients	1,939	123,730	125,669

The impact of My Health Record was further investigated on other adverse health events over the preceding 12 months including admissions, ED presentations, potentially preventable hospitalisations and unplanned readmissions within 28 days. The proportion of patients with each of these outcomes is shown in Figure 7.

In Table 4, the effects of having a My Health Record, after adjusting for other characteristics, is shown as odds ratios. The likelihood of having an adverse health event is slightly higher among patients with a My Health Record. This is consistent with earlier analyses showing that patients with a My Health Record tend to be older and have more chronic conditions and medications.

Figure 7: Proportion of patients with a My Health Record by selected adverse health events
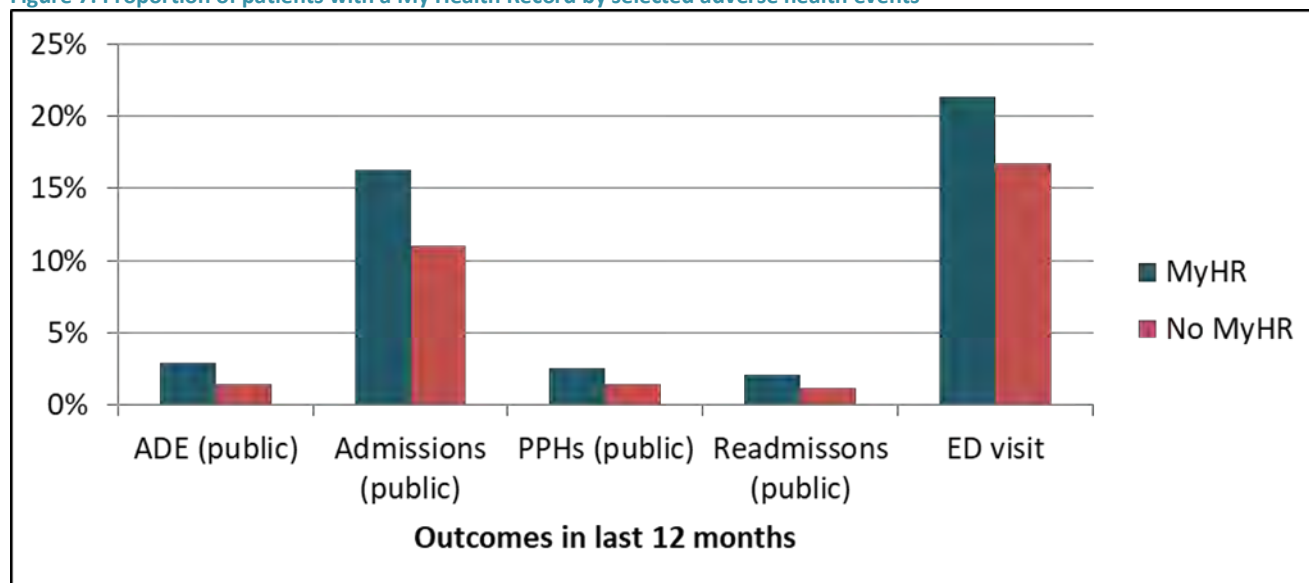
Table 4: Likelihood of selected health events among people with and with no My Health Record, and after adjustment

Outcome (MyHR vs No MyHR)	Crude Odds ratio of having MyHR	95% CI OR	Adjusted Odds ratio* of having MyHR	95% CI OR
ADE last 12 months	2.11	(1.85 - 2.40)	1.43	(1.24 - 1.66)
Admissions last 12 months	1.57	(1.48 - 1.66)	1.31	(1.23 - 1.40)
ED last 12 months	1.35	(1.28 - 1.42)	1.27	(1.20 - 1.34)
PPH last 12 months	1.86	(1.61 - 2.13)	1.30	(1.11 - 1.51)
Readmissions last 12 months	1.81	(1.55 - 2.11)	1.31	(1.11 - 1.56)

*Adjusted for age group, gender, clinical information system, chronic conditions and medication flags

Impact of using My Health Record

It is possible that patients who have a My Health Record do not actively use it. Active use of My Health Record may, in turn, have an impact on incidence of adverse health events among patients with My Health Record. To explore this, further analyses carried out among patients with a My Health Record who had an uploaded shared health summary compared to those who did not. It was found that My Health Record patients with a shared health summary had higher rates of adverse health outcomes than those who did not. However when this was adjusted for other characteristics, this difference was not significant. See Table 5.

Table 5: In patients with My Health Record, likelihood of having an adverse health event and a shared health summary.

Outcome (health summary yes or no)	Crude odds ratio of having shared health summary	95% CI OR	Adjusted odds ratio* of having shared health summary	95% CI OR
ADE last 12 months	2.31	(1.80 - 2.96)	1.05	(0.76 - 1.46)
Admissions last 12 months	1.72	(1.53 - 1.94)	1.11	(0.95 - 1.30)
ED last 12 months	1.30	(1.17 - 1.45)	0.92	(0.80 - 1.06)
PPH last 12 months	2.03	(1.55 - 2.65)	1.00	(0.71 - 1.41)
Readmissions last 12 months	2.44	(1.82 - 3.28)	1.30	(0.89 - 1.88)

* Adjusted for age group, gender, clinical system information, disease and medication flag

Commentary and next steps

Patients in the My Health Record group tended to be older, have a higher proportion with chronic conditions and use more medications than patients in the No My Health Record group. Furthermore, the proportion of patients experiencing hospital admissions in the My Health Record group was around 5% higher than those in the No My Health Record group and was also similarly elevated for ED presentations. Therefore it appears that patients who had characteristics of poorer health were more likely to have a My Health Record.

This finding is unsurprising, given that the Project was based in the Western Sydney Primary Health Network region, which required patients and carers to 'Opt-In' to have a My Health Record. It might be expected that patients with poorer health, more complex health care needs and requiring more regular contact with health services, were also those most likely to be early adopters of the My Health Record in Western Sydney. To summarise, the uptake of My Health Record in Western Sydney was much lower than in an opt-out trial region (98%, Nepean Blue Mountains Primary Health Network) and predisposed towards sicker individuals.

Adverse health outcomes were also higher among patients in the My Health Record group than among patients in the No My Health Record group. Again, this likely reflects the generally poorer health among the My Health Record group rather than any impact of having a My Health Record per se and that having a My Health Record was not, at this early stage of roll out, sufficient to mitigate, or even detect, adverse health outcomes for patients with more complex health care needs.

Adverse health outcomes and the active use of My Health Record was explored among those patients with a My Health Record. This was done because it is conceivable that while a My Health Record may be created, the Record is not subsequently accessed and used. The GP records included in Tranche 3 of the Pilot Project include shared health summary upload dates to My Health Record. These dates were used to further categorise My Health Record patients into those with and without a shared health summary. However no difference was detected in adverse health outcomes among these two groups after adjustment for other characteristics.

The information here provides an initial look at the early uptake of My Health Record. Even with further investigation it remains to be seen whether the currently available data are sufficient to detect differences outcomes such as service duplication, particularly diagnostic services, in relation to whether a patient has a My Health Record.

We conclude that this report establishes a plausible methodology for monitoring some characteristics and outcomes of individuals that may be concurrent with and without having a My health Record that can be repeated over time if primary care data continues to be linked to health system data collections in other regions of NSW.

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NPS MEDICINEWISE

THE IMPACT OF MY HEALTH RECORD ON PRIMARY CARE

Final report

August 2018 | v0.1

THE UNIVERSITY OF MELBOURNE

POSTERA CRESCAM LAUDE

Contents

EXECUTIVE SUMMARY

Introduction

In Australia, patient[1] health information is stored in siloes in primary care, hospitals, community health centres and private consulting suites. Patients themselves have limited access to their own health information. In July 2012, the Personally Controlled Electronic Health Record (PCEHR, now referred to as My Health Record) was developed, with the aim of improving access to health information to improve patient safety, reduce the duplication of pathology testing and provide information on medical history and medicines to assist with provision of optimal care. My Health Record is still evolving in terms of its functionality, with hospital discharge summaries and pathology tests starting to be incorporated into the record.

In September 2017, NPS MedicineWise and the University of Melbourne responded to the Australian Digital Health Agency (ADHA) request for tender to conduct a mixed methods evaluation to establish a baseline of My Health Record activity for primary care practice and to develop methodologies which will be able to track the impact of My Health Record as it continues to be implemented and enhanced. The evaluation also sought to explore the early signs of benefit that My Health Record can bring to both patients and general practitioners (GPs).

The mixed method evaluation involves four discrete studies, two of which utilised MedicineInsight, the largest general practice dataset in Australia. These studies have involved the development of methodologies to estimate My Health Record activity over time and the impact of that activity.

This report outlines the results of the four studies used for the evaluation, which was driven by the four questions set by the ADHA,

➢ Using MedicineInsight data, explore whether My Health Record activity was associated with reduced: (1) HbA_{1c} tests in people with type 2 diabetes within a 90-day period; (2) repetition of knee X-rays in people with osteoarthritis within a 12-month period; and (3) rate of prescribing of benzodiazepines.

➢ Using MedicineInsight data, determine the proportion of primary care patients with a recorded allergy or adverse drug reaction (ADR) to antibiotics who had 1) recorded My Health Record activity and 2) a shared health summary or other My Health Record document which would contain information about allergies and ADR uploaded to My Health Record.

➢ Explore the impact My Health Record has had on clinicians and consumers in improving medication safety and management using a qualitative approach. GPs and patients who had used My Health Record were identified from MedicineInsight data for interviews.

➢ Use a novel simulation approach to explore how GPs use the My Health Record in a consultation where there is potential for an adverse drug reaction.

Working with the ADHA we were able to create a simulation environment that linked a clinical environment to the My Health Record.

Studies 1 and 2 used MedicineInsight data from between 1 January 2013 and 31 December 2017, with cohorts developed for each topic by identifying patients with the condition of interest. The cohorts and topics chosen were based in the likelihood that My Health Record activity, if present, may produce benefits to the patient, the GP and the health care system.

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[1] The term 'patient' is used in this document to describe a person who consults a health professional or attends general practice, rather than the traditional definition of a passive recipient of health care.

Key results

Uptake of My Health Record within MedicineInsight practices

It is early days in the implementation cycle and the evaluation found less than 10% of patients in each of the cohorts had My Health Record activity recorded in their general practice record, with a lower proportion recording an upload or download of health information.

Impact of My Health Record on medication safety and management

The general practitioner view

➢ GPs welcome the potential benefits of My Health Record, especially for emergency situations, adverse events/allergies and reducing the duplication of tests

➢ The Practice Incentive Payment has encouraged GPs to upload information for some patients, but current incentives do not appear to encourage upload of shared health summaries for all patients.

➢ GPs are not yet using My Health Record as a source of trusted information in routine consultations.

➢ My Health Record needs to be quick to use and to integrate with other systems within the consultation. GPs reported difficulty with navigating the system, and that interoperability with practice-based electronic medical records could be enhanced.

➢ GPs reported concern about the completeness, accuracy and currency of information in the My Health Record and reported concern about being responsible for the quality of that information.

➢ Using a simulated consultation:

➢ GPs found My Health Record a useful way of accessing medication information and pathology results in one location

➢ GPs were able to access allergy information and used this to inform safe prescribing

➢ GPs reported that My Health Record helped them to save time and improve communication, reducing the potential for error and possibly decreasing patients' 'doctor shopping' practices.

The patient view

➢ Patients understood My Health Record as a tool for health professionals that should contain information about medical conditions, medication and allergies, rather than something for them to actively engage with and use for the management of their medicines.

➢ Some patients assumed that information from general practice visits is automatically uploaded.

➢ As this evaluation pre-dated the commencement of the national opt-out period the current public sentiment around privacy concerns may not have been captured.

Pathology, radiology and medication use

➢ Baseline rates have been determined for testing of HbA_{1c} in less than the recommended testing interval, repeat knee X-rays and benzodiazepine prescribing for those with recorded My Health Record activity

> Of people in the MedicineInsight cohort with type 2 diabetes and at least one HbA_{1c} test with a between-test interval of less than 90 days over the 5-year study period, 8.7% (888/10177) had recorded My Health Record activity.

> Of people in the MedicineInsight cohort with osteoarthritis with at least one knee X-ray within 365 days of a preceding test within the 5-year study period, 9.0% (836/9278) had recorded My Health Record activity.

> Of people in the MedicineInsight cohort who attended multiple practices, 2.7% (169/6218) had a recorded activity for My Health Record at least once between 2013 and 2017.

HbA_{1c} testing for people with type 2 diabetes

> A higher proportion of people with at least one HbA_{1c} test result occurring within a 90-day test interval had My Health Record activity recorded compared to those who did not have a test within a 90-day test interval (888/10177, 8.7% vs 1611/23579, 6.8%).

> The percentage of HbA_{1c} tests ordered within the 90-day test interval was lower if a My Health Record had been uploaded in the practice (9.4% vs 20.3%, -10.9%, 95% confidence intervals -20.9 vs -0.90).

Ordering of knee X-rays for people with osteoarthritis

> A similar proportion of patients with recorded My Health Record activity had at least one knee X-ray occurring within a 365-day test interval compared with those who did not (9.0% vs 8.7% respectively).

> Patients who attended one practice (8838/16809, 52.6%) were more likely to have had at least one knee X-ray test result within 365 days compared with patients who attended multiple practices (440/927, 47.5%).

Rate of benzodiazepine prescribing

> The rate of benzodiazepine prescriptions per person-year was higher for patients who attended multiple practices compared with those who attended one practice (2.1 vs 1.6/person-year), a relative increase of 30% (95% CI: 1.3 to 1.4).

> For patients who attended multiple practices, the rate of benzodiazepine prescriptions per person-year was higher for patients who had a My Health Record activity reported compared to when no My Health Record activity occurred or where the patient was not registered for a My Health Record (3.6 vs 2.0, Risk ratio=1.8, 95% CI: 1.4 to 2.2).

Allergies and ADRs to antibiotics

> Baseline rates of recorded My Health Record activity have been determined for people with allergies and adverse drug reactions (ADRs) to antibiotics within the MedicineInsight cohort.

> Only a small proportion of people with a documented allergy or ADR to antibiotics had My Health Record activity recorded (4490/114499; 3.92%) and a smaller proportion had a shared health summary (4231/114499; 3.7%).

> Of those who had a shared health summary, the majority of the summaries captured the recorded ADR (3873/4231; 91.5%), but 8.5% of people had a shared health summary that was not updated after the recording of an ADR.

> There was higher My Health Record activity in opt out areas, but this did not appear to translate to an increased proportion of people with shared health summaries that would have contained information about allergies and ADRs in My Health Record.

All the results reported in this study should be interpreted with caution due to the small numbers of people with recorded My Health Record activity.

Discussion

This mixed methods evaluation sets a baseline against which the My Health Record implementation can be monitored over time. It is early days in the implementation of My Health Record and the evaluation found less than 10% of patients in each of the cohorts had My Health Record activity recorded within their general practice record between 1 January 2013 and 31 December 2017. GPs and patients both identify clear potential benefits of My Health Record use for sharing health information and for reducing duplication of investigations. This evaluation is based on the use of innovative and repeatable methods, developed and enhanced specifically to explore the use of My Health Record in general practice. The evaluation used the largest general practice dataset in Australia, MedicineInsight, consisting of 3.6 million regular patients, based on the RACGP definition. We extracted indicators of My Health Record activity in the general practice clinical information system (CIS) for the first time and applied linkage algorithms to identify patients attending multiple practices so that the dataset was reflective of individual patients, rather than individual patient records. We were able to simulate an environment that linked a mocked clinical environment to the My Health Record.

A series of analyses were undertaken investigating whether My Health Record activity was associated with improved pathology and imaging practice using HbA$_{1c}$ testing and knee X-ray imaging as examples. Statistically significant differences were not identified between those patients with My Health Record activity and those without in terms of diagnostic testing using HbA$_{1c}$ tests for patients with type 2 diabetes and knee X-rays for patients with osteoarthritis. This is not unexpected, as radiology results are not currently routinely uploaded to the My Health Record and pathology results from private pathology companies only commenced uploading in April 2017.

Further exploratory analysis is required to understand the higher rate of benzodiazepine prescription observed with My Health Record activity and to understand the true effects of My Health Record activity on the rate of prescribing benzodiazepines. The small number of My Health Record uploads and downloads affects the ability of GPs to know that patients are being prescribed this medication at other practices. Over the 5-year study period, there was an average of 8 prescriptions per patient for those who had more than one recorded prescription. A small number of people received a very large number of prescriptions.

The qualitative study found that GPs and patients expected that use of My Health Record will assist in avoiding adverse and allergic drug reactions. Allergies can be recorded in multiple document types within the My Health Record, including shared health summaries that are uploaded by a patient's regular GP. We found that only 3.7% of patients with a recorded antibiotic allergy or adverse drug reaction (ADR) had a shared health summary uploaded. Of those who had a shared health summary, the majority captured the recorded ADR (3873/4231; 91.54%), but 8.46% of people had a shared health summary that was not updated after the recording of an ADR. This suggests that there is room for improvement in the process of updating the My Health Record when a new allergy or ADR is recorded. The importance of access to this information was demonstrated in our simulation study, where all GPs accessed allergy information from the My Health Record to inform safe prescribing of an antibiotic.

The results of the qualitative and simulation studies indicate that GPs and patients saw benefit in the My Health Record, but that the drivers for My Health Record use need to be explored and integration of My Health Record with GP CIS needs to be optimised with the end user in mind.

An important finding was that patients saw the My Health Record as a tool for doctors and believed that information from their general practice visits would be automatically uploaded. It was not seen as a tool for them to use to manage their health or medicines. It is possible that this lack of engagement from patients may be one contributing factor to the low levels of My Health Record activity seen in the quantitative studies.

Drivers for GP engagement require additional exploration. There appears to be a lack of trust among GPs in the accuracy and completeness of the data recorded in the My Health Record. There is also a perception that hospital clinical staff and specialists have decided not to access My Health Record, and this is influencing GPs' decisions about whether to spend time using the new system.

In our simulation study, all GPs were able to access allergy information from the My Health Record and use this to inform safe prescribing. Positive benefits of the My Health Record were the potential to save time, improve communication and reduce error. However, a number of GPs had difficulty in uploading information to the My Health Record. Insufficient integration of the My Health Record with the CIS was a concern, as was concern about responsibility for the quality of information recorded in the system.

There are some key study limitations which are important to acknowledge. The findings from our quantitative studies should be interpreted with caution because of low My Health Record activity in the study cohorts. There may be patients who are attending multiple practices, some of which are not captured in the dataset. The activity reported in this study may not be generalisable to all general practices, as MedicineInsight general practices have volunteered to participate in a quality improvement activity. Finally, we were only able to analyse My Health Record activity that was recorded in general practice records. In our qualitative study, we aimed to recruit GPs who were high users of the My Health Record. However, recruitment was challenging and a wider recruitment drive outside of the MedicineInsight practices resulted in not all GPs interviewed being regular users of My Health Record. Similarly, many patients had limited understanding of the My Health Record or the way it could be used.

The My Health Record is an evolving digital resource and its impact is likely to increase with the improved functionality and patient registrations that will occur as the system changes from opt-in to opt-out recruitment. This study has developed innovative methods to provide a snapshot of My Health Record activity in general practice at the beginning of its integration into health professional work flow and this methodology can be used again to measure the impact of this important national program over time. The patient linkage algorithm and My Health Record flags were developed for this study, creating a unique patient cohort from the MedicineInsight practices.

Recommendations

Six key recommendations are proposed to increase the impact and patient benefit of the My Health Record.

1. Improve integration of My Health Record with current GP clinical information systems to ensure optimum functionality and compatibility. Co-design with end users and simulation testing will be important to this work.

2. Continue to design patient engagement strategies for My Health Record based on qualitative research.

3. Conduct follow up research into duplication of pathology testing once pathology results are routinely available in My Health Record.

4. Explore the use of longitudinal or time series analysis of MedicineInsight data for evaluating My Health Record given the restrictions with My Health Record data. This will require accurate records of the timing and distribution of new functionality roll out.

5. Use the patient linkage algorithm and My Health Record flags that were developed for this study to create a unique linked patient cohort from the MedicineInsight practices to My Heath Record data to assist with documenting activity types, validating My Health Record flags and exploring activity by provider.

6. Investigate the effect of current privacy concerns about My Health Record on usage by patients and health professionals.

INTRODUCTION

My Health Record is a secure online health information system, which allows people to control their health information. It builds on the Personally Controlled Electronic Health Record and was envisioned to be an online infrastructure platform that would facilitate sharing of patient information across all health care settings. Shared health summaries are uploaded to My Health Record by a patient's nominated healthcare provider and include information about allergies and adverse drug reactions (ADRs), immunisations, medical conditions and medicines. Event summaries can be uploaded by healthcare providers who are not the regular, nominated provider of care. These summaries capture information about a significant healthcare event, including the initiation or completion of treatment and results of medical tests. The functionality of My Health Record is still evolving, with hospital discharge summaries and pathology tests starting to be incorporated into the record (see Figure 1).

NPS MedicineWise and the University of Melbourne collaborated to conduct a mixed methods study to develop methodologies to explore the impact of My Health Record and to see if there were early signs that the My Health Record is associated with benefits to both patients and GPs.

Figure 1:   Timeline of My Health Record Activity

July 2012	• Personally Controlled Electronic Health Record (PCEHR; the first iteration of the My Health Record) launched
January 2013	• PCEHR incorporated into GP records
February 2013	• First e-Health Practice Incentive Payment (ePIP)
March 2016	• Trial of Opt Out of the My Health Record launched in Northern Queensland and Nepean Blue Mountains. Innovative approaches to Opt In trialled in Ballarat and Western Australia
May 2016	• Second ePIP commenced with GPs incentivised to upload shared health summaries to My Health Record
April 2017	• Pathology results start being shared to the My Health Record. This commenced with public hospitals in New South Wales Health, Northern Territory Department of Health, Tasmanian Health Service, ACT Health and Queensland Health
June 2017	• Private pathology results start to be uploaded to My Health Record (Sonic)
July 2018	• Nationwide Opt Out period commences

This report outlines the results of the mixed methods study which aimed to:

1. explore whether My Health Record activity was associated with reduced: (1) HbA_{1c} tests within a 90-day period for people with type 2 diabetes; (2) repetition of knee X-rays within a 12-month period for people with osteoarthritis; and (3) rate of prescribing of benzodiazepines

2. determine the proportion of primary care patients with a recorded allergy or adverse drug reaction (ADR) to antibiotics who had 1) recorded My Health Record activity and 2) shared health summary or other My Health Record document which would contain information about allergies and ADR uploaded to My Health Record.

3. explore the impact My Health Record has had on clinicians and consumers in improving medication safety and management, using a qualitative approach

4. use a novel simulation approach to explore how GPs use the My Health Record in a consultation where there is potential for an adverse drug reaction.

The study was approved by the University of Melbourne Human Research Ethics Committee (HREC ID: 1750888) and received MedicineInsight Data Governance approval (ID 2017-022 and 2018-003).

Studies 1 and 2 use the largest general practice dataset in Australia, MedicineInsight, consisting of 3.6 million regular patients, based on the RACGP definition. MedicineInsight extracts longitudinal de-identified patient health records from the software GPs use to manage patient records and write prescriptions. De-identified patient data are extracted weekly from each participating practice. Practices recruited to MedicineInsight are not randomly selected. However, the data provides a proxy measure of My Health Record activities given that My Health Record data are not available. We extracted indicators of My Health Record activity and applied a novel linkage algorithm to identify patients attending multiple practices so that the dataset was reflective of individual patients, rather than individual patient records.

SUB-STUDY 1: REDUCTION OF DUPLICATION OF MEDICINES, TESTS AND DIAGNOSTIC IMAGING

With routine use of the My Health Record a number of benefits can be anticipated, including a reduction in unnecessary duplication of pathology and radiology testing and improvements in medication management. Potential benefits are postulated to be greater for patients who attend multiple general practices or health services and whose records are therefore not consolidated within one general practice record.

To realise these benefits for an individual patient, shared health summaries, test results and Pharmaceutical Benefits Scheme (PBS) information must first be uploaded to the patient's My Health Record, and health professionals must be able to view, download or update those records during a patient consultation. While appropriate My Health Record functionality exists, it is not yet fully implemented and may not be optimally available in general practice workflow.

The aim of this study was to develop a methodology to explore the impact of My Health Record on testing and prescribing and to find out whether My Health Record activity was associated with reduced: (1) HbA$_{1c}$ tests within a 90-day period for people with type 2 diabetes; (2) repetition of knee X-rays within a 12-month period for people with osteoarthritis; and (3) rate of prescribing of benzodiazepines; both overall and in those attending multiple practices.

As pathology results and radiology reports were not being routinely uploaded to the My Health Record during the study period (See

Figure **1**, Introduction), we did not expect to find a clear association between use of the My Health Record and reduced HbA$_{1c}$ or knee X-ray testing in this study. GPs have been incentivised to upload shared health summaries since May 2016. This makes it likely that, with patient consent, benzodiazepine prescriptions have been uploaded to the My Health Record as part of a patient's medication list. For patients who consented, PBS dispensing information also may have been uploaded. For this reason, we hypothesised that the rate of prescribing of benzodiazepines may have been reduced, particularly for people attending multiple practices.

Cohorts for each study were provided from the MedicineInsight dataset. Detailed information about the MedicineInsight dataset is available in Appendix 1. A linkage study within the MedicineInsight dataset was undertaken using the unique GRHANITE hashing linkage technology to identify individuals 18 years and over who were attending multiple practices. A new variable was created in the dataset that identified the records that belonged to the same individual across multiple practices. Information about this process is available in Appendix 3.

1.1 My Health Record and HbA$_{1c}$ pathology testing

Current Australian guidelines recommend that HbA$_{1c}$ tests be performed at 3-month intervals for patients with type 2 diabetes who are not pregnant. For this study, duplication of HbA$_{1c}$ pathology was defined as an HbA$_{1c}$ test that was reported less than 90 days from the preceding HbA$_{1c}$ test for patients with type 2 diabetes. That is, the interval between tests was less than 90 testing days. It was hypothesised that use of the My Health Record has the potential to reduce HbA$_{1c}$ testing occurring within a 90-day period, particularly for patients who are attending multiple general practices. However, this may be limited by the fact that pathology uploads from pathology providers are not yet routinely occurring on a national basis.

Aim

Study 1.1 aimed to:

- Describe (a) the proportion of people with type 2 diabetes who had at least one HbA_{1c} test with a between-test interval of less than 90 days recorded, and (b) the proportion of these patients with at least one episode of Health Record activity recorded.

- Determine whether HbA_{1c} testing with a between-test interval of 90 days was reduced when there was My Health Record activity recorded between the paired tests, compared to when there was no My Health Record activity recorded, for patients who attend multiple practices. For the purposes of this study we defined My Health Record activity as uploading or downloading a relevant document or viewing or accessing a record. We were not able to differentiate between My Health Record activity related to different kinds of documents, eg event summary, pathology record, discharge summary etc

Population

- Inclusion criteria: Patients with type 2 diabetes with at least two HbA_{1c} tests within the study period (1 January 2013 to 31 December 2017).

- Exclusion criteria: Pregnant women

Statistical analysis

Descriptive statistics were used to summarise:

- general practice characteristics

- patient characteristics

- single or multiple practice (two or more) attendance

- the number of HbA_{1c} tests reported per patient

- the number of patients with at least one HbA_{1c} test with a between-test interval of less than 90 days

- whether patients had My Health Record activity recorded.

My Health Record Activity was defined as My Health Record accessed but no upload or download registered *or* an upload occurred *and/or* download occurred. Days between HbA_{1c} tests were summarised as medians and range (minimum to maximum).

The outcome was a binary variable created to identify whether patients with type 2 diabetes had an HbA_{1c} test result returned less than 90 days after the preceding test. A two-sample test of proportions was used to test for differences in the percentage of HbA_{1c} pathology tests that were recorded within 90 days by whether there was a My Health Record activity for the paired records, or not, for patients who attended multiple practices within the study period. 95% confidence intervals were calculated using the survey command in Stata to adjust for repeated outcome measures within patients. Estimates were reported as the difference in the percentage of HbA_{1c} tests with a between-test interval less 90 days by whether there was a My Health Record activity between the two tests or no activity recorded. Analysis was conducted in Stata 15.1.

Results

The cohort dataset consisted of 238 139 people with type 2 diabetes. Of these, 33 756 (14.2%) people attending 438 general practices had at least two HbA_{1c} tests between 1 January 2013 and 31 December 2017 and were included in this study (See Figure 2). The characteristics of the general

practices contributing data for these patients is summarised in Table 1.1.1 and patient demographics are summarised in Table 1.1.2. Overall, the characteristics of patients included in this study cohort were similar to patients with type 2 diabetes in the MedicineInsight data set provided, with the exception of attendance at multiple practices. Of the MedicineInsight dataset provided, 67 467 (28.3%) people attended multiple practices, and this was reduced to 1 165 (3.5%) once the inclusion criteria were applied.

The included patients contributed a total of 147 717 HbA_{1c} test results (average 4.4 HbA_{1c} test results per patient, range 2 to 35 HbA_{1c} results) over the 5-year study period.

Figure 2:   Identification of patients with at least two HbA_{1c} tests recorded between 2013 to 2017
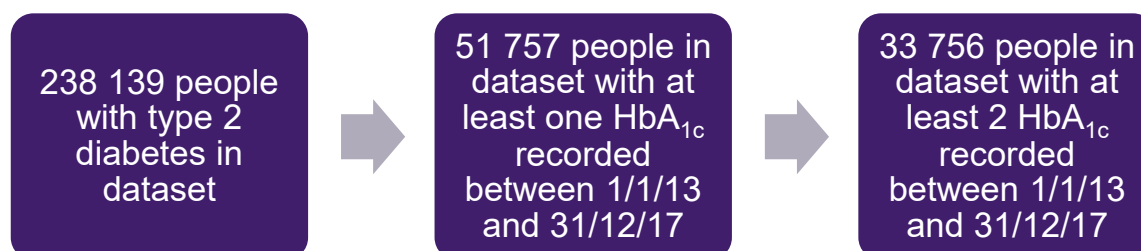
Table 1.1.1:   Characteristics of general practices (N=438)

Practice details		n (%)*
State	ACT	7 (1.6)
	NSW	143 (32.7)
	NT	10 (2.3)
	QLD	80 (18.3)
	SA	12 (2.7)
	TAS	36 (8.2)
	VIC	89 (20.3)
	WA	61 (13.9)
SEIFA Quintiles#	1	71 (16.5)
	2	70 (16.0)
	3	107 (24.5)
	4 and 5	189 (43.3)
Rurality^	Major cities	259 (59.3)
	Inner regional	109 (24.9)
	Outer regional, remote and very remote	69 (15.8)

*Note: Discrepancies in totals due to missing data;

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.1.2:   Count (%) of patient characteristics for all patients with diabetes in the cohort and who had at least two HbA$_{1c}$ tests recorded between 2013 and 2017

Patient characteristics		All patients with diabetes in the cohort		Patients with at least two HbA$_{1c}$ pathology tests	
		n	(%)	n	(%)
Total		238139		33756	
Sex	Female	115413	(48.5)	15539	(46.0)
	Male	121982	(51.2)	18190	(53.9)
	Indeterminate	744	(0.3)	27	(0.1)
Age groups (years)	0-9	783	(0.3)	20	(0.1)
	10-19	2405	(1.0)	117	(0.3)
	20-29	7362	(3.1)	358	(1.1)
	30-39	18004	(7.6)	878	(2.6)
	40-49	23865	(10.0)	2113	(6.3)
	50-59	38871	(16.3)	4891	(14.5)
	60-69	56806	(23.9)	8881	(26.3)
	70-79	52994	(22.3)	9743	(28.9)
	80-89	36915	(15.5)	6754	(20.0)
SEIFA Quintiles#	1	48082	(20.4)	6298	(18.8)
	2	43107	(18.3)	5260	(15.7)
	3	55363	(23.5)	9707	(28.9)
	4 and 5	89426	(37.9)	12289	(36.6)
Rurality	Major city	142951	(60.5)	19977	(59.5)
	Inner regional	60814	(25.8)	9363	(27.9)
	Outer regional, remote and very remote	32444	(13.7)	4256	(12.7)
Attended multiple clinics	No	170672	(71.7)	32591	(96.5)
	Yes	67467	(28.3)	1165	(3.5)

*Note: Discrepancies in totals due to missing responses;

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.1.3 summarises the count and percentage of patients by whether they had at least one HbA$_{1c}$ test recorded within 90 days of a preceding test (rows) and had at least one My Health Record activity recorded (columns), for all patients combined, and by whether they attended one or multiple practices. Overall, 10 177 (30.2%) patients had at least one HbA$_{1c}$ test result recorded with a between-test interval that was less than 90 days over the 5-year study period.

A total of 2 499 (7.4%) patients had at least one My Health Record activity recorded (that is, they may have viewed the record only, uploaded and/or downloaded a shared summary) at any time during the study period. Of these, 888 (35.5%) had at least one HbA$_{1c}$ test that occurred within 90 days of a

preceding test in the 5-year study period. Overall, a higher proportion of people with at least one HbA$_{1c}$ test result occurring within a 90-day test interval had My Health Record activity recorded compared to those who did not (888/10 177, 8.7% vs 1 611/23 579, 6.8%).

A greater proportion of patients who attended multiple practices (2 or more) had at least one HbA$_{1c}$ test result with a between-test interval of less than 90 days (457/1 165, 39.2%) compared to patients who attended one practice (9 720/32 591, 29.8%). Most patients with at least one HbA$_{1c}$ test result within 90 days of a preceding test had both tests recorded in the same practice (10 088/10 177, 99.1%).

For patients who attended one or multiple practices, the percentage who had any record of a My Health Record activity (view, upload, download) was less than 10% and the percentage of patients with My Health Record activity recorded was similar for patients who did or did not have at least one HbA$_{1c}$ test result recorded with a between-test interval less than 90 days.

Table 1.1.4 shows My Health Record uploads and downloads for the 1 165 patients who attended two or more practices between 2013 and 2017. There was a total of 5 388 HbA$_{1c}$ records for these patients, an average of 4.6 per patient, ranging from 2 to 20 HbA$_{1c}$ pathology tests per patient. The first occurrence of the HbA$_{1c}$ test for each of the 1 165 patients was excluded for the analysis as there was no preceding test result for comparison, resulting in 4 223 paired HbA$_{1c}$ test results available for analysis. The 28 patients attending multiple practices with a recorded My Health Record Upload (see Table 1.1.3) contributed 32 paired HbA$_{1c}$ tests, 3 of which were identified as having a between-test interval of less than 90 days in the same practice. No tests were repeated with test intervals of less than 90 days across practices. The 11 patients with a My Health Record Download (see Table 1.1.3) contributed 8 paired HbA$_{1c}$ records of which only one HbA$_{1c}$ test was repeated within a 90-day interval within a practice.

Results show that the percentage of HbA$_{1c}$ tests with a between-test interval of less than 90 days within the practice was lower if a My Health Record upload had occurred between the time these tests were received (9.4% vs 20.3%, −10.9, 95% confidence intervals −20.9 vs −0.90). Similarly, there is an indication that there was a reduction in HbA$_{1c}$ test results with a between-test interval less than 90 days with My Health Record downloads (12.5% vs 20.2%, −7.7, 95% confidence intervals −30.6 to 15.6). However, these estimates have wide confidence intervals and were based on a very small number of patients who attended multiple practices and had at least one My Health Record upload or download, so these results should be interpreted with caution.

For the 852 patients with testing intervals of less than 90 days recorded either within the same practice or between practices, the median testing interval was 61 days. The median time between testing was shorter for the subset of patients whose results were recorded across different practices (n=104, median=38.5 days).

Table 1.1.3:   HbA$_{1c}$ test results and My Health Record activity by practice attendance between 2013 and 2017 (N=33756)

Variable	Total patients		Any My Health Record activity recorded		My Health Record upload		My Health Record download	
	n	(col %)	n	(row %)	n	(row %)	n	(row %)
Total patients who attend one or multiple practices	33756		2499	(7.4)	775	(2.3)	163	(0.48)
No HbA$_{1c}$ test recorded within 90 days of a previous test	23579	(69.9)	1611	(6.8)	403	(1.7)	82	(0.35)
At least one HbA$_{1c}$ test recorded within 90 days of a preceding test	10177	(30.2)	888	(8.7)	372	(3.7)	81	(0.80)
One practice attended	32591		2458	(7.5)	747	(2.3)	155	(0.47)
No HbA$_{1c}$ test recorded within 90 days of a previous test	22871	(70.2)	1567	(6.9)	386	(1.7)	76	(0.33)
At least one HbA$_{1c}$ test recorded within 90 days of a preceding test	9720	(29.8)	861	(8.9)	361	(3.7)	79	(0.81)
Multiple practices attended	1165		71	(6.1)	28	(2.4)	8	(0.69)
No HbA$_{1c}$ test recorded within 90 days of a previous test	708	(60.8)	44	(6.2)	17	(2.4)	6	(0.85)
At least one HbA$_{1c}$ test recorded within 90 days of a preceding test within practice only	368	(31.6)	22	(6.0)	7	(1.9)	2	(0.54)
At least one HbA$_{1c}$ test recorded within 90 days of a preceding test across practices only	52	(4.5)	2	(3.9)	1	(1.9)	0	(0)
At least one HbA$_{1c}$ test recorded within 90 days of a preceding test within and across practices	37	(3.2)	3	(8.1)	3	(8.1)	0	(0)

n – total number of patients; col % – column percentages for each sub-group (all patients combined, patients who attended one practice and patients who attended multiple practices; row % – row percentages of the total patients in each row.

My Health Record activity – includes viewing, upload and/or downloads. This column indicates the number of patients with at least one My Health Record activity recorded.

My Health Record upload – indicates the number of patients that had at least one My Health Record[*] document uploaded.

My Health Record download – indicates the number of patients who had at least one My Health Record* document downloaded.

* We are unable to differentiate between My Health Record activity related to different documents (event summary, pathology record, discharge summary etc).

Table 1.1.4:   Association between HbA$_{1c}$ testing intervals of less than 90 days and My Health Record uploads/downloads in patients attending multiple practices (N=1165 patients with 4223 paired HbA$_{1c}$ test results)

My Health Record		Total number of paired HbA$_{1c}$ tests recorded in CIS (N)[*]	HbA$_{1c}$ results with testing interval of < 90 days recorded						HbA$_{1c}$ results with testing interval of < 90 days recorded across different practices only					
			n	(row %)	Diff	(95 % CI)		Median (Range)	n	(row %)	Diff	(95 % CI)		Median (Range)
Upload	Yes	32	3	(9.4)	-10.9	(-20.9,	-0.90)	65 (50, 68)	0	(0)	--			
	No	4191	849	(20.3)				61 (1 to 89)	104	(2.5)				38.5 (1 to 88)
Download	Yes	8	1	(12.5)	-7.7	(-30.6,	15.2)	65	0	(0)	--			
	No	4215	851	(20.2)				61 (1 to 89)	104	(2.5)				38.5 (1 to 88)

N – total number of paired HbA$_{1c}$ tests across practices in the CIS.

*The first occurrence of the HbA$_{1c}$ test for each of the 1165 patients was excluded for the analysis as there was no preceding test result for comparison.

row % = percentage calculated using the total number of paired HbA$_{1c}$ tests recorded in CIS in each row; Diff – difference in percentage of HbA$_{1c}$ tests; CI – Confidence interval; Median (range) of the days between pathology tests that were less 90 days

CIS – clinical information system

1.2 My Health Record and the duplication of knee X-ray procedures for people with osteoarthritis of the knee

X-rays are not generally required for diagnosis and ongoing management of knee osteoarthritis, although they may be required for assessment for surgery. Use of the My Health Record has the potential to reduce knee X-rays by making results available to health professionals working in multiple practices or settings so that additional X-rays are not ordered simply because previous results are not available.

Aim

Study 1.2 aimed to:

> ➢ Describe the proportion of people with osteoarthritis who had at least one occurrence of knee X-rays being reported within a 12-month period during the study period (1 January 2013 to 31 December 2017).

> ➢ Explore whether knee X-ray testing within 12 months was reduced when there was My Health Record activity between paired tests compared with when there was no My Health Record activity for patients who attend multiple practices

It was hypothesised that My Health Record activity might be associated with a reduction in repeat knee X-rays occurring within a one-year period. However, it was expected that such an association would be unlikely to be detected in this study, as information on knee X-rays is not currently uploaded to the My Health Record by radiology service providers.

Population

> ➢ Inclusion criteria: Patients with osteoarthritis with at least two knee X-ray tests within the study period (1 January 2013 to 31 December 2017).

Statistical analysis

Descriptive statistics were used to summarise:

> ➢ general practice characteristics

> ➢ patient characteristics

> ➢ single or multiple practice (two or more) attendance

> ➢ the number of knee X-ray tests reported per patient

> ➢ the number of patients with at least one knee X-ray test with a between-test interval of less than 365 days

> ➢ whether patients had My Health Record activity recorded.

My Health Record Activity was defined as My Health Record accessed but no upload or download registered *or* an upload occurred *and/or* download occurred. Days between knee X-ray tests were summarised as medians and range (minimum to maximum).

The outcome was a binary variable created to identify whether patients with osteoarthritis had a knee X-ray test result returned less than 365 days after the preceding test.

A two-sample test of proportions was used to test for differences in the percentage of knee X-rays tests that were recorded within 365 days by whether there was a My Health Record activity for the paired records for patients who attended multiple practices within the study period. 95% confidence

intervals were calculated using the survey command in Stata to adjust for repeated outcome measures within patients. Estimates were reported as the difference in the percentage of knee X-ray tests with a between-test interval less than 365 days by whether there was a My Health Record activity between the two tests or not. Analysis was conducted in Stata 15.1.[2]

Results

The dataset consisted of 332 836 people with osteoarthritis, of whom 31.9% (106 117) attended more than one MedicineInsight practice. There were 99 353 knee X-ray tests for 74 267 patients with osteoarthritis. The number of X-ray tests recorded was 1 to 13 per patient between 1 January 2013 and 31 December 2017, an average of 1.3 per patient. Of these, 17 736 (23.9%) people attending 459 general practices had at least two knee X-rays and were included in this study (See Figure 3).

The characteristics of the general practices contributing data for these patients are summarised in Table 1.2.1 and patient demographics are summarised in Table 1.2.2. As knee osteoarthritis was not always marked within the electronic medical record (eg, a patient may have a diagnosis of osteoarthritis, but not specifically knee osteoarthritis) we used the record of at least one X-ray as a proxy for knee osteoarthritis being present. Patients who had more than one knee X-ray record were slightly older, lived in inner regional areas, and a higher proportion attended multiple clinics compared to those with one X-ray recorded.

56 531 (76.1%) patients who had only one test were excluded from further analysis because at least two X-ray tests were required per patient to determine if tests were repeated within 365 days. The remaining 17 736 (23.9%) patients had a total of 42 822 test results, with an average of 2.4 records per patient, ranging between 2 to 13 records. Although 31.9% of patients with osteoarthritis attended multiple practices, 5.2% of patients (927/17 736) who had at least two knee x-rays had over the 5-year study period.

Figure 3:   Identification of patients with at least two X-ray tests recorded between 2013 and 2017
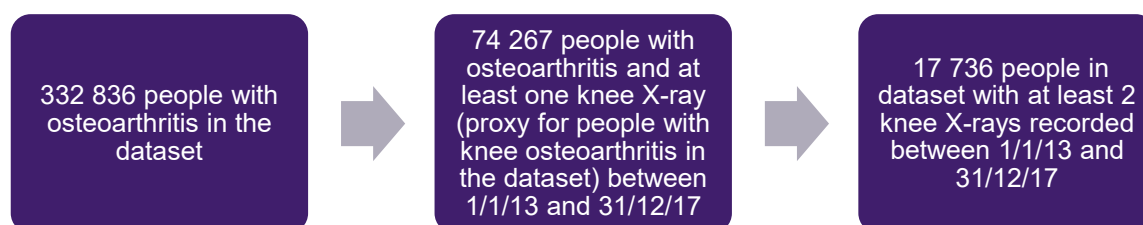
332 836 people with osteoarthritis in the dataset → 74 267 people with osteoarthritis and at least one knee X-ray (proxy for people with knee osteoarthritis in the dataset) between 1/1/13 and 31/12/17 → 17 736 people in dataset with at least 2 knee X-rays recorded between 1/1/13 and 31/12/17

Table 1.2.1 shows the characteristics of the 459 practices who had at least one patient with at least two knee X-ray results recorded between 1 January 2013 and 31 December 2017. Table 1.2.2 summarises the characteristics of the 74 267 patients with one or more knee X-ray record.

Table 1.2.1:   Count and percentages of characteristics of general practice (N=459)[*]

Practice characteristics		n (%)
Practice state	ACT	9 (2.0)
	NSW	159 (34.0)
	NT	7 (1.5)
	QLD	97 (21.1)
	SA	13 (2.8)
	TAS	38 (8.3)
	VIC	88 (19.2)
	WA	51 (11.1)
Practice SEIFA Quintiles[#]	1	79 (17.3)
	2	72 (15.7)
	3	104 (22.7)
	4 and 5	203 (44.3)
Practice rurality[^]	Major cities	287 (62.7)
	Inner regional	110 (24.0)
	Outer regional, remote and very remote	61 (13.3)

*Discrepancies in total due to missing data;

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.2.2: **Count (%) of characteristics of patients who had at least one knee X-ray test result recorded, in total and by the number of knee X-ray test results recorded, between 2013 and 2017 (N=74267)***

Variable		Total patients with at least one X-ray test	Patients with one X-ray test	Patients with at least two X-ray tests
		74267	56531 (76.1)	17736 (23.9)
		n (%)	n (%)	n (%)
Sex	Female	45274 (61.0)	34082 (60.3)	11192 (63.1)
	Male	28925 (38.9)	22399 (39.6)	6526 (36.8)
	Indeterminate	68 (0.1)	50 (0.1)	18 (0.1)
Age groups (years)	0-9	12 (0.02)	12 (0.02)	0 (0)
	10-19	375 (0.5)	325 (0.6)	50 (0.3)
	20-29	417 (0.6)	368 (0.7)	49 (0.3)
	30-39	1054 (1.4)	913 (1.6)	141 (0.8)
	40-49	3882 (5.2)	3234 (5.7)	648 (3.7)
	50-59	11631 (15.7)	9275 (16.4)	2356 (13.3)
	60-69	21614 (29.1)	16372 (29.0)	5242 (29.6)
	70-79	21699 (29.2)	15824 (28.0)	5875 (33.1)
	80-89	13582 (18.3)	10207 (18.1)	3375 (19.0)
Patient SEIFA Quintile [#]	1	16617 (22.4)	12160 (21.6)	4457 (25.2)
	2	15115 (20.4)	11373 (20.2)	3742 (21.2)
	3	17492 (23.6)	13196 (23.4)	4296 (24.3)
	4 and 5	24819 (33.5)	19630 (34.8)	5189 (29.3)
Patient rurality	Major cities	39322 (53.1)	30845 (54.7)	8477 (47.9)
	Inner regional	25622 (34.6)	18663 (33.1)	6959 (39.3)
	Outer regional, remote and very remote	9136 (12.3)	6879 (12.2)	2257 (12.8)
Attended multiple clinics within time frame	No	72552 (97.7)	55743 (98.6)	16809 (94.8)
	Yes	1715 (2.3)	788 (1.4)	927 (5.2)

*Discrepancies in total due to missing responses;

[#] Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.2.3 summarises the count and percentage of patients by whether they had at least two knee X-ray tests recorded (rows) and had at least one My Health Record activity recorded, overall and by practice attendance. Overall, 9 278 (52.3%) people had at least one knee X-ray reported where the between-test interval was less than 365 days over the 5-year study period. The majority of these occurred within the same practice (9 113, 98.2%).

Fewer than one in ten people (1 574; 8.9%) had at least one My Health Record activity recorded (this included view, upload or download) over the 5-year study period. Of these, 836 (53.1%) patients had at least one knee X-ray test result recorded with a between-test interval of less than 365 days. Overall, a similar proportion of people with recorded My Health Record activity had at least one knee X-ray occurring within a 365-day test interval at least one knee X-ray occurring within a 365-day interval (9.0% vs 8.7% respectively).

A lower proportion of patients who attended multiple practices had at least one knee X-ray test result with a between-test interval of less than 365 days (440/927, 47.5%) compared with patients who attended one practice (8 838/16 809, 52.6%). Most patients attending multiple practices and with at least one knee X-ray test result with a between-test interval of less than 365 days had both tests recorded within the same practice (275/440, 62.5%).

Table 1.2.4 shows the number of knee X-ray tests with a between-test interval of less than 365 days by whether they had a My Health Record uploaded or downloaded during the between test interval. The 927 patients who attended two or more practices between 2013 and 2017 contributed a total of 2 321 knee X-ray test results, an average of 4.6 tests per patient, ranging from 2 to 9 knee X-ray test results per patient. The first occurrence of the knee X-ray test result for each of the 927 patients was excluded for this analysis because there was no preceding test result for comparison, resulting in 1 394 paired knee X-ray test results available for analysis. The 20 patients attending multiple practices with a recorded My Health Record Upload (see Table 1.2.3) had 20 paired knee X-ray test results, six of which were identified as having a test interval of less than 365 days. Only two tests were repeated with test interval of less than 365 days across practices. The four patients with a My Health Record Download (see Table 1.2.3) had four paired knee X-ray test results, of which only one knee X-ray test was repeated within a 365-day testing interval within a practice.

The results indicate that the percentage of X-ray tests with a between-test interval of less than 365 days was reduced from 46.4% to 30.0% if a My Health Record had been uploaded between the time these tests were conducted compared with no My Health Record document being uploaded, a 16.4% reduction. However, based on the 95% confidence intervals, the true difference may be as much as a 36% reduction or a 3.3% increase, or there may be no difference. Similarly, there is an indication that some duplication in tests was reduced in association with downloads. As only very few patients had a recorded upload or download of a My Health Record document these results should be interpreted with considerable caution. There were too few patients with an upload/download to determine whether having a My Health Record activity was associated with a reduction in the number of X-ray tests with a between-test interval of less than 365 days across different practices.

Table 1.2.3: Knee X-ray test results and My Health Record activity recorded by practice attendance between 2013 and 2017 (N=17736)

Variable	Total patients		Any My Health Record activity recorded		My Health Record upload		My Health Record download	
	n	(col %)	n	(row %)	n	(row %)	n	(row %)
Total patients who attend one or multiple practices	17736		1574	(8.9)	654	(3.7)	104	(0.59)
No knee X-ray result recorded within 365 days of a previous X-ray	8458	(47.7)	738	(8.7)	339	(4.0)	53	(0.63)
At least one knee X-ray result recorded within 365 days of a previous X-ray	9278	(52.3)	836	(9.0)	315	(3.4)	51	(0.55)
One practice attended	16809		1504	(8.9)	634	(3.8)	100	(0.59)
No knee X-ray result recorded within 365 days of a previous X-ray	7971	(47.4)	701	(8.8)	330	(4.1)	50	(0.63)
At least one knee X-ray result recorded within 365 days of a previous X-ray	8838	(52.6)	803	(9.1)	304	(3.4)	50	(0.57)
Multiple practices attended	927		70	(7.6)	20	(2.2)	4	(0.43)
No knee X-ray result recorded within 365 days of a previous X-ray	487	(52.5)	37	(7.6)	9	(1.9)	3	(0.62)
At least one knee X-ray result recorded within 365 days of a previous X-ray – within practice only	275	(29.7)	16	(5.8)	4	(1.5)	0	(0)
At least one knee X-ray result recorded within 365 days of a previous X-ray – across practices only	115	(12.4)	5	(4.4)	2	(1.7)	0	(0)
At least one knee X-ray result recorded within 365 days of a previous X-ray – within and across practices	50	(5.4)	12	(24.0)	5	(10.0)	1	(2.0)

n – total number of patients; col % – column percentages for each sub-group (all patients combined, patients who attended one practice and patients who attended multiple practices; row % – row percentage of the total patients in each row

My Health Record activity – includes viewing, upload and/or downloads. This column indicates the number of patients with at least one My Health Record activity recorded.

My Health Record upload – indicates the number of patients who had at least one My Health Record[*] document uploaded.

My Health Record download – indicates the number of patients who had at least one My Health Record[*] document uploaded

[*] We are unable to differentiate whether the My Health Record activity related to any event summary, pathology records, discharge summaries etc. It was not possible to determine whether knee X-rays occurring within 365 days were of the same or different knees.

Table 1.2.4: **Association between knee X-ray tests with testing interval < 365 days and My Health Record uploads/downloads in patients attending multiple practices (N=927 patients with 1394 paired X-ray tests)**

Type of My Health Record activity		Total number of paired knee X-ray results recorded in CIS (N)	Days between X-ray tests was less than 365 days (duplication)									
			Knee X-ray results with testing interval < 365 days recorded in the same practice and/or between different practices					Knee X-ray results with testing interval < 365 days recorded across different practices only				
			n	(row %)	Diff	(95 % CI)		Median (range)	n	(row %)	Diff	(95 % CI)		Median (range)
Upload	Yes	20	6	(30.0)	-16.4	(-36.2, | 3.3)	138.5 (14 to 363)	2	(10.0)	-3.1	(-16.4, | 10.2)	(72, 363)^
	No	1374	638	(46.4)				152 (1 to 364)	180	(13.1)				183 (1 to 364)
Download	Yes	4	1	(25.0)	-21.3	(-63.4,	-20.9)	205	0	(0)	--			--
	No	1390	643	(46.3)				151 (1 to 364)	182	(13.1)				183 (1 to 364)

N – total number of paired knee X-ray test results in the CIS

The first occurrence of the knee X-ray test for each of the 927 patients was excluded for the analysis as there was no preceding test result for comparison

row % = percentage calculated using the total number of paired knee X-ray test results recorded in CIS in each row; Diff – Difference in percentage of knee X-ray test results occurring with a testing interval < 365 days; CI – Confidence interval

Median (range) of the days between diagnostic tests that were less 365 days; ^ the two days are reported for the two duplicated tests

CIS – clinical information system/electronic medical record

1.3 My Health Record and reduction in benzodiazepine prescribing

Benzodiazepines are a class of medications which are minor tranquilisers. They are prescribed for indications including anxiety and insomnia but have the capacity for producing tolerance and dependence. As a result, it is recommended that benzodiazepines are prescribed by one health professional who can provide appropriate monitoring.

Aim

Study 1.3 explored whether having My Health Record activity (eg, view, record upload or download) in the general practice Clinical Information System (CIS) reduced the number of prescriptions for benzodiazepines among patients who attended multiple practices (2013 to 2017).

Study 1.3 aimed to examine:

➢ the rate of prescriptions for benzodiazepines per year among patients who attended multiple practices compared to those who attended one practice.

➢ for patients who attended multiple practices, the rate of prescriptions for benzodiazepines when My Health Record activity occurred (any activity including upload or download to My Health Record, or viewing the My Health Record) compared to when no My Health Record activity occurred Population

➢ Inclusion criteria: Patients who have been prescribed benzodiazepines with at least 2 prescriptions within the study period (1 January 2013 to 31 December 2017).

Statistical analysis

Descriptive statistics were used to summarise:

➢ general practice characteristics

➢ patient characteristics

➢ single or multiple practice (two or more) attended;

➢ he number of benzodiazepine medications reported per patient

➢ the number of patients with benzodiazepine medications

➢ whether patients had My Health Record activity recorded.

Poisson regression was used to examine whether the rate of prescriptions for benzodiazepines medication per year was higher among patients who attended multiple practices compared to those who attended one practice. Poisson regression analysis was also used to test for an association in the rate of prescriptions for benzodiazepines between My Health Record activity recorded (any activity including upload or download to My Health Record) compared to no My Health Record activity recorded over the 5-year study period. Estimates were reported as rate ratio with respective 95% confidence intervals. Analysis was conducted in Stata 15.1.[3]

Results

There were 752 974 patients provided in the benzodiazepine dataset, of whom 236 683 (31.4%) attended multiple practices. Of the 752 974 patients available in the dataset, 226 717 patients (with a total of 946 338 benzodiazepine prescriptions) were prescribed at least one benzodiazepine

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[3] StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC

medication during the study period (2013 to 2017). 103 532 patients attending 494 general practices had at least two prescriptions recorded (see Figure 4), with a total of 823 153 prescriptions and average of 8 prescriptions per patient (range 2 to 290).

Figure 4: **Identification of patients with at least two benzodiazepine medications prescriptions recorded between 2013 and 2017**

752 974 people with with prescriptions → 226 717 people with at least one prescription for benzodiazepine medication between 1/1/13 and 31/12/17 → 103 532 people with at least two prescriptions for benzodiazepine medications between 1/1/13 and 31/12/17
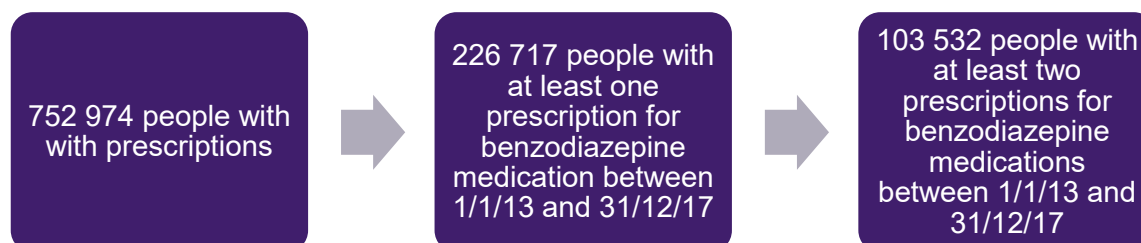
Table 1.3.1 shows the characteristics of the 494 practices attended by patients who had at least two prescriptions. Table 1.3.2 summarises the characteristics of the 226 177 patients who had at least one prescription between 2013 and 2017. The sex distribution was similar between patients with one prescription and those with two or more prescriptions; however, those with at least two prescriptions tended to be older, attend multiple clinics, live in inner regional areas and were more likely to be from less advantaged areas based on their postcodes.

Table 1.3.1: **Count (%) of general practice characteristics (N=494)***

		n (%)
Practice state	ACT	9 (1.8)
	NSW	167 (33.8)
	NT	10 (2.0)
	QLD	99 (20.0)
	SA	14 (2.8)
	TAS	38 (7.7)
	VIC	94 (19.0)
	WA	63 (12.8)
Practice SEIFA Quintiles#	1	82 (16.7)
	2	80 (16.3)
	3	113 (23.0)
	4 and 5	216 (44.0)
Practice rurality^	Major cities	301 (61.2)
	Inner regional	114 (23.2)
	Outer regional, remote and very remote	77 (15.7)

*Discrepancies in total due to missing data;

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to both practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.3.2: **Count (%) of patient characteristics who had at least one prescription for benzodiazepine medications recorded, in total and by the number of prescriptions recorded, between 2013 and 2017 (N= 226,177)***

Characteristics		Total patients with at least one prescription	Patients with one prescription	Patients with at least two prescriptions
		n (%)	n (%)	n (%)
Total		226717	123185 (54.3)	103532 (45.7)
Sex	Female	138979 (61.3)	74974 (60.9)	64005 (61.8)
	Male	87401 (38.6)	47978 (38.9)	39423 (38.1)
	Indeterminate	337 (0.2)	233 (0.2)	104 (0.1)
Age groups (years)	0-9	175 (0.1)	126 (0.1)	49 (0.0)
	10-19	2463 (1.1)	1932 (1.6)	531 (0.5)
	20-29	22165 (9.8)	15160 (12.3)	7005 (6.8)
	30-39	34821 (15.4)	21424 (17.4)	13397 (12.9)
	40-49	39599 (17.5)	22568 (18.3)	17031 (16.5)
	50-59	38087 (16.8)	21006 (17.1)	17081 (16.5)
	60-69	34251 (15.1)	17704 (14.4)	16547 (16.0)
	70-79	28179 (12.4)	12732 (10.3)	15447 (14.9)
	80-89	26969 (11.9)	10528 (8.5)	16441 (15.9)
Patient SEIFA Quintile#	1	39768 (17.6)	19843 (16.2)	19925 (19.3)
	2	36913 (16.4)	19318 (15.8)	17595 (17.1)
	3	54908 (24.3)	29054 (23.7)	25854 (25.1)
	4	93945 (41.7)	54199 (44.3)	39746 (38.5)
Patient rurality^	Major cities	127142 (56.3)	71446 (58.3)	55696 (54.0)
	Inner regional	66335 (29.4)	34031 (27.8)	32304 (31.3)
	Outer regional, remote and very remote	32297 (14.3)	17095 (14.0)	15202 (14.7)
Attended multiple clinics within time frame	No	219228 (96.7)	121914 (99.0)	97314 (94.0)
	Yes	7489 (3.3)	1271 (1.0)	6218 (6.0)

*Note: Discrepancies in totals due to missing responses

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5. Lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

^ Rurality is assigned to both practices based on practice postcodes and calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote. Outer regional, remote and very remote categories were combined due to low numbers in these categories.

Table 1.3.3 shows that the rate of benzodiazepine prescriptions per year was higher for patients who attended multiple practices compared with those who attended one practice (2.1 vs 1.6 per person-year), a relative increase of 30% in the rate of prescriptions for patients who attend multiple practices compared to one practice only. We can be 95% confident that the true relative increase in the rate of benzodiazepine prescriptions between patients who attend multiple or one practice lies between 28%

and 38%. However, the estimated rates assumed that these patients were active in the practice for the full 5 years of the study (that is, between 2013 and 2017), and as the rates of prescriptions per year may be underestimated.

Table 1.3.3: **Count, rate and rate ratio of benzodiazepines prescriptions per person-year by number of practices attended between 2013 and 2017**

	N (col %)	n	Rate of benzodiazepine prescriptions/ person-year	RR (95% CI)
Number of practices attended (N=103532)				
One practice	97314 (94.0)	758719	1.6	Ref
Multiple practices	6218 (6.0)	64434	2.1	1.3 (1.3 to 1.4)

N – total number of patients prescr bed benzodiazepines; n – total number of prescriptions for benzodiazepines in the GP records; Rate = n/N/5 years, Ref = reference group

RR – Rate ratio; CI – Confidence interval

Of the 103 532 patients with at least two benzodiazepine prescriptions between 2013 and 2017, 4 780 (4.6%) patients had recorded My Health Record activity (this included view, upload or download) during the 5-year study period. Of the 6,218 patients who attended multiple practices, 169 (2.7%) had My Health Record activity recorded at least once between 2013 and 2017. For these 169 patients, the time in years, from the beginning of the study period (1 January 2013) to the first date a My Health Record activity was recorded, ranged between 9 months and 4.99 years, with a median of 3.6 years. This indicates that for over 50% of the 169 patients there was no My Health Record Activity recorded until mid-2015.

Table 1.3.4 shows that for patients who attended multiple practices, the rate of benzodiazepine prescriptions per person-year was higher for patients who had at least one My Health Record activity reported (any activity including view, upload or download to My Health Record) compared to when no My Health Record activity occurred or where the patient was not registered for My Health Record.

Two assumptions were made for this analysis: (1) patients were active in the practice across the 5 years of the study period (2013–2017); (2) if the patient had at least one My Health Record activity recorded at any time point between 2013 and 2017, then they were coded as having a My Health Record for the entire period of the study, a proxy for having registered for a My Health Record. However, these assumptions are unlikely to be true, in which case, the estimated risk ratio will most likely be conservative under the first assumption, that is they will be underestimated. It is unlikely that the second assumption holds, but it is harder to determine the direction of the bias in the estimated rate ratio in this instance. The second assumption does not take into account that patients may have registered for a My Health Record at different time points during the 5-year study period or whether an occurrence of My Health record activity was related to a particular medication prescription. Although we were able to calculate the time in years that a patient had one or more My Health Record activities, we could not adjust the rates for length of time exposed before or after the first My Health Record activity occurred as we could not calculate the total time that patients were active in the general practice. Further exploratory analysis is required to understand the higher rate of benzodiazepine prescription observed with My Health Record activity and to understand true effects of My Health Record activity on the rate of prescribing benzodiazepine across practices. To achieve this, the My Health Record activity flags used in the MedicineInsight dataset, in addition to having the My Health activity records linked to the patient, needs fields identifying who performed the activity, such as the patient, general practitioner or hospital.

Table 1.3.4: **Count, rate and rate ratio of benzodiazepine prescriptions per person-year by My Health Record activity for patients who attended multiple practices between 2013 and 2017**

	N (col %)	n	Rate of benzodiazepine prescriptions/ person-year	RR (95% CI)
My Health Record activity recorded[*] (N=6218)				
Yes	169 (2.7)	3033	3.6	1.8 (1.4 to 2.2)
No	6049 (97.3)	61401	2.0	Ref

N – total number of patients prescr bed benzodiazepines; n – total number of prescriptions for benzodiazepines in the GP records; Rate = n/N/5 years, Ref = reference group

RR – Rate ratio; CI – Confidence interval

[*]My Health Record activity recorded at least once during the 5-year period

Discussion

Less than 10 per cent of patients in the three cohorts examined had a record of My Health Record activity (including views, uploads and downloads) during the 5-year study period (1 January 2013 to 31 December 2017). At the time that this study was conducted, X-ray results were not routinely uploaded to the My Health Record and private pathology companies only started uploading pathology results in June 2017. As a result, it was not anticipated that My Health Record activity would be associated with reduced proportion of people with type 2 diabetes having HbA_{1c} tests with between-test intervals of less than 90 days or fewer people with osteoarthritis having knee X-ray tests with between-test intervals of less than 365 days. Benzodiazepines are recorded as part of a shared health summary, and, if permission has been provided by the patient to allow PBS dispensing data to be recorded on My Health Record, that is recorded as well. Hence, this component of the study had the greatest potential to show an impact from My Health Record use.

In the type 2 diabetes dataset and osteoarthritis datasets, a higher proportion of patients with recorded My Health Record activity had at least one HbA_{1c} test with a between-test interval of less than 90 days or at least one knee X-ray with a between-test interval of less than 365 days respectively, compared to those who did not have any tests with these test intervals.

The percentage of HbA_{1c} tests with between-test intervals of less than 90 days within one practice was lower if a My Health Record had been uploaded between the time these tests were received (9.4% vs 20.3%, –10.9, 95% confidence interval –20.9 to –0.90) demonstrating some potential for My Health Record to have an impact in this regard. However, caution should be applied when interpreting these results due to the small numbers and wide confidence interval.

Use of My Health Record may have particular benefits for patients who attend multiple practices if their information can be easily accessed by the health professionals involved in their care. In these studies, there were too few patients attending multiple practices with My Health Record activity recorded to demonstrate any impact from use of the My Health Record on frequency of HbA_{1c} tests or knee X-rays.

The rate of benzodiazepine prescriptions was higher for patients who attended multiple practices compared with those who attended one practice (2.1 vs 1.6), a relative difference of 30% (95% CI 1.28 to 1.38). The low number of My Health Record uploads and downloads would affect the ability of GPs to be aware that patients are being prescribed this medication at other practices. In addition, over the 5-year study period, there was an average of 8 prescriptions per patient for those who had more than one recorded prescription. A small number of people had a large number of prescriptions

(up to 290 prescriptions) that could warrant further investigation, although these patients may not want to be identified as attending multiple practices for benzodiazepine prescriptions.

For patients who attended multiple practices, the rate of benzodiazepine prescriptions per person-year was higher for patients who had My Health Record activity recorded compared with those with no My Health Record activity recorded. This observation may be confounded by other factors and therefore may not be reliable. For instance, patients with more benzodiazepine prescriptions may have higher rates of multimorbidity and therefore visit their general practitioner more often and be more likely to have a My Health record, resulting in an overestimation of My Health Record activity associated with benzodiazepine prescription. The rate of benzodiazepine prescriptions may also be underestimated because it was assumed that patients were active in the practice for the 5 years of the study period. Further investigation is therefore warranted.

The studies presented here provide baseline measures and the methodologies developed here could to be used to monitor the impact of My Health Record over time. One of the major strengths of these studies is the use of a large, national, general practice dataset, MedicineInsight. The use of health data from population-based registers is used extensively in international settings, however the use of data collected from medical records and registers is not as well established in the Australian healthcare setting. The empirical studies presented in this report have demonstrated the potential value of using 'big data' methodologies to assess the impact of an intervention on primary health care practice. We were able to develop records for My Health Record activity and created a new linkage algorithm to identify patients attending multiple general practices.

It is important to acknowledge the limitations of these studies. Firstly, the low number of patients with My Health Record activity resulted in the studies not having enough power to determine effect, should there have been one. The linkage of patients across practices and the extraction of data related to My Health Record activity were developed for these studies and have not been validated. We used a history of osteoarthritis with at least one X-ray to define the knee osteoarthritis cohort – as a result, we are likely not to have included all people with knee osteoarthritis. We did not determine whether subsequent knee X-rays were of the same or different knees, resulting in likely overestimation of repeat X-rays occurring with a between- test interval of less than 365 days. We were unable to link My Health Record activity to individual practitioners, which would have facilitated a more in-depth analysis. For patients with at least two benzodiazepine medications identified as attending multiple clinics, it was not possible in this analysis to differentiate whether the benzodiazepine medications were prescribed by the same or different providers across practices. The rate of benzodiazepine prescriptions may be underestimated because it was assumed that patients were active in the practice for the 5 years of the study period; this does not account for patients that leave a practice, die, or become a new patient at a practice during the study period. Finally, we were also unable to distinguish whether patients who attended multiple practices were attending at the same time or had moved sequentially from one practice to another during the study period.

SUB-STUDY 2: ALLERGIES TO ANTIBIOTICS

One of the key aims of the My Health Record is to improve medication safety. Recording of allergies and adverse drug reactions (ADRs) in the My Health Record has the potential to ensure that health professionals across the health system have access to this information, reducing the likelihood of a medication being prescribed that could result in an adverse event such as anaphylaxis. Information about allergies can be recorded in multiple areas of the My Health Record including shared health summaries, event summaries and hospital discharge summaries. GPs have been incentivised since May 2016 to upload shared health summaries to the My Health Record as part of the e-Health Practice Incentive Payment.

Aim

The aim of Sub-study 2 was to measure the proportion of people attending general practices with a recorded allergy or ADR to antibiotics who had:

➤ recorded My Health Record activity

➤ a shared health summary document uploaded containing information about allergies and ADR uploaded to My Health Record as at 31 December 2017.

We hypothesised that, among patients with a My Health Record, a high proportion with a recorded allergy or ADR to antibiotics would have a shared health summary that was uploaded after the recording of an allergy or ADR.

Method

The cohort for this study consisted of people with a recorded allergy or ADR to an antibiotic[4] who had data captured in the MedicineInsight dataset as at 31 December 2017. Detailed information about the MedicineInsight dataset is available in Appendix 1. A linkage study within the MedicineInsight dataset was undertaken to identify individuals who were attending multiple practices using the unique GRHANITE hashing linkage technology. A new variable was created in the dataset that identified the records that belonged to the same individual across multiple practices. Information about this process is available in Appendix 3.

A cross-sectional study was conducted to determine:

➤ the proportion of people with a recorded allergy or ADR to antibiotics in the MedicineInsight dataset who had recorded My Health Record activity

➤ the proportion of people with a recorded allergy or ADR to antibiotics in the MedicineInsight dataset who had a shared health summary (which would contain information about allergies and ADR to antibiotics) uploaded to the My Health Record as at 31 December 2017.

Count and proportions with 95% confidence intervals are reported.

A sub-analysis of the Primary Health Networks (PHNs) involved in the 'Opt Out Trial' (Northern Queensland and Nepean Blue Mountains) was also conducted.

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[4] ATC classes included in this study were D06AX, D06BX, D10AF, J01AA, J01CA, J01CE, J01CE, J01CF, J01CR, J01DB, J01DC, J01DD, J01DE, J01DH, J01EA, J01EC, J01EE, J01FA, J01FF, J01GB, J01MA, J01XA, J01XD, J01XE, J01XX, J04AB, N03AG, P01AB, R01AX, S01AA, S01AB, S01AE, S02AA, S02CA

Population

> Inclusion criteria: Patients with a recorded allergy or ADR to antibiotics recorded as at 31 December 2017.

Statistical analysis

Data was collapsed to one record per patient and categorical variables were created to:

1. identify when the first instance of an allergy or ADR to antibiotics was recorded in the GP records for each patient;

2. identify whether the patient had My Health Record activity recorded; and

3. determine for those with My Health Record activity recorded, whether a new shared care health summary was uploaded after the first recorded instance of an ADR or allergy to antibiotics. Using the information in the general practice data, this variable is used as a proxy to mirror the summary data related to the ADR or allergies to antibiotics uploaded to My Health Record for patients attending a MedicineInsight practice.

Descriptive statistics were used to summarise the general practice and participant characteristics. Count and proportion of patients with My Health Record activity recorded, and for those with My Health Record activity recorded, whether they had a shared health summary uploaded to My Health Record after the first instance of a documented allergy to antibiotics were reported. Proportions were reported with 95% confidence intervals using robust standard errors to allow for the correlation of patients belonging to the same general practice and repeated measures of individuals (where applicable).

Results

A total of 114 499 patients across 494 general practices had a recorded allergy or ADR to antibiotics. The characteristics of the practices are described in Table 2.1 and the characteristics of patients are described in Table 2.2. 1 959 patients (1.72%) attended practices in Nepean Blue Mountains PHN and Northern Queensland PHN, which were included in the Opt Out My Health Record Trial. 12 327 (10.77%) patients in this cohort attended more than one general practice.

Table 2.1:   General practice characteristics

Characteristics		n (%)
State	ACT	9 (1.8)
	NSW¥	167 (33.8)
	NT	10 (2.0)
	QLDℲ	99 (20.0)
	SA	14 (2.8)
	TAS	38 (7.7)
	VIC	94 (19.0)
	WA	63 (12.8)
SEIFA Quintiles#	1	82 (16.7)
	2	80 (16.3)
	3	113 (23.0)
	4 and 5	216 (44.0)
Rurality*	Major cities	301 (61.2)
	Inner regional	114 (23.2)
	Outer regional, remote and very remote	77 (15.7)

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5 – lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

*Rurality is assigned to both practices and patients, based on practice and patient postcodes, respectively. Rurality is calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote.

¥ NSW practices include those in the Nepean Blue Mountains PHN included in the Opt Out My Health Record Trial

Ⅎ Queensland practices include those in the Northern Queensland PHN included in the Opt Out My Health Record Trial

Table 2.2:   Characteristics of patients with a recorded allergy or ADR to antibiotics

Patient characteristics		n (%)
Gender	Female	83570 (73.0)
	Male	30764 (26.9)
	Indeterminate	165 (0.14)
Age groups (years)	0-9	5221 (4.6)
	10-19	6524 (5.7)
	20-29	12518 (10.9)
	30-39	13793 (12.1)
	40-49	14985 (13.1)
	50-59	15684 (13.7)
	60-69	16130 (14.1)
	70-79	14646 (12.8)
	80-89	10610 (9.3)
	90-99	4386 (3.8)
	99-110	2 (0.0)
SEIFA Quintiles#	1	18124 (16.0)
	2	18728 (16.5)
	3	26141 (23.0)
	4 and 5	50457 (44.5)
Rurality*	Major cities	68156 (60.0)
	Inner regional	32495 (28.6)
	Outer regional, remote and very remote	12983 (11.4)
Attended multiple clinics	No	102172 (89.2)
	Yes	12327 (10.8)

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5 – lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas.

*Rurality is assigned to patients based on patient postcodes. Rurality is calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote.

Less than 5 per cent (4 490/114 499; 3.9%) of patients with a recorded allergy or ADR to antibiotics had any documented My Health Record activity and only 3.7% (4 231/114 499) had evidence that a shared health summary had been uploaded. The proportion of patients with My Health record activity attending one practice only compared to those attending multiple practices was similar (3 961/102 172 (3.9%) vs 529/12 327 (4.3%) respectively) as was the proportion of patients with shared health summaries uploaded (3 731/102 172 (3.7%) vs 500/12 327 (4.1%)).

Of those with a shared health summary, the majority of patients (3 884/4 231; 91.8%) had a shared health summary that would have contained information about their allergy, unless the GP or patient had elected not to upload that information (see Table 2.3). Just over eight in ten patients (347/4 231;

8.2%) with a shared health summary had an allergy or ADR recorded after the upload of a shared health summary; their allergy or ADR would therefore not have been captured in the My Health Record.

Table 2.3: **Recording of antibiotic allergies and ADRs in shared health summaries for patients with a recorded allergy or ADR to antibiotics**

Variable	n (%)	Proportion (95% CI)
Total number of patients with a recorded allergy or ADR to antibiotics (n)	114499	
My Health Record activity recorded	4490 (3.9)	(3.8 – 4.0)
Shared health summary (SHS) ever uploaded	4231 (3.7)	(3.6 – 3.8)
Reporting of an allergy to antibiotics in an SHS uploaded after the recording of an ADR in My Health Record	3812 (90.1)	(89.2 – 91.0)
Reporting of an allergy to antibiotics in an SHS uploaded before the recording of an ADR in My Health Record	347 (8.2)	(7.4 – 9.1)
Reporting of an allergy to antibiotics in an SHS uploaded on the same day as the recording of an ADR in My Health Record	72 (1.7)	(1.3 – 2.1)

SHS – shared health summary

ADR – Adverse drug reaction

A sub-analysis of patients in Opt Out PHN areas was conducted. The characteristics of these practices and patients compared to those in Opt In areas is summarised in Appendix 2. Patients in Opt Out areas included a lower proportion of people in SEIFA quintile 1 (highest socioeconomic status) and a higher proportion in Quintile 3. There was a higher proportion of people in Outer regional, remote and very remote areas and patients were less likely to attend multiple practices. Just over 5% (113/2 038, 5.5%) of patients in the Opt Out areas with a recorded antibiotic allergy or ADR had My Health Record activity recorded and 4.4% (89/2 038) had a shared health summary uploaded (see Table 2.4). Caution should be used when interpreting these results due to the small numbers of shared health summaries uploaded in the Opt Out PHNs, and the wide confidence intervals. The results indicate that there was higher My Health Record activity in Opt Out compared to Opt In areas, but that this did not translate to significant differences in uploads of shared health summaries which would include recording of allergies and ADRs to antibiotics (see Table 2.4).

Table 2.4: **Recording of antibiotic allergies and ADRs in shared health summaries for patients with a recorded allergy or ADR to antibiotics**

Variable	Patients in Opt Out PHNs		Patients in Opt In PHNs	
	n (%)	Proportion (95% CI)	n (%)	Proportion (95% CI)
Total number of patients with a recorded allergy or ADR to antibiotics (n)	2038		112603	
My Health Record activity recorded	113 (5.5)	(4.6 – 6.6)	4385 (3.9)	(3.8 – 4.0)
Shared health summary (SHS) ever uploaded	89 (4.4)	(3.5 – 5.4)	4148 (3.7)	(3.6 – 3.8)
Reporting of an allergy to antibiotics in an SHS uploaded after the recording of an ADR in My Health Record	82 (92.1)	(84.5 – 96.8)	3749 (90.4)	(89.4 – 91.3)
Reporting of an allergy to antibiotics in an SHS uploaded before the recording of an ADR in My Health Record	3 (3.4)	(0.70 – 9.5)	337 (8.1)	(7.3 – 9.0)
Reporting of an allergy to antibiotics in an SHS uploaded on the same day as the recording of an ADR in My Health Record	4 (4.5)	(1.2 -11.1)	62 (1.5)	(1.2 – 1.9)

Discussion

The majority of patients with a recorded allergy or ADR to antibiotics did not have any My Health Record activity (96.08%) or a shared health summary uploaded (96.30%). Of those who did have a shared summary, most had this uploaded after an allergy or ADR was recorded, and so their My Health Record should have this important information recorded. It is concerning that just over 8% of patients with a shared health summary had not had this updated since the recording of a new allergy or ADR, increasing the potential for patient harm, and potentially undermining trust in the currency and accuracy of the My Health Record. Interventions to prompt health professionals to upload a new shared health summary if an allergy or ADR is recorded should be considered. This would be of particular value to patients attending multiple health settings for their care.

Currently, the proportion of people with a My Health Record or a shared health summary is slightly higher in people attending multiple practices; it is unclear whether this indicates that effort has been made to target this patient group. While our sample only consisted of a small number of patients attending practices in the My Health Record Opt Out areas, data suggested that although there was higher My Health Record activity recorded, this did not translate to a significantly higher proportion of shared health summaries uploaded which would have contained information about allergies and ADRs to antibiotics. These results should be interpreted with caution, however, given the small number of patients included in these areas.

The strengths and limitations of this study are similar to those noted in Study 1. The major strength of this study is that we have used a national dataset consisting of over 100 000 patients with a recorded allergy or ADR to antibiotics. We have been able to extract data relating to My Health Record activity and identify people attending multiple practices using a novel linkage algorithm. Results should be interpreted with caution given the low number of patients with recorded My Health Record activity. We were only able to identify patients who were attending multiple general practices participating in the MedicineInsight program, not those who were attending clinics outside of the program, and the algorithm that we used has not been validated. In addition, these results may not be generalisable to the entire general practice population. This is because MedicineInsight practices may not be representative as they have chosen to participate in a quality improvement program.

SUB-STUDY 3: MEDICATION MANAGEMENT

Aim

This study aimed to explore the impact My Health Record had on improving medication safety and management from the perspective of GPs and primary health care patients.

The objectives for this study were to:

➤ Investigate how My Health Record is used for the management of allergies to medicines and if it contributes to a reduction of adverse drug events.

➤ Explore barriers and facilitators to using My Health Record for the management of allergies to medicines.

➤ Examine how My Health Record has affected medicines use and improvements in safety.

Method

Recruitment

Participant GPs for interviews were sought from six different practices in New South Wales and six in Victoria with the goal of three located in metropolitan and three located in regional and/or remote areas in each state. MedicineInsight data from practices in New South Wales and Victoria was merged with My Health Record flags in a data warehouse during the week of 19 February 2018. The analysis determined the highest proportion of My Health Record activity by GPs so that those contacted for interview would have some experience with uploading or downloading My Health Records. A list of names and contact details was also generated from NPS MedicineWise systems and an email was sent to New South Wales GPs listed in the NPS MedicineWise Customer Relationship Management (CRM) software. NPS MedicineWise sent invitations to participate in a telephone interview and collected written consent from participating GPs. Incentives were provided to participating GPs in the form of gift vouchers.

Interviews commenced after GPs provided signed consent. Contact details for Victorian GPs were sent to the University of Melbourne where a researcher contacted GPs and organised interview times. In New South Wales, GP interviews were conducted by NPS MedicineWise researchers.

Once a GP agreed to participate, a list of patients was generated that only the general practice could identify, and the GP or practice staff recruited one or more patients to also participate in a telephone interview. In some cases, practice managers assisted in this recruitment. NPS MedicineWise collected patient written consent and provided details for the University of Melbourne research team to contact Victorian patients to schedule interview times. In New South Wales, patient interviews were conducted by NPS MedicineWise researchers. Gift vouchers were provided to participating patients.

Data collection

A structured interview schedule was prepared for the GP and patient groups (see Appendix 4). The interview schedules for GPs and patients covered general use and understanding of My Health Record, and the perceived benefits of My Health Record with a particular focus on:

➤ medication management
➤ safe use of medicines
➤ prevention of adverse events
➤ coordination of medication management from the GP perspective

➢ potential patient use of My Health Record.

The interviews were completed by telephone, audio recorded and transcribed verbatim via a professional transcription company (Healy Research and Administrative Support Services). Interviews ranged from 15 to 30 minutes for both GPs and patients.

Data analysis

GP and patient interview data were analysed thematically in separate groups. The initial analysis was conducted at the level of GP or patient with some consideration of differences between states and geographic locations (metro vs regional/remote). Due to the small numbers of participants, analysis of differences between states and regions was not possible. The original analysis had planned to examine if a GP or a patient was a higher or lower user of My Health Record and to explore any associated differences in benefits or perceptions of My Health Record, but due to changes in GP recruitment and the early stage use of My Health Record by patients, it was not possible to examine the data by high or low user type in this study.

Analysis of the interview data was carried out over five stages.

➢ Stage 1: Data authentication – each of the interview recordings was transcribed by a professional transcription service and the transcripts checked by the researchers for accuracy.

➢ Stage 2: Coding – the data were separated into GP groups and patient groups and organised into codes using QSR NVivo 12 software. Codes were formulated based on the research objectives and each of these codes was separated into individual data files for further analysis.

➢ Stage 3: Searching for themes – using the codes devised in Stage 2, the codes were examined to search for broader themes using analytical strategies such as repetitions, metaphors and analogies, transitions, similarities and differences, and linguistic connectors.

➢ Stage 4: Reviewing themes – each theme was revisited and refined.

➢ Stage 5: Defining themes – the story of each theme was developed and the way in which each theme fit the objectives was explained.

Results

GPs

The analysis identified a number of themes relating to GPs' understanding and use of My Health Record, some of which reflected the research objectives: GPs' use of My Health Record to manage allergies to medicines and coordination of medicines with other health professionals.

GP participants were recruited in an even split between regional and metropolitan areas across New South Wales and Victoria (see Table 3.1). Most GPs had been practising for 21 years or longer and all but one GP was practising full time (see Table 3.2). Most of the GPs were employed in independent practices as opposed to corporate-owned practices.

Table 3.1.   Geographic distribution of practices

State	Geographical region	Location
NSW	Regional and remote	Newcastle
		Queanbeyan
		Tamworth
	Metropolitan	Edensor Park
		Kiama
		North Ryde
VIC	Regional and remote	Murchison
		Alfredton
	Metropolitan	Warburton
		Melbourne (2 practices)
		Bannockburn

Table 3.2.   Time practising as a GP

Time practising as a GP	Status	Frequency
0–10 years	Full-time	3
	Part-time	0
11–20 years	Full-time	1
	Part-time	0
21–30 years	Full-time	5
	Part-time	1
31–40 years	Full-time	2
	Part-time	0

Understanding of My Health Record

GPs were knowledgeable about My Health Record and its intended purpose. GPs perceived My Health Record to be a system containing summaries of patients' medical information relating to events in which care was provided across different settings, including hospitals, pharmacies, specialist practices and primary care. GPs reported that they perceived My Health Record to be a tool to enhance communication between them and other health professionals across health care settings to assist in improving patient care.

There was an overall theme in the way GPs discussed My Health Record. Discussions often centred on hypothetically using My Health Record in the future or on how they are currently using it. Some discussions related to what GPs perceived My Health Record could and should do as well as the potential problems. My Health Record is perceived by GPs as a secondary source of summary information about patients.

NSW GP #4   'The purpose is to make it easier to communicate in times where it's urgent to get a patient's history, when they can't reach the patient's usual GP. It also helps when used as a reference for medication dispensing if you try and clarify scripts if the patient doesn't usually attend your practice. It's to share health information securely between health professionals.'

NSW GP #5   'My understanding is it's like a summary you can access online which has past histories, allergies, and medications on it.'

GPs prioritise patient groups for My Health Record use

There were differences in how GPs used My Health Record with their patients. Some GPs reported encouraging all their patients to register and use My Health Record while other GPs targeted and prioritised the registration of certain patient groups with My Health Record. GPs thought that some patient groups would stand to gain more from using My Health Record than the average patient. Examples of these patient groups included:

➢ middle-aged or elderly patients and patients in nursing homes

➢ patients with comorbidities, chronic conditions, mental health conditions or complex histories

➢ patients treated by multiple specialists, or patients at a greater risk of being hospitalised

➢ patients who travel frequently or attend different practices often.

NSW GP #1   'Patients with comorbidities for sure. Usually the elderly. Those with chronic conditions and mental health issues too.'

VIC GP #2   'If I've got patients who are travelling in Australia, I encourage them to have it uploaded because then if they do see someone they do have the option to look it up.'

VIC GP #6   'Patients with complex histories, people that see multiple specialists or hospital visits, they'd be the ones I'd prioritise definitely.'

Some GPs did not see the benefit of using My Health Record for their usual patients because they had already recorded the patient's health information in their practice clinical information systems. GPs were therefore unsure of the benefits that use of My Health Record would add to the existing benefits with use of clinical software. Information recorded in clinical information systems was seen as more readily available, and quicker and easier to access than information in My Health Record. The usefulness of information from other health providers was not evident to these GPs.

VIC GP #2   'Pathology all write it down directly into our software, X-ray do the same. We've been paperless for about 20 years in this practice...so I don't see how it is going to add anything because everything comes into our software directly, how is it going to add?'

NSW GP #5   'If other practitioners have used it, then I could see it being useful but as I've already got the information on my existing patients, I don't really need it.'

GPs also felt that it was unnecessary to upload patient information to My Health Record because usual patients' health care was not often shared with other providers. GPs were also more reluctant to upload information for their healthy and younger patients because these patients were perceived as being less likely to have pre-existing conditions that would impact future care and were less likely to be hospitalised.

Privacy concerns

One GP expressed a concern over privacy stating that he did not trust the security of the system, particularly for younger patients aged 20 to 40 years because this age group often considers private health insurance. The GP was concerned about entering medical conditions such as mental health

disorders into a file which could be accessed by private health insurers and could affect any claims made. Access to records for law enforcement was also mentioned as a concern by this GP.

NSW GP # 4 'I have more concerns for younger patients regarding their privacy, in an age group where a lot of people are considering taking up private health insurance. I honestly don't 100 per cent trust the security of it. I also have concerns about law enforcement being able to access it.'

The PIP e-Health Incentive is not well understood by GPs

Most GPs reported using My Health Record from its inception or from when they had been prompted through a payment offered by the Practice Incentive Program (PIP). For My Health Record, GPs can apply for the PIP payment if they have compliant software for accessing My Health Record, apply to participate in My Health Record and upload shared health summaries to My Health Record for a minimum of 0.5% of the Standardised Whole Patient Equivalent (SWPE) or the default SWPE, depending on which is greater. The PIP eHealth Incentive encourages the meaningful use of the My Health Record by healthcare providers, including uploading of clinically relevant information to the My Health Record embedded into day-to-day clinical practice.

The PIP payment had both positive and negative connotations for GPs. Some GPs said that they felt encouraged by the payment whereas others felt forced to upload summaries to My Health Record to obtain the PIP payment, either through pressure from a practice manager or due to economic strain in the practice. The PIP also acted as a disincentive to uploading summaries to My Health Record. One GP felt that the structure of the PIP discouraged the continuous upload of summaries, in that the payment was provided for every 3-month period in which a small percentage of patient summaries were uploaded.

VIC GP #1 'The main gripe is we get an e-PIP payment for uploading summaries to My Health Record and we get paid by uploading 0.5 per cent summaries each 3 months so that's two per cent per year. It's going to take 50 years to upload summaries to My Health Record if we go at that rate and if we do it as slowly as that we will continue to be paid the e-PIP payment but if by magic we actually uploaded the summaries for all our patients in a 3-month period, we would get paid the e-PIP payment once and once only. We would be penalised because we've done it in 3 months, and that's completely ridiculous that you get penalised by losing 49 years' worth of payments, it's crazy. I wasn't using it prior to there being an e-PIP payment, I just fiddled with it a little bit before then.'

VIC GP #2 'We were forced to upload patient health summaries as part of the PIP.'

VIC GP #4 'From a general practice point of view, it's kind of encouraged us to use it through various PIP payments. I know when it first came out, the PIP incentives were quite helpful but my only issue is that a lot of the PIP incentives were started like 20-odd years ago and they haven't been indexed and with the Medicare rebate, it's heading towards asking us to do more with less, which is frustrating.'

NSW GP #2 'We were encouraged by the practice manager obviously I think we've signed up for the practice incentive and I think that was the main reason.'

GPs are more likely to upload than download information

GPs reported that My Health Record was most commonly used as a system to upload information rather than as a source of information. GPs often remarked that the process for uploading information to My Health Record was easy and efficient but reported experiencing difficulties when attempting to access, explore or download information.

Lack of trust

Some GPs perceived it to be unlikely that other health professionals are regularly using My Health Record and thought that when its use becomes routine it will be of great benefit to patients and health care providers. GPs expressed frustrations with My Health Record generally not being up to date due to low use, and with being unable to tell if the information contained within the record is current. For example, if an entry is made by one GP 6 months before another GP accesses the record, the second GP then questions whether this is truly the last update for this patient or if it is the last time a GP 'bothered' to upload the information; there is no way of discerning this.

The use of written information and referrals was often still preferred. There was a tension between the quantity and quality of information needed by GPs. Some GPs expressed the need for more information than is currently provided in the shared health summaries while others discussed the concern that there is too much information that is not helpful or of good quality.

VIC GP #1 'Normally when I'm communicating with other health professionals, I still do most of it by printer and referral letter sent or given to the patient...and so people get written information directly from me that should be more accurate than anything that might have been uploaded to My Health Record in the past because it's here and now and I can see if I should have made any alterations to it that have happened since the previous upload.'

VIC GP #2 'People don't use it. GPs upload files to it but I don't know of any colleagues that have ever referred to it. I can upload a record fairly quickly from Best Practice, but I can't download records from there into Best Practice and therefore, I don't see that it's ever going to be very useful. So if hospital discharge summary's on there, it's going to be useless from my perspective. I need them to send them directly to me so that they go into my software.'

VIC GP #3 'Any health record is only as good as the doctor that puts the information into it and makes sure it's all up to date and current, otherwise it's useless. It has to be a very up-to-date history that's well coded with up-to-date information and medication.'

NSW GP #2 'At the moment, I think, other than uploading the details, we're not usually opening it up to see any sort of referral details or reports, but I think it will probably be more useful once the other practitioners get on board.'

NSW GP #4 '98 per cent of the time, the purpose is uploading records and only two per cent of the time, it's for actually taking a record out in the unlikely event that their previous GP has bothered to upload one and that's helpful when a patient changes practices. I find it fantastic being able to take a record off the system and have that information pre-populated. My understanding is that it's a snapshot in time of what someone has provided to the My Health Record. There's that key limitation which is expressed in my view that it's a snapshot rather than current...it depends on the last time someone clicked upload.'

GPs feel their contribution is undervalued in other healthcare settings

GPs recognised that My Health Record has a great potential for use in emergency departments and hospitals. GPs said they were more likely to upload information for patients who had an increased likelihood of being hospitalised. However, GPs believed that concerns around data quality (eg, incompleteness of information and inconsistencies in reports entered by GPs) and reliability (eg, whether the information is truly current or just reflects the last time that a GP uploaded information) precluded the system's use in these settings.

NSW #4 GP 'The rumours are that most of the emergency department doctors are directed never to use it, what I'm uploading and never to trust it. It doesn't make me feel like it's extremely valid, which is a shame. But they've been instructed that because it can never be said to be 100 per cent current and because record keeping at other general practices is extremely poor and a lot of them, it's just flooded with unhelpful information.'

NSW #5 GP 'It would be relevant, if a patient turns up to an ED and they needed information, then at least they've got access to the summary of this patient.'

VIC #4 GP 'I think it will benefit us by providing access to information more readily. At the moment if there's particular information we want to get we have to ring up the emergency departments or hospitals and get the information sent down, so I think once it becomes more readily used, because hopefully those hospitals or the doctors will put the information up, we won't have to ask for it and it will be more readily accessible.'

There is a need for GPs to be validated in what they are doing by others across the health care system. If other health professionals are not using My Health Record it is a disincentive to those who are uploading records.

My Health Record has the potential to reduce duplication of medical tests

One of the theoretical benefits highlighted by GPs was improved efficiency in their practices and reduced costs because of improved access to information that could be provided by My Health Record. GPs were conscious that improved access to information relating to previous medical tests performed, and test results, would reduce duplication. The current lack of availability of this information encouraged a culture of re-ordering tests that has decreased efficiency and increased costs to the health system.

However, in terms of fulfilling this purpose in its current state, most GPs did not perceive the utility of My Health Record to be high for various reasons (eg, low use, and sparse or poor-quality data). GPs were also unsure of how widely My Health Record is being used by both patients and clinicians in different settings but estimated it to be low.

VIC GP #1 'In theory, it should be able to prevent the ridiculous amount of duplication of investigations that currently happen. A certain number of people go from doctor to doctor having multiple investigations, a lot of which are replicated elsewhere.'

VIC GP #4 'If it's more generally used then it's going to be a valuable tool, especially with costs blowing out especially for people. I think it's often easier for doctors in hospital or perhaps GPs to just reorder a set of tests rather than looking for some to see if a patient's had them recently. So that's like a couple of hundred dollars just for one instance, if that can be saved by someone looking on some central repository of patient information, it's going to be much better for the community and the costs.'

VIC GP #5 'For me personally, the benefit I would hope for most would be up-to-date information about hospital assessments, the specific events that might have happened...pathology is the big one...enormous duplication because there's different providers and it can be difficult to find what's been done and if it has been done, to get the results.'

Information exchange should be automated between clinical software and My Health Record

One of the key limitations of My Health Record highlighted by GPs was the lack of trust in the currency of the information uploaded to My Health Record. GPs frequently mentioned the superiority of their clinical software and suggested that allowing for the automation of upload and download between these two systems would be beneficial for ensuring that information was current and consistent across healthcare settings.

NSW GP #5   'It's helpful that I can have a summary if I need it and it's helpful that I can be able to supply a patient summary record for someone else to use. I guess it would be a lot easier if the whole thing was done without me needing to actually physically upload the record like it could be easily extracted from the medical software without me having to do anything that would make it easier.'

VIC GP #2   'We normally get a history direct from the patient, or direct from the previous doctor if they're a new patient and then we input the information. It never occurred to me to use the My Health Record to do it that way, a part of the reason for that would be the small likelihood of actually finding information on there.'

We recommend development of methods to improve the automated transfer of information between clinical software and My Health Record.

Managing allergies to medicines

My Health Record had not been used by the majority of GPs interviewed as a tool for managing patients' allergies to medicines. My Health Record was not used as a primary information source, unlike their clinical software or direct knowledge from their patients. Most GPs indicated that they would not access My Health Record to locate information on potential allergies before using their clinical software or asking their patients. This reliance on clinical software and their patients as sources for information about potential allergies to medicines was driven by a number of factors:

➢ Clinical software perceived as having more complete information than My Health Record.

➢ Clinical software is more readily accessible than My Health Record.

➢ Clinical software has features that alert GPs to patients' allergies which are not currently available in My Health Record. It reduces the time and effort of manually searching for a patient record in the clinical software or in My Health Record.

➢ Patients were perceived as a more easily accessible and reliable source of information by some GPs, even in cases where the patient could not recall any reactions to medicines.

Other GPs recognised the potential utility of My Health Record for obtaining information about allergies for people who were not their usual patients, particularly in instances where patients may be frequent travellers. However, in cases where a patient was new, GPs reported that they would request this information directly from the patient or from previous doctors first, before using My Health Record.

NSW GP #2   'Our practice software already alerts us if we have sort of recorded allergies...I haven't come across an instance where My Health Record has prompted me.'

NSW GP #4   'Most of the time, I'd expect a patient to recall that...that patient that I remember having allergies downloaded automatically into the software [from My Health Record], I would have asked that question when I took on the new patient anyway...'

VIC GP #1   'I mainly get the information from the person now, sometimes people can't remember and you sort of think, is there any other reliable source of information? Or do I just say oh well, if you can't remember it, can't have been too bad. There's a potential to stick your neck out there...it's tricky because the recording of this is very subjective...'

VIC GP #2   'We normally get a history direct from the patient, or direct from the previous doctor if they're a new patient and then we input the information. It never occurred to me to use the My Health Record to do it that way, a part of the reason for that would be the small likelihood of actually finding information on there.'

VIC GP #4   'I think our own software on our computer systems is pretty up to date with allergies, so if it's our patients who we're seeing…we've got that data already on our own computer so My Health Record becomes a bit less useful. But if they have interactions with other doctors or come out of hospital with an allergy and that's the way we find out, then that would be worthwhile, but we usually know that because we just ask our patients directly. I've been relying on them rather than relying on My Health Record to tell us.'

Coordinating medication management

Most GPs reported that they had not used My Health Record to coordinate the management of their patients' medicines. Only one GP reported attempting to use it for this purpose for a patient who had experienced an adverse drug reaction. However, the reports that were contained on the patient's My Health Record were inconsistent, which made it difficult to identify the medicine that had caused the reaction.

VIC GP #1   'I saw someone yesterday in different places in their record that reported she'd had diarrhoea in response to an antidepressant medication. However, the three reports were not consistent. Two of them referred to one antidepressant and another referred to a third, and they were all around the same time. They couldn't remember whether they'd tried one of the antidepressants so I was unclear whether she actually had both antidepressants and they both caused diarrhoea or only one. So I was just completely bamboozled.'

Patients

Ten patients, 6 women and 4 men, were recruited; 6 were from New South Wales and 4 from Victoria. Patients reported seeing their GPs for between 2 and 27 years. For some patients, their GP was their sole provider of care, others reported accessing other GPs on an as-needed basis. Reasons for accessing another GP included having a separate GP for the family, seeking a female GP for women's health issues or because the current GP was not available. Availability to their GP was mentioned by a small number of people as an issue.

Registration and activation of My Health Record varied for interviewed patients. In some instances, patients reported that GPs or practices had activated My Health Record on their behalf and 4 of 10 patients (2 in New South Wales and 2 in Victoria) had not yet registered for its use; for these participants the interviewer asked about future perceived benefits of My Health Record.

Knowledge of My Health Record

Most patients understood My Health Record as a tool for information sharing between health care providers and settings, rather than as a tool used by patients to gather and share information. Patients suggested that it was about collecting information relating to procedures or treatments and keeping a record of medications. A very small number of patients mentioned being able to add their own information and actually using My Health Record in this way. Most indicated that it was the doctor who added information. Patients indicated that My Health Record should include records of diagnoses and medications taken, allergies and information that could help to reduce or avoid mistakes.

The most commonly mentioned purpose for My Health Record was if a person was hospitalised (particularly if they were unable to convey their health information due to injury or illness) or travelling. This was followed by the ability to have a health record available anywhere, any time and to improve continuity of care by reducing the need to retell one's story:

NSW Pt #5   "It's good in emergency purposes and when you go interstate, so that like our, like members of the health care team can just have a look into it with our consent to provide us care and if it's an emergency then they can actually look up if we have any allergies to anything, so they won't hesitate in giving us any medication, something like that, but it works only here in Australia".

NSW Pt #1   "You don't have to repeat your history to the next GP and the next GP will not be writing your history again, so everything will be consolidated, so for instance if you have an x-ray, you have all those, it's all in one file and that can be accessed easily".

Some patients however had not accessed My Health Record at all and were not aware of its existence. Patients presumed that information from their GP visit would automatically be included into the My Health Record without the need for the GP to upload any information.

NSW Pt #6   "I mean I get a printout from my doctor about health management that's got everything on it so I presume that must be in my records".

One patient indicated that their GP currently printed a health summary from the current clinical software system for them to carry around.

VIC Pt #4   "[The GP] does a printed summary when I ask him and if anything changes he changes it and he'll print off another one, and then I've got a little job at the library so I run off about eight copies and it's got my name and address, social history, family history, allergies, and then over the page it's got current active problems and past medical history. And when I go into, if I need somebody different to my normal doctor I just take one of these along, you know what I mean?"

The majority of patients interviewed knew how to access My Health Record via the MyGov portal. Under half of the patients interviewed suggested that they accessed it via their own computer or tablets, and some indicated that despite not being active users at the time of the interview that they could see benefits.

Medication management

Most (80%) patients interviewed reported that they took medications (conditions included high blood pressure, diabetes and gastric reflux, and contraceptive medication). Some medications were complementary (eg, vitamins) rather than prescription medicines. Most took only one medication for their condition, but some patients reported taking up to four different medications to manage their diabetes, asthma, or other comorbid conditions (both physical and mental health). There was one participant who had had an organ transplant and took up to 15 medications. For those who took prescribed or complementary medicines, the use of My Health Record was varied. For the group of patients who said that they took complementary medicines there was a perception that My Health Record did not change how they managed their medicines.

Overall, of the 10 patients interviewed in the two states, few reported using My Health Record as a tool to actively manage their own medication use. Instead they relied on personal reminders on their phones or on their memories to take medicines as prescribed, they followed the instructions on the medication packets, used a written list, used a medication dispenser or managed their medicines within their day-to-day routine.

VIC Pt #4   "I've even got a swag of [the medications that I take] printed off in a folder, so every time I got to hospital or anything like that I always take along my list of medications".

Some noted that if they had more medications to manage, My Health Record might play a role in helping to keep a file of these in one place if a script needed to be refilled.

NSW Pt #4   "It's a fairly new thing to me, the local doctor created the record just a few weeks ago but I did notice having gone through it that it registers there when you last got your script, so you know, if I wasn't sure, if I couldn't find my script, like obviously I keep the scripts in a certain place and when you finish your repeats I make an appointment or arrange to get a replacement script but I notice My Health Record will show when I got the last one, and keep track of it that way".

Only two out of the 10 patients interviewed reported having allergies, and while the potential benefit of this information being available to other providers in the future was noted, none of the patients had experienced any benefit directly. Patients who suggested that My Health Record had not impacted on

management of medicines also questioned if they were using it correctly and did not realise they could use it personally. While one patient perceived potential benefit of My Health Record for medication management, another patient held the opposing view that My Health Record would not impact or change current medication practices and management.

VIC Pt #1 "I'm very up to date with all my medication and I know exactly what I'm doing and exactly where they are, and my husband is there to give me those tablets if I'm not very well or whatever, no, no, everything's fine".

Patients suggested using My Health Record if their script had run out and they needed to check on repeats available or to determine when they are due for follow-up with another health care provider.

VIC Pt #4 "I think being in the health system I do like to know what's happening to me, and I think technology now is quite advanced, you can see information about yourself, what are the, sometimes if we get sick, sometimes oh is it, I need to know what medicine I took 5 years ago, I wouldn't remember that, they can possibly go back there and look up, yes that's the one, and then the doctor can actually even look at that, then I can also access perhaps, you know if I have allergies, I've got food dislikes or anything related to my health, then, or dietary restrictions, then I think that that should be where the information be put in".

Most patients' understanding of My Health Record was about providers' access to information about the patient rather than My Health Record as a tool that can be used by the patient. Some patients mentioned being able to add their own information and that the doctor can also add information. They indicated that the main information in My Health Record should be diagnosis and medications taken, allergies and information that would help to reduce or avoid mistakes.

Benefit of My Health Record

There were three common themes in relation to perceived benefits to My Health Record use and medication management. These related to keeping track of information, coordination of care (seamless care) and getting better health outcomes in the future. The My Health Record was strongly perceived as having future potential benefit as a mechanism to provide a connection between past and future health information for both the patient and GP.

NSW Pt #5 "It's just a way of informing my future doctors on what was my health then so they would be able to make a better plan of my, of any you know, of my health in the future, so just for a better health outcome".

Patients overall viewed My Health Record as a way to share their information and keep track of it accurately.

NSW Pt #1 "In terms of keeping track of medicines and things like that, I mean I wasn't too sure about that...that's a benefit too, you can help track of all that stuff."

NSW Pt #3 "There's a documented proof of my issues I have, medical issues I've got or medication I'm on and my history".

VIC Pt #3 "I usually go to the Metropolitan Hospital but other times I've had to go to another hospital and they have access to the records too as well as what my condition is and what medications I'm on".

NSW Pt #4 "The benefits are access from any number of locations, keep an accurate record of dates and make information available to different health professionals".

Barriers to use and implementation of My Health Record

A smaller number of the patients interviewed commented on concerns about how their privacy would be protected and managed. Another patient had experienced a good deal of difficulty accessing

information and did not find the system itself to be user-centred. Patients did raise concerns around the system being hacked and in particular about the information held impacting on insurance companies.

NSW Pt #5   "...One of the reasons why I was thinking of opting out is that some people were saying that in like, if we have a lot of like declared health problems in My Health Record that insurance companies might be able to get, you know, hack into it and get our file".

One patient had attempted to use My Health Record but found it difficult to navigate and extract information from.

NSW Pt #6   "It's a waste of time trying to get into it, it's just too complicated".

Discussion

All interviewed GPs were aware of My Health Record and its intended purpose, whether or not their use of it was low. The general consensus was that My Health Record was a tool for storing patient information to improve communication about patient care between different health professionals. GPs tended to conceptualise the benefits of My Health Record theoretically or practically. Patients, however, varied in their knowledge of My Health Record and its uses. Some were early adopters who saw the main benefits as information sharing around medication, diagnoses and allergies between healthcare providers, and having information all in one place in case of an emergency.

GPs were more likely to use My Health Record for certain higher risk patients who were perceived as more likely to benefit from the record, including elderly patients, patients with chronic or complex conditions who received healthcare from different providers across different settings, patients who travelled frequently and those who were more likely to be hospitalised. Patients perceived that their use of My Health Record might increase in the future and some patients noted that having the medication information in one place would assist them for refilling scripts if these had been lost, or accessing histories of tests if seeing a new healthcare provider. There was a perception from patients that My Health Record could provide reductions in medication errors, but no patients had experienced these benefits directly.

GPs explained that patients who were younger and healthier were less likely to have chronic and complex conditions or be hospitalised. Therefore, updating their shared health summaries was thought to be less critical because the summaries did not usually contain information that would impact the patients' care if they were to access different healthcare providers. There were also concerns about data security and how sensitive health information might be accessed by health insurers or law enforcement. These concerns about privacy, confidentiality, security and sharing of information with insurance companies were also shared by a number of patients.

The PIP encourages general practices to continue providing quality care, enhancing capacity, and improving access and health outcomes for patients. There were some misconceptions among GPs about the structure of the PIP payment, which had a negative impact on the way in which they interacted with My Health Record. A key factor causing some GPs to upload information to My Health Record was the receipt of the PIP payment, although GPs were ambivalent on whether this was a positive or negative influence.

GPs explained that the structure of the PIP payment discouraged the regular upload of summaries, by providing payment for a small percentage of patient summaries over a certain time frame. This perception of the PIP payment could be addressed by further education for GPs. GPs' indication that the process for uploading information to My Health Record was easy and efficient, but downloading information was difficult demonstrates that GPs are not as familiar with downloading information. From a patient perspective, uploading and downloading information was not done regularly.

GPs and patients were positive about the potential benefits of My Health Record and repeatedly discussed how these benefits could be realised if certain changes were made to the system. GPs and patients reported that My Health Record had a high potential to benefit patients and health

professionals in emergency situations; for patients this was one of the main benefits identified. However, it was not believed by GPs to be used in these settings very frequently, because of perceptions by health professionals in hospitals that the quality of information in the system is poor (eg, incomplete, inconsistent, potentially outdated). Patients reported that they were still carrying written lists of information about their health conditions and medications.

GPs believed that an increase in the availability and quality of medical test information in My Health Record would reduce duplication of medical tests, improve efficiency and decrease costs to the health system. However, information about certain medical tests was not currently available in the system, and the information that was available was perceived to be of poor quality (eg, incomplete, inconsistent, potentially outdated). Patients felt that theoretical benefits might be to reduce error in an emergency, and minimise adverse events from medications and allergies.

Issues with information quality, completeness and currency were often the focus of GP discussions. A recurring recommendation made by GPs was the automation of information exchange between My Health Record and GPs' clinical software to remove the need to manually upload information. This would increase GPs' trust in the information because it would not be contingent on the fact that a GP had 'bothered' to upload information.

In terms of managing allergies to medicines, GPs did not report that they would rely on My Health Record to do this, and instead preferred to use their clinical software and information from patients themselves. Reasons for this included GPs' assumptions that patients would be able to recall their allergies, that the information was already available in clinical software, and reliance on the 'alert' feature within clinical software that notified GPs about patient allergies and made it unnecessary to manually search for the information. Patients felt that if the information about allergies was in the system, this would prevent possible errors.

Only one GP reported using the system to manage their patients' medications. For patients, My Health Record was perceived to be more an information-sharing system than a management tool. Management of medications was still undertaken manually by patients using a written list or phone reminders, reading the labels of the medication packets or committing medicine regimens to memory. One GP recalled attempting to clarify which medicine had caused an adverse reaction for a patient but due to the poor quality of information and reports contained within the system, My Health Record did not effectively fulfil this purpose.

There was tension between the theoretical benefits conceptualised and the actual benefits experienced by GPs. This tension was shared in the patient group. The notion of a centralised data repository containing patient information was positively perceived by GPs and patients, but the practicality and usability was low for the reasons outlined in the earlier results sections.

A key recommendation arising from these interviews was the automation of information exchange between clinical software and the My Health Record system. Some patients also reported that usability was an issue for them and that they found access to the system difficult. The benefits of relying on clinical software were thought to have outweighed the benefits of using My Health Record and there were a small number of patients who felt that they were already up to date and managing on their own, so My Health Record would not add anything further to their care.

Limitations of the study

Interviews with GPs and patients revealed important information about future use and benefits of My Health Record, although they had limited experience (particularly the patients) of My Health Record as a tool for medication management. This was mostly due to limited use by some patients and the fact that a substantive number of patients did not know much about My Health Record at the time of interviews.

Key findings from this study include:

➢ The concept of My Health Record is well understood by GPs and patients.

➤ GPs perceived My Health Record as having different levels of utility for patient groups and certain patient groups were more likely to have their information uploaded than others.

➤ GPs were able to conceptualise many potential benefits of My Health Record. However, they highlighted limitations in the software, which they thought would need to be addressed before these benefits can be realised.

➤ The limited use of My Health Record across healthcare settings has led to a decrease in GPs' confidence in the reliability of the system.

➤ A major barrier identified by GPs is the inadequately automated information exchange between clinical software and My Health Record.

SUB-STUDY 4: SIMULATION LABORATORY – SAVING TIME

Aim

The aim of the investigation for Study 4 was to explore how use of the My Health Record impacts on clinicians' and patients' time on clinical tasks, time on communicating with other clinicians or patients and assists with medication safety.

Approach

Simulation laboratory

The University of Melbourne's 'simulation laboratory' within the Networked Society Institute was set up as a GP consulting room. GPs were video recorded undertaking a consultation with a 'mock' (simulated) patient and screen recordings were also undertaken to explore the flow of My Health Record use within the consultation.

Box 1 provides a summary of the simulated patient's conditions and history. The mock patient scenario specifically included the potential for an adverse drug event or for medication mismanagement. In this simulation the patient expressed that they knew about My Health Record, that their GP had told them about it and that the GP was responsible for uploading information.

Using the simulated patient history developed by the research team, a mock up My Health Record was made available. This mock record was facilitated by the Australian Digital Health Agency, for the GP to access via either Best Practice or Medical Director clinical software programs.

Technical preparation of My Health Record

Establishment of the mock My Health Record comprised three main components: the technical setup of the environments; creating the simulation data within Best Practice and Medical Director; and training the Study 4 interviewer on how to navigate and reset the simulation environment. Appendix 5 details the processes that were developed and followed throughout Study 4.

Box 1: Summary of patient simulation

'Farrah Easton', a 61-year-old woman, presents to a general practice with symptoms of a urinary tract infection and requiring prescriptions for routine medications. Farrah usually resides in Western Australia but has come to Melbourne as part of an urgent visit to assist her daughter who has been involved in an accident. As a result, she was unable to organise to have enough medication to last for the duration of her stay. She arrived at the clinic to see the doctor and immediately talked about her urinary symptoms, need for prescriptions, and her feelings of stress.

Medication safety issues related to this presentation, which could be addressed by using My Health Record, included:

- Shared health summary documenting allergy to a previous antibiotic
- Pathology report documenting organism and sensitivities for a previous urinary tract infection
- Shared health summary accurately stating current medications and dosages.

Her GP in Western Australia cannot be contacted at the time of the appointment to provide this information because the clinic is not open.

Sample and recruitment

The goal was to recruit five GPs, familiar with either Medical Director or Best Practice. GPs were sourced through the Victorian primary care practice-based Research Network (VicReN). VicReN members include GPs, general practice nurses and practice managers, academics and others interested in primary healthcare research (www.gp.unimelb.edu.au/vicren).

A total of 208 VicReN members were emailed an invitation on 16 March 2018 although not all these recipients were GPs or eligible to participate. A $200 gift voucher was offered to participants to reimburse them for participation in the simulation. Nine GPs expressed interested and one GP agreed to participate in a pilot simulation to test the reflective questions and the software functionality and capability. Eight GPs participated in the simulation in April 2018.
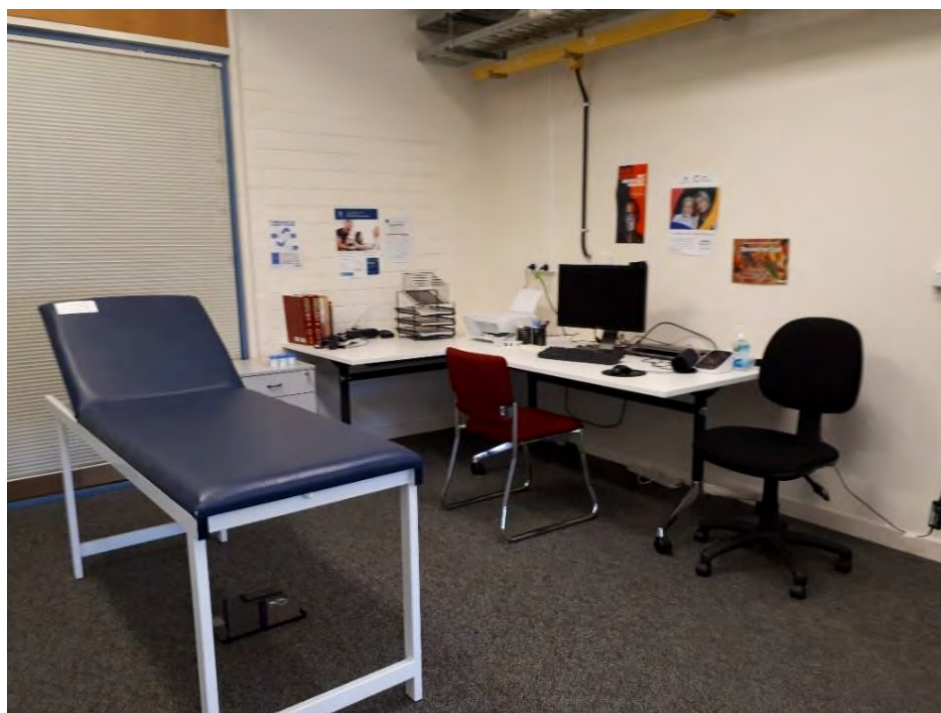
Photo: Simulated GP consulting room at the Networked Society Institute, The University of Melbourne, 20–21 April 2018. One digital video camera on a tripod recorded the consultations from the back of the room and screen recordings were taken of use of My Health Record via the computer monitor for 6 of 7 simulations.

Method

Data collection

GP decision making within the consultation and the effect of My Health Record on this was explored using reflective Think Aloud interviews. Think Aloud is based on the use of verbal reports as data, whereby the participant talks aloud the thoughts as they occur in immediate memory. Think Aloud can include concurrent and retrospective data collection[5]. GPs were asked to approach the scenario as they would a normal consultation and interact with the clinical information system and My Health Record as part of the consultation. GPs were encouraged to talk out loud their use of My Health Record and thoughts about benefits and challenges; however, where this did not occur (largely because of the focus on the patient), additional questions were asked at the end of the simulation about the GP's use of My Health Record.

[5] Burbach B, Barnason S, Thompson SA (2015) Using "think aloud" to capture clinical reasoning during patient simulation. Int J Nurs Educ Scholarship 12 (1):1-7

The simulations were video recorded, both diagonally from behind and from a computer monitor camera. Observational notes were also taken to document how the GPs engaged with the software and its flow within the consultation.

In the reflective Think Aloud interviews, GPs were asked about what worked well when My Health Record was used, what could be better if anything and what could be changed to make My Health Record perfect. Additional questions were asked about whether My Health Record influenced decision making in the consultation, fitted into the consultation, affected decisions about prescribing or ordering tests, and about other information that was available that informed decisions in the consultation (apart from My Health Record).

Video analysis

The videos were watched to examine how My Health Record was situated and used within the consultation and if it influenced decisions that were made. In particular, the analyst looked at the fit, flow and decisions made for the simulated patient. For the reflective interview key themes were identified around general views on My Health Record, usability and changes that GPs would like to see made.

Results

Eight GPs were recruited to the simulation study, but only seven simulations were possible. This was due to the server system crashing for one simulation on Friday, 20 April 2018.

Of the seven who took part, five were metropolitan and two were regional GPs. The length of consultation time varied for GPs from 11 minutes to 28 minutes. Two of the seven GPs were not high users of My Health Record.

Situated use of My Health Record in consultations

GPs approached the simulated scenario similarly. They discussed the patient's concerns and addressed her indication that she was suffering from a urinary tract infection. Not all GPs used the existing medical record to read the nurse results that were uploaded ahead of the consultation (not all GPs checked for this information and it varied whether the patient told them about visiting the clinic earlier and taking a test). GPs varied in whether they took the patient's blood pressure or not, if this was conducted at the beginning or the end of the consultation (and in two simulations blood pressure was not checked at all).

For all simulations the patient requested a script for her medications and all GPs asked the patient if she knew what medication she was on. The patient suggested that she had left her script behind as she was travelling interstate and was not sure what medications she was taking. The patient also indicated that she had had a blood test and were waiting on results and that she had had a reaction to previous antibiotics.

The reaction to antibiotics acted as a prompt for all the GPs to go to My Health Record, most went to the record early within the consultation (within approximately 3–5 minutes). In terms of identifying the link for My Health Record, this was easy and fitted within the consultation flow. GPs generally accessed the shared health summary to explore diagnoses and medication lists. A few GPs discussed accessing pathology tests although the pathology results took longer to find.

Regardless of the order in which they discussed medications or results of tests and the allergy in the consultation, each GP reviewed the medication list thoroughly. Only two GPs checked if patient date of birth or GP names were correct in the results. GPs also discussed the results of the pathology report and when the patient introduced the idea that medication changes had been suggested by their home GP, six GPs indicated that this would be best addressed at home and one made the decision to

change medications. Most GPs indicated in the reflective interviews that they would not change diabetes medications for someone while they were travelling if it was not necessary.

All GPs identified the allergy documented in My Health Record and sourced alternative medication for this. Three of the seven GPs updated the patient medical record to indicate that there was an allergic reaction. Some of the GPs considered the allergies that were listed as side effects rather than allergic reactions to the medication. They did not prescribe the same medications but still questioned if the reactions that were noted were allergies in the strict sense. GPs focused on the kidney decline information in various ways within the consultations. Some discussed this at length with the patient but tried to reassure them that this was a normative part of ageing. In the reflective interviews all GPs noted that this issue was something they felt should be addressed by the home GP in the future.

General views on My Health Record

GPs thought that My Health Record was beneficial for accessing correct diagnostic information, medications and test results for patients. Some were positive that it could improve communication between primary and tertiary settings. Two mentioned that the patient history information made it difficult to navigate and that they would like more contextual information about the patient to be held within My Health Record.

Overall, however, for the patient in question who was travelling and had forgotten their script, My Health Record was logical and useful:

GP Sim 2 (Rural): "It was clearly important to access My Health Record data. Without My Health Record it may involve finding contact number for practice, and phoning. Instead you can click on My Health Record and identify the shared health summary and that gives as much or as little as she needs. If I need to it's got other information down there. There is a training issue here about how to play around in it if there could be hospital discharge information too".

In the reflective interviews, GPs noted that there was still some level of patient suspicion of My Health Record in terms of what information it would contained, who would see it and how it might be used by insurance companies in the future. In addition, they mentioned the viability of maintaining different systems of information and how the general practice-held medical record may be the one that the patient sees as containing their private and protected information. This was particularly relevant to patients who may have a stigmatised condition or who may not wish to disclose alcohol and other drug use or other conditions in their My Health Record.

Usability

Overall My Health Record had good usability and fit for the GPs in terms of finding the records. However, in the simulations GPs struggled with finding the right pathways to complete an upload of an event summary and they did not use download functions of reports and results to import these into the patient medical record (screenshot examples of the issues that GPs experienced are available in Appendix 6). One GP suggested that they were responsible for changing the shared health summary rather than uploading an event summary which indicated a misunderstanding of the technical concepts and functions of My Health Record.

The GPs also did not always find it easy to identify the tabs to be used within Best Practice and Medical Director for uploading event summaries. This impacted on the consultation, resulting in frustration and a sense that the system did not feel intuitive:

GP Sim 1 (Rural): "This again is another problem with this technology, I find that sometimes I spend so much time just looking at the screen that I forget, I don't forget that I have got a patient there in front of me, I just think that this should be easier for me. This should be more intuitive for me and it is not".

GP Sim 4 (Metro): "Whoever invented the My Health Record did not ask me. They do not understand how a GP organises their mind. It is better than a piece of paper but it is not set out logically in the way that I think. I think there will a massive amount of data in a record in the future that means nothing. I can search through my patient record using memory and I can see everything".

This was described further by a second GP in terms of the extra tool being added into the usual consultation practice and flow.

GP Sim 2 (Rural): "I suppose the whole thing of an extra [tool] and coming into the records that I have already got is sometimes a little bit difficult because it means that you have to think in two windows and you have to think right what is going into this and what is going into my own record. That can sometimes be a little bit difficult and to be honest I picked the wrong thing there. I thought that the – this is interesting for me because I looked at the shared health summary and I thought why is that not up here, and I didn't realise that was going into my record and not to the My Health Record".

Overall GPs found that My Health Record in its current format was sufficient in terms of containing the most critical information about diagnoses, medications and results from tests. GPs had the view that it could reduce prescribing errors and increase safety.

GP Sim 4 (Metro): "It's for doctors to not make medication errors and to prescribe safely. Not that there is anything here but it should stop doctor shopping so being able to access in real time if people are on the drug and what dose is very helpful".

Some GPs did think that there could be more information available in My Health Record and did question how to keep the information up to date. Questions were asked about how to ensure that the information would be high quality.

GP Sim 5 (Metro): "Seeing what has actually been prescribed would be good. That was not obvious there, for me, this is one of the problems with My Health Record, it is very different to how we think. I looked down the bottom and thought where are all the scripts – that is what I was scrolling down and looking for. I thought that is where I should find the scripts she has had. That would have said the latest scripts, now that summary might have been uploaded six months ago – but dispensing information might be more up to date than a doctor's record".

Discussion

Main findings

All GPs found My Health Record beneficial as it allowed them to access allergy, medication information and pathology results in one location. All GPs in this study were able to access My Health Record to identify an allergy and make appropriate prescribing decisions. My Health Record was seen to save time and improve communication, reduce the potential for error and possibly decrease patients' 'doctor shopping' practices. Because the simulated patient was travelling and interstate, she fitted into this scenario. There was a tension however between time saved and time added when trying to find new information through a different system.

A small number of GPs mentioned to the patient that they would like to upload the results for the home GP so that they could address any issues at future consultations. This was seen to be a positive way to communicate information. GPs raised questions about responsibility for keeping the information up to date and who might be the final curator of the record. They questioned whether patients had adequate knowledge of the system to be able to engage with it and add further information if they wished to.

GPs did not feel that they needed to be notified if a patient had had further information uploaded to My Health Record by someone else. They indicated that more notifications would result in further

noise and that they would be unlikely to access patient information until the patient attended a future consultation.

GPs appear to create their own workflows within consultations for when issues or problems are addressed and in what order. My Health Record to some extent relies on GPs conforming to a standardised workflow that focuses on prior diagnoses, medications and test results.

A major point of concern for the GPs was what to do if they saw information within My Health Record from another practitioner that they felt was incorrect or needed addressing. So, while time might be saved by being able to see diagnosis and medication and test results, time might be added by needing to follow up or consider how to respond to incorrect information or medical errors that might be identified.

Limitations

The GP recruitment advertisement specified previous use of My Health Record. Despite this, there were two participants who had only early stage use of the system. These two GPs did not navigate the upload of the event summary in the final stages of the consultation and took longer to identify reports and information. GPs were largely unable to conduct the Think Aloud component of the interview within the consultation setting. Retrospective Think Aloud was positive and yielded good discussion, but the cognitive load of thinking aloud while undertaking a consultation and navigating My Health Record was possibly too high.

APPENDIX 1: MEDICINEINSIGHT

MedicineInsight

Sub-studies 1 and 2 utilised NPS MedicineWise's MedicineInsight dataset. Extracted data includes the demographic and clinical data for patients as recorded by providers, (except for progress notes), prescriptions written, pathology testing and system-generated data (eg, start time and date of an encounter) and GP-identifiable information (with consent) for administration of quality improvement activities. After data capture, the program codes and transforms the data through the application of sophisticated data mapping and algorithms to facilitate reliable and predictable data analytics and interpretation. These processes are managed by a large team of data architects and modellers, coders, data analysts and epidemiologists to enable the development of meaningful insights and reports that are tailored to the needs of practice staff, researchers, and policy makers. The extraction collects incremental data weekly, allowing development of a longitudinal database in which patients within practices can be tracked over time.

Boxes 1 and 2 summarise the MedicineInsight content and data collected from general practices including:

1. patient demographic and clinical data entered directly by GPs and practice staff into the system;
2. system-generated data (eg, start times and dates of patient encounters); and
3. practice and GP information for the administration of quality improvement activities by NPS MedicineWise.

Box 1: MedicineInsight Summary (August 2018)

- **14.2 million individual patients in total**

- **4,200 general practitioners from over 650 general practices**

- **Data from every Australian state, territory, and Primary Health Network**

- **There are more than 26 projects approved for use of MedicineInsight data for research and quality use of medicines, see website: https://www.nps.org.au/medicine-insight/using-medicineinsight-data.**

Box 2: Data currently collected by MedicineInsight

Practice	Encrypted unique ID, software, extract date, location
Provider	Encrypted unique ID, consent, profession (e.g. GP/nurse)
Patient	Encrypted unique ID, birth year, sex, indigenous status, postcode, pension, year of death
Encounter	Reason for encounter, duration, date
Medical history	Diagnosis, onset date, status (active/inactive), date
Prescriptions	Medicine, ATC, product code, frequency, dose, strength, repeats, authority, reason for prescription, date
Tests (pathology/imaging)	Tests performed, name, test result received, LOINC code, unit of result, date
Observations	BP, pulse rate, height, weight, BMI, waist circumference, temperature
Other risk factors	Smoking status, alcohol
Management activities	Referrals, health assessment, management plans, immunisations
Allergies/ADRs	Type, reason, date

The MedicineInsight dataset is underpinned by GRHANITE, a unique privacy-protected data extraction and linkage tool developed by the University of Melbourne, which de-identifies data at the source of its extraction, thereby making it impossible for patient records to be re-identified at any point other than the site of their creation.

APPENDIX 2: ALLERGIES AND ADVERSE DRUG REACTIONS – ADDITIONAL INFORMATION

Characteristics of practices in My Health Record Opt Out and Opt In PHN areas

Variable		Practices in Opt Out PHNs n (%)	Practices in Opt In PHNs n (%)
Practices (n)		12	482
SEIFA Quintiles#	1	1 (8.33)	81 (16.91)
	2	1 (8.33)	79 (16.49)
	3	3 (25.00)	110 (22.96)
	4 and 5	7 (58.33)	209 (43.63)
Rurality	Major cities	6 (50.00)	295 (61.46)
	Inner regional	1 (8.33)	113 (23.54)
	Outer regional, remote and very remote	5 (41.67)	72 (15.00)
State	ACT		9 (1.87)
	NSW	7 (58.33)	160 (33.20)
	NT		10 (2.07)
	QLD	5 (41.67)	94 (19.50)
	SA		14 (2.90)
	TAS		38 (7.88)
	VIC		94 (19.50)
	WA		63 (13.07)

PHN – Primary Health Network

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5 – lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas

*Rurality is assigned to patients based on patient postcodes. Rurality is calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote.

Characteristics of patients in My Health Record Opt Out and Opt In PHN areas

Characteristic		Patients in Opt Out PHNs n (%)	Patients in Opt In PHNs n (%)
Patients (n)		2038	112603
Gender	Female	1507 (74.0)	82173 (73.0)
	Male	52 5(25.8)	30270 (26.9)
	Indeterminate	6 (0.29)	160 (0.1)
Age groups (years)	0-9	85 (4.2)	5140 (4.6)
	10-19	115 (5.6)	6413 (5.7)
	20-29	227 (11.1)	12313 (10.9)
	30-39	258 (12.7)	13566 (12.1)
	40-49	256 (12.6)	14753 (13.1)
	50-59	296 (14.5)	15400 (13.7)
	60-69	321 (15.8)	15828 (14.1)
	70-79	238 (11.7)	14425 (12.8)
	80-89	183 (9.0)	10435 (9.3)
	90-99	59 (2.9)	4328 (3.8)
	99-110	0 (0)	2 (0.0)
SEIFA Quintiles#	1	234 (11.5)	17908 (16.1)
	2	342 (16.8)	18402 (16.5)
	3	546 (26.8)	25629 (23.0)
	4	916 (45.0)	49612 (44.5)
Rurality	Major cities	558 (27.4)	67650 (60.6)
	Inner regional	225 (11.0)	3229 7(28.9)
	Outer regional, remote and very remote	1255 (61.6)	11788 (10.6)
Attended multiple clinics	No	1972 (96.8)	100468 (89.2)
	Yes	66 (3.2)	12135 (10.8)

PHN – Primary Health Network

Socio-Economic Indexes for Areas (SEIFA) are assigned to practices based on practice postcodes. SEIFA is calculated in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles. SEIFA 4 and 5 were combined due to the low number in category 5 – lower scores indicate more disadvantaged areas and higher scores indicate more advantaged areas

*Rurality is assigned to patients based on patient postcodes. Rurality is calculated in accordance with the Australian Bureau of Statistics' geographical framework (the Australian Statistical Geography Standard) 'Remoteness Areas' which include: Major cities; Inner regional; Outer regional; Remote; and Very remote.

APPENDIX 3: PATIENT RECORD LINKAGE AND DE-DUPLICATION

GRHANITE privacy-preserving record linkage was utilised in this project to identify patients who have presented at more than one general practice. Like any record linkage technique, the larger the number of participants, the greater the likelihood that different patients may share commonality in name, date of birth or other traditional identifiers used for record linkage.

The following de-duplication mechanisms were employed on the study datasets.

All possible joins between patient records were compiled including allowing multiple joins utilising the four cryptographic hashing algorithms employed by GRHANITE. Each potential join was assigned flags indicating: 'join validated', 'join suspect' and 'invalid join'.

Patient attributes such as (but not limited to) sex, year of birth, PHN area code, state, practice, encounter profile, drug prescription profile and test result profile were compiled to assess commonality across the patients where a join was indicated. The size of the data populations allowed for the assessment of the value of different patient attributes in assessing commonality.

In many cases, data content from particular practices was sparse for individuals. In such cases, the nature of any commonality between records was difficult to assess. In these cases, the number of hashes in common (up to four) was used as an indicator of how closely the patient demographics for each individual aligned and hence to allow for assumptions on join accuracy to be made.

Patient records are occasionally moved electronically between practices when a patient changes their principal general practice. Analysis of the linked dataset was undertaken to identify mirroring of clinical data content (and health provider anonymised ID) across practices. Records with such mirroring were definite, validated joins. Analysing the linkage of such cases allowed the performance of hash joins to be analysed, thus helping to refine the algorithm for assessing whether other joins may be valid or not.

On completion of the analysis, the GRHANITE record linker tool was able to be run, excluding join records deemed to be suspect or invalid. A refined, de-duplicated dataset was generated for each study. The approach taken was designed to minimise the chance of false-positive joins over record linkage sensitivity.

The table below summarises the results of this process.

Patient record linkage and de-duplication statistics	Study 1.1	Study 1.2	Study 1.3	Study 2
	HbA$_{1c}$ testing	X-ray for knee osteoarthritis	Benzodiazepine Rx	Antibiotic allergy
n Patient records before linkage	325508	475853	1089050	180842
n Patient records after initial linkage	217177	305740	670258	112864
n Patient records after de-duplicated linkage	238139	332836	752974	126883
Difference in record numbers after de-duplication	20962	27096	82716	14019
Percentage reduction in patient numbers when linked	33%	36%	38%	38%
Percentage reduction in patient numbers when linked – de-duplicated	27%	30%	31%	30%

APPENDIX 4: GP INTERVIEW PROTOCOL

NPS MEDICINEWISE

EVALUATION OF MYHR – GP INTERVIEW PROTOCOL

INTRODUCTION

Thank you for agreeing to participate in this interview. Your responses will provide Australian Digital Health Agency (ADHA) with valuable insights about how My Health Record (MyHR):

- is utilised by GPs
- impacts practice

The information you provide will assist the ADHA to enhance the current MyHR system.

A few things to note before we begin:

▷ The interview will take approximately one hour
▷ Your feedback will be included in an evaluation report for ADHA on an anonymous basis
▷ You may stop the interview at any time or choose not to answer any questions
▷ Are you still happy for this interview to be audio-recorded for the purpose of analysis?
▷ Only the researchers involved in the study will have access to the recording and it will be stored as per the NPS MedicineWise and the University of Melbourne privacy policy

BACKGROUND

1. How many years have you been practicing as a GP?
2. How many years have you been working in your current practice?
3. What is your current work status? F/T, P/T, Not currently working, or Retired?
4. Is your primary practice an independent clinic or a medical centre?
   - ☐ Independent/Private Clinic
   - ☐ Medical Centre
5. Where is your practice located? Suburb Postcode?
6. How would you describe the demographics of the practice location?

GENERAL GP USE AND UNDERSTANDING OF MYHR

1. Can you tell me about your current understanding/s of how MyHR works?
2. What is the purpose of MyHR?
3. How long have you been using MyHR?
4. Why do you use MyHR?

   (Ascertain whether upload SHS 0.5% (n=5) of patients per quarter to qualify for ePIP funding is a motivator?)

5. When do you use MyHR?
   a. For which patients?

   (Ascertain whether shared health summary uploaded for less complex conditions [easy to upload data] or for patients they think would benefit the most).

6. How do you feel about using MyHR?
7. When was the last time you used MyHR?
   a. For what purpose?

BENEFITS OF MYHR

8. Can you describe the relevance of MyHR to your practice as a GP?
    a. (If so), how?
    b. (If not), why isn't MyHR relevant to your practice?
9. What do you find most helpful about the MyHR system?
10. Was there anything you didn't find helpful about MyHR?
11. Has MyHR impacted your practice as a GP?
    a. (**if yes**) In what ways do you think the MyHR system impacted your practice as a GP?
        i. (prompt) Can you expand on that some more please?
    b. (**if no**) Why do you think MyHR hasn't impacted your practice?
12. Reflecting on your use of MyHR, can you think of an example/s when the system has been useful in:
    a. Coordinating the management of medicines for patients with allergies to particular medicines?
        i. (if example provided, prompt) How do you think this has benefited the patient?
        ii. How did this make you feel about your treatment of this patient?
        iii. How did you feel about MyHR after this event/experience?
        iv. Did this influence your use of MyHR? If so, how?
        v. Was your patient aware of MyHR's role in influencing their treatment/healthcare?
            - (If yes), do you think this has influenced their use of MyHR?
            - (If no), why not?
    b. Prevented an adverse drug event (ADE) for patients with allergies to medicines?
        i. (if example provided, prompt) How do you think this has benefited the patient?
        ii. How did this make you feel about your treatment of this patient?
        iii. How did you feel about MyHR after this event/experience?
        iv. Did this influence your use of MyHR? If so, how?
        v. Was your patient aware of MyHR's role in influencing their treatment/healthcare?
            - (If yes), do you think this has influenced their use of MyHR?
            - (If no), why not?
13. Have you found that MyHR has improved the safe use of medicines?
    a. Can you provide an example/ other examples of how MyHR has improved the safe use of medicines?
        i. (if example provided) How did this make you feel about your treatment of this patient?
        ii. How did you feel about MyHR after this event/experience?
        iii. Did this influence your use of MyHR? If so, how?
        iv. Was your patient aware of MyHR's role in influencing their treatment/healthcare?
            - (If yes), do you think this has influenced their use of MyHR?
            - (If no), why not?
14. Has MyHR assisted coordinating medication management with other healthcare providers?
    a. How? Can you provide an example?

CONCLUSION

▷ This brings us to the end of the interview.

▷ Before we finish do you have any other questions or comments you would like to make relating to this interview?

▷ Your participation in this interview is greatly appreciated. You will be receiving a $150 gift voucher which will be sent to your designated email account to thank you for your time.

▷ Can you please confirm your email address?

▷ If you have any further questions you may contact: Dr Nyrie Nalbandian (Audience Insights Specialist – NPS MedicineWise) (02) 8217 8781 or Dr Victoria Palmer (Senior Research Fellow, The University of Melbourne) (03) 8344 4987.

APPENDIX 5: PATIENT INTERVIEW PROTOCOL

NPS MEDICINEWISE

EVALUATION OF MYHR – CONSUMER INTERVIEW PROTOCOL

INTRODUCTION

Thank you for agreeing to participate in this interview. Your responses will provide Australian Digital Health Agency (ADHA) with valuable insights about how My Health Record (MyHR):

- is utilised by patients
- impacts treatment

The information you provide will assist the ADHA to enhance the current MyHR system.

A few things to note before we begin:

▷ The interview will take approximately one hour
▷ Your feedback will be included in an evaluation report for ADHA on an anonymous basis
▷ You may stop the interview at any time or choose not to answer any questions
▷ Are you still happy for this interview to be audio-recorded for the purpose of analysis?
▷ Only the researchers involved in the study will have access to the recording and it will be stored as per the NPS MedicineWise and the University of Melbourne privacy policies

BACKGROUND

1. How many years have you been seeing your current GP?
2. Do you always see the same GP?
    a. Do you generally wait to see your family GP or do you see the next available GP?
3. Do all the members of your family see the same GP?
    a. Why, why not?
4. Could you tell me if you currently take medicines and if so, how many and for what conditions?
    a. How do you manage to keep a track of your medicines?
    b. Has MyHR impacted your management of medicines?
    c. (If so), how?

GENERAL CONSUMER USE AND UNDERSTANDING OF MYHR

5. Take me through when you started using MyHR and how you use it? You might like to think about when you last used and what that was for and how you understand it works?
    a. How were you introduced to MyHR? (Letter in the mail; GP conversation?)
    b. When did you register with MyHR?
        i. Did you consider opting out?
        ii. (If no) Why didn't you choose to opt-out?
6. Have you had a conversation about MyHR with your healthcare provider?
7. What is your current understanding/s of how MyHR works?
8. What is the purpose of MyHR?
9. How do you access MyHR?
10. Have you uploaded any information on MyHR (shared health summary)?
    a. Have you uploaded your:
        i. Medical history on your shared health summary? Why?
        ii. Medicines on your shared health summary? Why?
        iii. Allergies to medicines? Why?
        iv. Any adverse reactions to medicines or immunisations? Why?

11. Why do you use MyHR? (GP, specialist recommendations?)
12. When do you use MyHR?
13. How do you feel about using MyHR?
14. When was the last time you used MyHR?
    a. For what purpose?
15. Are you aware whether your healthcare provider is using MyHR?

BENEFITS OF MYHR

16. Can you describe the benefits or otherwise of using MyHR?
17. How have these benefits been brought to your attention? (Conversation with specialist, GP?)
    a. Have you personally experienced the benefits of being a MyHR user?
        i. (if yes), can you explain this in further detail?
        ii. (if no), why do you think you haven't experienced the benefits of MyHR?
18. Has your GP talked to you about how they have used/uploaded information on MyHR?
19. Do you believe MyHR has changed GP's management of your medicines?
    a. (If so), how?
20. Has MyHR changed with the management of your medicines across other health services, such as:
    a. Any hospital care?
        i. (If so), how?
    b. Your community pharmacy?
        i. (If so), how?
    c. Any complimentary care (such as naturopaths, chiropractors, physiotherapist, etc.)?
21. Do you have any allergies to medicines?
22. Have you recorded any allergies to medicines in your shared health summary (SHS) on the MyHR site?
    a. (If yes) Why have you uploaded this information onto the MyHR shared health summary?
    b. (**If not**), why not?
23. Since having a MyHR, have you experienced any allergic reactions to your medicines?
    a. (If yes), which medicines?
    b. (If yes), were these prescribed to you by your GP?
        • If not, by who?
24. Can you recall an instance when you believe MyHR has prevented an adverse reaction to a medicine?
    a. (If yes) when?
    b. (If yes) how?
25. How do you feel about MyHR after this experience?
26. Has MyHR assisted with the management of your medication/s across various healthcare providers (e.g., specialists, GPs, hospital staff)?
    a. (If so), how?
27. Will you continue to update your information on MyHR?
    a. Why?
    b. Why not?
28. Do you think this information on MyHR may benefit your healthcare in the future?
    a. How?

CONCLUSION

▷ This brings us to the end of the interview.

▷ Before we finish do you have any other questions or comments you would like to make relating to this interview?

▷ Your participation in this interview is greatly appreciated. You will be receiving a $100 gift voucher which will be sent to your designated email account to thank you for your time.

▷ Can you please confirm your email address?

▷ If you have any further questions you may contact: Dr Nyrie Nalbandian (Audience Insights Specialist – NPS MedicineWise) (02) 8217 8781 or Lauren Humphreys (Junior Epidemiologist) (02) 8217 9233 or Dr Victoria Palmer (Senior Research Fellow – The University of Melbourne) (03) 8344 4987.

APPENDIX 6: TECHNICAL DEVELOPMENT OF STUDY 4 SIMULATION ENVIRONMENT

The figure outlines the technical support and data application processes that were followed during the creation of the simulation environment used in Study 4.
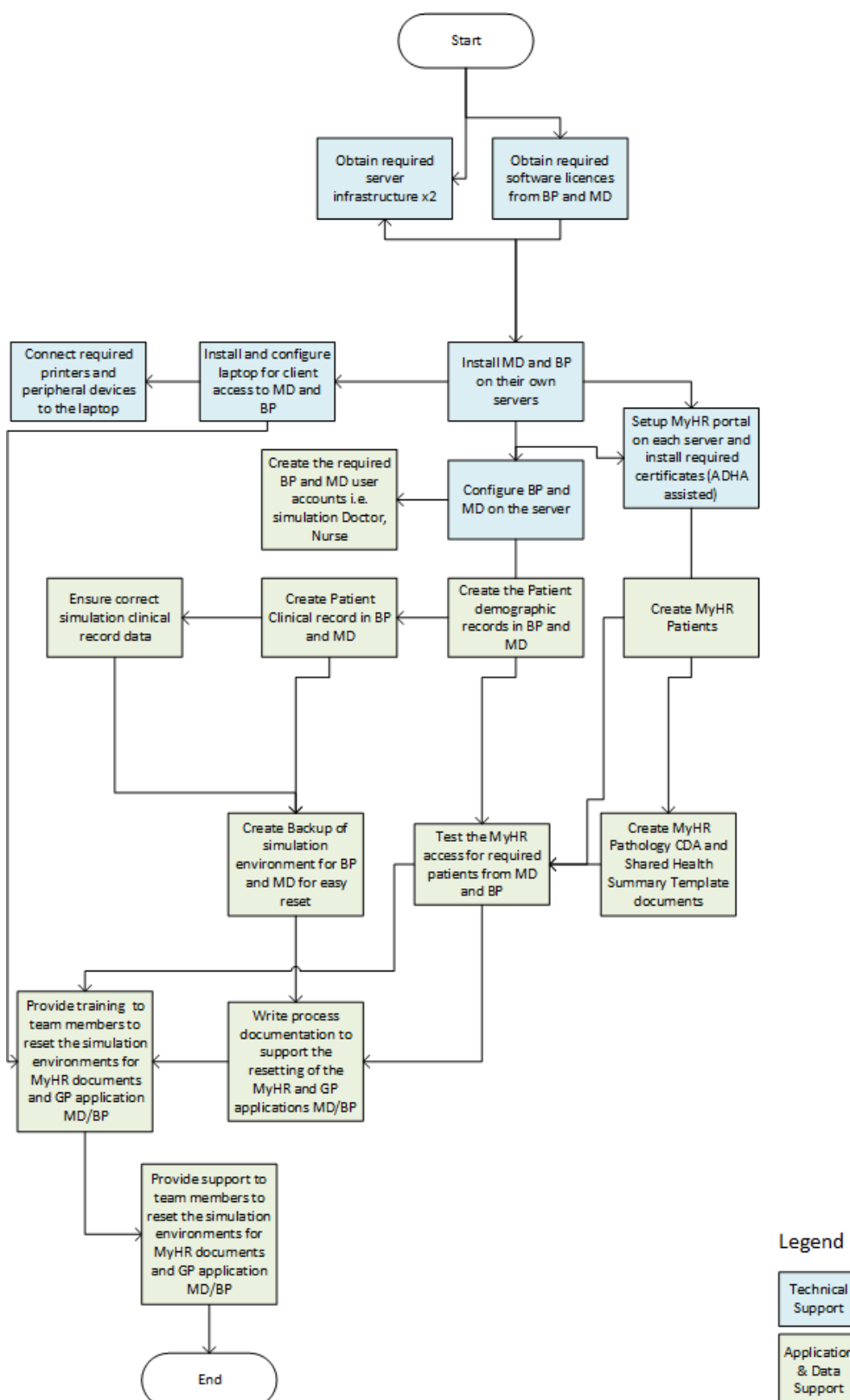
The University of Melbourne Health and Biomedical Informatics Centre, Research Technology Unit (HaBIC R2), Department of General Practice, set up the simulation environment so that the researchers and research participants could access Medical Director (MD) and Best Practice (BP) and a mock version of a 'mock' patient My Health Record (MyHR). This work had two main components to it and required varying resources from the team to ensure the successful setup and implementation, the two main components were as follows.

1. The technical setup of the environments consisted of the following:

- Obtaining two virtual servers for each application

- Configuring the servers

- Obtaining licences from the software vendors for BP and MD to use for the simulations

- Installing MD and BP onto the servers

- Configuring the software environments

- Setting up a laptop computer with the two applications that connected to the servers and simulated a GP clinic in the University of Melbourne Networked Society Institute

- Connecting peripheral hardware such, as laptops computers, to enable printing of prescriptions and pathology requests

- Help and support from Australian Digital Health Agency (ADHA) to setup the My Health Record (MyHR) environment on each server

- Connecting the software with the ADHA My Health Record

- Providing support to the simulation project team members

Creating the simulation data within BP, MD and My Health Record and training the team members on the project, including:

- Training from ADHA on how the My Health Record works and how to create the Shared Health Summary and Pathology reports

- Creation of the mock (simulated) patient record within BP and MD, ensuring all dates and information were included as required by the researchers to simulate a life-like patient with views of the patient's history such as past visits

- Ensuring the patient's record in BP and MD connected to the My Health Record and was able to upload and download the required documents

- Creation of the patient's Pathology Reports as a PDF and the associated CDA document for the pathology report, and ensuring these were loaded in the MyHR for the patient through XML templates that are the underpinning technology in creating the CDA document

- Creation of the patient's Shared Health Summary ensuring this was loaded in the MyHR for the patient through XML templates that are the underpinning technology in creating the CDA document

- Creation of backups, process and user documentation on how to quickly and easily restore the environments after each simulation was run

- Training and supporting researchers throughout the piloting and undertaking of the simulated consultations

APPENDIX 7: NAVIGATING MY HEALTH RECORD – SCREENSHOTS FROM THE SIMULATION LABORATORY

Screenshots and activities were recorded as GPs undertook the simulated consultation. Examples are provided which demonstrate how GPs tried to navigate My Health Record to achieve different tasks. These have implications for design of integration of My Health Record into clinical information systems/electronic health records.

GP1: Utilising Best Practice to try to upload a document to My Health Record.
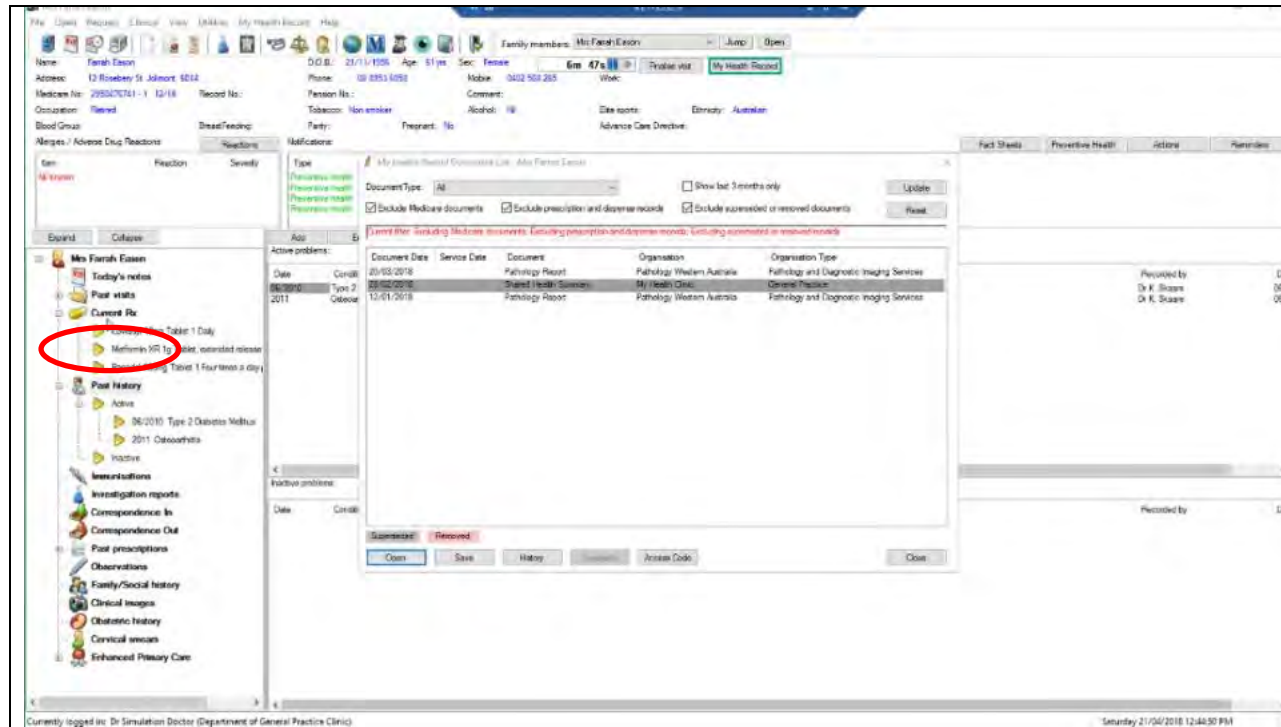
GP1 attempted to update the My Health Record by clicking on *Current Rx* in the Best Practice navigation pane. Due to the My Health Record being open, this did not result in any action being recorded.
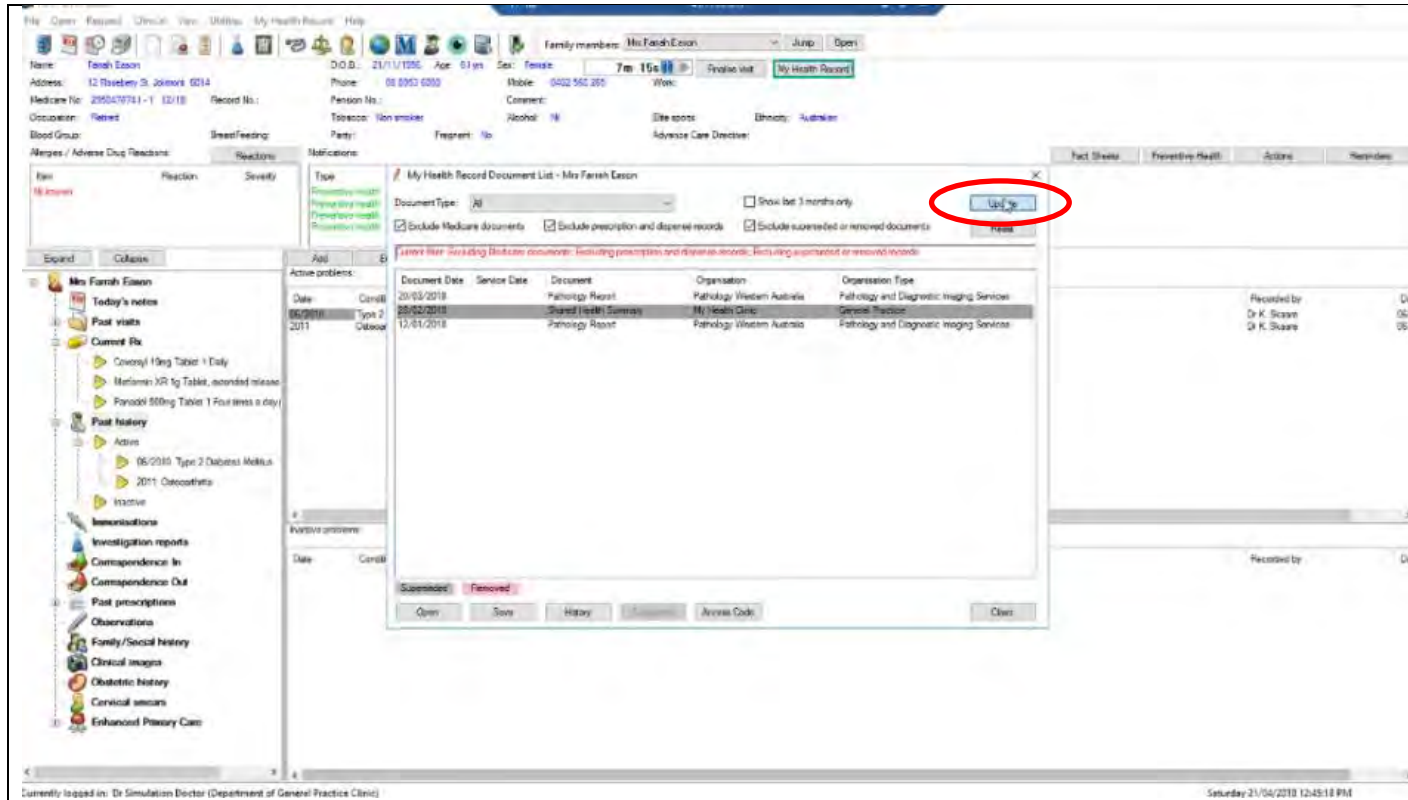
GP1 then tried to click the Update button in the My Health Record Document list. However, this did not result in an update to the documents saved in the My Health Record. The GP then proceeded to open the Pathology Reports.
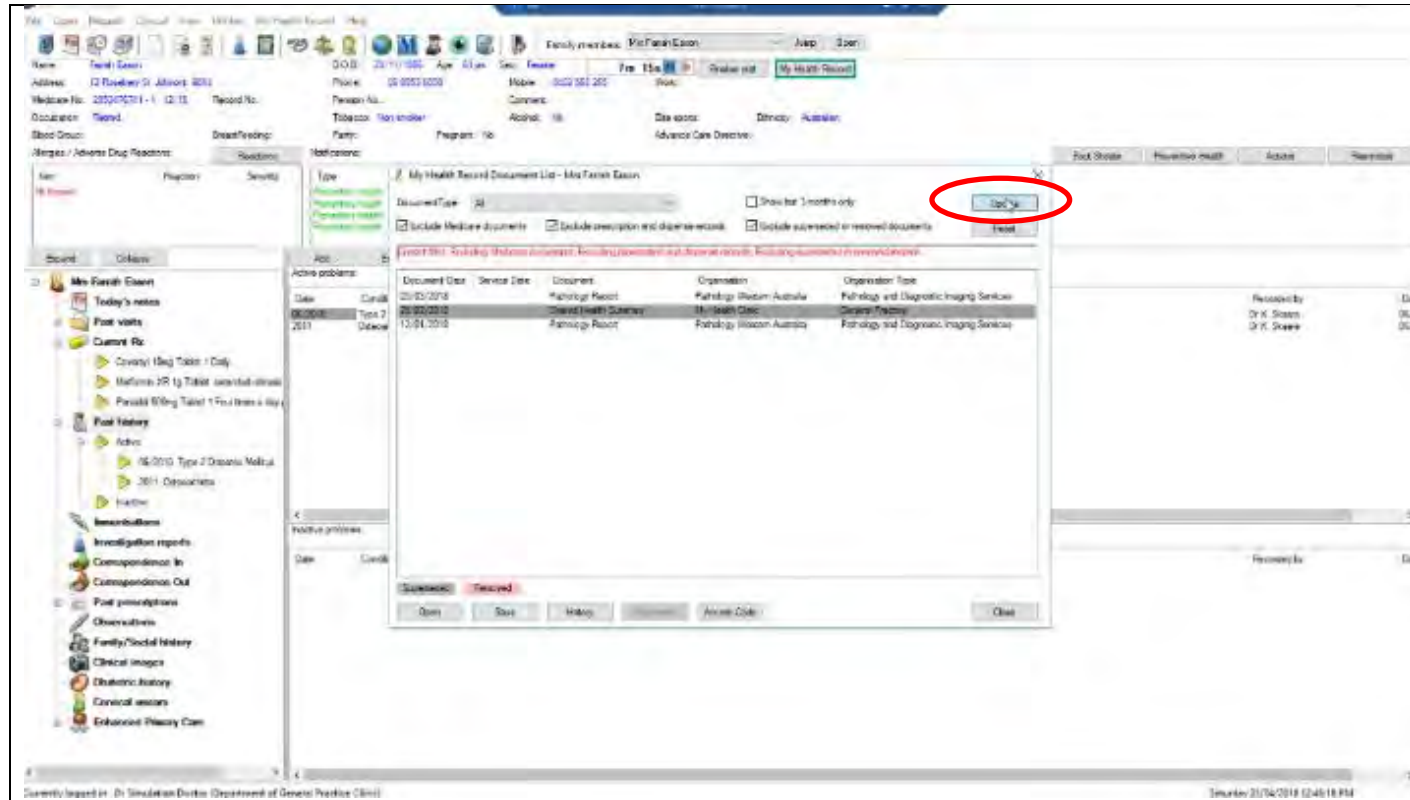
Later in the consultation, GP1 again attempted to update the My Health Record, using the *Update* button.
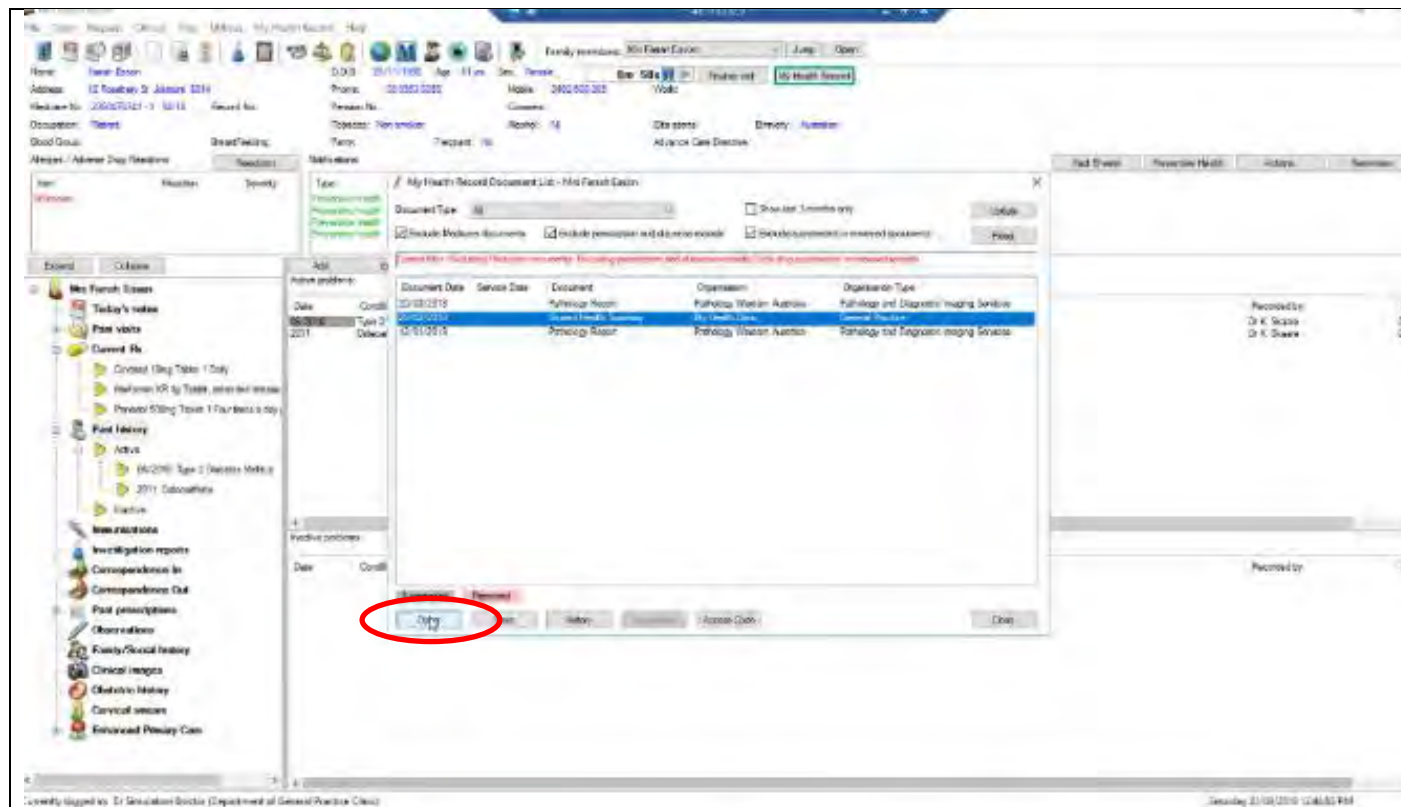
They then clicked the Open button and scrolled through the shared health summary before closing it.
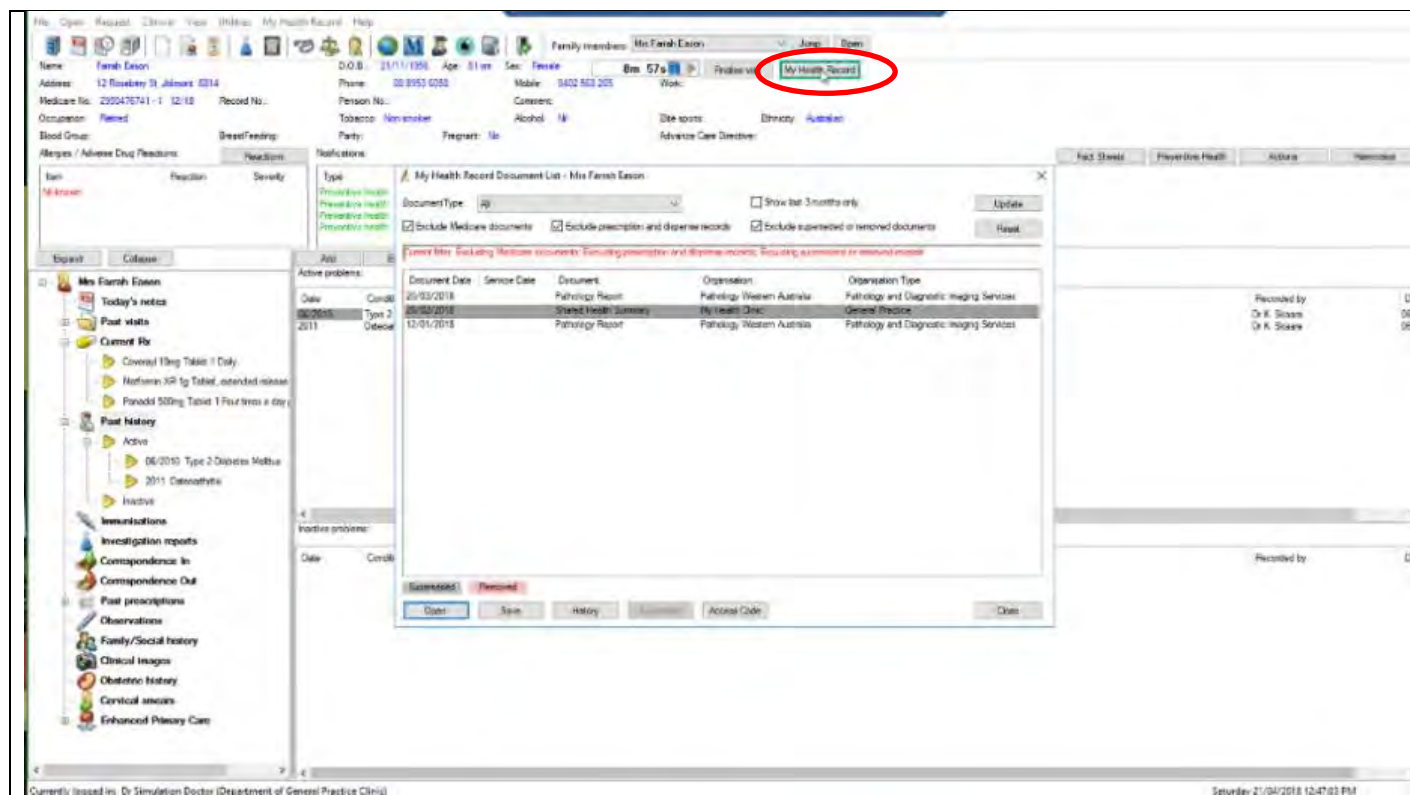
They tried clicking the *My Health Record* access button again with no result.

They then tried accessing the *My Health Record* drop-down menu, which was unsuccessful as the MyHR window was still open.
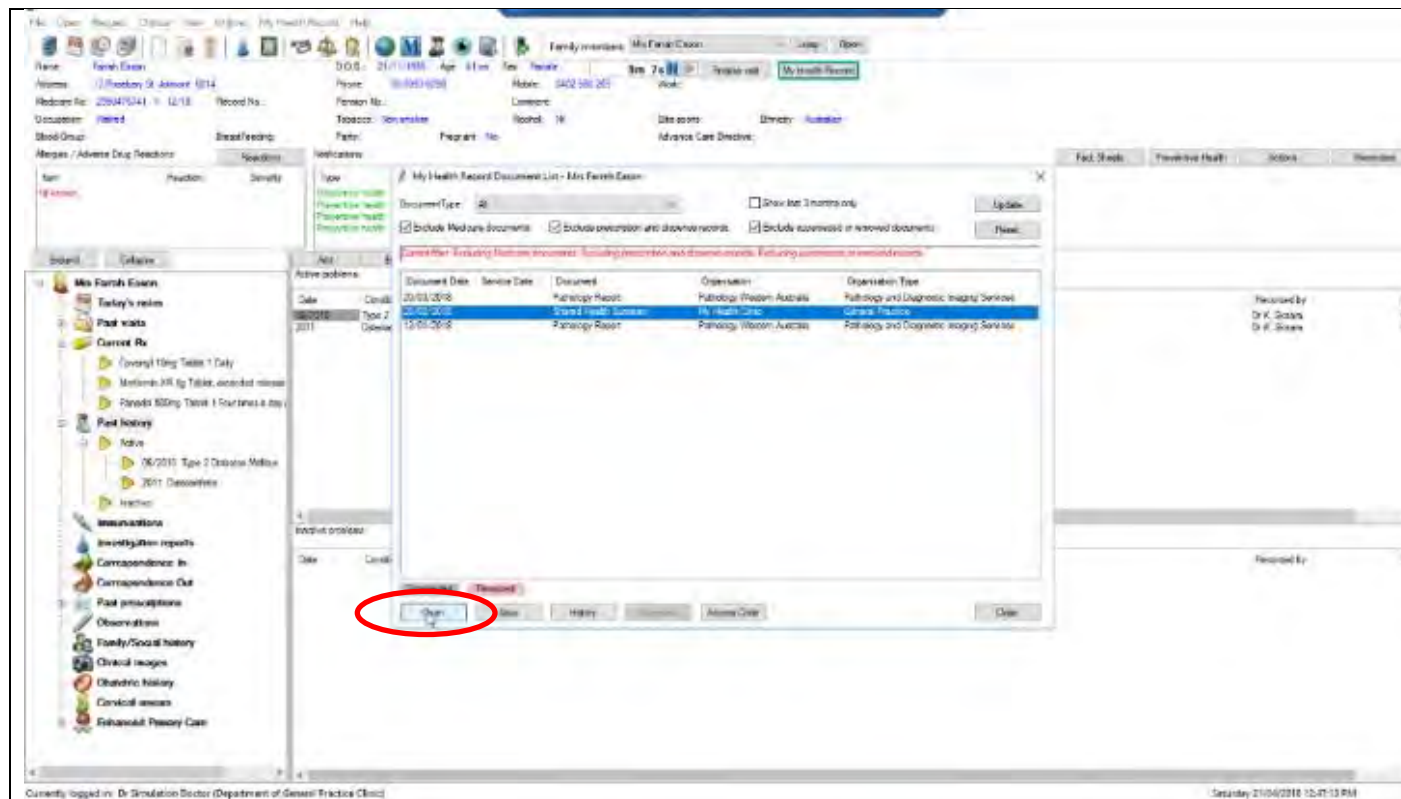
GP1 then tried to click on the Open button again.
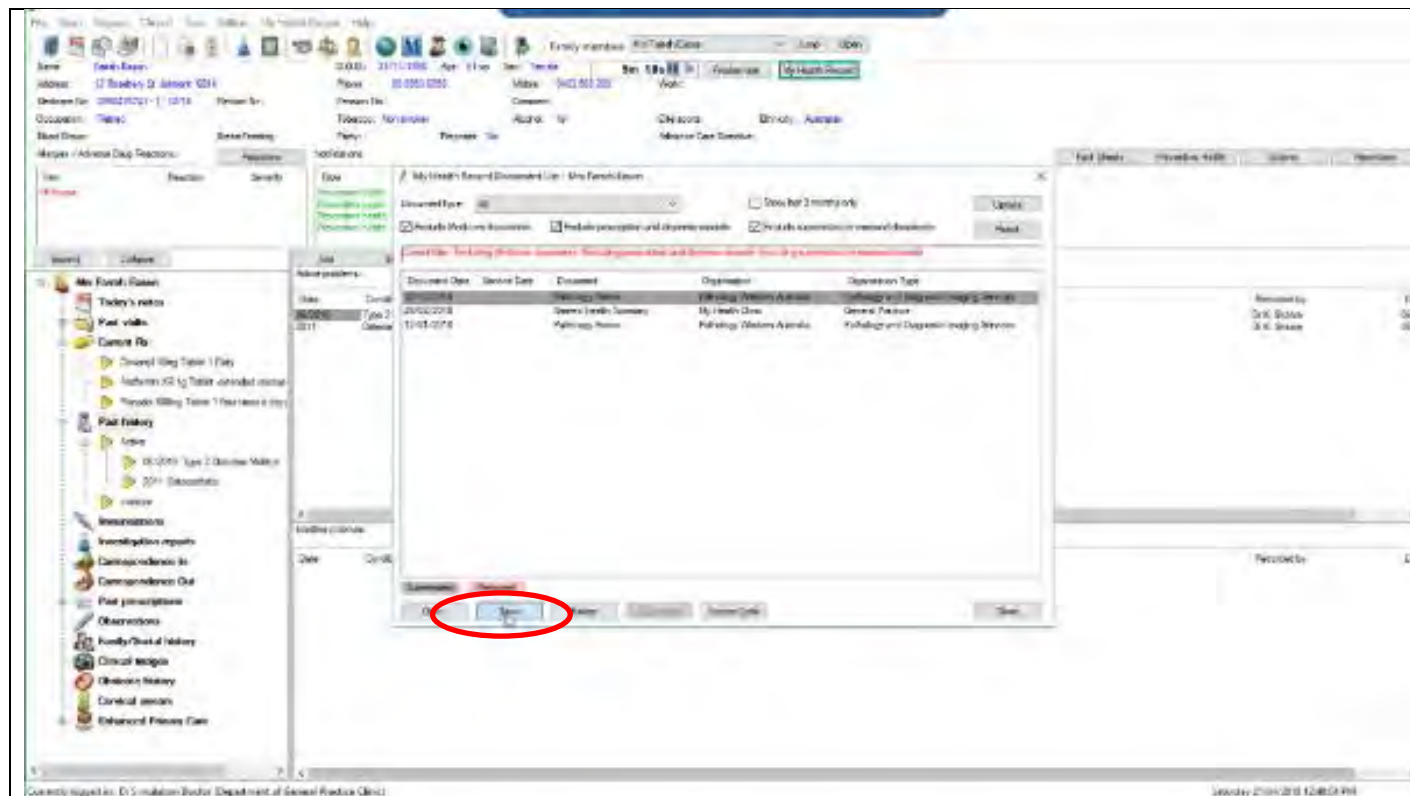
They then tried clicking on the *Save* button.

This resulted in a new window. GP1 appeared unsure what to do with this window, and at this point they stopped trying to update the MyHR during the consultation.

GP2: An alternate approach using Best Practice to try to upload a document to My Health Record.

GP2 initially attempted to upload information to the My Health Record using the My Health Record access button.

GP22 tried using the *Update* button to upload data to My Health Record
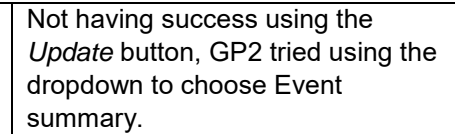
Not having success using the *Update* button, GP2 tried using the dropdown to choose Event summary.

GP2 clicked on *Update*

After not finding the dialogue box to upload a document to My Health Record, GP2 ceased trying to upload an event summary.

eHealth Literacy Study – Ballarat

Technical Report

28 February 2019

Health Services Improvement Unit
Centre for Population Health Research
Deakin University

DEAKIN
UNIVERSITY

This report was produced by the Health Systems Improvement Unit, Deakin University, Melbourne, Australia.
Website: http://www.deakin.edu.au/cphr/our-research/health-systems-improvement-unit

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Table of contents

Tables

Figures

Boxes

Acknowledgements

We would like to acknowledge the contribution made by members of the community residing in the Western Victoria Primary Health Network (WVPHN) region who participated in this research. We also gratefully acknowledge the staff from the WVPHN for sharing their perspectives and experiences throughout the project.

This project was funded by WVPHN through a grant from the Australian Digital Health Agency (ADHA)

Abbreviations and acronyms

ADHA	Australian Digital Health Agency
eHLQ	eHealth Literacy Questionnaire
HLQ	Health Literacy Questionnaire
MyHR	My Health Record
OR	Odds Ratio
WVPHN	Western Victoria Primary Health Network

Executive summary

This report presents the outcomes of a body of work undertaken by Deakin University on behalf of the Western Victoria Primary Health Network (WVPHN) and the Australian Digital Health Agency (ADHA). The rationale for the project was the knowledge that, globally, there are numerous examples of failures of implementation of technology and the recognition that successful uptake and utilisation of My Health Record (MyHR) by the full range of Australian citizens, including hard to reach populations, can only be done with deep knowledge of the diversity of eHealth literacy capabilities.

The aim of this project was to understand the eHealth literacy of residents in Ballarat and surrounding regions (City of Ballarat, Shire of Central Goldfields, Hepburn Shire, Moorabool Shire, and Pyrenees Shire), and to apply the Optimising Health Literacy and Access (Ophelia) process to access local experience and wisdom in order to identify existing effective local practices and potential innovative solutions to maximise the use of My Health Record (MyHR) and other digital technologies.

Specifically, the project sought to:
- Develop specific, implementable recommendations for ADHA and other stakeholders to address barriers and enablers;
- Identify education and communication strategies across eHealth engagement and uptake of MyHR, and;
- Recommendations that cover actions required at the individual, family/community, practitioner/professional and system level. These will include short term immediate solutions through to longer term structural solutions.

Methods and the Ophelia process

The project was based on the Optimising Health Literacy and Access (Ophelia) process which was developed by Deakin University as a means to:

a) Document and understand the diverse health literacy (or eHealth literacy) strengths and weaknesses in the community or in target groups for particular services or initiatives;

b) Obtain and organise experiential and tacit knowledge of both local healthcare providers and local consumers to develop intervention ideas to address these diverse strengths and weaknesses.

The Ophelia process as implemented in this project involved the following major activities:

1. Population-based survey using computer assisted telephone interviews (CATI) of 1000 people who completed the eHealth Literacy Questionnaire (eHLQ)[1] and selected scales of the Health Literacy Questionnaire (HLQ)[2].
2. Cluster analysis to identify groups of people with similar strengths and weaknesses across the seven scales of the eHLQ.
3. Semi-structured interviews with 50 of the respondents to the CATI including at least three from each of the identified clusters.

---

[1] **eHLQ** Scale 1: Using technology to process health information; Scale 2: Understanding health concepts and language; Scale 3: Ability to actively engage with digital health services; Scale 4: Feel safe and in control; Scale 5: Motivated to engage with digital services; Scale 6: Access to digital services that work; Scale 7: Digital services that suit individual needs

[2] **HLQ** Scale 1: Feeling understood by healthcare providers; Scale 3: Actively managing my health; Scale 4: Social support for health; Scale 7: Navigating the healthcare system

4. The creation of vignettes (brief plain language case stories) to illustrate each of the clusters, informed by both the CATI survey data and the semi-structured interviews of people in that cluster. Five vignettes were selected for discussion in community workshops on the basis of representing maximum diversity among the clusters.

5. Six Ophelia co-design workshops: workshops that follow a structured process to elicit intervention ideas to improve the use of digital health technologies, including MyHR, with health providers and consumers with extensive experience in the local community. This step is the heart of the Ophelia process and all previous steps lead into it. It is the basis of most of the recommendations in this report.

6. Organisation of the intervention ideas and the development of draft recommendations and a draft report followed by feedback and a workshop with WVPHN and ADHA personnel to refine the recommendations and to align them with past and current activities already underway.

Population-based CATI survey findings related to MyHR

Two key indicators of levels of engagement with MyHR were identified and the eHealth literacy, health literacy, and demographic information collected in the CATI survey was analysed in order to identify which factors were and were not associated with these indicators. The two indicators were:

Awareness of MyHR: People who knew that they either had or did not have a MyHR.

Intention to use MyHR: People who knew that they had a MyHR and expressed the intention to use it.

The strongest association with both indicators was with eHealth literacy, both the average score across all seven scales and the scores for most of the individual scales. The following table summarises factors that did and did not show an association with each of the indicators.

Factors associated with MyHR indicators	Factors not associated with MyHR indicators
Indicator 1: Awareness of MyHR	
• Sex • Using the Internet to search for health-related information in the past 12 months • eHealth literacy (eHLQ Scales 1, 3, 4, 5, 6, 7)	• Age • Educational attainment • Number of long-standing diseases or conditions • Self-rated health • Number of contacts with a health professional in the past 12 months • eHLQ Scale 2: Understanding health concepts and language • Health literacy (HLQ Scales 1, 3, 4 and 7)
Indicator 2: Intention to use MyHR	
• Sex • Using the Internet to search for health-related information in the past 12 months • Educational attainment • eHealth literacy (eHLQ Scales 1 to 7) • Health literacy (HLQ Scales 1, 3 and 4)	• Age • Number of long-standing diseases or conditions • Self-rated health • Number of contacts with a health professional in the past 12 months • Health literacy (HLQ Scale 7) • HLQ Scale 7: Navigating the healthcare system

The following graph shows the strong relationship between eHealth literacy and the intention to use MyHR. The horizontal axis shows the 12 clusters identified through the cluster analysis in descending order of overall eHealth literacy (also indicated by green to brown shading). The height of the bars is the number of people in each cluster while the blue line is the percentage of people in that cluster who intend to use MyHR.
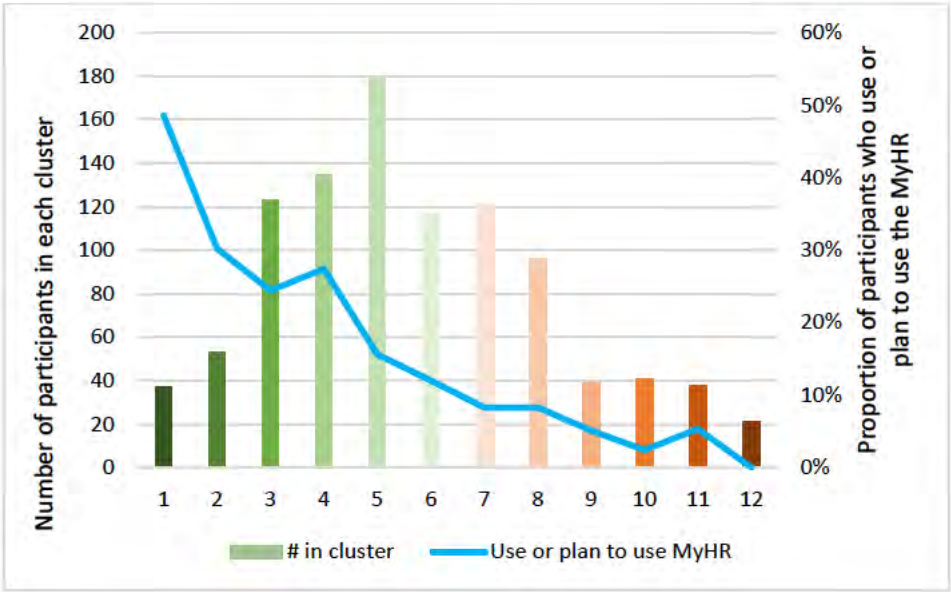
Key findings from semi-structured interviews

The main purpose of the semi-structured interviews was to inform the development of vignettes for use in the ideas generation workshops. The semi-structured interviews focused on people's experiences and perceptions about digital health services. The following diagram shows key themes from the semi-structured interviews about barriers to using digital health technologies in general (not specifically MyHR). The yellow boxes summarise spontaneously offered suggestions about what would help people to use digital health technologies.

Barriers to engaging with or managing health through technology, and strategies to address these barriers

T1. Lack of control over personal health information on eHealth records

T2. Attitude and skills around technology

T3. Not using technology to manage health

T4. Not interested in technology (emotive)

T5. Unaware of eHealth

T6. Prefer face-to-face health information

Communication strategies: Facts on eHealth around security, such as who can access, how to use, and how to have control over information

Software strategies: Easy passwords with prompts to access information and websites; easy to navigate websites and simple, clear information and links; get the people who will be using the software to design and test it

Education strategies: Education on how to use technology (computers, iPads, smartphones, the internet); face-to-face and online tutorials on how to use websites and access good quality health information online

Practitioner strategies: Facilitation of eHealth through information and educating patients or managing on their behalf

T7. Misleading information on the internet

T8. Inflexible technology

T10. Security concerns around eHealth

T12. Issues using government websites

T14. Health system barriers

Community hub to access technology and eHealth information

T9. Access (coverage issues or no internet)

T11. Lack of access to timely and appropriate health services

T13. Previous bad experiences with healthcare providers or services

T15. Navigating the health system

Individual level themes | System level themes

*T denotes theme number

While the semi-structured interview did not have specific questions about MyHR, several people spontaneously offered concerns or support for MyHR (see following table).

Concerns about using MyHR	Support for using MyHR
• Security concerns / lack of trust in government / others accessing information • Don't know how to use MyHR, how to access, what is stored, how to have control • Don't see the need for MyHR • Incompatible / inconsistent systems • Software difficult to use - passwords • Unable to manage records for children	• Healthcare provider access for timely and appropriate care • Managing health for family • Nothing to hide - not concerned about security

Key findings from ideas generation workshops

The workshops produced a wide range of ideas relevant to people with widely differing eHealth literacy strengths and weaknesses. The intervention ideas were grouped into nine categories with numerous subcategories under each heading. The main categories were:

1. Policies, laws and regulation
2. Organisations that promote or support the use of digital health technologies
3. Managing public information and perceptions
4. Features of the digital technologies
5. Process of engaging people
6. Role of healthcare providers
7. Understanding particular target groups
8. Community-based activities
9. Activities targeted at individuals and families

While many ideas were generated in each of these areas a key principle that arose was that the whole is more than the sum of the parts and that there is a need for a planned, integrated approach across all of these categories of action. Three issues were identified where an integrated approach is of particular importance:

1. The need to assist people to understand potential benefits, the relevance of possible benefits and to weigh benefits against possible risks.
2. The need to address a range of concerns about how MyHR and other developments in digital health technologies may impact on familiar and valued processes of care (especially relationships with GPs).
3. The fact that some of the people who might experience the greatest challenges engaging with MyHR may also be the people who have greatest need of the support that it offers and greatest capacity to benefit.

The recommendations (below) produced from the workshops were grouped into three areas:
- **Four broad principles** that need to underpin all activities to increase people's engagement with digital health technologies in general and MyHR in particular.
- **Category 1 recommendations:** which include three integrated sets of recommendations related to each of the three issues just listed. The emphasis is on integration and coordination of activities.
- **Category 2 recommendations:** which include specific actions related to each of the nine themes listed above.

In support of efforts to develop integrated, systemic strategies we considered the consumer journey from their personal context, through initial steps in engaging with MyHR, to eventually obtaining the full benefits of the technology. The following diagram identifies a range of key possible points in such a journey. These were identified from both the semi-structured interviews and the workshops. At each of these points, people can have experiences that either increase or decrease the likelihood of people deepening their engagement with MyHR, therefore each is a possible point of action where strategies to increase positive influences and minimise negative influences can be applied.

Pre-existing situation	Initial contact	Introductory experiences	Is it for me?	Experiences of use	Getting the benefit
Digital health experience	Media/mass communication	News stories	Understanding potential benefits in a personal way	User friendly and successful	
Health service experience/ relationships		Public education, information		Integrated into familiar and preferred health care	
Preferred healthcare and health literacy style		Discussion with health provider – self management orientation	Trust the technology and process		Stories of benefit are shared
Access to technology	Health professional/service	Discussion with health provider – 'we can help' orientation	Trust the information and potential users	Easy problem solving	People are aware of situations where they benefit
IT interest and ability		Introduced in health education program		Able to check the accuracy of data and get errors fixed	
Scepticism/trust in government and other agencies		General discussions with friends or family	What do I need to do and can I do it?		
		Practical exploration with friends or families in the context of a meaningful activity		Convenience for things that are important to me	
Particular groups (e.g. aged, people with a disability, remote)	Social setting		Will it affect my relationship with my doctor or other health provider?	Informed when a provider uses the data	
		Connection with familiar use of digital health technology			

Summary of recommendations

Following is a concise summary of recommendations. Specific actions for each recommendation are proposed in the full report.

Principles underpinning all recommendations

Principle A: Actions to promote the use of digital health technologies including MyHR need to be guided by a principle of equity and to recognise people who have the greatest need for a system like MyHR are often the people facing the greatest barriers to engagement.

Principle B: Achieving acceptable population-wide implementation and community engagement in digital health technologies and MyHR will require action at multiple levels of government, organisations and implementation in an integrated and synergistic manner.

Principle C: It is necessary to recognise that digital health technologies, including MyHR, can be perceived by many people as a change that poses a threat to systems of care that are comfortable and familiar to them. All actions to promote digital health technologies, including MyHR, must recognise and take systematic and proactive action to manage people's expectations and anxieties.

Principle D: There is no one-size-fits-all approach to education and communication. An extensive and diverse suite of approaches are needed to address the diverse needs of different groups. Promotional materials must reflect an understanding of the core concerns and desired benefits of different groups in the community.

Category 1 recommendations: integrated sets of recommendations related to key issues

Key issue 1: Assist people to understand potential benefits, the relevance of possible benefits, and to weigh benefits against possible risks.

Recommendation 1

There is a need for an integrated and synergistic strategy to help people **understand the potential benefits** of MyHR and other digital technologies in a way that is relevant to their life circumstances, perceived health risks, and preferences for receiving healthcare services. This strategy needs to facilitate the ability of people to assess perceived benefits against perceived risks and should, ideally, allow for people to choose a level of engagement that maximises their perceived benefit while minimising their perceived risks.

Key issue 2: Address concerns about the potential impact of developments in digital health on familiar and valued processes of care

Recommendation 2

General practices are the first point of care for most Australians, and the primary source of health data about patients into MyHR. There needs to be an integrated and systematic approach to enabling GPs and practices to support their patients in the most appropriate way. This approach requires action at multiple levels in a practice.

Recommendation 3

Where possible, utility should be built into the MyHR system to transparently enhance processes of care that people value, including:

a. Integration with other systems such as systems at pharmacies, [community health centres], hospitals/emergency centres and the medical practices.
b. Methods available for people who do not want to, or who are not able to, interact with MyHR to have it set up for them in such a way that they receive all desired benefits.

Key issue 3: Providing opportunities to people who experience substantial barriers to engagement but who also have high capacity to benefit

Recommendation 4

A flexible and multi-level approach will help people facing barriers to access and engagement to participate at the level of their interest, and to achieve benefits equitably with those who face fewer barriers. This approach should consider the stages that people go through in engaging with digital health technologies.

Category 2 recommendations: *specific actions at different levels*

Levels of health practitioner/professional roles

Recommendation 5

There should be clear guidelines [and training] for health professionals who access and use MyHR data for an individual in their care, and these need to be regularly and consistently communicated.

Recommendation 6

There is a need to ensure that all health professionals have an accurate and consistent understanding of MyHR and that they understand the potential benefits. Some health professionals feel that they have been bombarded with procedural information but still don't have an overall sense of what MyHR is really going to achieve: '*As health professionals we are bombarded but still don't know much about what it is*'.

Level of community engagement/outreach strategies

Recommendation 7

The workshops produced many suggestions for opportunities and contexts where people may learn about MyHR other than from a health professional or the media. Strategies and resources should be developed to encourage and enable community facilities and organisations to discuss digital health resources, including MyHR, as part of activities that already engage people in learning about and discussing related issues.

Level of family and individual engagement with digital health technologies

Recommendation 8

In many families, one person is substantially more engaged in digital health technologies, and likely to be more interested in MyHR, than other family members. Digital health technologies, including MyHR, should be implemented in such a way that engages participation of different family members where possible.

Level of the design and features of digital health technologies

Recommendation 9

Many participants in the workshop expressed desired characteristics of the system to do with the simplicity of the MyHR interface, the reliability of the system (even with poor Internet connections), and the ease of solving problems within the system. The reported negative experiences may not have related to MyHR but may reflect other negative past experiences including trying to interact with MyGov services.

Recommendation 10

The MyHR system should implement a range of strategies to enable concerned individuals to check and correct the information that is uploaded, including making sure that the information has sufficient context to be correctly interpreted by future users.

Recommendations

The recommendations in this report have been developed to meet these contractual requirements:

1. Develop specific, implementable recommendations for ADHA and other stakeholders to address barriers and promote enablers
2. Education and communication strategies across eHealth engagement and uptake of My Health Record (MyHR)
3. Recommendations will cover actions required at the individual, family/community, practitioner/professional, and system levels. These will include short term immediate solutions through to longer term structural solutions

While most of the recommendations in this report are derived directly from the data and discussions that occurred during the activities of the project, some select recommendations have been incorporated based on the wide experience of the consultants in developing and implementing health literacy policy and interventions. The recommendations that are not derived directly from the data in this project are [enclosed in square brackets].

Categories of recommendations to ensure coverage of all Australians

This project used a grounded approach where both community members and health professionals were exposed to graphic and contrasting representations of the digital health knowledge and experiences of community members so that the breadth of proposed solutions are intended to ensure broad coverage of all segments of society.

Box 1 Two categories of recommendations that seek to ensure coverage of all Australians

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Category 1 recommendations address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)

Category 2 recommendations for actions at specific levels including actions required at the individual, family/community, practitioner/professional and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR.

Category 1 recommendations are about longer term and structural solutions that need to be addressed synergistically at the multiple levels of local and national lead agencies, and through multiple strategies. These recommendations point to the role of policy and policy-makers to implement strategies for systems improvement even though the workshops to generate ideas for strategies were conducted with local residents and health professionals, and not with high level policy makers. This local consultation was to ensure that the ideas generated were practical and informed by local consumer and practitioner experience and wisdom. However, the synergistic development and implementation of an integrated set of locally-generated strategies require the holistic, helicopter view and careful planning of local and national lead agencies.

Category 2 recommendations address local perceptions and awareness of gaps or problems in eHealth engagement or uptake of MyHR, and where new education and communication approaches, styles, emphases, and strategies may be required. These recommendations include actions that can be implemented at the individual, family/community, practitioner/professional, and systems levels.

What the recommendations do and do not say about past and current implementation of MyHR

It is important to note that the recommendations are not based on a detailed organisational or systems analysis of what has been or is being done to increase eHealth engagement and uptake of MyHR. Rather, the recommendations are based on the actual perceptions and awareness of the people and health professionals in the community (i.e., the data are derived using a grounded research approach). **The recommendations should not be taken as suggesting that nothing is being done to address a proposed gap or problem.** The recommendations may mean different promotion strategies are required and specific locally-generated solutions are needed to maximise the uptake of eHealth technology and MyHR by as many people as possible.

Table 36 (Appendix I) correlates the recommendations in this report to consumer education, consumer access, healthcare provider education, and systems/policy, as requested by ADHA. Table 36 is a template that will show the activities and developments that relate to MyHR that have already occurred or are underway in relation to each of the recommendations in this report, as well as activities planned for the future. The past, current and future actions can be populated by the Australian Digital Health Agency (ADHA).

Principles underpinning the recommendations

There are four fundamental principles arising from this research study that could be considered recommendations themselves but which, importantly, are critical to nearly all the other recommendations. Therefore, these four principles have been highlighted as core principles for action.

Box 2 The four principles underpinning the recommendations

Principle A: Actions to promote the use of digital health technologies including MyHR need to be guided by a principle of equity and to recognise that the people who have the greatest need for a system like MyHR are often the people facing the greatest barriers to engagement. Therefore, in planning for improvement, strategies should aim to maximise the benefits for people with the greatest needs and health systems should be developed with the flexibility to allow for this.

Principle B: Achieving acceptable population-wide implementation and community engagement in digital health technologies and MyHR will require action at multiple levels of government and organisations and implementation in an integrated and synergistic manner across these levels. In considering the recommendations, it is necessary to always reflect on how the whole may be more than the sum of the parts. (See Recommendations 1 to 4 as examples of synergistic sets of interventions.)

Principle C: It is necessary to recognise that the introduction of digital health technologies, including MyHR, is perceived by many people as a change that poses a threat to systems of care that are comfortable and familiar to them. People's expectations are coloured by past experiences with new technologies that have promoted self-service and are associated with a reduction in services, especially services where contact with a person is preferred. Such a scenario is a source of anxiety to many people when it relates to their health and health care. All actions to promote

digital health technologies, including MyHR, must recognise and take systematic and proactive action to manage people's expectations and anxieties.

Principle D: There is no one-size-fits-all approach to education and communication. In particular, approaches that depend solely on mass media and/or uniform printed materials will not engage all the different groups of people in a community. An extensive and diverse suite of approaches are needed to address the diverse needs of different groups, and these approaches will very often need to involve community members having opportunities to discuss potential benefits, concerns, and what is required of them with peers and/or health professionals. Promotional materials must reflect an understanding of the core concerns of community members, and what different groups of people are likely to consider a significant and practical benefit to engagement in digital technologies such as MyHR.

Category 1 Recommendations: address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)

1.1 Assist people to understand potential benefits, the relevance of possible benefits, and to weigh benefits against possible risks.

Recommendation 1

There is a need for an integrated and synergistic strategy to help people **understand the potential benefits** of MyHR and other digital technologies in a way that is relevant to their life circumstances, perceived health risks, and preferences for receiving healthcare services. This strategy should consider both the intellectual and experiential aspects of understanding (where experience can be personal or gained vicariously through the experiences of others). It needs to facilitate the ability of people to assess perceived benefits against perceived risks and should, ideally, allow for people to choose a level of engagement that maximises their perceived benefit while minimising their perceived risks. Some components of an integrated and synergistic approach could include:

a. [A comprehensive taxonomy of potential benefits of MyHR with an emphasis on the types of benefits experienced and desired by consumers].

b. Description and presentation of potential benefits in terms of the user *not* the health system (e.g., reduced need to tell the same information repeatedly, reduced waiting times, less chance of an accident, convenience in accessing services or purchasing health products, advantages for travel).

c. Sharing simple, true and positive stories in the community (as well as negative stories, which are already widely shared). For this to occur, people need to know when their MyHR has been accessed and how it has streamlined and benefited the services that they have received. Providers who access and use a person's MyHR should be encouraged to, and given a process to, share this fact with their patient.

d. Simple, true stories of how people have benefited need to be made widely available in a range of formats.

e. Simple tools and processes that assist people to assess potential benefits of MyHR against potential risks, and to choose a level of utilisation that suits them. For example, a GP says 'how about I just upload your medications and allergies in case

you have to go to hospital sometime?'; or a chart displaying different levels of engagement with MyHR and potential uses and benefits of each level (similar to the charts presented for many software products).

f. Regular communication/promotion to people to increase awareness of the things that don't exist or don't happen in the current system but that they believe already happen (e.g., a belief that emergency departments somehow already know their history and medications).

1.2 Address concerns about the potential impact of developments in digital health on familiar and valued processes of care

Recommendation 2

General practices are the first point of care for most Australians and the primary source of health data about patients. There needs to be an integrated and systematic approach to enabling GPs and practices to support their patients in the most appropriate way to engage with MyHR. This approach requires action at multiple levels in a practice.

a. Fully engaging general practice in the design of the system [and ensuring that it integrates with all clinical software systems].

b. Providing training and resourcing to GPs and practice nurses for approaches to introduce MyHR in a gentle and minimally burdensome manner that builds on the patient's belief that the doctor is in control of their care. This should include options that do not require the patient to use technology at all but that still support patients to understand what information a doctor uploads on their behalf.

c. Providing materials that make it easy for doctors or practice nurses to easily discuss what data can be uploaded and what the patient does and does not want uploaded, as well as potential benefits of use including both health and convenience benefits.

d. Ensure that it is easy for the doctor to only upload data agreed with the patient.

e. Supporting practices to provide computers that patients can access within the practice that include easy access to MyHR and high quality information sites.

Recommendation 3

Where possible, utility should be built into the MyHR system to transparently enhance processes of care that people value.

c. Integration with other systems such as systems at pharmacies, [community health centres], hospitals/emergency centres and the medical practices. Particular potential benefits/conveniences that were identified include streamlined prescription filling, better reminders and appointment making with the medical practice, reduced time waiting at emergency departments, and less need to spend time completing forms and repeating information when referred to other services.

d. As with Recommendation 2, there should be methods available for people who do not want to, or who are not able to, interact with MyHR to have it set up for them.

These conveniences will only help to increase the extent to which people value and trust MyHR if they are made aware of them, both as potential benefits and when they experience these benefits. Many consumers assume that integration of these supports, services and systems is already in place.

1.3 Providing opportunities to people who experience substantial barriers to engagement but who also have high capacity to benefit

(Note: Recommendation 2 is also particularly important for this issue)

Recommendation 4

A flexible and multi-level approach will help people facing barriers to access and engagement to participate at the level of their interest, and to achieve benefits equitably with those who face fewer barriers. This approach should consider the stages that people go through in engaging with digital health technologies, and the barriers that different groups of people[3] might face. Figure 25 shows some of the issues and points of action that should be considered at each stage of a person's journey to engage with digital health technologies and MyHR. Some of the components of a flexible, integrated approach identified in the workshops were:

a. Implement Recommendation 2.

b. To facilitate access to important health websites, including MyHR, provide computers in community settings such as libraries, neighbourhood houses, medical practices, pharmacies, centres providing University of the Third Age (U3A), and Men's Sheds. This is especially important in areas with poor Internet connections and for people without personal access to computers and good Internet services. There will be additional benefits if there are people at these places who can provide some guidance about how to access and use these websites.

c. Engage organisations like U3A, neighbourhood houses, libraries, and Men's Sheds in providing simple training to use computers for practical purposes.

d. Make systems easily accessible through alternative technologies such as tablets and phones.

- Ensure that MyHR can be accessed through simple smartphone applications.
- Implement a system where people who don't have smartphones can interact through a mix of SMS and phone calls [e.g., a summary of what information is uploaded, notifications of access, who to call to discuss concerns].
- Ensure that all promotional and informational materials contain a phone number to call, not just a web address.
- Ensure that complaints and problem-solving processes allow people to talk to an actual person.

e. Provide all services and interfaces in multiple languages.

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[3] 'Groups of people' does not just mean people with certain demographic or health state characteristics such as people with different disabilities, older people, socially isolated people etc. but also people with different eHealth literacy profiles.

Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR

This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.

2.1 Health practitioner/professional roles

Recommendation 5

There should be clear guidelines [and training] for health professionals who access and use MyHR data for an individual in their care. These should include:

a. Circumstances in which access and use is or is not appropriate and permissible
b. Communicating with and engaging the patient whose record is being accessed, including:
   - Informing the person that they have accessed the data
   - Allowing the person to make any comments or clarifications that they wish
   - Reassuring the person, where appropriate, that the practitioner will undertake their own assessment and provide an independent opinion
   - If the MyHR data have proved useful in any way, explaining this to the person
   - Discussing any data that will/could be uploaded as a result of the episode of care.
c. Procedures if data are found to be out of date or incorrect
d. How to access problem solving support

Recommendation 6

There is a need to ensure that all health professionals have an accurate and consistent understanding of MyHR and that they understand the potential benefits. This has been difficult to achieve due to ongoing changes during the MyHR roll out. Some health professionals feel that they have been bombarded with procedural information but still don't have an overall sense of what MyHR is really going to achieve: *'As health professionals we are bombarded but still don't know much about what it is'*. It was also noted frequently in the workshops that health professionals have high opt-out rates although the evidence for this was not cited. At the earliest possible time the following should be implemented.

a. As a priority, Recommendation 1 should be fully implemented for health professionals.
b. Provision of simple up-to-date resources and training for health professionals with a focus on the following points as soon as the components of the MyHR system are sufficiently settled:
   - Exactly what MyHR is and is not
   - Specific benefits of MyHR
   - Safeguards for security, quality, and appropriate use
   - How MyHR can synergise with and enhance usual care
   - Options for engaging patients as per Recommendations 2 and 5
   - Resources and financial supports that are available

2.2 Community engagement/outreach strategies

Recommendation 7 presents many of the ideas from the workshops about options for increasing access to and support for the use of computers and of digital health technologies, including MyHR, in community settings.

Recommendation 7

The workshops produced many suggestions for opportunities and contexts where people may learn about MyHR other than from a health professional or the media. Some of these contexts may make it easier to highlight particular potential benefits and for people to develop their understanding in a shared and reflective manner: *'… social engagement is credible really because if you can find a small increase of people that do understand or can use that, that can easily permeate out into their social circles and get gradual exposure to the thing. It does not matter if they are homeless or otherwise if you can get a couple of people who are advocates that can permeate through their social circles. Often when you are presenting there will be two that really get it and the others will trickle in after talking to people and start to understand bits of it.'*

Strategies and resources should be developed to encourage and enable community facilities and organisations to discuss digital health resources, including MyHR, as part of activities that already engage people in learning about and discussing related issues. These could include:

- Health education and promotion events
- Computer training activities (see also Recommendation 4)
- U3A and other lifelong education activities
- [Retirement and financial planning activities]
- Activities that engage people in using computers for other important tasks in life such as MyGov
- Travel planning and sharing events
- Farming events and other business planning and management events

To take advantage of such opportunities, it would be highly desirable to have materials available that present potential benefits in practical, relevant ways as discussed in Recommendation 1.

It would also be useful to ensure that there are links to MyHR or relevant information about MyHR on web pages and materials related to the activities listed above.

2.3 Strategies for engaging families and individuals

The recommendations that have already been presented include many recommendations to support flexible implementation of MyHR to support a wide diversity of individual needs and preferences within the community. This section has a focus on suggestions that were made in workshops about engaging families and about families supporting each other.

Recommendation 8

A significant finding of both the semi-structured interviews and workshops was that in many families one person was substantially more engaged in digital health technologies, and likely to be more interested in MyHR, than other family members. This can have both positive and

negative aspects. It can be positive because the strengths of one person can help other family members. It can be negative if that person becomes unable to continue that role and other family members do not have the knowledge of what has been done for them or the ability to be engaged on their own behalf. Digital health technologies, including MyHR, should be implemented in such a way that engages and reaches individuals as well as families.

2.4 Design and features of digital health technologies

Recommendations 2 to 4 emphasised the need to provide options for people who do not wish to or who are unable to directly engage in the IT interfaces of MyHR. The recommendations in this section are about supporting individuals who do wish to interact with and control their MyHR but who, in order to engage, need the design and features of digital health technologies to be easy to access and navigate.

Recommendation 9

Many participants in the workshop expressed desired characteristics of the system to do with the simplicity of the MyHR interface, the reliability of the system (even with poor Internet connections), and the ease of solving problems within the system. While many community members reported having experienced difficulties with these issues in the past, their negative experiences may not have related to MyHR but may reflect other negative past experiences including trying to interact with MyGov services. None-the-less both consumers and health professionals indicated that the following would be required for ease of use:

a. Extremely simple language used throughout.
b. Ensure short loading times for MyHR web pages and minimum need to load new pages.
c. Available on multiple platforms including phones and tablets.
d. Options for people who can't remember passwords (fingerprint, retina, [face]).
e. Ability to easily solve most problems online or with support that is quick and involves the option to talk to a real person.

Recommendation 10

For some people, it is important that the MyHR system enables them to check and correct the information that is uploaded, including making sure that the information has sufficient context to be correctly interpreted by future users. These people are also likely to want to exert control over what information is uploaded and to be able to add comments or information of their own. The MyHR system should make it as easy as possible for users to:

a. Identify and read all information that is uploaded, and identify who uploaded it
b. Have the ability to block particular information from being visible to other users
c. Add notes of comment or explanation to provide context to any particular uploaded information
d. Add general notes of their own
e. Select a set of information that they want available for a particular purpose (e.g., travel)
f. Print out an extract of selected information for overseas travel or for other purposes

Many of these points would only be effective if health professionals who upload information are easily contactable and have the time, willingness, and technical capability to explain about information that has been uploaded, correct errors, and/or remove uploaded information.

Background

Australia's low rate of health literacy is arguably one of the country's greatest challenges to our well-being, and a challenge that will become more serious as the rates of chronic disease rise and health care becomes increasingly more complex. In an increasingly digitised world, the prospect of challenges with digital health services looms large and, as such, addressing eHealth literacy has become a prominent issue for governments around the world.

Health literacy refers to the personal characteristics and social resources needed for people to access, understand, remember/retrieve and use information to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions. Previous studies, undertaken using tools that mainly capture reading and numeracy skills, have shown associations between low health literacy and poorer health including less appropriate use of health services, less participation in preventive activities, poorer self-management of long term conditions, and adverse health outcomes (1). Health literacy is also a potentially modifiable contributor to health inequities (2).

The Australian Bureau of Statistics (ABS) 2006 Adult Literacy and Life Skills Survey found that 59% of Australians have difficulty with the basic skills needed for health self-management (3). These difficulties include being able to locate information on a bottle of medicine about the maximum number of days the medicine could be taken, and being able to indicate medication dosage, such as one third, on a given container. When people are then confronted with the need to access the Internet and use computers to access information about health and/or health services, the task may be far more challenging for them. Not only does this require strong health literacy, but also the ability to access and understand digital technologies. Consequently, the introduction of a requirement to access digital health information can lead to many people experiencing insurmountable challenges to their self-care.

Research into health literacy has found that people with low health literacy are less likely to seek preventive health care, such as immunisations, and are more likely to miss appointments, misuse medication, and fail to follow the advice provided by their doctors. This leads to adverse events, poorer health outcomes, higher rates of hospitalisation, a lower quality of life for individuals, and increased healthcare costs overall. If these difficulties and health outcomes are transferred to a world where many health services are accessed only or primarily through digital technologies then there is cause for concern for people with low digital health literacy, also called eHealth literacy.

It is becoming increasingly apparent that knowledge about, access to, and use of digital health services is a health equity issue. Research is urgently needed to understand the effects that digital health technologies will have on health outcomes and health equity, especially as digital technologies become embedded in national health policies and health practice.

The introduction of the My Health Record (MyHR) has the potential to dramatically increase every Australian's exposure to health technology and their exposure to health information. Globally, there are numerous examples of failures of implementation of technology at the local and national level (1). Successful uptake and utilisation of MyHR by the full range of Australian citizens, including hard-to-reach populations, can only be done with deep knowledge of the diversity of eHealth literacy capabilities, and in environments with security, safety and provenance of the data.

It is important to note that while health literacy refers to the competencies of individuals, it implies a responsibility for organisations and health professionals to respond appropriately and effectively to the health literacy needs of the consumers they serve (4). Accordingly, health literacy has become a focus of governments, health and community services, consumer groups and researchers due to its relevance and importance to population health, and its implications for ongoing healthcare reform.

Three recent advances in health literacy are the Health Literacy Questionnaire (HLQ), the eHealth Literacy Questionnaire (eHLQ), and the Ophelia process, each of which has provided opportunities to understand and effectively respond to health literacy needs including in the rapidly advancing digital world.

eHealth literacy and its measurement

The World Health Organization (WHO) describes eHealth as 'the use of information and communication technology (ICT) for health' (5) and eHealth literacy is defined by Norman and Skinner as 'the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem' (6).

eHealth may improve consumers' engagement with health services through ready access to online interventions (7). Strategies to increase consumers' knowledge and management of health has evolved through uptake of computers, smart phone applications, and mobile devices. In order to understand if and why these online platforms or interventions are engaging the population, a targeted measurement tool is required.

The eHealth Literacy Questionnaire (eHLQ) comprises 35 items across 7 scales. It is patient-centred and was derived from extensive consultation with patients and practitioners. It is a multidimensional instrument with strong psychometric properties. The 7 scales of the eHLQ are never added to give a single score. Rather, the scores are presented as 7 separate scores in order to identify the different eHealth literacy strengths and weaknesses among people in the community. We refer to the pattern of strengths and weaknesses of an individual or group of individuals as an eHealth literacy profile. Understanding the range of profiles enables the targeted selection of digital health interventions and supportive strategies for the use of these interventions according to the various strengths and weaknesses identified (8). The eHLQ's development was led by Richard Osborne and Roy Batterham (Deakin University) in collaboration with Lars Kayser and Ole Norgaard (University of Copenhagen, Denmark). The 7 scales are described in Box 3.

Box 3 Seven scales of the eHealth Literacy Questionnaire

1. Using technology to process health information - Be able to use technologies to read, write and remember, apply basic numerical concepts, and understand context-specific language (e.g., health, IT or English), as well as to critically appraise information. Know when, how and what information to use.

2. Understanding of health concepts and language - Know about basic physiological functions and one's own current health status. Aware of risk factors and how to avoid them or reduce their influence on one's own health.

3. Ability to actively engage with digital services - Be comfortable using digital services for handling information.

4. Feel safe and in control - Feel ownership of personal data stored in the systems and that the data are safe and can be accessed only by people to whom they are relevant (own doctor/nurse etc.).

5. Motivated to engage with digital services - Feel that engaging in the use of digital services will be useful for managing health.

6. Access to digital services that work - Have access to digital services that the users trust to be working when needed and as expected.

7. Digital services that suit individual needs - Have access to digital services that suit the specific needs and preferences of the users. This includes responsive features of both IT and the healthcare system as well as adaptation of devices and interfaces to be used by people with physical and mental disabilities.

Figure 1 shows a schematic image of the relationship between the 7 scales of the eHLQ as described in Norgaard 2015 (9). This schema identifies scales that relate more to the individual (1 and 2), scales that relate to characteristics of particular digital health systems (6 and 7), and scales that are a product of the interaction between individuals and systems (3, 4 and 5), based on both past and current experiences that people have had engaging with digital health technologies.

Figure 1 The eHealth literacy framework (eHLF)
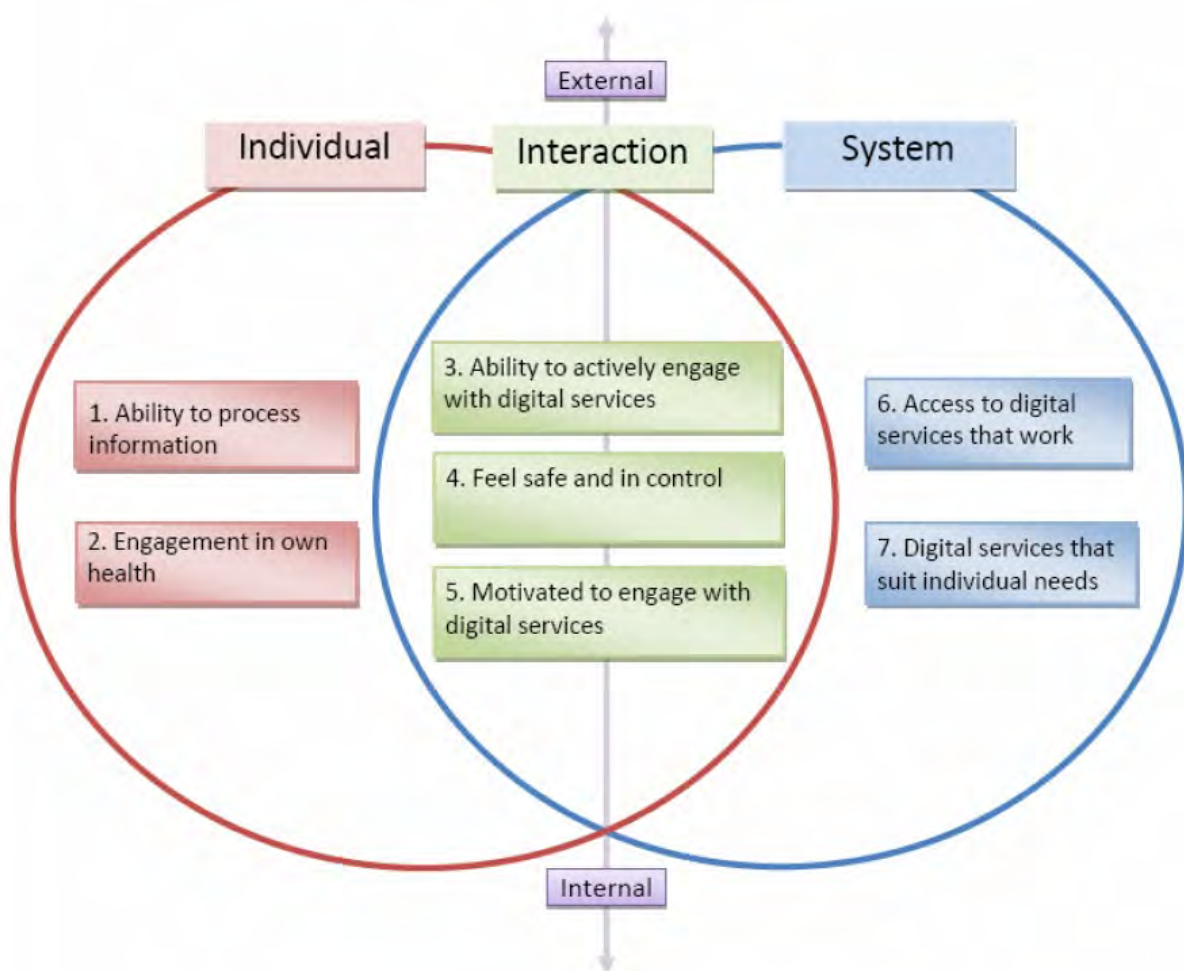
Source: Norgaard et al 2015 (9)

The Health Literacy Questionnaire (HLQ) is a widely-used, multi-dimensional measure of health literacy that provides detailed information about two key areas: the health literacy

competencies of individuals and their lived experiences in attempting to engage with health and community services (10). The tool detects the diversity of health literacy needs of people in the community and can be used for a range of purposes: from describing the health literacy of the population in health surveys, through to measuring outcomes of public health, and building social and clinical interventions designed to improve a wide range of health equity outcomes. The HLQ was attached to the 2018 ABS National Health Survey and will provide Australian national norms and extensive insight into health equity in Australia in the coming months.

The HLQ's 9 separate scales are shown in Figure 2. The HLQ is not designed to provide one overall score. Rather, it provides a comprehensive picture of a person's (and groups of people's) health literacy needs and strengths through the 9 scale scores.

Figure 2 The Health Literacy Questionnaire (HLQ) and an example profile of an individual.

HLQ scale	Example score
1. Feeling understood and supported by healthcare providers	High
2. Having sufficient information to manage my health	Mod
3. Actively managing my health	Low
4. Social support for health	Very high
5. Appraisal of health information	Very low
6. Ability to actively engage with healthcare providers	High
7. Navigating the healthcare system	Low
8. Ability to find good health information	Very low
9. Understand health information well enough to know what to do	Very high

This person scores highly on their ability to understand health information (scale 9) and to engage with healthcare providers (scale 6). They have at least one trusted healthcare provider (scale 1) and strong social support for health (scale 4).

They have lower scores in their ability to find and appraise health information (scales 5 & 8), and to navigate the healthcare system (scale 7) and manage their health.

OPtimising HEalth LIteracy and Access (Ophelia)

The Ophelia process was developed by Deakin University in collaboration with Monash University and the Victorian Department of Health and Human Services to guide small and large scale development and implementation of health and community service improvements (11). The Ophelia process provides organisations with a structured approach to recognise, understand and respond to the health literacy needs of members of their community. The process identifies health literacy strengths and needs within a community and then uses co-design processes to generate equitable and locally relevant responses to these strengths and needs. The Ophelia process includes three phases. Each phase has either two or three steps, as shown in Figure 3. Over 20 Ophelia projects have been implemented around the world and it has been adopted by the World Health Organization (WHO) as the primary health literacy approach in health promotion interventions across chronic conditions and the life course (2).

Ophelia is also underpinned by 8 principles:
1. Outcomes focused: Improved health and reduced health inequities
2. Equity driven: All activities at all stages prioritise disadvantaged groups and those experiencing inequity in access and outcomes
3. Co-design approach: In all activities at all stages, relevant stakeholders engage collaboratively to design solutions
4. Needs diagnostic approach: Participatory assessment of local needs using local data
5. Driven by local wisdom: Intervention development and implementation is grounded in local experience and expertise
6. Sustainable: Optimal health literacy practice becomes normal practice and policy
7. Responsiveness: Recognise that health literacy needs and the appropriate responses vary across individuals, contexts, countries, cultures and time
8. Systematically applied: A multi-level approach in which resources, interventions, research and policy are organised to optimise health literacy.

Figure 3 The phases of the Ophelia process

Phase 1
Identifying local strengths, needs and issues

Phase 2
Co-design of interventions

Phase 3
Implementation, evaluation and ongoing improvement

Health literacy data are collected from a representative sample of the target population. Data are presented to stakeholders for interpretation. Effective local practices and innovative solutions are identified

Local stakeholders make decisions about priorities for action. Interventions with potential to respond to local health literacy needs or improve information and service access are designed and planned

Health literacy interventions are applied as quality improvement cycles where organisations implement trials and actively improve the effectiveness, local uptake and sustainability of the interventions

It is important to note that the eHealth Literacy Ballarat project involves only Phase 1 – i.e., the identification of local strengths, needs and issues, including effective local practices and innovative solutions.

Methods

The study procedure is outlined in Figure 4.

Figure 4 Overview of the study procedures

1: Project set-up - July to Oct 2018

   a) Signing of agreements
   b) Governance / Ethics

2: Data collection - Oct 2018

   The study was undertaken in the Ballarat Goldfields region of the WVPHN catchment

   a) <u>Quantitative data</u> Computer Assisted Telephone Interviews (CATI survey) of 1000 people
   b) Cluster analysis to identify groups of people with similar eHLQ patterns
   c) <u>Qualitative data</u> Semi-structured interviews from the full range of 12 clusters were collected from community members

3: Preliminary data analysis – Nov 2018

   a) Quantitative data analysis (CATI survey)
   b) Qualitative data analysis (Semi-structured interviews)

4: Development of vignettes – Nov 2018

   a) Vignettes developed from Step 3 using eHLQ data

5: Community member and clinician/professional consultation workshops 4-6 Dec

   a) Vignettes presented at the 3 community member workshops and 3 clinician / professional workshops across the region
   b) Ideas to develop strategies and interventions to address barriers and enablers to eHealth engagement and uptake of MyHR were developed by community members and clinician / professionals.

6: Data coding and analysis from workshops post 7 Dec

   a) Solution ideas from the workshops collated into similar concepts and then synthesised into themed idea lists
   b) Similar ideas condensed to represent common concepts linked to interventions

Step 1: Project set-up (Governance, Ethics and agreements) – July to Oct 2018

Stakeholders agreed in the scope of the project and Human Ethics Approval was granted on 24 September 2018 (Project number HEAG-H 157_2018).

Step 2a: Quantitative data collection - Oct 2018

A population-based CATI survey of 1000 people was conducted. The CATI survey included the eHLQ (electronic Health Literacy Questionnaire) and additional questions about engagement with digital health services (see the CATI survey instrument in <u>Appendix A</u>).

Computer Assisted Telephone Interview (CATI survey) undertaken by a contract research company

Adults living in the Ballarat Goldfields region of the Western Victoria Primary Health Network (WVPHN) were randomly selected and called (land line or mobile) and invited to participate until a sample of 1000 was reached[*].

Eligibility criteria were:

- Aged 18 years or over – if a person under the age of 18 answers they were asked if an adult was available.
- Not cognitively impaired.
- Able to provide informed consent and complete the telephone conversation in English.

[*]Two participants gave invalid responses and were excluded from the final sample.

Eligible respondent

- Contract research company outlined the project requirements and consent process. Respondents who consented were included in the survey through a computer assisted telephone phone interview.

Optional consent for semi-structured interviews and/or workshop sought – community members

- Two questions at the end of the CATI survey that ask participants if they are willing to be contacted for a semi-structured interview or workshop. Participants indicated willingness to take part in further research (workshop or semi-structured interview) to discuss their experiences with digital health technologies.
- Completed CATI surveys de-identified and provided to project team.

Community member semi-structured interviews and workshops

- 50 participants were interviewed. The semi-structured interviews helped to create vignettes for the workshops for participants to brainstorm how to improve engagement with eHealth services.
- Up to 36 community members were invited to attend one 2-hour workshop (3 workshops in total) to suggest ideas about how to improve access and engagement with eHealth services, with the discussion based on 5 vignettes.

Clinician / health professionals workshops

- As for consumers, up to 36 health professionals were invited to attend one 2-hour workshop (3 workshops in total) to suggest ideas for ways in which the local community can address the identified barriers to engaging in eHealth. Discussion was based on the same 5 vignettes as used in the consumer workshops.
- Expressions of interest emails were sent to clinicians / health services in the local area.
- Workshops were facilitated by Deakin researchers.

Data analysis and reporting

- Analysis of data from the 6 workshops to generate recommendations and actions to improve the implementation of digital health reforms in Australia.

A population-based sampling frame was developed for the study in the Ballarat Goldfields region of the Western Victoria Primary Health Network (WVPHN) using the services of a survey specialist contractor[4]. Postal areas in the Ballarat Goldfields region were ordered by their Index of Relative Socioeconomic Disadvantage (IRSD) ranking. A database of landline and mobile telephone numbers was then matched to the postal areas and a random start fixed interval sampling technique was undertaken to draw the sample. A random start fixed interval sampling process gave a pseudo-random sample that was implicitly stratified by IRSD index without allocating the postal areas to strata. A step interval was calculated by dividing the total population by the desired sample size within the following local government areas: Shire of Central Goldfields, City of Ballarat, Hepburn Shire, Moorabool Shire and Pyrenees Shire regions.

The CATI survey (see Appendix A) included the eHLQ, 4 scales from the HLQ, and demographic and health service usage. Selection criteria for inclusion were being able to answer a survey in English and being over the age of 18 years.

Between 8 and 12 interviewers collected data across 6 days of the week. The questionnaires took about 17 minutes to administer with the most time consuming components being the introduction and definitions at the beginning and discussions about further research participation at the end.

A data quality check was undertaken by the research team on 8 October 2018. There were no questions that were problematic for the interviewers to administer. All questions were clearly worded and were well understood by CATI survey participants. No changes to the CATI survey were deemed necessary.

Step 2b: Cluster analysis for preparation of vignettes

Cluster analysis (see Figure 5) is a process that allocates people into groups with other people who have a similar data profile: in this case, a similar digital health literacy profile. Digital health literacy is not just one entity but has different elements to it and people can have different strengths and weaknesses across these elements. For example, some people might trust a digital system but have poor personal IT skills whereas others might be the opposite. That is the reason that the eHLQ has 7 scales because these capture the different elements of digital health literacy.

Given that people have these different strengths and weaknesses, it is more useful to think of a profile of scores across the 7 scales rather than trying to give people one total score. People who have a similar profile (i.e., similar strengths and weakness across the 7 scales) are likely to have similar needs to help them use digital health technologies more effectively. Cluster analysis enables us to identify these groups of people so that when we do the planning workshops we can identify strategies to assist each group.

Table 32, Table 33, Table 34 and Table 35 show the results of the cluster analysis. It is important to note that people were grouped only on the basis of their scores on the 7 scales of the eHLQ (not on HLQ or demographic data). Each row in the table is one cluster, which is one group of people. The number of people in that group is shown in the column with the heading 'Num in cluster'. The columns with the traffic-light colours are the 7 scales of the eHLQ. The colours indicate whether the groups score on that scale is relatively high (dark green) or relatively low (dark red) or in between light-green

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[4] Strahan Research Pty Ltd

to yellow to orange. For convenience, in the second column the groups are shown in order from the highest average scores to the lowest average scores across all 7 scales.

Table 1 shows the demographic and digital health use details and the general health literacy scores for each cluster. It is important to note that these variables were **not** used to do the grouping, so that a relationship between the groups and a variable can be considered to show a relationship between digital health literacy and that variable. For example, Table 32 is an extract from Table 1 and shows a strong relationship between digital health literacy and the intent to use MyHR.

Figure 5 Cluster analysis process
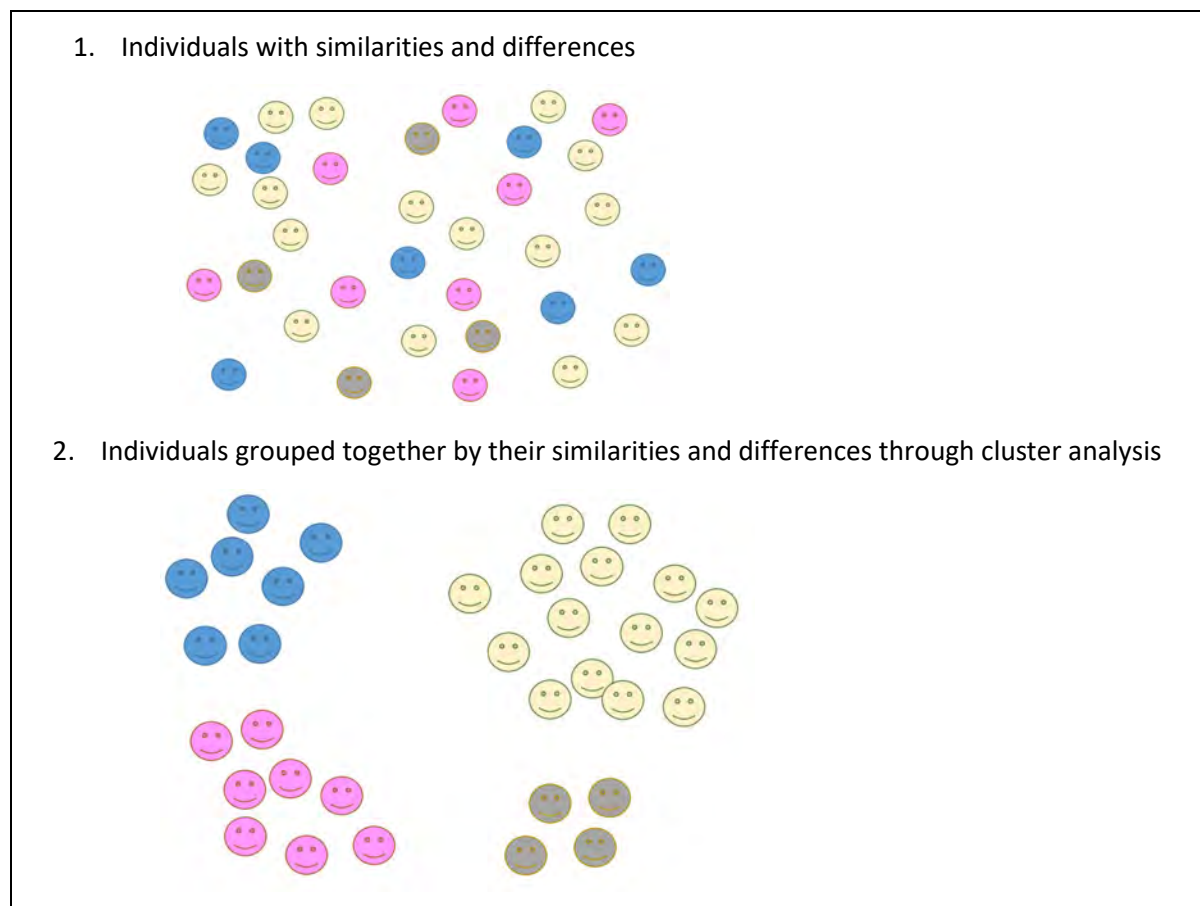
Step 2c: Qualitative data collection - Oct to Dec 2018

On completion of the CATI survey, participants were invited to take part in a semi-structured interview (or workshop) at a later date. Those who agreed were asked to provide their name and email (if applicable) for a researcher to contact them. The purpose of the semi-structured interviews was to elicit further information about their experiences with health technologies in general and with health services in their region. Participants were chosen based on which cluster they fell into (minimum 3 interviews per cluster) in order to gain a broad range of responses and experiences from people across the cluster spectrum. 50 semi-structured interviews were undertaken, each of which took between 15 and 20 minutes to conduct. Semi-structured interviews were audio-recorded and transcribed verbatim.

Step 3: Data analysis of CATI survey and semi-structured interview data

As previously noted, quantitative and qualitative methods were used in this study. See Appendix C for detailed description of procedures.

Step 4: Vignette development

The process of developing the vignettes was based on the 3 components below:

1. Cluster analysis data (eHLQ and HLQ)
2. Qualitative data from the CATI survey, grouped by cluster
3. Key data from the semi-structured interviews, grouped by cluster

The same 5 vignettes were presented at each of the community and clinician co-design workshops. The vignettes can be found in Appendix D.

Step 5: Community member and clinician / health professional consultation workshops – December 2018

Thirty community members took part in three co-design workshops, and 32 health professionals took part in three workshops (i.e., six workshops in total). Each workshop was conducted over two hours, with four held in Ballarat and two in Daylesford.

Community members were recruited for workshops from the people who completed the CATI survey.

Recruitment of clinicians included emailing and calling clinicians from the study area to see if they would be interested in attending the workshop.

Deakin researchers facilitated each workshop. Participants and providers were asked to identify the key issues for the aggregated client profiles described in each vignette and then to generate potential solutions for those issues.

Workshops with community members

Five vignettes were selected to present at the community member workshops. The aim of the workshops was to generate response ideas to the issues embodied within each vignette. In each workshop, participants were asked four key questions:

1. Does this person seem to be like someone you know?
2. What issues can you identify about this person's use of digital health technologies?
3. What could be done to help improve things for this person?
4. Given that there are many people like this in your community, what could be done to support them?

Workshops with clinicians / health professionals

The same five vignettes were presented at the clinician workshops, which were held with WVPHN staff and community health workers and managers. The aim of the workshops was to generate response ideas to the issues embodied within each vignette. In each workshop, participants were asked the same four key questions as the community members. With consent from participants, all workshops were audio-recorded and transcribed verbatim. Findings from the community member workshops and clinician workshops were grouped into key themes.

CATI Survey results

Demographic background and contacts with health professionals

The respondents to the CATI survey were on average 66 (IQR 58 to 74) years of age (29% below 60 years, 48% 60 to 75 years, and 23% 75 years and older) (see Figure 6), 54% were women, only 1% did not speak English at home and 2% identified as Aboriginal or Torres Strait Islander. Around one third of participants (31%) completed up to year 12, 25% had completed a trade certificate, apprenticeship, diploma or college/TAFE, and 31% had completed tertiary education (Figure 7). See Appendix H for more detailed demographic background.

Compared to the population of the Western Victorian Primary Health Network, the CATI survey sample had a similar proportion of people who identified as Aboriginal or Torres Strait Islander and a similar proportion of women (54% compared to 51%) (Table 16) The CATI survey sample had a higher proportion of those aged 55 to 70 years (39% compared to 19%) and aged over 70 years (41% compared to 13%), and a higher proportion of those with a tertiary education (31% compared to 14%) compared to the Western Victorian Primary Health Network.

Figure 6 Age of CATI survey participants
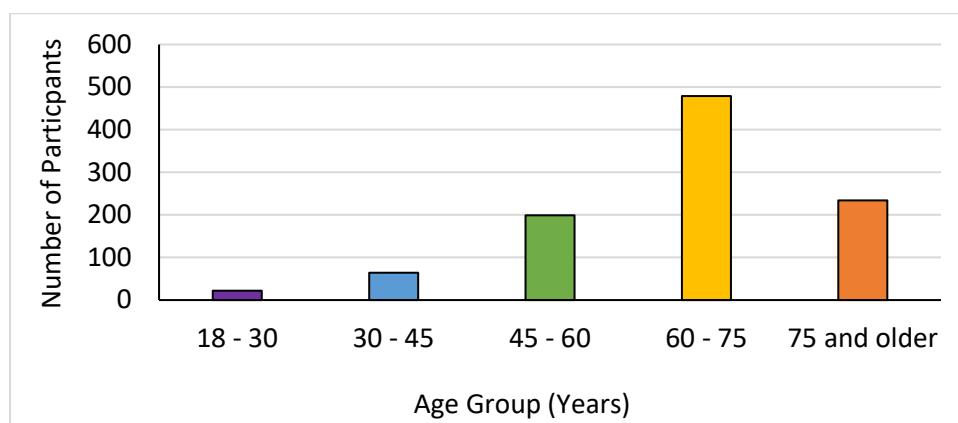
Figure 7 Highest educational attainment of CATI survey participants
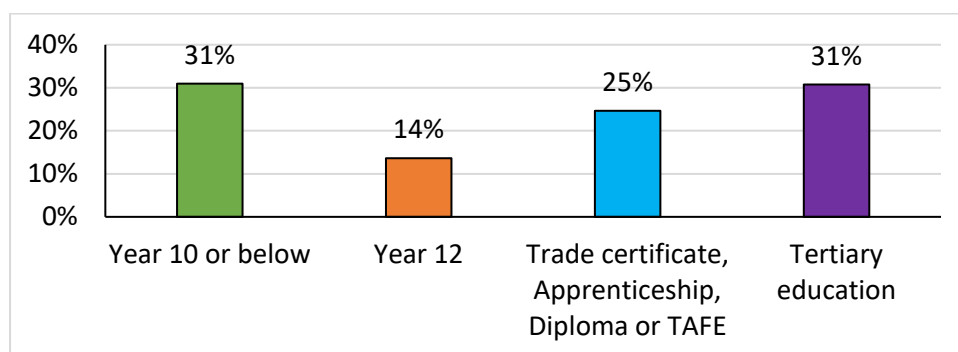
Health conditions

Close to half the respondents (43%) reported having no long-standing illness or disability, 34% reported having one, and 23% reported having 2 or more. The most common reported conditions were arthritis (14%) and heart disease (13%). Other frequent conditions were chronic pain (9%),

diabetes (8%) and cancer (5%). Depression and anxiety were reported by 5% and 3% of respondents, respectively. See Figure 9 and Appendix H for further details.

Figure 8 Number of long term diseases or illnesses reported by CATI survey participants
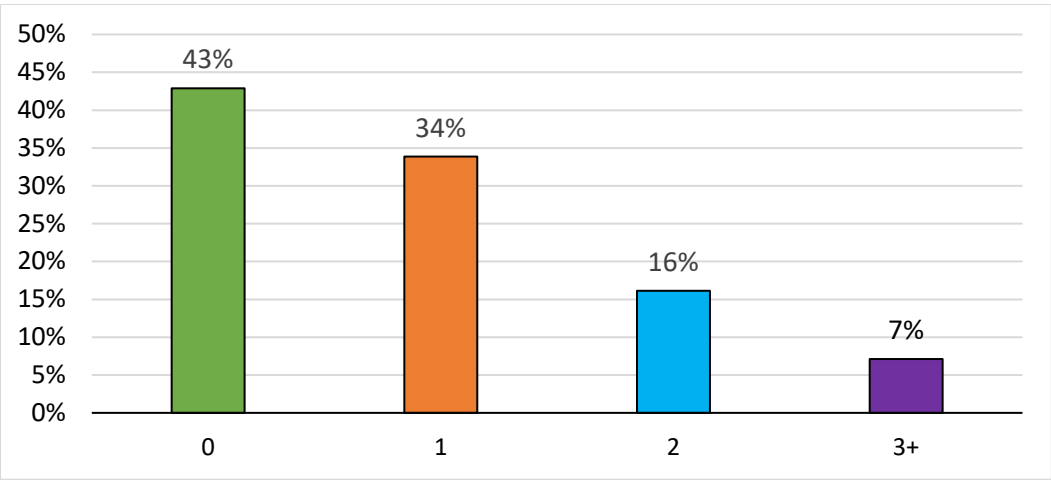
Figure 9 Long term diseases or illnesses* reported by CATI survey participants
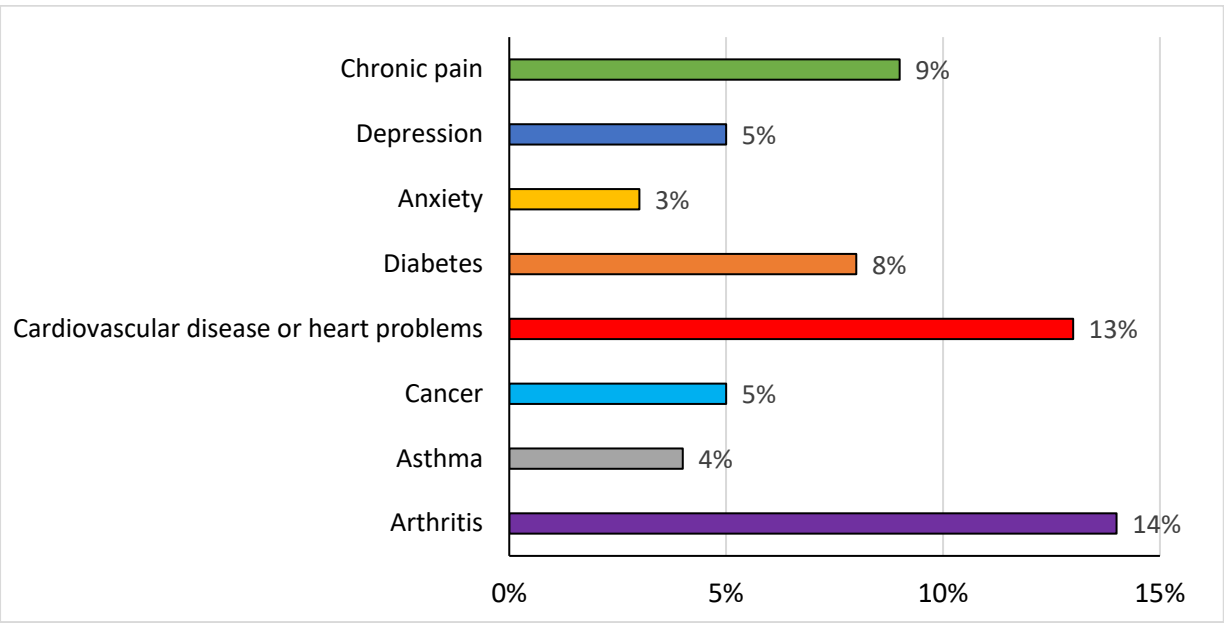
*Note that participants could select more than one disease or illness

Contacts with health professionals

Over a quarter (27%) of respondents reported having contact with a health professional more than 12 times in the past 12 months. The majority reported contact between 2 and 6 times (45%), whereas only 6% reported only 1 contact, and 3% reported no contacts in the past 12 months. See Appendix H Table 14 for further details.

Figure 10 Number of contacts with a health professional in the past 12 months by CATI survey participants

Legend: 12 or more · 7 to 11 · 2 to 6 · Once · Not at all
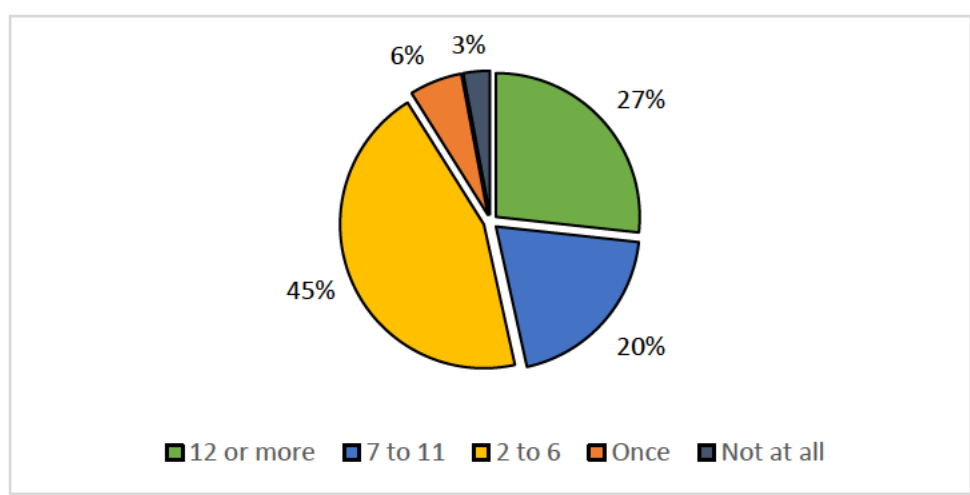
Engagement with the Internet and My Health Record (MyHR): who and why?

To explore the community's engagement with MyHR, the data were organised in the following way:

- *Access to and use of the Internet,*
- *eHealth literacy and Health literacy*
- *MyHR Awareness* (did participants know whether or not they had a MyHR)
- *Engagement* (for participants who were aware whether or not they had a MyHR, did they have a MyHR)
- *Usage* (for participants who had engaged with the MyHR, did they use or intend to use it).

Access and use of the Internet

Close to half the respondents (42%) reported not using the Internet to search for health-related information in the past 12 months. Of these, the most commonly selected reasons for not accessing the Internet were 'I prefer face-to-face interaction with health services' (41%), 'I don't have the right technology (equipment)' (22%) and 'I don't want to' (21%).

Among the 58% of respondents who used the Internet to search for health-related information in the past 12 months at least a few times, most commonly accessed the Internet using a computer (68%). See Appendix H

Table 15 Use of the internet to access health-related information for further details.

Figure 11 Usage of the Internet in the past 12 months by CATI survey participants to search for health related information
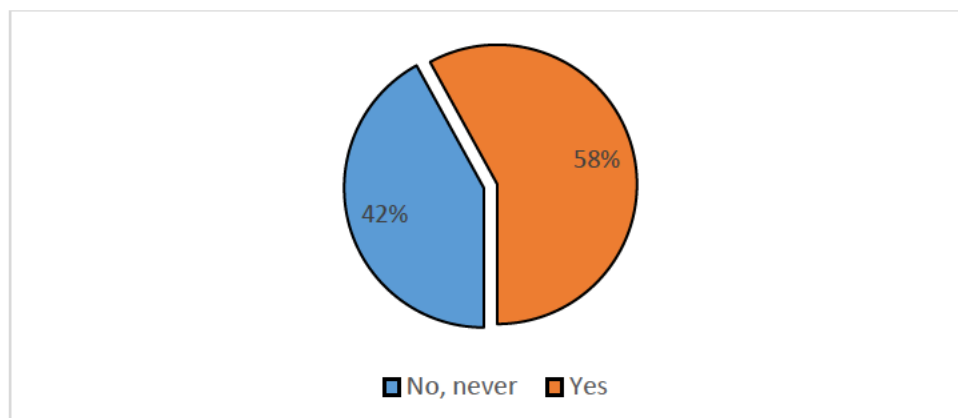
eHealth literacy and health literacy

As this is the first epidemiological study of eHealth literacy in Australia, it is not possible to compare the results with other groups and reference the scores on each scale to an external standard. We assessed eHealth literacy using all seven scales of the eHealth literacy questionnaire (eHLQ). Overall, participants generally disagreed (mean <2.5 on a scoring scale that ranges from 1 *strongly disagree* to 4 *strongly agree*) that they had eHealth literacy skills (eHLQ) relating to: eHLQ Scale 1. 'Using technology to process health information', eHLQ Scale 3. 'Ability to actively engage with digital services', eHLQ Scale 5. 'Motivated to engage with digital services', and eHLQ Scale 7. 'Digital services that suit individual needs'. However, participants generally agreed (mean ≥2.5) that they had eHLQ Scale 2. 'Understanding of health concepts and language', eHLQ Scale 4. 'Feel safe and in control', and eHLQ Scale 6. 'Access to digital services that work'.

We assessed health literacy using four of the nine scales of the health literacy questionnaire (HLQ): HLQ Scale 1, Feeling understood and supported by healthcare providers; HLQ Scale 3, Actively managing my health; HLQ Scale 4, Social support for health; HLQ Scale 7, Navigating the healthcare system. Overall, participants tended to agree (mean ≥2.5 on a 1 to 4 scale) that they had health literacy skills (HLQ) relating to HLQ Scale 1. 'Feeling understood and supported by healthcare providers', HLQ Scale 3. 'Actively managing my health', HLQ Scale 5. 'Social support for health', and generally found it somewhat difficult (mean <4 on a 1 to 5 scoring scale of *cannot do or always difficult* to *always easy*) to HLQ Scale 7. 'Navigating the healthcare system'.

My Health Record access and use or intention to use

About one third of participants reported having a MyHR (Engaged with MyHR, 32%), about one third reported they did not have a MyHR (Not engaged with MyHR, 32%), and about one third of participants were unsure if they had a MyHR (Uncertain, 36%). Only 17% of the sample were engaged with the MyHR and either currently used it or had a strong intention to, while 15% of the sample were engaged with the MyHR but either did not intend to use it or were not sure if they intended to (see Table 17 and Figure 12).

Figure 12 Awareness, engagement and use, or intention to use, the My Health Record by CATI survey participants
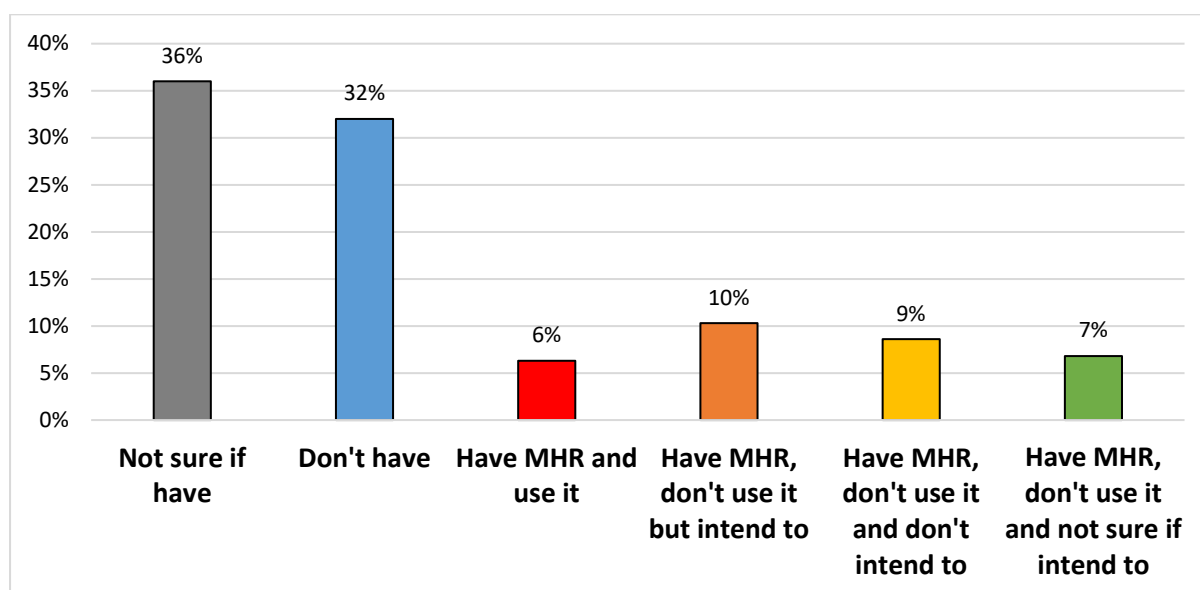
The sample demographics for each sub-category of MyHR awareness, engagement and use or intention to use are reported in Appendix H, Table 17, Table 18, and Table 19. Results from prediction analyses are summarised in Figure 13, Figure 14 and Figure 15 below, and comprehensive results from these analyses are reported in Appendix H. Table 20, Table 21, Table 22, Table 23, Table 24 and Table 25.

The prediction analyses explored if one subgroup was more or less likely to be aware of whether they had a MyHR (Figure 13), engage with the MyHR (Figure 14) or use the MyHR (Figure 15) compared to a reference subgroup, adjusting for differences in age between subgroups. This analyses presents the associations using odds ratios, which can be interpreted as follows: an odds ratio of 1 indicates no association, an odds ratio greater than 1 indicates the subgroup was more likely to be aware, engage or use the MyHR compared to a reference subgroup, and an odds ratio of less than 1 indicates the subgroup was more likely to be uncertain, to not engage and to not use the MyHR compared to a reference subgroup.

Men and women and MyHR awareness, engagement with MyHR and use or intention to use MyHR

Compared with men, women had a 1.4 fold higher odds of being aware of whether or not they had MyHR (see Figure 13). Among those who had a MyHR, women had a 1.8 fold higher odds of using or having a strong intention to use the MyHR compared with men (Figure 15). There was no difference between women and men in the odds of MyHR engagement (among those who were aware of having a MyHR) (see Figure 14).

Age and education and MyHR awareness, engagement with MyHR and use or intention to use MyHR

There was no clear pattern between age and people's awareness of having a MyHR (in the overall sample) or intention to use MyHR (among those who had engaged with the MyHR). However, among

those who knew if they had a MyHR, the odds of MyHR engagement decreased by 0.02 for each additional year of age.

There was no clear relationship between education and awareness of having a MyHR (in the overall sample) or engagement with the MyHR (among those who were aware of having a MyHR). However, among those who had a MyHR, with increasing education, there was increasing use/intention to use the MyHR – compared to those who completed Year 11 or below, those who had attained a university education had a 2.5 fold higher odds of using or intending to use MyHR.

Long-standing illnesses or disabilities, self-rated health, number of contacts with a health professional in the last 12 months and MyHR awareness, engagement with MyHR and use or intention to use MyHR

There was no observed relationship between number of long-standing diseases or conditions and MyHR awareness (in the overall sample) or intention to use MyHR (among those who had engaged with the MyHR). However, among those who were aware of whether or not they had a MyHR, there was a positive association between number of conditions and MyHR engagement – compared with those with no long-standing diseases or conditions, those with 2 or more conditions had a 1.8 fold higher odds of engaging with the MyHR.

There was no observed relationship between self-rated health and MyHR awareness, engagement or use or intention to use.

There was no observed relationship between number of contacts with a health professional in the past 12 months and MyHR awareness, engagement or use or intention to use.

Internet use and MyHR awareness, engagement with MyHR and use or intention to use MyHR

Compared with those who had never used the Internet to search for health related information in the previous 12 months, those who had used the Internet to search for health related information had a higher odds of MyHR awareness (OR = 1.52), engagement with MyHR (OR = 1.81) and use or intention to use MyHR (OR = 2.97).

eHealth literacy (eHLQ) and MyHR awareness, engagement with MyHR and use or intention to use MyHR

Overall, people who were aware of whether or not they had a MyHR, people who were engaged with the MyHR and people currently used the MyHR or intended to had higher scores across seven eHLQ scales compared to those who were unaware of whether they had a MyHR, those who had not engaged, and those who did not intend to use the MyHR, respectively (Table 28).

For the total sample, eHealth literacy was a strong predictor MyHR awareness (Figure 13 and Table 21). For the total population, the odds ratios indicate that, on average, people with a one unit higher score (i.e., a score of 3.5 versus a score of 2.5, on the 1 to 4 scale) on eHLQ Scale 6. 'Access to digital services that work' were twice as likely (i.e., an OR of 1.99) to be sure about their MyHR status. Across all the scales these data indicate that interventions to improve people's knowledge about their MyHR status should include a focus on eHLQ Scale 6 (OR 1.99), eHLQ Scale 1 (OR 1.77), eHLQ Scale 5 (OR 1.75) and to a lesser extent, eHLQ Scale 3 and eHLQ Scale 4 (OR 1.5 for both).

Among the subgroup of people who were sure about their MyHR status (N=639), eHealth literacy was a strong predictor of who did not or who did engage with the MyHR (Figure 14 and Table 23). All seven eHLQ Scales had an odds ratio greater than 1.6, and were statistically significant (p≤0.001). The strongest predictor was eHLQ Scale 2. 'Understanding health concepts and language' (OR 2.62, i.e., a one unit increase in this scale was associated with about two and half times more likelihood of having a MyHR). Interestingly, eHLQ Scale 4. 'Feeling safe' and eHLQ Scale 1. 'Active users of technology' were the weaker predictors compared with the other eHLQ scales.

Among the subgroup of people who were sure about their MyHR status, and did have a MyHR (N=252), eHealth literacy was a very strong predictor of who was or was not intending to use the MyHR (Figure 15 and Table 25). All seven eHLQ scales had an odds ratio greater than 2.2, indicating a strong association (p<0.005). The strongest predictors were eHLQ Scale 3. 'Ability to actively engage with digital services' (OR 4.44), eHLQ Scale 5. 'Motivated to engage with digital services' (OR 4.24), eHLQ Scale 1. 'Using technology to process health information' (OR 4.14) and eHLQ Scale 7. 'Digital services that suit individual needs' (OR 3.48).

Health literacy (HLQ) and MyHR awareness, engagement with MyHR and use or intention to use MyHR

The four domains of health literacy that were measured (HLQ Scale 1, Feeling understood and supported by healthcare providers; HLQ Scale 3, Actively managing my health; HLQ Scale 4, Social support for health; HLQ Scale 7, Navigating the healthcare system) did not differ substantially between those who were and were not aware of having a MyHR (Table 31**).** Those who had engaged with the MyHR and those who currently used or intended to use the MyHR had higher scores across the four domains of health literacy that were measured compared to those who had not engaged with the MyHR and those who did not intend to use the MyHR, respectively.

Compared to eHealth literacy, the health literacy scales measured were weaker predictors of MyHR awareness, engagement and usage. For the total sample, Health literacy was not a significant predictor of MyHR awareness (Figure 13, Table 21). For the subgroup of people who were sure about their MyHR status, HLQ Scale 1. 'Feeling understood and supported by healthcare providers' and HLQ Scale 4. 'Social support for health' were significant predictors of MyHR engagement: a one unit increase in HLQ Scale 1 and HLQ Scale 4 conferred a 1.6 and 1.7 fold higher odds of having MyHR, respectively (Figure 14 and Table 23). Conversely, HLQ Scale 3. 'Actively managing my health' and HLQ Scale 7. 'Navigating the healthcare system' were not statistically significant predictors of MyHR engagement.

For the subgroup of people who were aware of whether or not they had a MyHR, and had engaged with the MyHR, HLQ Scale 1. 'Feeling understood and supported by healthcare providers', HLQ Scale 3. 'Actively managing my health' and HLQ Scale 4. 'Social support for health' were strong predictors of using or intending to use the MyHR (Figure 15, Table 25). A one unit increase in HLQ Scale 1, HLQ Scale 3 and HLQ Scale 4 conferred a 1.9, 2.3 and 2.1 fold higher odds of using or intending to use MyHR, respectively. HLQ Scale 7. 'Navigating the healthcare system' was not a significant predictor of using or intending to use the MyHR.

Figure 13 The relationship between CATI survey participant's demographics, health literacy and eHealth literacy, and awareness^ of having a My Health Record (MyHR)
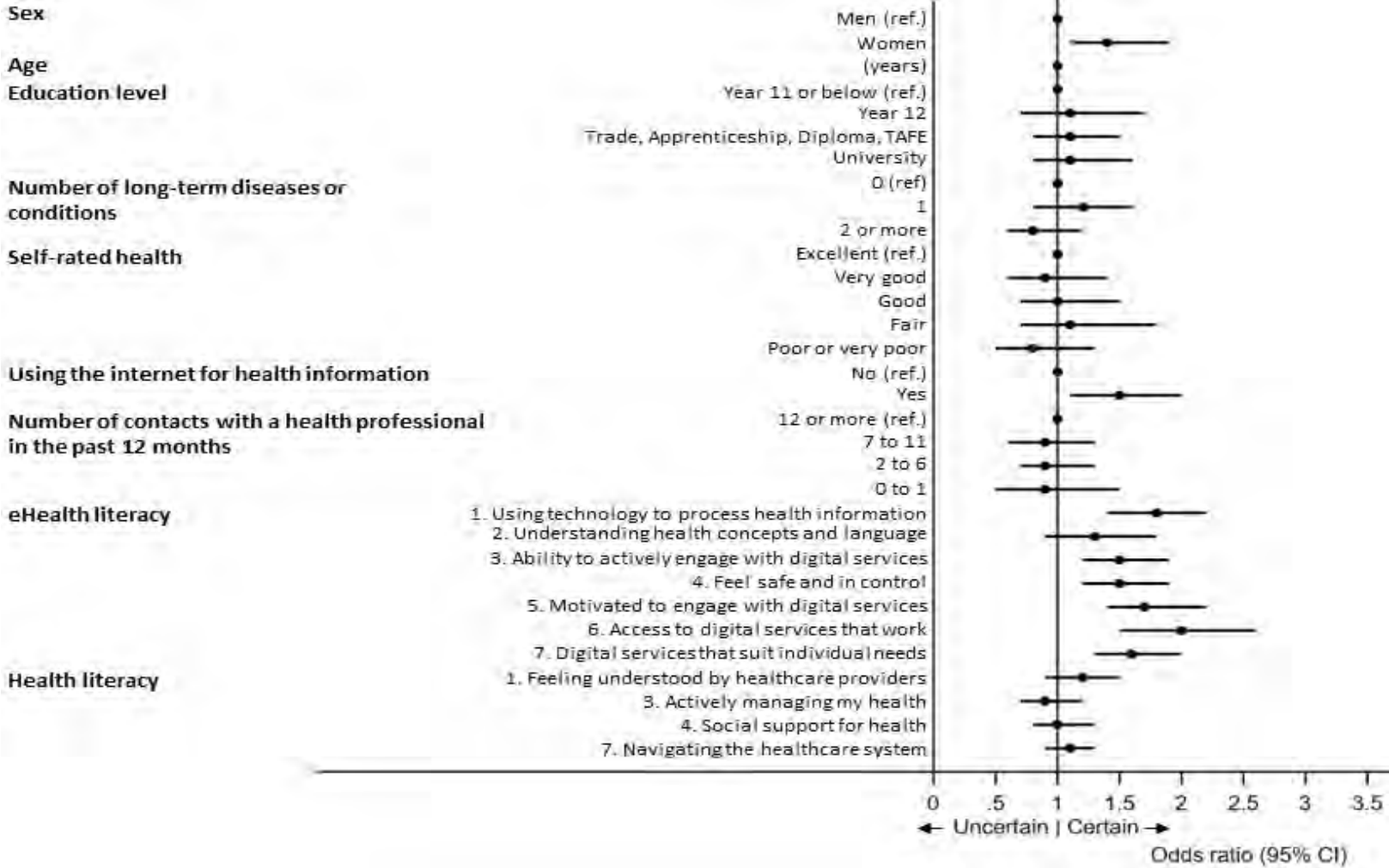
Note: ^Participants were asked "Do you have a My Health Record"; those who responded "I'm not sure" were characterised as Uncertain (N=639), those who responded either "Yes" or "No" were characterised as Certain (N=359); ref, reference subgroup; each circle on this graph represents the odds ratio for each subgroup, compared to the reference subgroup, and the horizontal line through each circle represents the 95% confidence interval (95% CI) for each odds ratio – which represents the likely range of the odds ratio for this subgroup in the Ballarat Goldfields population.

We here interpret odds ratios that are equal to 1 (represented by the dark grey vertical line) or have a 95% CI that includes 1, as being not statistically significantly different to the reference subgroup; odds ratios greater than 1 indicate the subgroup had higher odds of being certain of having a MyHR compared to the reference subgroup; odds ratios of less than 1 indicate the subgroup had higher odds of being uncertain of having a MyHR compared to the reference subgroup.

Figure 14 The relationship between CATI survey participant's demographics, health literacy and eHealth literacy, and engagement^ with My Health Record (MyHR)
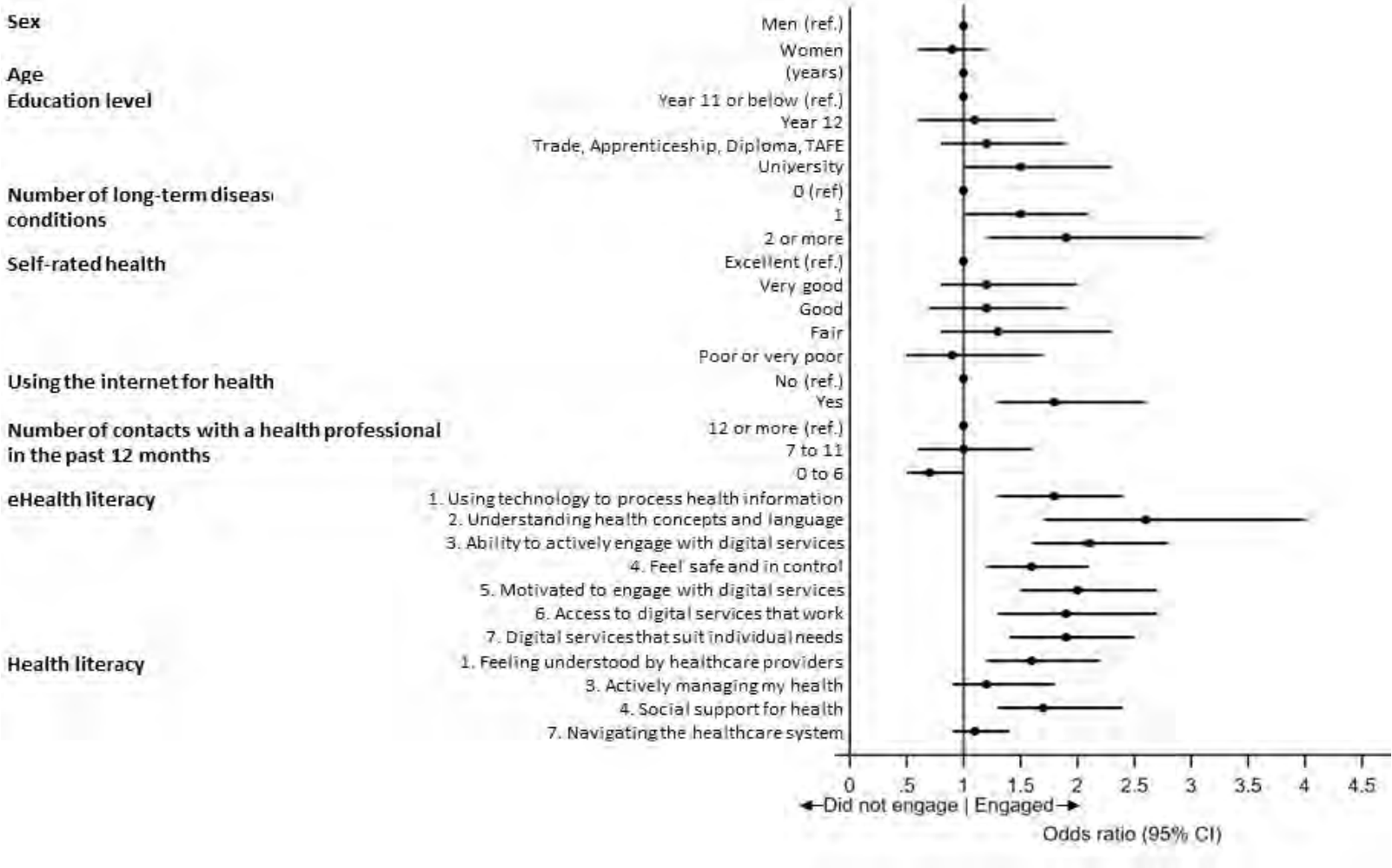
Note: ^Participants were asked "Do you have a My Health Record": those who responded "No" were characterised as Not engaged (N=319); those who responded "Yes" were characterised as Engaged (N=320); ref, reference subgroup; each circle on this graph represents the odds ratio for each subgroup, compared to the reference subgroup, and the horizontal line through each circle represents the 95% confidence interval (95% CI) for each odds ratio – which represents the likely range of the odds ratio for this subgroup in the Ballarat Goldfields population. We here interpret odds ratios that are equal to 1 (represented by the dark grey vertical line) or have a 95% CI that includes 1, as being not statistically significantly different to the reference subgroup; odds ratios greater than 1 indicate the subgroup had a higher odds of being engaged with MyHR compared to the reference subgroup; odds ratios of less than 1 indicate the subgroup had a higher odds of not being engaged with MyHR compared to the reference subgroup.

Figure 15 The relationship between CATI survey participant's demographics, health literacy and eHealth literacy, and intention to use^ My Health Record (MyHR)
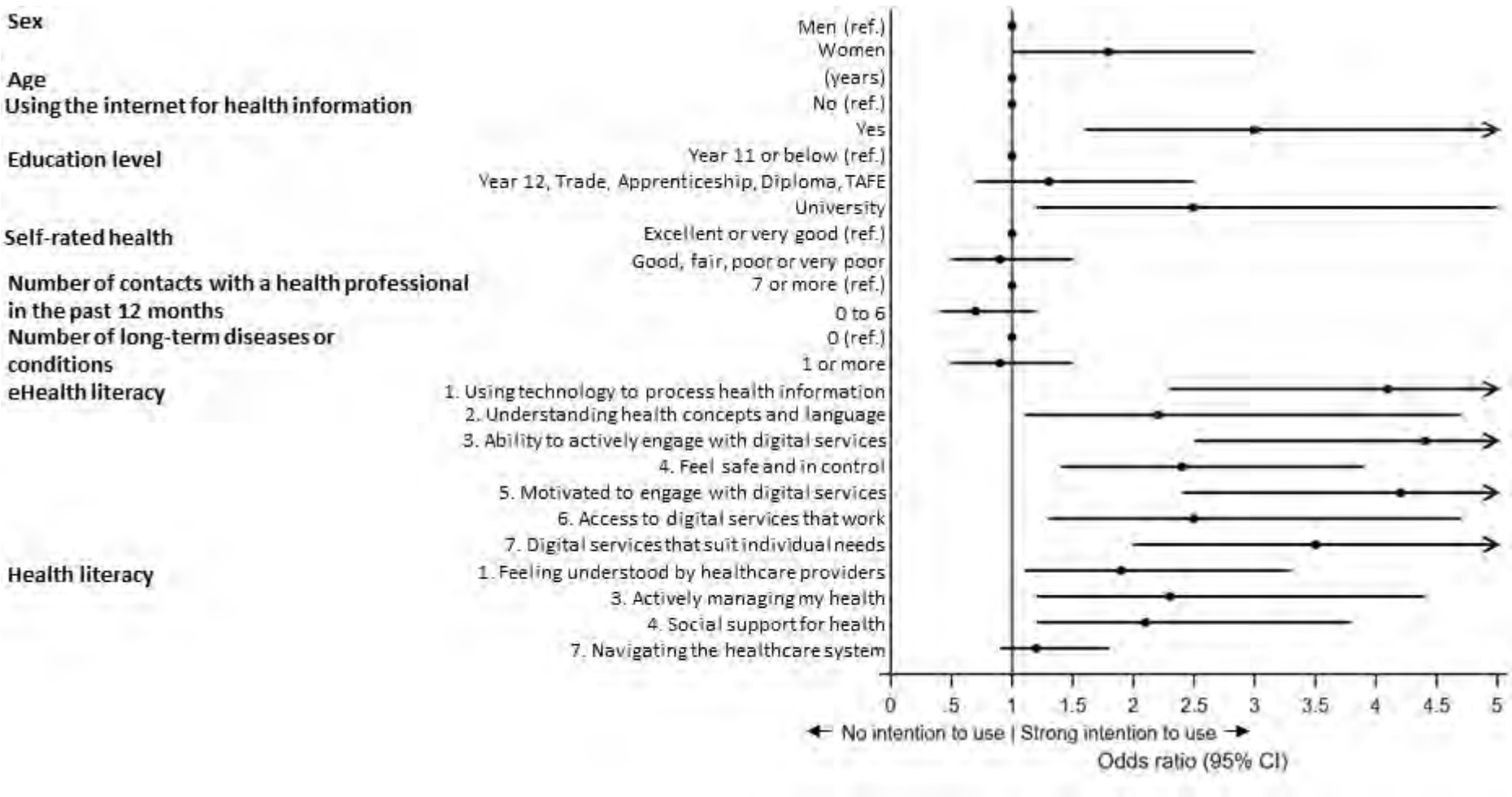
Note: ^Participants who were asked "Do you have a My Health Record"; those who responded "Yes" were then asked whether they use or intend to use their My Health Record; those who responded "No" were characterised as Not intending to use (N=86), those who responded that they currently use MyHR or intended to were characterised as Strong intention to use (N=166); ref, reference subgroup; each circle on this graph represents the odds ratio for each subgroup, compared to the reference subgroup, and the horizontal line through each circle represents the 95% confidence interval (95% CI) for each odds ratio – which represents the likely range of the odds ratio for this subgroup in the Ballarat Goldfields population. We interpret odds ratios that are equal to 1 (represented by the dark grey vertical line) or have a 95% CI that includes 1, as being not statistically significantly different to the reference subgroup; odds ratios greater than 1 indicate the subgroup had a higher odds of having a strong intention to use MyHR compared to the reference subgroup; odds ratios of less than 1 indicate the subgroup had a higher odds of not intending to use MyHR compared to the reference subgroup.

Cluster analysis of eHLQ CATI survey data

Table 1 below and Table 32, Table 33, Table 34 and Table 35 in Appendix H show the results of the cluster analysis with a 12 cluster solution selected (see Appendix H). Each row in these tables is one of the clusters. The column labelled 'Num people' gives the number of individuals in that cluster while the other columns provide summary statistics for eHLQ and HLQ. The demographics of each cluster are presented in Appendix H Table 32. It is important to remember that the cluster analysis was based only on the scores of the 7 eHLQ scales so a cluster is a group of people who have similar scores on all 7 scales and can thus be said to have a similar eHLQ profile. The traffic light colouring has been applied to give a quick visual indication of if groups have high (dark green), medium (yellow) or low (red) average scores on the scales of the eHLQ and HLQ.

The clusters have been sorted from high to low eHealth literacy based on the average of averages within that group across all 7 eHLQ scales, therefore clusters at the top can be said to have higher eHealth literacy overall while the bottom clusters have low eHealth literacy. Figure 16 and Figure 17 show the number of CATI survey participants in each cluster, as well as the proportion of people in each cluster who have engaged with the MyHR (Figure 16) and use or intend to use the MyHR (Figure 17). There is an extremely strong trend for people with higher overall eHealth literacy to be more likely to both engage with the MyHR and to use or intend to use the MyHR.

We also examined the relationship between eHealth literacy and average number of diseases and conditions (Figure 18), the average prevalence of specific diseases and conditions in each cluster (Figure 19), and the average self-rated health in each cluster (Figure 20).

Table 1 Cluster analysis with eHealth Literacy Questionnaire (eHLQ) data

12 Cl #	Cl ord *	Num people	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
3	1	37	3.17	3.60	3.26	3.65	3.37	3.57	3.43
12	2	53	3.25	3.66	3.45	2.66	3.20	2.80	2.83
2	3	123	2.90	3.04	2.87	3.00	2.95	2.96	2.95
8	4	135	2.63	2.90	2.81	2.46	2.67	2.60	2.56
10	5	179	2.30	2.88	2.35	2.96	2.47	2.71	2.64
7	6	117	2.45	2.92	2.75	1.92	2.46	2.31	2.13
5	7	121	2.00	2.72	2.10	2.78	2.01	2.36	2.04
6	8	96	2.15	2.69	2.30	2.16	2.13	2.22	2.10
9	9	39	1.56	2.90	1.41	2.86	1.75	2.29	1.92
4	10	41	1.75	2.87	1.89	1.74	1.75	1.92	1.60
1	11	38	1.07	2.99	1.13	2.79	1.09	1.79	1.18
11	12	21	1.16	2.48	1.29	1.50	1.23	1.44	1.25

Cluster number (as derived from cluster analysis)

* Cluster number when ordered from highest eHealth literacy to Lowest eHealth literacy.

Figure 16 Number of CATI survey participants in each of the 12 clusters, and the proportion of participants in each cluster who have engaged with My Health Record
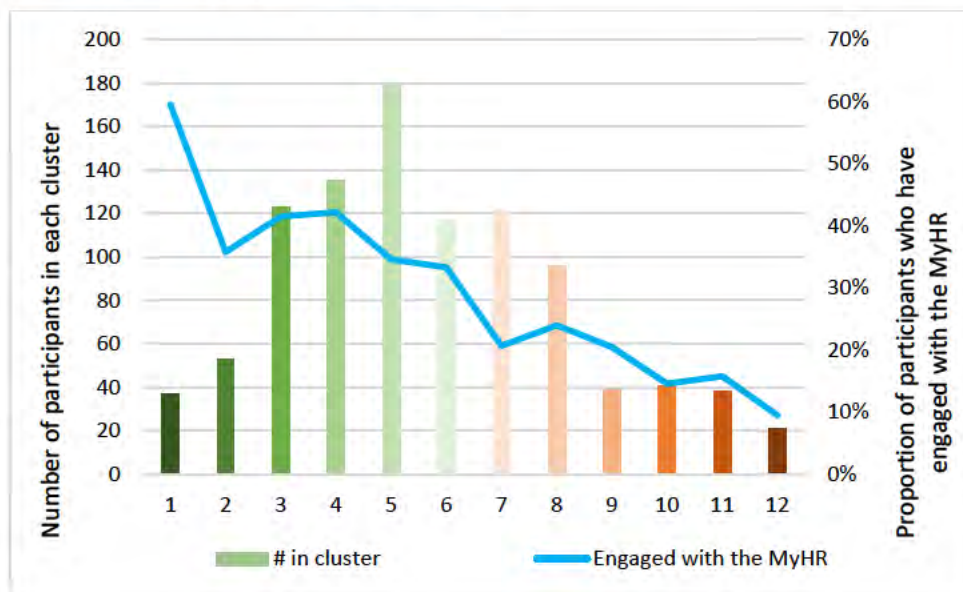
Figure 17 Number of CATI survey participants in each of the 12 clusters, and the proportion of participants in each cluster who are using, or planning to use, My Health Record
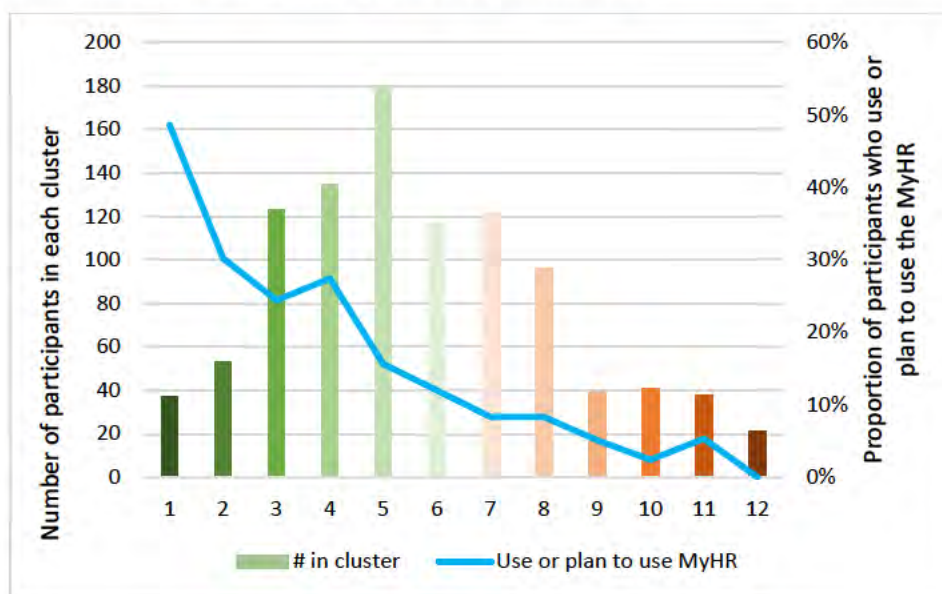
Figure 18 Number of CATI survey participants in each of the 12 clusters, and the average number of long-term diseases or conditions in each cluster
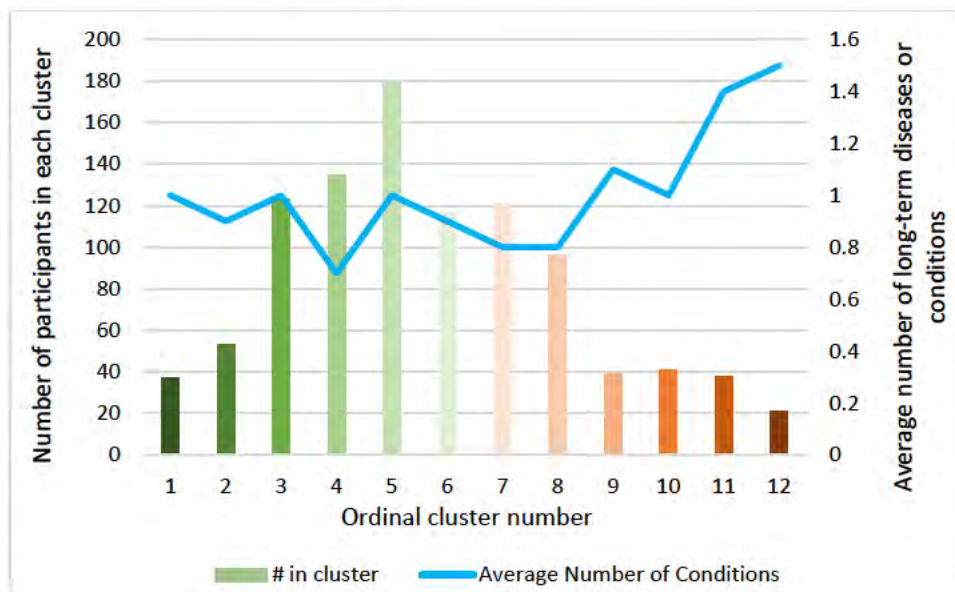
Figure 19 Proportion of CATI survey participants who reported select long term diseases and conditions in each of the 12 clusters
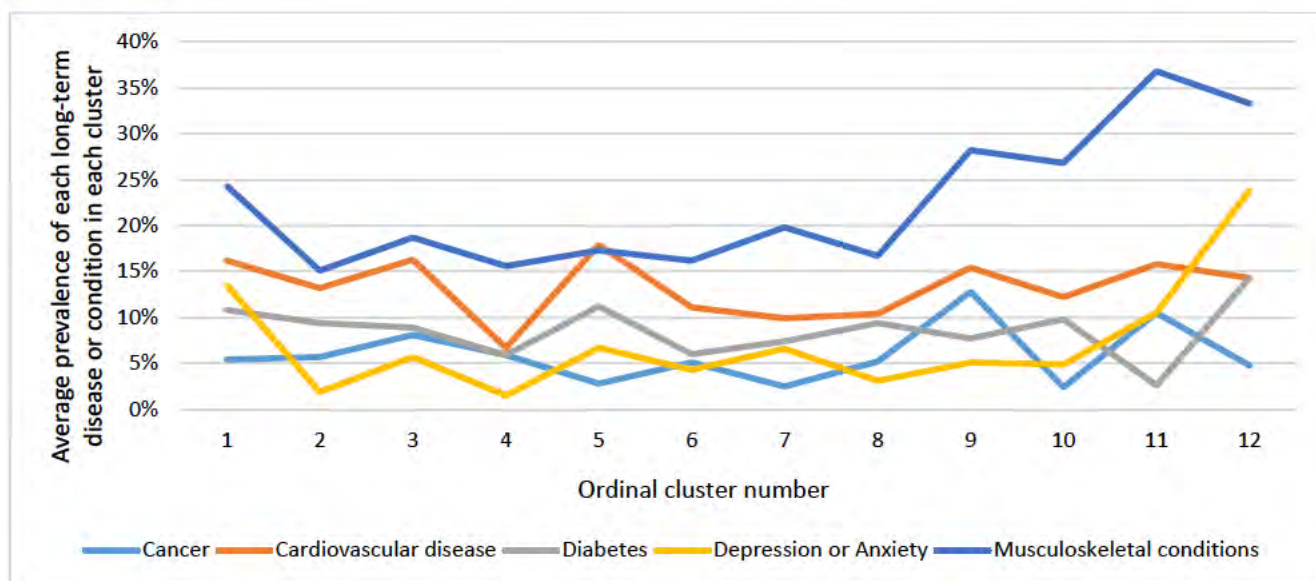
Note: Musculoskeletal condition refers to arthritis and/or chronic pain

Figure 20 Number of CATI survey participants in each of the 12 clusters, and the average self-reported health in each cluster
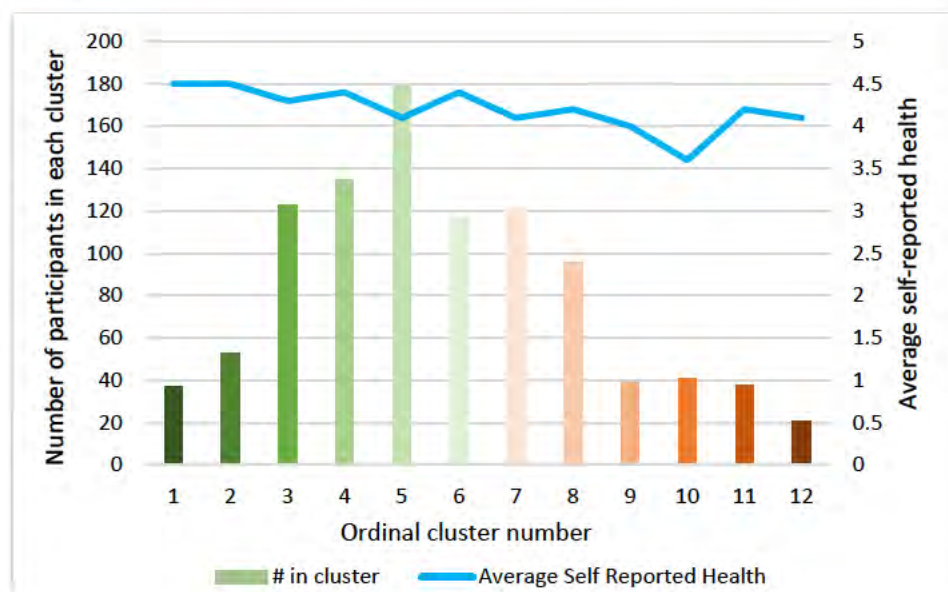
Semi-structured interview results

From the 50 people interviewed, 15 themes were identified (see Table 2) that relate to issues or barriers when engaging with or managing health through digital technologies. The 15 themes reflected barriers at the individual level (6 themes) and at the system level (9 themes). Refer to Appendix F for more detail about the semi-structured interview results.

Individual level barriers

A feeling of lack of control over personal health information that may be placed in eHealth records was commonly raised as a barrier to engaging in MyHR. Participants generally felt there was inadequate information online and expressed worries about who could access it and how it would be used now and in the future. Individual level barrier themes also included attitudes and preferences towards using technology, as well as skills and confidence about how in control of online health information participants felt. Participants discussed not being interested in technology in general, let alone wanting to use it to manage their health. Participants also expressed that they were unaware of eHealth and preferred receiving health information in a face-to-face consultation.

System level barriers

System level barriers include technological issues to do with access such as Internet coverage, misleading information on the Internet, concerns about security of online health information, difficulty accessing and using government websites, inflexible technology, and lack of information about eHealth (e.g., how to use it, where to get it). System issues also included lack of access to timely and appropriate health services, previous bad experiences with health care providers or health services, and difficulties navigating the health system.

Table 2 Themes from semi-structured interviews – barriers to use of eHealth services

Individual level themes, attributes - <u>barriers</u>
1. **Lack of control over personal health information on eHealth records** • Perceptions of lack of control over personal health information, don't know how to have control • Concerns about the accuracy of personal health information stored in eHealth records and how to amend incorrect information • Lack of privacy, don't want unauthorised people or organisations to access personal health information • Unsure as to who has access to personal health information
2. **Attitudes towards and skills with technology** • Lack of skills, confidence and training with digital technologies
3. **Not using technology to manage health** • Don't want to use technology to manage health • Don't have the need to use technology to manage health
4. **Not interested in technology** • Not interested, don't understand, don't need technology
5. **Unaware of eHealth** • Lack of awareness as to what eHealth is, where to access it, what it can do for individuals and how to use it

6. **Prefer face-to-face health information**
   - Preference to speak with health professionals face-to-face rather than looking up health information online

System level themes and attributes - <u>barriers</u>

7. **Misleading information on the Internet**
   - Not sure which websites to trust for access to reliable health information
   - Unsure how to distinguish which symptoms relate to what health conditions through online health diagnosis

8. **Inflexible technology**
   - Technology doesn't adapt to the needs of individuals for example booking appointments online or ordering prescriptions online
   - One-size-fits-all software or websites that don't suit everyone

9. **Access (coverage issues or no Internet)**
   - Difficulty accessing the Internet and/or mobile phones due to coverage issues or slow Internet speed
   - Difficulty accessing Internet due to cost

10. **Security concerns**
    - Don't trust/believe that the software is secure
    - Concerns about hackers accessing health information

11. **Lack of access to timely and appropriate health services**
    - Long wait times
    - International doctors / lack of continuity of health care
    - Long distances to travel to access health care services

12. **Issues accessing or using government websites including the My Health Record**
    - Difficulty with password protected websites
    - Difficulty navigating complicated websites
    - Incompatible technology to use Government websites

13. **Previous bad experiences with the health care providers or health services**
    - Previous bad experiences with health care providers
    - Previous bad experiences with health system

14. **Health system**
    - Misdirected resources or misalignment of services

15. **Navigating the health system**
    - Lack of information about how to get the right services or where to go.

Summary of Figure 21, Figure 22 and Figure 23

Figure 21 presents a concept map of themes by individual or system level barriers and their relationships based on the application of a lower triangular matrix shown in Appendix G. The frequently arising barriers were Theme 1 Lack of control over personal health information on eHealth records with 13 of 50 people raising this as a barrier for them to engage with or manage their health through technology. Note this is an individual level barrier as compared with most frequent system level barrier, Theme 7 Misleading information on the internet where 10 of 50 people raised this as a barrier.

Figure 22 presents a concept map of barriers and potential strategies to address these barriers, as expressed by participants in the semi-structured interviews.

Figure 23 presents enablers that support people to manage their health or engage with eHealth as expressed by participants in the semi-structured interviews, as well as connections to themes based on the lower triangular matrix.

The lower triangular matrix (Appendix G) indicates the relationship between multiple variables. In this case, themes that are related to each other through matching IDs to themes. For example, at the Theme 1 and Theme 2 intersection, participant IDs 26 and 28 both indicated that Theme 1 Lack of control over personal health information on eHealth records and Theme 2 Attitudes towards and skills with technology were barriers for them when engaging with or managing health through technology. Consequently, Theme 1 and Theme 2 are connected. All themes that have two or more matching IDs have been circled in the lower triangular matrix table. The only exception to this is Theme 14 and Theme 15 because the responses of so few people contributed to these themes. Connectors between themes have been shown in Figure 21.

Figure 21 Concept Map of themes by individual or system level barriers

Barriers to engaging with or managing health through technology

1. Lack of control over personal health information on eHealth records
2. Attitude and skills around technology
3. Not using technology to manage health
4. Not interested in technology (emotive)
5. Unaware of eHealth
6. Prefer face-to-face health information

7. Misleading information on the internet
8. Inflexible technology
10. Security concerns around eHealth
12. Issues using Government websites
14. Health system barriers

9. Access (coverage issues or no internet)
11. Lack of access to timely and appropriate health services
13. Previous bad experiences with healthcare providers or services
15. Navigating the health system

Individual level themes   System level themes

Figure 22 Concept Map of themes by individual or system level barriers and strategies to address barriers

Barriers to engaging with or managing health through technology, and strategies to address these barriers

1. Lack of control over personal health information on eHealth records

2. Attitude and skills around technology

3. Not using technology to manage health

4. Not interested in technology (emotive)

5. Unaware of eHealth

6. Prefer face-to-face health information

Communication strategies: Facts on eHealth around security, such as who can access, how to use, and how to have control over information

Software strategies: Easy passwords with prompts to access information and websites; easy to navigate websites and simple, clear information and links; get the people who will be using the software to design and test it

Education strategies: Education on how to use technology (computers, iPads, smartphones, the internet); face-to-face and online tutorials on how to use websites and access good quality health information online

Practitioner strategies: Facilitation of eHealth through information and educating patients or managing on their behalf

7. Misleading information on the internet

8. Inflexible technology

10. Security concerns around eHealth

12. Issues using government websites

14. Health system barriers

Community hub to access technology and eHealth information

9. Access (coverage issues or no internet)

11. Lack of access to timely and appropriate health services

13. Previous bad experiences with healthcare providers or services

15. Navigating the health system

Individual level themes   System level themes

Enablers

Six themes related to enablers to improve engagement or management of health through digital technologies were extracted from the data (Table 2). Again, these were divided into enablers at the individual and system levels, with a third category of enablers for communities or families.

Enablers at the individual level were drawn from the experiences of people who already used digital technology to manage their health (e.g., through smart phone applications or online health management systems), experienced or perceived benefits of managing health information in an eHealth record, and experiences that sharing online health information is safe and necessary.

At the system level, enablers included face-to-face training on eHealth systems, simple websites, easy passwords, linked health information all in one place, as well as practitioners helping to manage individuals' health by navigating the health system for them. Some participants also discussed the value of family or friends managing their health through technology on their behalf.

The enabler at the family level reflected the concept of distributed health literacy where support for health management and decisions is distributed through a community or family and is not solely within the responsibility of one individual (12).

Managing health through technology was raised by about half the participants. Participants discussed approaches that helped them to manage their health included using technology to navigate the health system and to find health services or find reviews of health services; managing or monitoring health through smart phone applications; and using online health services for convenience. Participants also discussed the use of the Internet to search for information about symptoms prior to and after seeing a GP to improve conversations and follow-up care. They felt it empowered them to ask specific questions when seeing health care providers and / or decisions post appointment.

Table 3 Themes from semi-structured interviews – enablers to use of eHealth services

Individual level themes - enablers
16. **Managing health through technology**
• Using technology to navigate the health system to find health services or find reviews of health services
• Using technology to manage or monitor health such as health apps
• Using online health services for convenience to manage health
• Using the Internet to search for information on symptoms to have conversations with GP pre consultation
• Using the Internet to search for more information on conditions or medications post GP consultation
17. **Benefits of eHealth records**
• Health records and information in the one place, easier for GPs and patients to manage health
• Easier to manage individual health or family's health through online records
18. **Sharing of health data is safe**
• Online personal health data is secure
• Not worried about sharing online health information or privacy of health information
• 'Nothing to hide' in terms of personal health information online
System level themes - enablers

19. **Health System supporting management of health**
    - Healthcare providers managing appointments or navigating the health system for patients
    - Specialists attending rural areas
    - Health services close by and accessible
20. **Enabling people to use technology to manage health**
    - Face-to-face training about how to use technology to manage health
    - Simple website layout, easy passwords, easy to find websites with linked information in the one spot
    - Publicity about what eHealth systems are available and how to use them

Community / family level themes - enablers

21. **Social support to facilitate managing health or using technology**
    - Supported health or eHealth management / engagement through friends or family in health field
    - Friends or family supporting technology use

Figure 23 Concept Map of enablers themes and strategies by individual or system level factors
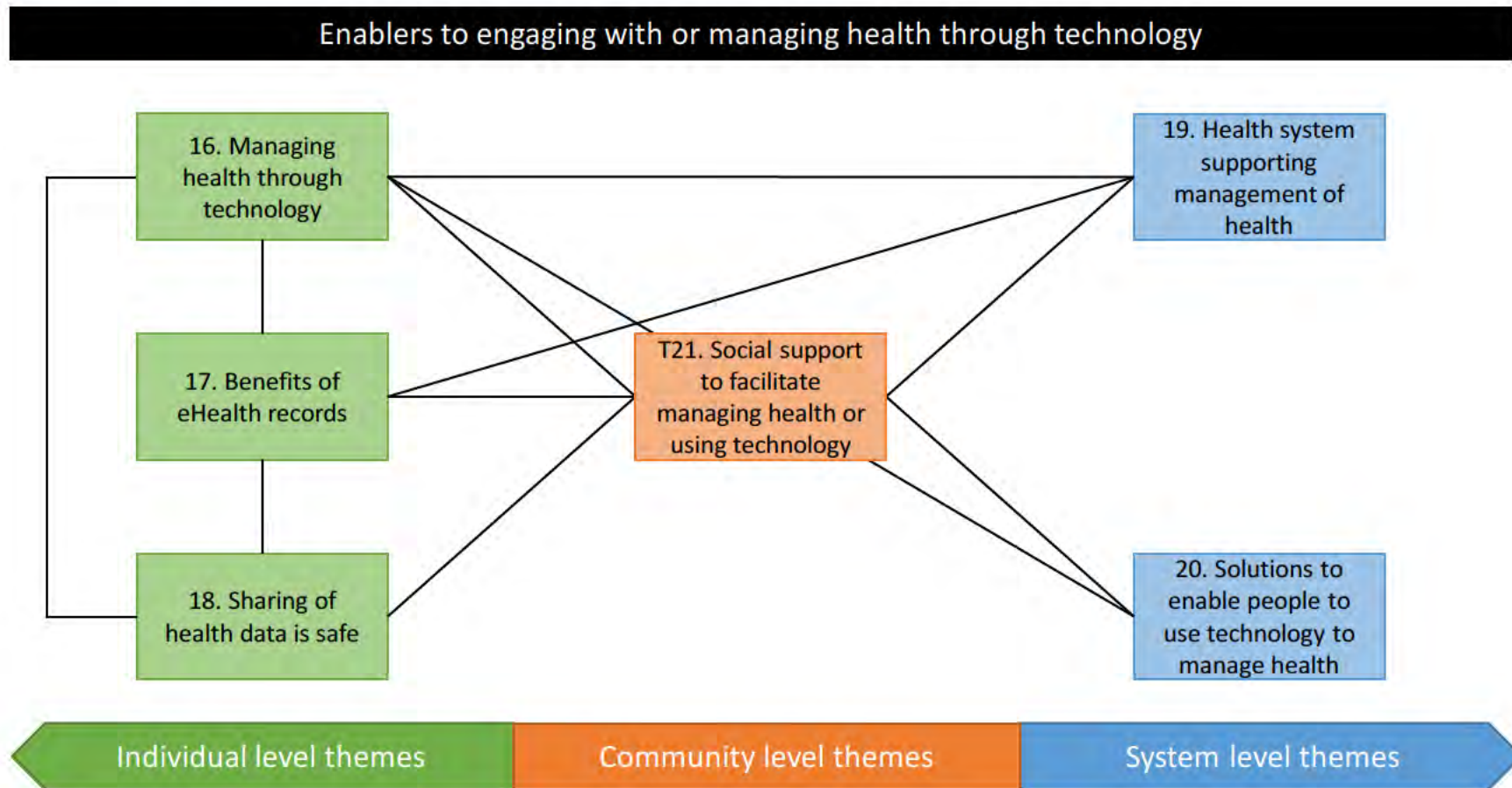
The lower triangular matrix, as described earlier in the report, indicates relationships between themes and indicates the connector lines between themes. Connectors between themes have been shown in the enablers to engaging with or managing health through technology see Appendix G.

Unsolicited comments in semi-structured interviews about My Health Record

The semi-structured interviews did not specifically ask about MyHR. However, there were instances when MyHR was mentioned by participants. These comments, where relevant, were coded separately as barriers or enablers to using MyHR. Types of barriers and enablers were grouped together to form categories and themes. The MyHR barriers and enabler themes and select key quotes are listed along with participant IDs, and the number of participants in Appendix F.

Themes from unsolicited comments - barriers to using MyHR

1. Security concerns / lack of trust in government / others accessing information
2. Don't know how to use MyHR, how to access, what is stored, how to have control
3. Don't see the need for MyHR
4. Incompatible / inconsistent systems
5. Software difficult to use - passwords
6. Unable to manage records for children

Themes from unsolicited comments - enablers to using MyHR

1. Healthcare provider access for timely and appropriate care
2. Managing health for family
3. Nothing to hide - not concerned about security

My Health Record barriers from unsolicited comments about MyHR

Within the 50 semi-structured interviews, 16 participants noted barriers for them to access and use MyHR. The main barrier for these participants was the security concern (expressed as a lack of trust in government) that their information would be available to other organisations (6 participants). Four participants said that they did not know how to access or use MYHR, and did not know what is stored on MyHR or how they have control over their information.

My Health Record enablers from unsolicited comments about MyHR

Within the 50 semi-structured interviews, 12 participants expressed ideas to supporting the use of MyHR: 7 of these indicated that healthcare providers having access for timely and appropriate care outweighed any security concerns they had. One participant said that MyHR was a good way for her to manage the health of her elderly mother, and four participants said that they didn't mind if their health information was online or if it was hacked because they had nothing to hide and were not concerned about security.

Workshop results

30 participants from the community took part in three co-design workshops, and 32 professionals took part in three workshops (i.e., six workshops in total). Each workshop was conducted over two hours with four held in Ballarat and two in Daylesford.

5 vignettes presented at each workshop. The aim of the workshops was to generate response ideas to the issues embodied within each vignette. In each workshop, participants were asked four key questions:

1. Does this person seem to be like someone you know?
2. What issues can you identify about this person's use of digital health technologies?
3. What could be done to help improve things for this person?
4. Given that there are many people like this in your community/ practice, what could be done to support them?

Detailed notes of all ideas were taken by two note takers and the workshops were audio recorded. The ideas were grouped into themes and subthemes (a process usually called 'coding') using NVivo. While questions 3 and 4 are the main questions about intervention ideas, within a dynamic discussion intervention ideas came up at each stage just as issues and problems people face with the use of digital health technologies could be raised during the discussion of any of the questions.

Table 4 Health professionals attending workshops

4th Dec - Ballarat	5th Dec - Ballarat	6th Dec - Daylesford	
Psychologist	Emergency Nurse	Pharmacy Clinical Advisor	
Prostate Cancer Specialist Nurse	Nurse - Acute & Community	Pharmacy Manager	
GP Practice Manager	Manager Psychologist	Nurse	
Surgeon	Psychiatric Nurse	Primary Care Consultant	
Clinical Nurse Manager	Social Worker	Primary Care Nurse	
Nurse	Primary Care Consultant	Practice Nurse	
Emergency Nurse	Pharmacy	Pharmacist	
Emergency Nurse	Pharmacy	Pharmacist	
Senior Critical Care Nurse	Physiotherapist	Speech Pathologist	
Pharmacist	GP	Community Health Nurse	
Pharmacy Manager	Podiatrist		
11	11	10	32

Organising intervention ideas from the workshop

Across the six workshops, more than 400 statements were produced about things that would help the people portrayed in the vignettes or people with similar eHealth literacy profiles. While we refer to all of the ideas as 'intervention ideas' they can vary from small specific ideas that are best viewed as a component of a package (e.g., a doctor should offer a simple way of starting that is not threatening; e.g., offering just to upload medicines and allergies information) to more complete and self-contained intervention ideas (e.g., should engage U3A, neighbourhood houses, Men's Sheds etc to give people confidence using computers including for health). In developing implementable intervention ideas, it is often useful to group all of the ideas that focus on a particular setting or

agency together; e.g., all the ideas related to general practice. A proposed intervention may include many of the ideas from the workshop such as the content of training for GPs and their staff.

For this reason, it is important to organise the large number of ideas into groups that have a similar point of action and have the potential to be combined into an integrated intervention package. Figure 24 and Figure 25 show the results of this organising process.

Figure 24 is a mind-map that shows the final coding system. There are nine top-level categorisations that could be considered points of action or sets of actions. Any one idea from the workshops could be coded into more than one category. For example, many of the ideas related to the 'process of engaging' people in digital health technologies, including MyHR, can be effectively implemented by medical practitioners and so many of these statements were included in both groups. Where there is a strong overlap between two of the top level categories, we have shown a relationship with an arrow.

Figure 24 Mind-map of solutions from workshops

Trusted sources of info

Organizations that manage or promote digital health technologies at any level (including health services)

Expectations of what will happen
Opinion leaders
Process of introduction-publicization
Thoughts on what is already happening
Uncertain perceptions-anxieties
Understanding benefits

Managing public information and perceptions

Legal controls of access
Offer alternative options (not dependant on ICT)

Policies-laws-regulation

Balance between doing it yourself and talking to professionals
Doctors and practices facilitate
Embedding in normal-familiar to reduce anxiety about change
Practitioners make own diagnoses-fix info
Practitioners understanding of MHR

Health practitioners

Develop IT skills
Discuss benefits and risks use with family
Other family members do or assist

Individual & family

eHealth Solutions

Process of engaging
Gentle, stepwise, flexible process
Interact with provider
Interact with technology or not
Social process
Timing (Opportunism-teachable moment)

Understanding target groups
Low health literacy
Low IT capability/access
Remote
People with a disability
Mental health

Community based activities
Community support training for use of computers
Context of engagement - place, social, purpose
General community supportiveness

Features of the digital technologies
Benefits-uses clear
Easy problem solving
Experiences-synergies with other digital health tech
Functionality of technology
Information quality, fixability
User friendliness, obviousness
Control of what information is put on
Control over who accesses

During the workshops it became clear that it is possible to think about the way in which people engage with digital health technologies as a journey involving several stages, and that people could face different issues at each stage. Figure 25 shows important issues or situations that people may encounter at each stage of engaging with digital health technologies and the MyHR. These issues and situations were drawn from both the discussions in the workshops and the analysis of the semi-structured interview data presented previously. The boxes in the diagram are described as 'issues or situations' rather than 'barriers and enablers' because most of them can be either a positive or a negative and some can be a combination of both. For example, 'remoteness' or 'having a disability' can both be a challenge to accessing digital health services but the semi-structured interview data also revealed that these factors can also be powerful motivators for why people wish to engage with digital health services.

The diagram starts with a pre-existing situation such as the digital health experience, relationships with health service providers and preferred healthcare interaction, and health literacy style. It then continues onto the initial contact which includes the mode of contact then onto the introductory experiences such as news stories or public education, information etc. Following on from here is a decision about 'is it for me', which includes understanding potential benefits in a personal way or what do I need to do and can I do it. The Figure then moves to experiences of use, which encompass attributes such as is the system user friendly and successful, and finally to getting the benefit where stories of benefit are shared. In Figure 25 the journey is organized in six stages:

1. Pre-existing situation
2. Initial contact
3. Introductory experiences
4. Is it for me?
5. Experiences of use
6. Getting the benefit.

In developing interventions that are really focused on the diverse circumstances and needs of people in the community, we need to understand the different situations that people may face at each stage and we need to have strategies to respond to these situations.

Table 5 combines two methods for organising the ideas, grouping the ideas by the point of action, and grouping by stages of peoples' journeys into use of digital health technologies. No attempt has been made to fill in every cell in the table, nor is the table comprehensive. Rather, the table provides examples of the ideas that came from the workshops to illustrate the value of a strategic approach that is integrated across both different levels of action (system design, mass communication, engaging health professionals, and engaging the community) and across the different journeys that people might experience as they engage with digital health technologies.

Figure 25 Journey into engagement with digital health technologies and MyHR

Pre-existing situation	Initial contact	Introductory experiences	Is it for me?	Experiences of use	Getting the benefit
Digital health experience	Media/mass communication	News stories	Understanding potential benefits in a personal way	User friendly and successful	
Health service experience/ relationships		Public education, information		Integrated into familiar and preferred health care	
Preferred healthcare and health literacy style		Discussion with health provider – self management orientation	Trust the technology and process		Stories of benefit are shared
		Discussion with health provider – 'we can help' orientation	Trust the information and potential users	Easy problem solving	
Access to technology	Health professional/service	Introduced in health education program		Able to check the accuracy of data and get errors fixed	People are aware of situations where they benefit
IT interest and ability		General discussions with friends or family	What do I need to do and can I do it?		
Scepticism/trust in government and other agencies		Practical exploration with friends or families in the context of a meaningful activity	Will it affect my relationship with my doctor or other health provider?	Convenience for things that are important to me	
Particular groups (e.g. aged, people with a disability, remote)	Social setting	Connection with familiar use of digital health technology		Informed when a provider uses the data	

Table 5 Example intervention ideas by stages

Pre-existing situation	Initial contact	Introductory experiences	Is it for me?	Experiences of use	Getting the benefit
Design/characteristics of the technology and system:					
• System needs to be very simple to be accessible to people with very different e Health Literacy profiles • System needs to recognize that many people have poor internet access and may prefer other platforms	• Need to recognise that people may be stimulated to interact with MyHR through diverse means and that the first interaction should convey a simple understanding of benefits and processes	• [Exploration mode with dummy data that could be used by consumers or in groups to explore how the system works and potential benefits] • Links or interfaces with government operated data systems that people are familiar with	• Very simple front-end explanation of potential benefits and options of levels of engagement (from completely provider driven to extensively controlled and used by the consumer themselves) • Easy access to Frequently Asked Questions and to other means to ask questions	• Very simple and rapid problem solving including an option of contacting a person	• N/A
Media, mass communication:					
• Need to recognize pre-existing scepticism that some people have about governments holding data. • Need strategies to overcome perceptions that digital equals self-service equals a loss of personal service	• Information services need to provide phone numbers for questions not just websites	• Encourage discussion with healthcare providers • Present options for types and levels of involvement	• Very clear information through multiple sources on provisions for data security and accuracy; preservation of normal interactions with providers; and benefits	• N/A	• Concrete stories of consumers receive a benefit to health outcomes or convenience should be shared
Health providers:					
• Health providers can help reduce fear that MyHR might undermine the provision of personal care • Health professionals can reassure people who do not want to be pre-judged that they will make their own assessment	• Recognize that diverse health providers could be the first point of contact with MyHR. Need to provide training and resources to a range of providers including GPs, pharmacists and others on how to introduce	• Doctors, practice staff and other providers trained in ways of sensitively and gently introducing MyHR • Provide opportunities to explore at doctors surgeries and pharmacies	• Health providers trained and provided with materials to explain a range of potential uses from an in-the-background extension of normal care to a tool that can help with a range of circumstances like getting medicines, receiving other services and travel • Assist consumers to check accuracy of information	• Health providers explain what data is uploaded and negotiate what consumer does and doesn't want uploaded • Present MyHR as an extension of normal care not a replacement • Tell patients if they have accessed data	• People need to be notified by health providers when the health provider has accessed the information and how it was beneficial

	MyHR accurately and gently			and explain that they will make their own assessment	
Community-based approaches:					
• Many community organizations have an important role in building community familiarity and confidence in interacting with computers and digital technologies, including government systems like MyHR	• Provide community organizations with accurate information and resources to discuss MyHR	• Provide opportunities to explore MyHR in public facilities like libraries and neighbourhood houses. Provide training to staff.	• Provide community groups with accurate information on management of risks, benefits and how to engage in a non-threatening, non-burdensome way	• [Provide community groups with resources that encourage and guide them in discussing experiences of use of MyHR]	• Community groups can encourage each other by sharing their experiences including experiences of benefit

Issues arising from workshops that require an integrated approach

Thus far, the analysis and presentation of intervention ideas from the workshops have focused on organising the ideas in terms of the main point of action. There were, however, issues that were repeatedly identified and linked with multiple possible points of action (i.e. an integrated, systemic approach is indicated). Three of these key issues were:

4. The need to assist people to understand potential benefits, the relevance of possible benefits and to weigh benefits against possible risks

5. The need to address a range of concerns about how MyHR and other development in digital health technologies may impact on familiar and valued processes of care (especially relationships with GPs)

6. The fact that some of the people who might experience the greatest challenges engaging with MyHR may also be the people who have greatest need of the support that it offers and greatest capacity to benefit.

This section discusses these three issues and the recommendations section seeks to piece together the various ideas proposed in the workshops to suggest features of an integrated approach to each issue. Intervention ideas from the workshops about these three issues were presented in the Category 1 recommendations).

1. Assist people to understand potential benefits, the relevance of possible benefits and to weigh benefits against possible risks

Across all of the groups, the need to clearly identify the benefits of participation in MyHR was the most commonly identified need. Group members identified this need not only for the people in the vignettes but, in many cases, for themselves as well. Potential benefits that were discussed can be grouped into a several categories:

- Safety benefits for emergency situations
- Convenience and reduced waiting times in emergency departments
- Healthcare while traveling
- Reduced paperwork when using new services
- Reduced need to explain things to new doctors or services.

In addition, participants raised the possibility of other benefits if the system can be integrated with other systems such as:

- pharmacy systems to streamline ordering of medications and to support special arrangements for provision of medications (e.g., provision of multiple refills at one time)
- systems for making medical appointments.

While an opt-out system may lead to greater participation overall, one effect has been to focus the debate on 'why should I consider opting out?' which leads to a focus on risks as has been seen in the public debate. An opt-in system may have led to a greater focus in the public debate on 'why should I opt in?' (i.e., a focus on the potential benefits of MyHR).

Many participants in the workshops were unaware of what the benefits could be and emphasised that the benefits need to be explained in very concrete ways, illustrated by stories of real people and circumstances. In addition, several people requested a tool that would enable them to easily see the possible benefits and risks.

2. Address concerns about the potential impact of developments in digital health on familiar and valued processes of care

While there were many anxieties about MyHR identified in the workshops (security, accuracy, appropriate use) there was an additional concern that underpinned many of the issues discussed in the workshops, this was the concern that MyHR may be forcing people to engage in a new process of 'self-service' care that may undermine the personal care that they are used to. Analogies were made with self-service petrol stations and supermarkets. This was also expressed as a concern that in order to effectively interact with the healthcare system people will need to learn computer skills and organise computer access or else they will be at a disadvantage. Many participants were unaware that the system could be used, and provide benefits to them, without them needing to engage with the technology at all just by discussing with the doctor what would be uploaded.

Several participants also identified that they themselves believed, or thought that many people believed, that many of the functions of MyHR already occurred. For example, that hospitals could already easily get access to the medications that their doctor had prescribed. For these people the relatively passive components of MyHR were thought to be already occurring while their perception of the active features of MyHR was seen as frightening or burdensome and a possible intrusion into the face-to-face, personal care that they prefer.

Several doctors and practice staff who attended the workshops reported on how they have introduced MyHR in a very gentle and minimal way: 'would you mind if I upload your medications and allergies just in case you have to go to a hospital or emergency department at some time?'

There is a need for processes and practices that help people to think of MyHR as an extension of their personal care and of the doctor's steering of their care, rather than as a burdensome alternative that puts the face-to-face care that they value at risk.

3. Providing opportunities to people with substantial barriers to engagement who also have high capacity to benefit

In several of the workshop groups, an interesting process occurred while discussing the fourth and fifth vignettes, which related to clusters of people with generally low eHealth literacy. The fourth vignette presented a case of a lady who just wanted her GP to manage her care. The fifth vignette described someone who has experienced a loss of social supports and has relatively low confidence in using IT but who is still trying to care for himself despite the sadness and loneliness of his life.

In most cases, the participants' discussion of the vignettes opened with the view that these people should not be pressured to participate in something that they are not interested in. However, as the discussion proceeded, someone usually pointed out that these people may also benefit from MyHR because they may have difficulty explaining all of their conditions and treatment to other health providers in emergency situations – MyHR can reduce the challenges of remembering and explaining, and can potentially improve the safety and quality of the care that they receive.

For people like these, there is a need to balance two imperatives, and their situation can be looked at in two ways. One way of looking at it is that people should not be pressured into engaging with a system that they are not interested in or that they find intimidating. The other way is that we should not just assume that someone is not interested or incapable of engaging (because of age,

circumstances or some other characteristic) and thus deny them important benefits that others in the community receive.

In addition, many barriers to engagement are real and practical such as poor internet connections, low levels of computer skills, and the unaffordability of technology. These can be exacerbated for people who live in remote areas and people who have difficulty travelling. Enabling all people, including those most in need, to participate in and benefit from digital health technologies requires a range of highly flexible approaches.

Limitations of the study

There are several limitations to this study that may impact on the generalisability of the findings. The presence of MyHR in the media around the time of data collection. From October to December 2018, there was substantial media coverage about MyHR due to the opening and then extension of the MyHR opt-out period between July 2018 and January 2019. It is therefore possible that, while MyHR was not mentioned until the end of the CATI survey, and was not initiated in discussions by interviewers within the semi-structured interviews, that participants were thinking about the MyHR when they responded to questions pertaining to their experiences with health technologies. This may mean that knowledge about whether or not a participant had a MyHR was higher in this sample than it may have been at a different time, and may have altered the association between a participant's eHealth literacy score and their MyHR knowledge, uptake and usage.

Our initial sample of 1000 participants for the CATI survey, which was used to draw a sample for the subsequent semi-structured interviews and workshops, was limited to adults who had a landline or mobile telephone number registered to a postcode in the Ballarat Goldfields region of the WVPHN. Consequently, individuals who do not have access to a phone, who lived in the region but had a phone registered to a different postcode, or have an unlisted number, were not eligible to be sampled. Such individuals may have different experiences with health technologies and services to the eligible population, and these experiences are not captured in our data.

It was not possible to directly compare the population of the Ballarat Goldfields region and the CATI survey sample; as such, comparisons were made to the entire WVPHN region. We therefore make the assumption that the Ballarat region population and the WVPHN is not dissimilar.

There were some differences between the demographics profile of the CATI survey sample and the demographics profile of all residents of the WVPHN catchment region (the target population of the study Table 16). While the CATI survey sample had a similar proportion of people who identified as Aboriginal or Torres Strait Islander and a similar proportion of women (54% compared to 51%), it also had a substantially higher proportion of those aged 55 to 70 years (39% compared to 19%) and aged over 70 years (41% compared to 13%). The impact of this discrepancy is that our findings are not generalisable to the entire general adult population in the Ballarat Goldfields region of the WVPHN due to lower representation from younger people (aged less than 55 years). It is important to note that this study sought to understand people's experiences, limitations and suggestions for improvement regarding eHealth services in the region. Given that most chronic diseases and conditions occur in mid to late adulthood, the study was strongly represented by the highest user groups. The CATI survey sample also has a higher proportion of individuals with a tertiary education compared with residents of the study region (31% compared to 14%). The comparator demographics for the study region are calculated for that population, which is primarily aged less than 55 years, so it is unclear if the distribution of highest educational attainment in the CATI survey sample is representative of members of the WVPHN region who are over 55 years.

Notwithstanding these caveats, the main data synthesis process for this study was the data derived from the co-design workshops. The workshops were informed by vignettes derived from cluster analysis. The cluster analysis segments the population into subgroups based on patterns of eHealth literacy and associated demographic factors. This process enabled the co-design workshops to

provide feedback on a wide range of people across the community, which helped to increase the representation of disadvantaged groups.

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Appendix A Computer Assisted Telephone interview (CATI)

DEAKIN
UNIVERSITY

Participant ID: _____

Understanding Digital Health and Health Information Questionnaire

Thank you for taking the time to complete this questionnaire.

We hope the results will help improve the way care is provided to people in our community.

We want to learn from you about how you find, understand and use health information, how you manage your health, and how you communicate with doctors and healthcare providers using digital technology.

Definitions

Health professionals/ Healthcare providers
People who provide health advice and treatments to you. They may include doctors, nurses, dentists, dieticians, physiotherapists, nurses, psychologists or any other health workers.

Digital health technology/ Health technology services
Electronic devices or online services you use to find, show, record or manage health information, or to contact health providers. They may include mobile phones, computers, tablets, monitoring machines, smart watches, electronic health records, doctor's websites, and other health websites.

The following questions are about the use of electronic devices and services as part of your healthcare. When answering these questions, we would like you to think back over the past few months.

Please indicate how strongly you disagree or agree with each of the following statements.

Please check only one box per statement by crossing it like this: ☒

Section 1.		Strongly Disagree	Disagree	Agree	Strongly Agree
1	I am sure that my health data are being used only by those who are supposed to use it		☐	☐	☐
2	Technology makes me feel actively involved with my health	☐	☐	☐	☐
3	Information about my health is always available to those who need it		☐	☐	☐
4	I know how to use technology to get the health information I need	☐		☐	☐
5	The knowledge I have helps me to have good conversations about health		☐	☐	☐
6	I know how to make technology work for me	☐	☐	☐	☐
7	I use technology to find information about health		☐	☐	☐
8	I can enter data into health technology systems	☐	☐	☐	☐
9	My healthcare providers deliver services that I can access through technology		☐	☐	☐
10	My electronic healthcare data are being stored safely	☐	☐	☐	☐
11	I often use technology to understand health problems		☐	☐	☐
12	I have enough information to take part in conversations about my health	☐	☐	☐	☐
13	Technology helps me decide what health care is best for me		☐	☐	☐
14	I have a clear understanding of how healthcare providers use my data	☐	☐	☐	☐
15	I understand medical results about me		☐	☐	☐
16	My health data are available to me wherever I am	☐	☐	☐	☐
17	I quickly learn how to find my way around new technology		☐	☐	☐

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		Strongly Disagree	Disagree	Agree	Strongly Agree
18	I find that health technology services adapt to my skills	☐	☐	☐	☐
19	I find technology helps me take care of my health				
20	I use technology to share information about my health	☐	☐	☐	☐
21	Overall, I understand how my body works		☐	☐	☐
22	I am sure that only authorised people can access my health data	☐	☐	☐	☐
23	All the health technology I use works together		☐	☐	☐
24	I find I get better services from my health professionals when I use technology	☐	☐	☐	☐
25	I use technology to organise my health information		☐	☐	☐
26	I use measurements about my body to help me understand my health	☐	☐	☐	☐
27	Technology improves my communication with health professionals		☐	☐	☐
28	I find health technology services seem to adapt to my individual needs	☐	☐	☐	☐
29	Most of my healthcare providers can be accessed through technology		☐	☐	☐
30	I am confident that healthcare providers use my data appropriately	☐	☐	☐	☐
31	I find health technology services are provided to me in a way that suits me		☐	☐	☐
32	I easily learn to use new health technologies	☐	☐	☐	☐
33	Health technology services provide me with easy ways to get what I need		☐	☐	☐
34	I have access to health technology that works	☐	☐	☐	☐
35	I find technology useful for monitoring my health		☐	☐	☐

Please continue to the next page

Please check only one box per statement by crossing it like this: ☒

Section 2.		Strongly Disagree	Disagree	Agree	Strongly Agree
1	I have at least one healthcare provider who knows me well	☐	☐	☐	☐
2	I set my own goals about health and fitness		☐	☐	☐
3	If I need help, I have plenty of people I can rely on	☐	☐	☐	☐
4	I have the healthcare providers I need to help me work out what I need to do		☐	☐	☐
5	Despite other things in my life, I make time to be healthy	☐	☐	☐	☐
6	I can rely on at least one healthcare provider		☐	☐	☐
7	When I feel ill, the people around me really understand what I am going through	☐	☐	☐	☐
8	I have strong support from family or friends		☐	☐	☐
9	I spend quite a lot of time actively managing my health	☐	☐	☐	☐
10	I have at least one healthcare provider I can discuss my health problems with		☐	☐	☐
11	I have at least one person who can come to medical appointments with me	☐	☐	☐	☐
12	I make plans for what I need to do to be healthy		☐	☐	☐
13	I can get access to several people who understand and support me	☐	☐	☐	☐
14	There are things that I do regularly to make myself more healthy		☐	☐	☐

Please continue to the next page

Please check only one box per statement by crossing it like this: ☒

Section 3.	Cannot do or always difficult	Usually difficult	Sometimes difficult	Usually easy	Always easy
1 Find the right health care	☐	☐	☐	☐	☐
2 Get to see the healthcare providers you need to	☐	☐	☐	☐	☐
3 Decide which healthcare provider you need to see	☐	☐	☐	☐	☐
4 Make sure you find the right place to get the health care you need	☐	☐	☐	☐	☐
5 Find out which healthcare services you are entitled to	☐	☐	☐	☐	☐
6 Work out what the best care is for you	☐	☐	☐	☐	☐

Some information about you

1. What is your year of birth? _____

2. What is your gender? ☐ Female   ☐ Male   ☐ Other

3. What is your post code? _____

4. Do you speak English at home? ☐ Yes   ☐ No

5. Do you identify as Aboriginal or Torres Strait Islander?

   ☐ Yes   ☐ No

6. What is the *highest* level of education you have attained? (Check only one box)

   ☐ Did not finish primary school

   ☐ Completed primary school

   ☐ Completed Year 10

   ☐ Completed Year 12

   ☐ Completed a trade certificate, apprenticeship, Diploma or college/TAFE certificate

   ☐ Completed a university degree or above

Please continue to the next page

7. Overall, how would you rate your health during *the past 4 weeks*? (Check only one box)

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

☐ Very poor

8. Do you have a long-standing illness or disability? (Check all boxes that apply)

☐ Arthritis

☐ Asthma

☐ Cancer

☐ Cardiovascular disease / heart problems

☐ Diabetes

☐ Anxiety

☐ Depression

☐ Chronic pain

☐ Other (please specify)

☐ None

9. *Within the past 12 months*, have you used the Internet to search for health-related information? This could include information on an injury, a disease, illness, nutrition, improving health etc.

☐ Yes, once a week or more often

☐ Yes, several times a month

☐ Yes, approximately once a month

☐ Yes, approximately once every two months

☐ Yes, a few times within the past year

☐ No, never

☐ Don't know / Not applicable

Please continue to the next page

10. If *Yes* to Q9: How do you tend to access online health services? (Check all boxes that apply)

☐ Smartphone

☐ Tablet or iPad

☐ Computer

☐ Other (please specify)_____

11. If *No* to Q9: Why don't you use online health services? (Check all boxes that apply)

☐ I don't know how to

☐ I don't know what's out there

☐ I don't want to

☐ I'm not sure I'd get what I need

☐ I can't afford it

☐ I don't have the right technology (equipment)

☐ I'm not confident enough to use computers/smartphones/iPads

☐ I'm not confident I'd be able to understand the information by myself

☐ I prefer face-to-face interaction with health services

☐ Other (please specify):_____

12. *Within the past 12 months*, how frequently have you consulted a health professional? Please include consultations as a carer if relevant.

Remember that health professionals are people who provide health advice and treatments to you. They may include doctors, nurses, dentists, dieticians, physiotherapists, nurses, psychologists or any other health workers.

Have you consulted a health professional…

☐ More than 12 times in the past year (that is, more than once per month)

☐ About 7 to 12 times

☐ About 2 to 6 times

☐ About 1 time

☐ Not at all in the past year

If you have consulted a health professional, what type of professional are they:

_____

13. Do you have a My Health Record?

    ☐ Yes   ☐ No   ☐ Not sure

14. If *Yes* to Q13: Do you use your My Health Record?

    ☐ Yes   ☐ No

15. If *No* to Q14: Do you intend to use your My Health Record?

    ☐ Yes   ☐ No   ☐ Not sure

16. Do you have any final comments about using digital health technologies?

    _____

    _____

Note: If respondent asks for more information about My Health Record, refer them to MyHR HelpLine on 1800 723 471 or website www.myhealthrecord.gov.au

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Future research

We will be doing more research to understand people's individual experiences when using digital technology for health. Are you interested in taking part in future research activities about this topic?

I agree to be contacted to discuss taking part in a 30-minute telephone interview to talk about my experience of using technology for health.

Yes   No

I agree to be contacted to discuss attending a 2-hour workshop with other community members to discuss ideas to improve services related to digital technologies.

Yes   No

If you agree to be contacted for either of the above activities, please provide your name, telephone number and/or email address:

Note: We will seek to include a wide range of people (up to 80) in the interviews and workshops, this includes across men and women, young and old, well and unwell and other information collected in this survey. If you consent to undertake further research, you may or may not be contacted. **Please advise your preferred day / time to be contacted.**

Name: _____

Phone number: _____

Email address: _____

Thank you for completing this questionnaire.
We appreciate you giving your time to support this research.

eHLB Questionnaire – version 2 25.09.18   The eHealth Literacy Questionnaire (eHLQ) ©2016

Appendix B Semi-structured interview schedule

Hello [client name]. My name is [your name] and I am a researcher from Deakin University. I'm calling to interview you about the recent telephone survey you completed where you kindly gave your name and phone number so that I could give you this call. Are you free now to talk or would you prefer I call you back at a specific time?

Your decision to participate or not to participate WILL NOT affect your relationship with any health services you attend or Deakin University in any way. Your participation in the interview is voluntary. If you agree to take part in an interview, you have the right to withdraw from the interview at any time, without giving any reason. You can withdraw during the two weeks after the interview date by contacting Crystal McPhee on 9244 6292. If you have any complaints or questions you can contact the Research Integrity department at Deakin University on 9251 7129.

Purpose: the main purpose of these semi-structured interviews is to explore the narratives behind why participants have answered questions from the survey in the way that they did. This information will be used to provide context for vignette development.

The information you give will contribute to the work we are doing in understanding healthcare, including your thoughts about digital technologies. Topics include; how you use digital health information, how you engage with digital services and how you access digital health services.

It will take us about 15-30 minutes to talk about the questions. There are no right or wrong answers, so please answer the questions based on your own experiences. If you need to stop at any time, just let me know.

If you feel distressed free counselling services such as lifeline are available. You can contact them on 13 11 14.

You will be given the opportunity at the end of the interview to be included in the prize draw to win a $50 supermarket voucher.

Do you understand the participant information that has been read to you? Yes > continue.   No > ask participant what they wish to have clarified.

Do you consent to being recorded for accuracy and writing up your responses? You will not be identified in any way. Yes > continue.   No > discontinue

Finally do you consent to participate in the interview? Yes > continue.   No > discontinue. (thank the participant for their time and advise the conclusion of the interview).

Before we begin I will give you the definition of digital health technology

Definition - digital health technology/ Health technology services

Electronic devices or online services you use to find, show, record or manage health information, or to contact health providers. They may include mobile phones, computers, tablets, monitoring machines, smart watches, electronic health records, doctor's websites, and other health websites

Electronic devices or online services you use to find, show, record or manage health information, or to contact health providers. They may include mobile phones, computers, tablets, monitoring machines, smart watches, electronic health records, doctor's websites, and other health websites

1. Using technology to process health information

Be able to use technologies to read, write and remember, apply basic numerical concepts, and understand context-specific language (e.g., health, IT or English) as well as critically appraise information.

- *Do you use technology to find information about health – tell me about why or why not.*
- *What difficulties do you have using technology for your health information?*
- *What might help you use technology for your health information?*

I use technology to find information about health

I often use technology to understand health problems

Technology helps me decide what health care is best for me

I use technology to share information about my health

I use technology to organise my health information

2. Understanding of health concepts and language

Know about basic physiological functions and own current health status. Aware of risk factors and how to avoid them or reduce their influence on own health.

- *Do you feel you have enough knowledge to have good conversations about health –why or why not do you think this is the case*
- *What difficulties do you have understanding health information such as risk factors and their influence on your own health?*
- *What might help you understand health information such as risk factors and their influence on your own health?*

The knowledge I have helps me to have good conversations about health

I have enough information to take part in conversations about my health

I understand medical results about me

Overall, I understand how my body works

I use measurements about my body to help me understand my health

3. Ability to actively engage with digital services

Being comfortable using digital services for handling information.

- *Do you feel that you know how to use technology to get the health information you need*
- *What would help you to feel more comfortable with using digital health services?*

I know how to use technology to get the health information I need

I know how to make technology work for me

I can enter data into health technology systems

I quickly learn how to find my way around new technology

I easily learn to use new health technologies

4. Feel safe and in control

Feel that they have the ownership of personal data stored in the systems and that the data are safe and can be accessed only by people to whom they are relevant (own doctor/nurse etc.).

- ***Do you feel you that you have ownership and control of personal data stored with health systems and health professionals?***
- ***What would help you to feel more comfortable with this?***

I am sure that my health data are being used only by those who are supposed to use it

My electronic healthcare data are being stored safely

I have a clear understanding of how healthcare providers use my data

I am sure that only authorised people can access my health data

I am confident that healthcare providers use my data appropriately

5. Motivated to engage with digital services

Feel that engaging in the use of digital services will be useful for them in managing their health.

- ***Do you feel actively involved in your health through technology? Why or why not?***
- ***Do you feel technology helps you to take care of your health? Why or why not?***
- ***What would help you to engage with digital services to manage your health?***

Technology makes me feel actively involved with my health
I find technology helps me to take care of my health
I find I get better services from my health professionals when I use technology
Technology improves my communication with health professionals
I find technology useful for monitoring my health

6. Access to digital services that work

Have access to digital services that the users trust to be working when they need it and as they expect it to work.

- ***Do you have difficulty accessing digital services when and where you need them? Why? What would help you to do this?***
- ***What types of digital services do you access? Do you trust that these digital services will be working when you need them in the way that you expect?***

Information about my health is always available to those who need it

My healthcare providers deliver services that I can access through technology

My health data are available to me wherever I am

All the health technology I use works together

Most of my healthcare providers can be accessed through technology

I have access to health technology that works

7. Digital services that suit individual needs

Have access to digital services that suit the specific needs and preferences of the users. This includes responsive features of both IT and the healthcare system (including carers) as well as adaptation of devices and interfaces to be used by people with physical and mental disabilities.

- ***Do you think eHealth systems adapt to your individual needs and skills? Why or why not and how could they do this better?***
- ***Do you have access to** digital services that suit your specific needs and preferences? **What has helped you to have access?***
- ***What makes it difficult for you to accessing** digital services that suit your specific needs and preferences? **What would help you to do this?***

I find that eHealth systems adapt to my skills

I find eHealth systems seem to adapt to my individual needs

I find eHealth systems are provided to me in a way that suits me

eHealth systems provide me with easy ways to get what I need

Is there anything else you would like to add about e health or digital health?

Are you happy to be included in the prize draw to win a $50 supermarket voucher?

Note: If respondent asks for more information about My Health Record, refer them to MyHR HelpLine on 1800 723 471 or website www.myhealthrecord.gov.au

Appendix C Quantitative and qualitative analytical procedures

Quantitative data analysis

Responses to the CATI included the eHLQ, HLQ, demographic, service use, attitudes, and perceptions data. There are presented as means with standard deviation (SD) or as proportions, as appropriate. The data were analysed using Stata version 15 (Stata Corp. LP., College Station, TX, USA). For each eHealth literacy scale and health-literacy domain, we also calculated the mean (95% confidence interval (CI)) for the total sample, as well as according to participant demographic characteristics and health-related information. For MyHR knowledge, use and intentions, we calculated the proportion (with 95% CI) of the total sample, and for demographic and health-related sub-categories of interest.

We then used key demographic and health-related information, and eHealth literacy and health-literacy scores, to examine the predictors of MyHR knowledge (did the participant know whether they had a MyHR), uptake (among those who knew if they had a MyHR, did they have one) and use (among those with a MyHR, did they use or intend to use it).

Qualitative data coding and analysis process

Semi-structured interview data were analysed using NVivo qualitative data analysis software (13). Themes for barriers and enablers were identified for each eHLQ domain.

From here, the semi-structured interview transcriptions were coded and analysed in NVivo 12 (13). The first cycle coding was conducted using a mix of Descriptive and In Vivo coding based on the methods from Miles, Huberman, Saldana (2014). In this instance Descriptive coding was in the form of summarising a topic based on participant responses. In Vivo coding was undertaken to capture the essence of thoughts and feelings based on participant experiences (14).

Prior to commencing coding the researcher listened to each semi-structured interview at least twice and took hand written notes (memos) on each. From here these memos were grouped by consistent and reoccurring barriers, enablers and experiences of the participants. These formed the basis of the first cycle coding nodes in NVivo.

First cycle coding – based on pre-determined deductive coding approach (descriptive categories)

The first cycle coding to be undertaken using a mix of *Descriptive* (summarising a topic based on participant responses) and *In Vivo* (to capture the phrase, thoughts and feelings based on participant responses). This process was guided by the coding and analysis processes described in Miles, Huberman, Saldana (14).

Subsequent coding and analysis

Next, coding based on the study aims was undertaken. The aims of this procedure were to:

a) Identify specific barriers and enablers regarding eHealth, and where relevant, grouped by individual, practitioner, or level of the system
b) Identify any education or communication strategies that participants have discussed
c) Group identified education or communication strategies into individual, practitioner or system level factors

The research team discussed the results from the first cycle coding and a process for moving forward to further rounds of coding and analysis. Further coding and analysis was undertaken to reflect specific barriers and enablers participants experienced regarding eHealth as determined by the semi-structured interview questions. Categories were grouped to form themes and construct descriptions of themes in a

tabular format. The number of participants who were included in each theme were counted and graphs were produced to explore the frequency of barriers or enablers to technology and eHealth were discussed. See Appendix E for the extended qualitative coding process and Appendix F for the semi-structured interview results.

Workshop qualitative data analysis

Solution ideas from the workshops were collated and analysed for similar concepts and then synthesised into themed idea lists. The same or similar ideas were condensed into statements that represented common concepts. As well as collating ideas for solutions to the issues presented in vignettes, the data from workshops were analysed to identify perceived barriers, enablers and solutions to eHealth interventions. These were then collated under themes for barriers and enablers by group. This analysis was undertaken using NVivo qualitative data analysis software (13).

Appendix D Vignettes

Cluster 12 demographics, technology use and eHLQ

12 Cl #	Cl ord	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
12	2	53	56.7	52.8%	96.2%	3.0	35.8%	30.2%	1.9%	3.25	3.66	3.45	2.66	3.20	2.80	2.83

Cluster 12 & HLQ

12 Cl #	Av Age	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
12	56.7	3.49	3.38	3.33	4.09

Cluster 12 and health conditions

12 Ci #	Av # of conditions	% Cancer	% Cardio Vascular Disease	% Diabetes	% Mental Health	% Muscular skeletal	Av Freq using Health care providers	Av Self Rated Health
12	0.9	5.7%	13.2%	9.4%	1.9%	15.1%	2.8	4.5

Cluster 12 characteristics – High and confident users of digital technologies but still not sure how much they trust putting information online

Cluster 12 has an average age of 56 which is the youngest of all the clusters. 96% of people used the internet in the past year for health information which is the highest of all the clusters. Only 35% have a My Health Record which is about average across all clusters. 30% of people in this cohort are currently using or plan to use the My Health Record which is the Secord highest of the groups. Cluster 12 are using technology regularly to process health information (eHLQ scale 1) and are motived to engage with digital services (eHLQ 3, 5). However they do not feel their online health is particularly safe (eHLQ scale 4). This group have no difficulty understanding health concepts and language when having conversations about health (eHLQ 2) this was the highest of all the clusters. Compared to the other clusters they have the highest engaging with digital services and accessing digital services and also believe technology adapts to their needs (eHLQ scales 6, 7). They feel very supported by their friends and family (HLQ 4) and by their health care providers (HLQ 1). They do not have difficulty navigating the health care system to get what they need and have the highest levels of managing their health (HLQ 3). Though they report close to average rates of heart disease and diabetes this cluster has the lowest level of mental health conditions and musculoskeletal conditions (arthritis and/or chronic pain).

Cluster 12 vignette

David is a 49 year old high school teacher. He works full time and lives with his wife and twin girls who are finishing high school this year. He has no health conditions except slightly high blood pressure and feels his overall health is very good. David considers himself to be adept at using the computer and technology as he does it daily when he does teaches the students. His girls show him things often on the tablet or smart phone and send him messages regularly. He sometimes looks up exercise programs on the net and also looks for cheap vitamins. He records his exercise on an app on his phone. One of his daughters needs to have minor surgery. She has lots of allergies and while he likes the idea of having all of her health records available on-line, he has some concerns about how secure it really is.

Cluster 7 demographics, technology use and eHLQ

12 CI #	CI ord	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
7	6	117	61.1	49.6%	81.2%	1.9	33.3%	12.0%	0.0%	2.45	2.92	2.75	1.92	2.46	2.31	2.13

Cluster 7 & HLQ

12 CI #	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
7	117	61.1	49.6%	81.2%	1.9	33.3%	12.0%	0.0%	2.96	2.95	2.91	3.64

Cluster 7 and health conditions

12 CI #	# in cluster	Av Age	% Female	Av # of conditions	% Cancer	% Cardio Vascular Disease	% Diabetes	% Mental Health	% Muscular skeletal	Av Freq using Health care providers	Av Self Rated Health
7	117	61.1	49.6%	0.9	5.1%	11.1%	6.0%	4.3%	16.2%	2.5	4.4

Cluster 7 characteristics – Getting by through using technology to manage health conditions

Cluster 7 has an average age of 61 which is the fourth youngest group of all the clusters. Over 80% of people used the internet in the past year for health information which is quite high in comparison to the other clusters. Over 33% have a My Health Record while only 12% currently use it or plan to use it. Cluster 7 are using technology occasionally to process health information and feel motived to engaged with digital services (eHLQ 1,3,5) but feel their online health is not particularly safe (eHLQ scale 4). They feel they can understand health concepts and language well when having conversations about health (eHLQ 2). Compared to the other clusters they are using technology to process health information, engaging with digital services and accessing digital services they might adapt to their needs occasionally (eHLQ scales 1, 3, 5, 6, 7). They feel they have minimal support from their friends and family (HLQ 4) but feel adequately supported by their health care providers (HLQ 1). They have difficulty navigating the health care system to get what they need and don't feel particularly involved in managing their health (HLQ 3).

Cluster 7 vignette

Michael is 54 and works as a landscaper 50 minutes out of Ballarat. He uses technology in his everyday life to call people, order materials and equipment that he needs to run his small business. He is a type 1 diabetic and orders his medication online because it saves him time waiting in line at the chemist. He loves the sms system that he gets from his doctor to say that he has an appointment the following day. It means he doesn't have to think about it and knows that he will get a reminder. He sees his doctor regularly and knows how to manage his health after so long being a type 1 diabetic. He gets frustrated with online technology that doesn't understand what he wants, for example he wants to order 3 lots of his medication but it will only let him order 2 and he doesn't know why so gets frustrated with the online process. He has heard about My Health Record but still isn't sure how he feels about having his medical information online.

Cluster 10 and 5 demographics, technology use and eHLQ

12 Cl #	Cl ord	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
10	5	179	67.3	54.7%	49.7%	1.0	34.6%	15.6%	1.7%	2.30	2.88	2.35	2.96	2.47	2.71	2.64
5	7	121	69.8	59.5%	25.6%	0.4	20.7%	8.3%	2.5%	2.00	2.72	2.10	2.78	2.01	2.36	2.04

Cluster 10 and 5 & HLQ

12 Cl #	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
10	179	67.3	54.7%	49.7%	1.0	34.6%	15.6%	1.7%	3.18	2.97	3.06	4.17
5	121	69.8	59.5%	25.6%	0.4	20.7%	8.3%	2.5%	3.07	2.89	2.96	3.92

Cluster 5 and health conditions

12 Cl #	# in cluster	Av Age	% Female	Av # of conditions	% Cancer	% Cardio Vascular Disease	% Diabetes	% Mental Health	% Muscular skeletal	Av Freq using Health care providers	Av Self Rated Health
10	179	67.3	54.7%	1.0	2.8%	17.9%	11.2%	6.7%	17.3%	2.6	4.1
5	121	69.8	59.5%	0.8	2.5%	9.9%	7.4%	6.6%	19.8%	2.6	4.1

Cluster 10 & 5 characteristics: It's not you, it's me

Clusters 10 and 5 together are an important and large group containing almost 30% of the sample. They are similar on most characteristics with the main difference being that cluster 5 is a more extreme version of cluster 10 in terms of having relatively low confidence in their ability to use technology. Cluster 5 are also less motivated to use technology (eHLQ5) and less likely to perceive that technology is suited to their needs (eHLQ7). Both groups trust the technology (eHLQ) and have sufficient understanding of health concepts (eHLQ2). The lower confidence and motivation in cluster 5 is reflected in lower percentage having or planning to use My Health Record. Both clusters also have a low number of health conditions with cluster 10 having a higher number than cluster 5, especially CVD and diabetes. The very low number of health conditions in cluster 5 may also contribute to their low motivation to engage with digital health services.

Cluster 5 vignette

David is a 70 year old retired plumber who lives with his wife. Bill retired a few years ago because the work became too heavy and he was getting a lot of back pain. He has never used computers much and now uses the computer a bit but mostly for entertainment. He doesn't trust the information you get on the internet, and says that he has trouble distinguishing proper information from advertising. He has a MyGov account but keeps forgetting his password and has to try and reset it each time so he gave up on trying to log in. David's wife is a bit more confident and manages health appointments and reminders for both of them from her smart-phone. Since his retirement Bill has been in good health and has little reason to engage with doctors. His life is busy with gardening and looking after grandchildren after school each day.

Cluster 9 and 1 demographics, technology use and eHLQ

12 Cl #	Cl ord	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
9	9	39	71.7	53.8%	20.5%	0.3	20.5%	5.1%	0.0%	1.56	2.90	1.41	2.86	1.75	2.29	1.92
1	11	38	75.2	52.6%	0.0%	0.0	15.8%	5.3%	0.0%	1.07	2.99	1.13	2.79	1.09	1.79	1.18

Clusters 9 & 1 HLQ

12 Cl #	# in cluster	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
9	39	71.7	53.8%	20.5%	0.3	20.5%	5.1%	0.0%	3.38	3.06	3.30	4.04
1	38	75.2	52.6%	0.0%	0.0	15.8%	5.3%	0.0%	3.49	3.23	3.31	4.17

Cluster 9 and 1 health conditions

12 Cl #	# in cluster	Av Age	% Female	Av # of conditions	% Cancer	% Cardio Vascular Disease	% Diabetes	% Mental Health	% Muscular skeletal	Av Freq using Health care providers	Av Self Rated Health
9	39	71.7	53.8%	1.1	12.8%	15.4%	7.7%	5.1%	28.2%	2.7	4.0
1	38	75.2	52.6%	1.4	10.5%	15.8%	2.6%	10.5%	36.8%	2.9	4.2

Clusters 9 and 1 characteristics – We're doing okay engaging health services the way we are thanks. No need for this new-fangled stuff.

Cluster 9 and 1 are similar in many aspects and cluster 1 could be viewed as a more extreme version of cluster 9 in both clusters the main issue seems to be a strong disinterest in using technology (eHLQ 5 and 7) and limited experience and ability using technology (eHLQ 1 and 3) despite the fact that they have reasonable good understanding of health concepts and language (eHLQ2), that they trust digital health services (eHLQ 4) and that they have very high levels of confidence in their ability to navigate health services and quite high trust in health providers. The high confidence in navigating health services suggests extensive experience and satisfaction with the way that they currently do things which may explain their disinterest in doing things in new ways. While both had low use of the internet for health in the last year cluster 1 was the lowest of all clusters at 0%. Cluster 1 has a relatively high prevalence of mental health conditions and was highest of all clusters for musculoskeletal conditions (arthritis and/or chronic pain) but very low for diabetes, i.e. it is high on conditions that have active symptoms, this may be why they are more active in managing their health (HLQ3) than cluster 9. **Cluster 1 vignette**

Jeannie is a 74 year old woman who lives alone and uses the internet to email gown children and grand-children who live interstate. While she has good friends nearby, she often feels lonely after the death of her husband and due to the fact that his children don't live nearby. She mostly visits the doctor for occasional flare-ups of back pain and to renew prescriptions for blood pressure, she also visits the chiropractor about once a month for her back. While she doesn't like the fact that the doctors surgery seems to always have a new doctor, she knows the nurse there well. She also got to know the local hospital and nursing service pretty well while her husband was dying. She hasn't really heard or thought much about new ways of using the internet for dealing with health services and if asked doesn't see the point since everything is 'just a phone-call away'. Jeannie went to the doctor recently to get a new prescription. It was a new younger doctor and they tried to talk to her about the online health records. Jeannie had no idea what the doctor was talking about or what she was meant to do. She told the doctor she wanted him to manage her health for him. She didn't want to have anything to do with any of the technology.

Cluster 11 demographics, technology use and eHLQ

12 Cl #	Cl ord	# in cluster	Av Age	% Female	% use internet last year for health	% have MyHR	% use or plan to use MyHR	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
11	12	21	69.6	47.6%	14.3%	9.5%	0.0%	1.16	2.48	1.29	1.50	1.23	1.44	1.25

Cluster 11 & HLQ

12 Cl #	Av # of conditions	% Cancer	% Cardio Vascular Disease	% Diabetes	% Mental Health	% Muscular skeletal	Av Freq using Health care providers	Av Self Rated Health
11	1.5	4.8%	14.3%	14.3%	23.8%	33.3%	2.2	4.1

Cluster 11 and health conditions

12 Cl #	Av Age	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
11	69.6	3.07	2.93	2.73	3.63

Cluster 11 characteristics –Not engaging with technology at all

Cluster 11 has an average age of 69. Less than 14% of people used the internet in the past year for health information which is amongst the lowest of all the clusters. Only 9% have a My Health Record which is the lowest group in comparison to other clusters, while none are currently using it or plan to use it. Cluster 11 are not using technology to process health information (eHLQ scale 1) and they do not feel motived to engage with digital services (eHLQ 3, 5). However they do feel their online health is quite safe (eHLQ scale 4). They have difficulty understanding health concepts and language when having conversations about health (eHLQ 2), this was the lowest score for this scale. Compared to the other clusters they are not engaging with digital services or accessing digital services and they do not believe technology adapts to their needs (eHLQ scales 6, 7). They do not feel supported by their friends and family (HLQ 4) which is the lowest score for this scale and do not feel supported by their health care providers (HLQ 1). They have some difficulty navigating the health care system to get what they need and feel reasonably unable to managing their health (HLQ 3). This cluster has the highest number of people with diabetes and mental health issues.

Cluster 11 vignette

Mark is a 75 year old widow. His wife died 3 years ago and he lives on his own in a small unit in the northern suburbs of Ballarat. Mark and his wife previously had land about 20 km out of town but they moved into town five years ago due to declining health, especially his wife's. Since his wife's death Mark feels lonely and cut off from what he has spent his whole life doing and a bit angry that they sold up the farm only to have his wife die shortly after. His doctor told him that he was depressed but he thinks his sadness is completely natural in the circumstances. While Mark used to use a computer on the farm, he doesn't own one now. He does use his smart phone to talk to his daughter and grandchildren in Perth quite often. He sometimes uses an app on his phone to measure how far he has walked. Mark was watching the TV and saw an for the new Government health thing but they put up a website with no phone number so she decided it was too hard for her to find out anything about it. Mark doesn't see the need for any sort of online health records. He sees the doctor face-to-face when he needs to.

Appendix E Qualitative data coding process and semi-structured interview results

First cycle coding semi-structured interview results - qualitative data

Initial prior to coding top level categories
Semi-structured interviews were reviewed > note reoccurring barriers, enablers and experiences of the participants which formed the first basis of the first cycle coding – see below:

Key **barriers** to eHealth:
1. Access to health technology - negative (don't understand, don't use, no need to use, coverage issues)
2. Lack of info about eHealth systems (don't know how to use or about it)
3. Misleading information on internet
4. Prefer face-to-face health care rather than using technology
5. Adapting technology to skills or needs - negative (generic info software)
6. Health data security ownership - negative (who has access)
7. Managing health difficulty not managing health through technology
8. Navigating Health System - difficult (new to area, not sure where to go, don't know about services)
9. Health system level feeling unsupported

Key **enablers** to eHealth:
1. Access to health technology - positive (convenience. easy. enabling health and conversations with GP or to research information)
2. Actively asking questions (Health Care Providers, GP, doing own research)
3. Managing health through diet, exercise, technology
4. Social support - positive (getting health information, or supportive in general)
5. Health data security ownership - positive (nothing to hide, it's a good thing, feeling in control)
6. Do what doctor says to do (to facilitate Health or eHealth)
7. Health system level feeling supported

2. Coding (descriptive categories)
2.1 First cycle coding was conducted using broad descriptive (summarises topics) and In Vivo (participant phrases) (14).
2.2 Subsequent coding and analysis was undertaken to recoding to reflect the study aims and to pull out any specific barriers and enablers regarding eHealth.

Recoded to below **barriers** based on 2.1 and 2.2:
1. **Access – coverage issues (lack of internet connection, no internet)**
2. **Lack of skills (lack of confidence & training, not interested, don't understand, no need, don't know how to)**
   2.1 Don't know how to use computer / lack of confidence and skills
   2.2 Not interested in technology (emotive)
   2.3 Don't need to or want to use technology to manage health or for health information
   2.4 Prefer face-to-face compared to online health information
3. **Misleading info on the internet (not sure what to look up or to trust the information)**
4. **Barriers to accessing or using Government websites**
   4.1 Difficulty navigating the website (too complex, lack of skills, password issues)
   4.2 Don't see the need of My Health Record or haven't looked at
   4.3 Incompatible technology to access website
   4.4 Lack of information about what to do with the record and how to use it and how to interpret results

5. **Health system barriers**
    5.1 Misdirected resources
    5.2 Misalignment between health services
    5.3 Lack of access to health services (wait times, international doctors, lack of continuity)
    5.4 Bad experiences with the health system
    5.5 Bad experiences with health care providers (practitioner level)
    5.6 Navigating the health system barriers
6. **Technology / Internet doesn't adapt (to needs, or individuals)**
    6.1 Health technology not adapting to needs (booking appointments or ordering prescriptions)
    6.2 Internet search for health information not adapting – generic information
    6.3 Not knowing what to search to get the right information
7. **Lack of awareness about eHealth, eHealth records**
8. **Security issues as barrier (don't trust, not secure, lack of privacy, don't want people to access info)**
    8.1 Lack of control over personal health data
    8.2 Incorrect information on health records
    8.3 Lack of security – hackers
    8.4 Concern about how health information will be used
9. **Prefer hard copy information or directories to find health information**

Recoded to below **enablers** based on 2.1 and 2.2:
1. **Managing health through technology**
    1.1 Using technology to navigate the health system
    1.2 Using technology to manage health (using health apps or online systems)
    1.3 Using the internet to search for more information on conditions or health to be better informed to have conversations with GP (pre or post consultation) for self or family / friends
2. **Enablers to eHealth - information all in the one spot (easier for GPs and patients to manage health)**
    2.1 Using MyHR to centralise health info to help self-manage health for self or family
    2.2 Health providers having access to health info (including MyHR) - enabler for better health care
3. **Health system supporting them to manage their health**
    3.1 Health care providers managing appointments, navigating the health system for patient, HCP attending rural areas
    3.2 Health services close by, all in one spot, easily accessible
4. **Sharing of health data is safe**
    4.1 Don't mind if health information is shared
    4.2 Online health data is secure / safe
    4.3 Feeling in control of health data
    4.4 Nothing to hide (online health records)
5. **Supported eHealth engagement**
    5.1 Friends / family facilitating health management through technology (don't use technology themselves)
    5.2 GP facilitating health management through technology
6. **Friends / family helping to manage health (in health field)**

Appendix F Semi-structured interview results – themes and selected quotes

Table 6 Issues around eHealth and technology when engaging with or managing health – individual level

T#	Theme	Attributes of **individual** theme	*Select key quotes*	ID & No. participants
1	Lack of control over personal health information on eHealth records	• Perceptions of lack of control over personal health information, don't know how to have control • Concerns around the accuracy of personal health information stored in eHealth records and how to amend incorrect information • Lack of privacy, don't want unauthorised people or organisations to access personal health info • Unsure as to who has access to	*They need to revise the legislation around the My Health Record. It's just that at the moment, it's open to being misused by departments other than those that actually need it. I have a concern that it's going to be bundled in with driver's licence information and other information, and become a really targeted issue. And given the privacy commissioner's words about the release of information to defend the department, I find it really really moving towards something that is a bit of a dystopia. My concern is that the government doesn't take care of people's information. Int 42* *I guess to have all my information readily available to anyone and everyone means that I won't feel comfortable about that because I can't control who uses it. I can't control who accesses it and I cannot control why they access it. So what me and my doctor know to be simple and controlled, may to other people refuse me to get a job or to be advised against my children getting into a job because I had anxiety. But not that I still have anxiety and have dealt with it but it still comes up. So I can't control what other people use my data and I can't control who accesses it and why they accessed it. And it's one thing to say it's only available to the health professionals but there is a big world of health professionals, and then there are hackers and then there is this and then there is government interventions and everything. Int 37* *My GP, for instance, keeps my medical records and I believe I have a My Health Record but I don't have direct access to that, and personally I'm not sure how I could get direct access to that or have some say or control over which medical professionals get access to that. I think after all it's my data, I would like to know who is using it and what is on the record. Int 33* *Years ago when I had a lot of depression problems and I asked the doctor not to put that information on my file… I was suicidal. I really was suicidal and I was worried that WorkCover could come along and go into it and say okay that could have an effect, a bad effect on me. That's the only thing that I worry about. It's certain*	13, 14, 16, 22, 26, 28, 33, 35, 36, 37, 39, 42, 45 Total = 13 participants

		personal health information	*things like that when you are working you don't want to have WorkCover know certain things. I was more worried that WorkCover could get a court order to look at the things because I was on WorkCover at the time for different things but I was a bit worried that they could say we are coming to look at your file and I didn't want that on there. I didn't want them to know about that. Int 22* *It's so easy to make a mistake. People can type something and it can be wrong and things can change and try to get an address change because they have typed incorrectly into the computer into one of their systems and once it's put into the computer its set in granite. I have seen this happening with regard to medical information and incorrect medical information typed in. People make mistakes and it can cause real problems, which is why I've opted out. This is the decision of a well-educated intelligent person. Int 39*	
2	Attitude and skills around technology	• Lack of skills, confidence & training around technology	*I don't know how to use the computer anymore so I get people to access that for me. I give them the information or they will look it up and find it for me. Int 06* *I do have an old computer. I can send an email and look up on the internet but nothing complicated. If something goes wrong, I get my son to come and look at it. I don't have skills in terms of being able to work out, you know, anything terribly much. I just use, you know, the basics. The really basic things like emails. Int 29* *I'm just not particularly comfortable with using IT generally. Nearly everything I know about digital technology I have learnt myself by playing around with it. Even then it's not something I'm comfortable with. Int 05*	01, 04, 05, 06, 09, 23, 26, 28, 29, 40 Total = 10 participants
3	Not using technology to manage health	• Don't want to use technology to manage health • Don't have the need to use technology to manage health	*I don't use technology for my health information. I don't need to really. Int 01* *I don't use any smart phone apps to manage my health. It's something I really don't want to do. I don't think it's necessary. Int 33* *I don't know anything about it [My Health Record] because I haven't used it yet – the new Government system, my health something or other. I heard about it. I got a brochure that came in the mail from the chemist I think. So no, I haven't looked into that. I haven't really had the need to bother about it. Int 47*	01, 05, 13, 28, 29, 33, 47 Total = 7 participants

4	Not interested in technology (emotive)	• Not interested, don't understand, don't need technology	*I'm not interested in either one of them [eHealth or technology] because I've never been interested and I don't think it's necessary for us. I did have heaps of electronic stuff that I'm not interested in. Mobile phones you get dragged away all over the place. If you want to be pestered you get a mobile phone but I've never wanted one. I had a computer but I got rid of that as well a few years ago now. I mean I'm 84 and my wife is 83 and we are just not interested in all this modern stuff. I got a mobile phone that I bought in England and I've got it here but I've never used. It's still in the cupboard so we have no need for it. Int 44* *[Do you use technology to find health information] I don't. I don't because I am pigheaded number one. I'll pay a doctor to tell me, not go to images on Google. Sorry that's as honest as I can get. I can't even turn it on [computer] and I don't turn it on. You can say I'm an ignorant. I'm born in between all this digital stuff and you know we find it hard to do it so I just avoid it all the time. Int 50*	4, 12, 19, 38, 39, 50 Total = 6 participants
5	Unaware of eHealth	• Lack of awareness as to what eHealth is, where to access it, what it can do for individuals and how to use it	*The awareness is a big thing for me to know what is available out there. That often skips you by. If you knew things were there, you would take advantage of them. Int 02* *I don't really understand. I'm not really sure how to use it or how the doctor would use it [eHealth record] or any other professionals that use it or what has actually been put on. I probably really need to understand a bit more I think. Int 23*	02, 03, 05, 23, 38 Total = 5 participants
6	Prefer face-to-face health information	• Preference to speak with health professionals face-to-face rather than looking up health information online	*I would rather talk face-to-face with someone and find out all the information I require. Int 06* *I like personal things. You know talking to people face-to-face because I really feel I can ask questions. If I look it up on the computer I sort of can't really ask questions. Int 23* *I probably have more confidence, you know, being face-to-face with, say, my own doctor or specialist or whatever. I don't think the internet does much for me as far as, say, a personal issue goes. I just feel more comfortable talking to the GP anyway. Int 07*	06, 07, 10, 23, 30 Total = 5 participants

Table 7 Issues / barriers around eHealth and technology when engaging with or managing health – system level

T#	Theme	Attributes of system level theme	Select key quotes	ID & No. participants
7	Misleading information on the internet	• Not sure which websites to trust for reliable health information • Unsure how to distinguish which symptoms relate to what health conditions through online health diagnosis	*Generally I find looking things up on the Internet can be problematic in that you get so much information with so many symptoms so you suddenly have everything. Int 18* *A lot of the time you Google information about health you would get yourself quite distressed because some symptoms can vary for a lot of different things. Int 25* *I have enough knowledge to know that you know, you can't necessarily trust what you're reading on the Internet. Int 28* *I just Google but I am aware you need to be careful of some of the American Hospital websites and that sort of thing because there is a lot of misinformation even though you use it. You are supposed to take some of it not quite with a grain of salt but not take it as gospel. Int 48*	03, 11, 18, 22, 24, 25, 28, 33, 48, 49 Total = 10 participants
8	Inflexible technology	• Technology doesn't adapt to the needs of individuals for example booking appointments online or ordering prescriptions online • One size fits all software or	*I use hot doc when I book GP appointments. That doesn't really adapt to me. I have to work with it rather than it working with me. Int 35* *I think we have to adapt to the geeks who are designing it to be honest. By that I mean I don't think anything technological really adapts to me as an individual. I have to adapt to it. I have to learn how to use it and I have to know how to navigate it. Int 11* *A lot of things are designed for people who understand technology and can work their way around it quickly. So no, I don't think they're always accessible or adaptable, particularly not for vision impaired people who really need something. Int 31* *I think any sort of computer program is probably going to have to be one-size-fits all. My problems, in a general sense, may be the same for somebody else but my experience may be something different. eHealth*	11, 20, 31, 26, 35, 37, 40, 42 Total = 8 participants

		websites that don't suit everyone	*information probably would not cover the various shades of how somebody experiences a particular physical problem or mental problem. Int 40*	
9	Access (coverage issues or no internet)	• Difficulty accessing the internet and / or mobile phones due to coverage issues or insufficient internet speed • Difficulty accessing internet due to cost	*I struggle with the Internet and the signal out here. You know, you go onto where you can manage your Medicare and everything. The MyGov account where you have to give them a mobile phone number so that they can send you a code. By the time I get the code and run around the block to get signal to get the code then that time has lapsed and I have to try it again. Int 41* *As much as I would love to be a bit more useful on computers and technology, it's just a matter I have got to go to the library to get Wi-Fi or whatever. I don't have it at home. It's cheaper to go there [the library]. Int 40* *There is a computer black hole and these things that I do have to be done in the library. We don't have mobile phone access or computer access. Because it is a country area and I don't know quite what it is about but it doesn't work. Int 04*	04, 13, 25, 26, 33, 40, 41, 42 Total = 8 participants
10	Security concerns around eHealth	• Don't trust software is secure • Concerns about hackers accessing health information	*It's a fact that if you put something out into the ether in the cloud, you have to accept that it has the ability to be accessed by anyone who has intelligence or a computer, basically. Int 37* *I actually don't have a My Health Record because I don't trust the government with the internet security to the position where I am willing to have absolutely everything from me accessed on there by any other doctor who chooses so I prefer to be carrying that information with me or have my family know that information. I am really concerned that there are some very clever hackers out there. Int 31* *The fact is our health records are being accessed. It's just probably very easy for any experienced hacker to get into that regardless of how much security they put on it. So I don't think anyone, not just me, has pure confidence in not just availability in the security of medical health records. Int 40*	27, 31, 38, 39, 40, 42, 49 Total = 7 participants

| 11 | Lack of access to timely and appropriate health services | • Long wait times
• International doctors / lack of continuity of health care
• Long distances to travel to access health care services | *My partner has been in hospital for three weeks. After being admitted, she was being transferred to intensive care for a week and she tried to get to see her doctor prior to going to hospital and there was a waiting list of three weeks or something and she needed urgent attention and she just took herself off to the emergency department. Int 47*

I'm in rural Victoria. You can't get a quack. You can ask them questions and that's fine and then you go a few months later and there is a different quack there. This is not a racist comment; it's an observation most of them are foreigners and then most of them are difficult to understand. The problem is they talk too fast they don't seem to want to know except write a prescription and send you on your way. So I don't have any confidence in the health system here where I am. None at all. It's 40 minutes travel to go to the quack each way. Int 14

You can't get an appointment in Clunes anyhow. You have to wait a month or more for a doctor's appointment. Int 15

It's very difficult because you cannot get a doctor's appointment within a month. So that's why you don't go to the doctor because you can't get in. That's why I go to Ballarat. That is the whole population here – we all have terrible trouble getting in and when you're really sick you just can't get in.

It used to be a long-term one [GP] but our doctors now swap and change quite a bit so… every couple of years I get a different doctor. Int 50

I have already changed to a different clinic because I was having a lot of issues with the doctors that they were employing because they were employing a lot of non-native English speaking doctors and, as a person who can't see, I sometimes struggle with their communication. But also I've had a situation where they don't understand what my requirements are as a person with a disability. So, for instance, when I was applying for NDIS one of the doctors with a non-English speaking background actually filled out my form to say that my blindness had no impact on any part of my life. So I was rejected as a NDIS participant. I know they are trying to support young doctors and they are trying to support doctors from overseas getting experience and all that but it has made it very difficult for me so I changed to a different clinic. Int 27 | 08, 11, 14, 15, 27, 47, 50

Total = 7 participants |

| 12 | Issues accessing or using Government websites including the My Health Record | • Difficulty with password protected websites
• Difficulty navigating complicated websites
• Incompatible technology to use Government websites | *MyGov for instance is extremely difficult to access. You have very tricky questions that you have to remember the answer to and I know they are all about you but then after I get an email that tells me I have got a message to check on MyGov and it's not a matter of clicking on my email and getting in. It's a matter of then having to log onto MyGov to then send the code to your mobile and then you have to access the code on the mobile and if it is small print someone else always has to help me. There is no way I can do it myself. Int 31*

One problem with the Australian Government health records is accessing it because I can't, you know. I logged on ages ago with a password and it not easy to use. I joined [My Health Record] ages ago and I can't remember the password so I haven't bothered. You know a lot of people can't remember their password so they don't bother to access the My Health Record and see what it says. Int 48

I can't get onto MyGov. The computer won't let me. It's blank. I access the Centrelink parts of it and then it just all stops. I can't access it. It's blank, it's grey and they [Centrelink] said I have to have something else on the computer and I don't have it so it doesn't interact. Int 25

I have set up the My Health Record. I have set it but then I didn't know what I was meant to do next. I have put all my information in and then I wasn't sure what to do next. Do I tell my health practitioner that I am on there or can they send my health information to that site? I don't know enough about how to actually go about setting it up completely. Int 08

We were travelling around Australia and I did it [My Health Record] before I left Darwin. I put up our health record for easy access for all the doctors wherever I went. In WA, Queensland and South Australia it didn't work. The only place it seemed to work was here in Victoria… I don't think it ever got uploaded properly but everywhere you go you say I have an eHealth record because that's what you are meant to do, and they are meant to be able to access it. But a lot of doctors didn't know even what we were talking about. Int 41 | 08, 25, 31, 41, 48, 45

Total = 6 participants |
| 13 | Previous bad experiences with the health care | • Previous bad experiences with health care providers | *I feel at the moment we are badly let down by our health services. Extremely let down and it's getting to the stage where if I was any sort of person I'd sue the staff there [at a particular clinic]. Int 50*

I have lost a bit of confidence in the health system. I think the health system needs reforming, desperately needs reforming. I called the ambulance a while ago to transfer me to the Ballarat Base Hospital. I had to wait for two hours for an ambulance response then I went into emergency at the Base Hospital and they put me in a | 14, 15, 19, 49, 50 |

	providers or health services	• Previous bad experiences with health system	*wheelchair with all my gear and I had to wait in that wheelchair for about 15 hours before I was placed into a bed in emergency. Int 15*	Total = 5 participants
14	Health system barriers	• Misdirected resources or misalignment of services	*I think there is too much money wasted on unnecessary – what do they call it? – diagnostic tools. Realistically, in my opinion, I should only have enough to ensure I am comfortable because I feel that money could be better sourced for people who are working age, who have children and whose children need that, and I think personally that would help alleviate the waiting list and the resources that are available to people. You only have to look into any major hospital, – rural or Metropolitan – and there are people in there taking up beds that realistically they are only waiting for a nursing home, and I don't feel that public hospital beds should be used for that. Int 10* *I'm on the boundary of two different shires so some services I go to in one and others in the other, and I don't know if they are talking to each other. I went to a falls program in the neighbouring shire – I think they are a prevention program. There is a falls prevention program in this shire but I don't qualify because really I am on the boundary. It does make it difficult if you don't know your way around. Int 04*	02, 04, 10, 48, Total = 4 participants
15	Navigating the health system barriers	• Lack of information on how to get the right services or where to go	*I am quite experienced with the healthcare system but absolutely do not know where to go and I do not know the right things to say and I don't know how to best get what I need out of our health care system. I do feel that I am a very privileged educated, capable, person who has worked inside the health system. Int 37* *I will usually go to the GP because unless you know the people in the health industry, the GP usually refers you and you just don't know who is competent or who is better than others. It is one of the issues. We just don't know which specialists are better than others. It's usually word of mouth or your GP. It is an issue, no doubt about it, because some of the specialists are much better than others but it's really hard. How do I know? Int 48*	12, 37, 48 Total = 3 participants

Table 8 Solutions to eHealth and technology when engaging with or managing health

T#	Theme	Attributes of individual level theme	Select key quotes	ID & No. participants
16	Managing health through technology	• Using technology to navigate the health system and find health services or find reviews of health services • Using technology to manage or monitor health such as health apps • Using online health services for convenience to manage health • Using the internet to search for information on symptoms to have conversations with GP pre consultation • Using the internet to search for more information on conditions or	*I still use the Internet and apps to locate practitioners. So I go online and Google a particular doctor or an area with certain practitioners. But I might need to look up to know what sort of practitioner I need. Int 37* *I have looked up in the past certain doctors in Ballarat, like my cardiologist. I have just looked them up online and looked at his Linkedin profile and got to know who he was from that aspect. And looking up a map to know where to go as well, and I have done some research online to see if I can find GPs or doctors online who are open to more holistic therapies. Int 11* *I can make appointment to see my GP online and I have found it to be very useful because I can do it at two in the morning online. Int 28* *On my phone and my watch and my treadmill when I'm exercising I can get information about how fast I am going and my heart rate and how many calories I have burnt and all that sort of stuff. Int 27* *I order my medications from the local chemist. We are in a rural area and it's a 15 minute drive into the village so it's easier. They have all of my prescriptions online and I just go to the box and click on what I want. It's 15 km into town. I can do it now if I want to and tomorrow I get an email back to say my prescription is ready and I just go pick it up. Int 26* *I have been to the doctor but sometimes when I've been I want to read up a little bit more about it. I want to read something that is niggling me so I look it up and I make a decision about if I should contact him. If you are confident, you know that you can go ahead and find out all the information that you want if you need to and that's what I think is important. So if the doctor suddenly said to me I had something and I wasn't quite sure of it and his explanation didn't quite work with me, I would then go and check up on the net. Int 22*	03, 07, 08, 11, 14, 17, 18, 20, 21, 22, 26, 27, 28, 31, 33, 34, 35, 36, 37, 42, 43, 46, 48, 49 Total = 24 participants

		medications post GP consultation	*[I'll search online] before I go to my GP or my pharmacist if it is something I don't think I'll need a lot of expertise on. It's something that I look up to see what medical site the computer says. I would do this beforehand on my tablet. I always check out the side-effects of drugs. I always check out whether there are other options that will aid as well. So I check on those sort of sites to see what might help. Int 31*	
17	Benefits of eHealth records	• Health records and information all in the one spot, easier for GPs and patients to manage health • Easier to manage individual health or family's health through online records	*I know that the new Australian health service online, which is called My Health and I know with my mother it has been very useful to have access to that. It basically helps me work out what services she has access to and it centralises it all so that if she needs an OT or when she needs particular, specific healthcare through the Government, it can be managed all in one place. It's called My Aged Care. She is not using it but I am using it on her behalf and I have only recently become aware of that but it's been centralising Government health services that has been quite useful. Int 20* *I think it's very good because I have unfortunately the last few years have had a bit of a history with various things so, if I had to be far away from my clinic, I know that some other doctor could get the immediate history about me and I would be glad of that. Int 34* *I think it is a good idea because instead of repeating my story all the time, it's there and anyone can access it – the doctor I go to, the healthcare, the hospitals or the ambos even. I think it is a good idea, it really needs something like that where any medical professional can access information to find out what is going on, past things, history. I have got a lot of allergies and reactions to medications. Int 06*	06, 07, 11, 13, 17, 19, 20, 30, 34, 41 Total = 10 participants
18	Sharing of health data is safe	• Online personal health data is secure • Not worried about sharing online health information or privacy of health information	*In terms of my health, I don't mind if my information is shared. If it needs to be shared, I don't really mind that happening. Naturally I would want to consent to it if I could. If I couldn't consent in the given time and if it was needed, I would be OK with it being shared. Int 01* *I guess I don't worry too much about privacy and I'm not too worried about who knows what is wrong with me or what my age is. It really doesn't particularly worry me if the information is passed on to someone else. Int 18*	01, 02, 06, 07, 09, 10, 18, 24, 50 Total = 9 participants

T#	Theme	Attributes of system level theme	Select key quotes	ID & No. participants
		• 'Nothing to hide' in terms of personal health information online	*I think the government owns that they can use it to whatever advantage they want to use it. I have got nothing to hide. I'm not one of these people that says you can't look at this, you can't look at that. They can look at my file any time. I don't care. It doesn't mean a thing to me that security. Not at all. Int 50* *I don't have a problem. If people want to break into my digital information, let them break in and have a look. There is nothing there to hide. I'm not only human. I have had a heart attack. I have done this. I have done that. So what? Lots of other people have done the same. I have got nothing to hide. It does not worry me. Int 09*	
19	Health System supporting management of health	• Health care providers managing appointments or navigating the health system for patients • Specialists attending rural areas • Health services close by and accessible	*I live in city with very good health services [Ballarat]. Everything is within 10 km. Int 39* *We have very good health services. I have good service with them and they monitor me my health very well. Ballarat – that's where they are. That they are accessible when you need them. Int 45* *I just had a procedure and I went through my local GP who had a specialist come in and I went to the local hospital in Daylesford because the specialist goes there and there are a number of specialists that do; they attend certain days of the month. They come from Ballarat I think – they are based there. There are about 3-4 specialist clinics that do rotating. Int 37* *I do not have private health insurance and because my knee was hit with arthritis, my GP put my name down years ago so that when I finally got an appointment, it was at the right time. The GP would put me down five years before I needed things to help me get in. Int 22*	18, 19, 22, 34, 36, 37, 39, 45 Total = 8 participants
20	Solutions to enable people to use technology	• Face-to-face training on how to use technology to manage health	*I know that the Government is trying to digitise health records. What would make me feel comfortable is an easy-to-access website. So easy to remember the name that you could find it on the Internet… and that you can get in with an easy four digit pin and it's all there. Int 03*	03, 05, 06, 12, 21, 33

				Total = 6 participants
	to manage health	• Simple website layout, easy passwords, easy to find websites with linked information in the one spot • Publicity about what eHealth systems are available and how to use them	*Having a bit more publicity so that more country people know about it; like in the general practitioner's office… We don't always go in there on a weekly basis so maybe in the town that has its own little paper. The My Health Record – the only reason I know about it is because it's all in the media and some people made it to the media with people complaining. Otherwise I wouldn't even know about it. How would you know about the phone number and website if you didn't know it was out there? There needs to be something out there that can get people talking so that they don't have to pick up the information from the doctor. Why isn't it in other places? Int 21* *The best thing would be some sort of simple training night. If something could be done in a couple of hours. If someone could work through steps about the digital records medical information. I have done a little bit of technology for fire-brigade stuff with online training records. They have had somebody with a computer up on a large screen and there will be a number of us where each person has access to a laptop and they just walk us through. You need to do this step so we can actually do it while they are showing you. If there is a sort of a way that there are steps to refer back to or something to refresh your memory or probably some files to take home. More as a prompt. Int 05*	
T#	**Theme**	**Attributes of community level theme**	***Select key quotes***	**ID & No. participants**
21	Social support to facilitate managing health or using technology	• Supported health or eHealth management / engagement through friends or family in health field • Friends or family supporting technology use	*I don't know how to use the computer anymore so I get people to access that for me. I give them the information or they will look it up and find it for me. Int 06* *I would just go and ask my wife. I'll do research to get into our Centrelink and the health is all connected together. We have got different accounts. All of our history has been put up. She operates that. I don't operate that and I have handed her over the books. I don't see that I need to do it. I can get the wife to chase up our account; like have a look at what is there. I could do it if I had to but I'm not as fluent as what she is. I have got a phone but I use my phone only as a phone. My wife does all that. Int 09*	02, 05, 06, 09, 19, 25, 26, 32, 36, 38, 43, 44, 50 Total = 13 participants

			My wife was a nurse and my daughter is also a nurse educator and because of them I asked them questions and they give me the answers and I can talk to them about it. I talk to my daughter now about it so I've got a bit of an idea of what I am asking and the sort of questions I want answered and expecting to get from the health team. Int 38 *I've got my brother who is a surgeon and four of my sisters-in-law are nurses, two of my brothers-in-law are paramedics. My niece is a physio. Yeah, look, I'm pretty well supported certainly without professionals and GP – they're only a phone call away. Int 02*	

Table 9 enablers to using or accessing the My Health Record and selected quotes

MyHR Theme & selected quotes	Id & No. ppl
MyHR 1. Health Care Provider access for timely & appropriate care	
I like the idea of doctors being able to look and say this is the history, it's all there. Doctors having that accessibility is more important than me worrying about every Tom, Dick and Harry getting into my files. Int 11 *I think it's very good idea and I have been on it. Well, I first heard about it [MyHR] from my GP couple of years ago when she mentioned it to me and how it was involved, and I thought it was a good idea. My GP asked if I would like to go on the health record so if I was anywhere else and I needed something like a doctor's advice, and I said yes I was happy to do it and I haven't changed my mind yet. It suits me down to the ground. Int 34*	11, 13, 19, 30, 34, 41, 48 Total = 7
MyHR 2. Managing health for family	
I know that the new Australian health service online, which is called my health and I know with my mother it has been very useful to have access to that. It basically helps me work out what services she has access to and it centralises it all so that if she needs an OT or when she needs particular, specific healthcare through the Government it can be managed all in one place. Int 20	20 Total = 1
MyHR 3. Nothing to hide - not concerned about security	
I think the government owns that they can use it to whatever advantage they want to use it. I have got nothing to hide. I'm not one of these people that says you can't look at this, you can't look at that. They can look at my file any time. I don't care. It doesn't mean a thing to me that security. Not at all. Int 50	06, 09, 24, 50Total = 4

Table 10 barriers to using or accessing the My Health Record and selected quotes

MyHR Theme & selected quotes	Id & No. ppl
MyHR 4. Security concerns / lack of trust in Government / others accessing info	
I actually don't have a My Health Record because I don't trust the government with the internet security to the position where I am willing to have absolutely everything from me accessed on there by any other doctor who chooses. So I prefer to be carrying that information with me or have my family know that information. I am really concerned that there are some very clever hackers out there. Int 31 *Just keep the records safe is the most important thing. I have always worried about private entities getting their hands on my health records because then I will be inundated with ads for whatever all the time or they might sell it off. Int 22*	14, 22, 31, 35, 40, 42 Total = 6
MyHR 5. Don't know how to use MyHR, how to access, what is stored, how to have control	
I'm not quite sure what's stored and what's not. I first got onto this my health what's it called and I spoke to the doctor about it and he said I'm probably best not to even be on it. I'm still on it but I don't look after anything. I'm not really sure about all the sort of records that are stored. I don't know enough about it… I don't really understand a lot of it or what's stored or what should be stored, what shouldn't be stored and all the rest of it. Int 23 *My GP, for instance, keeps my medical records and I believe I have a My Health Record but I don't have direct access to that… Personally, I'm not sure how I could get direct access to that or have some say or control over which medical professionals get access to that. I think after all it's my data. I would like to know who is using it and what is on the record. Int 33*	05, 08, 23, 33 Total = 4
MyHR 6. Don't see the need for My Health Record	
I opted out of the My Health Record because I just didn't want the bulk of my data sitting online. I don't think it's necessary. I'm pretty stable at this point in my life. I live in one area, I go to one particular clinic, it's not like I'm not on a lot of medication. I'm fortunate that I don't have a lot of health complaints so there is not a lot of things that anybody should be able to access. I don't have chronic diseases. Int 28	11, 28 Total = 2

MyHR 7. Incompatible / Inconsistent systems	
We were travelling around Australia and I did it [My Health Record] before I left Darwin. I put up our health record for easy access for all the doctors wherever I went. In WA, Queensland and South Australia it didn't work. The only place it seemed to work was here in Victoria… I don't think it ever got uploaded properly but everywhere you go you say I have an eHealth record because that's what you are meant to do, and they are meant to be able to access it. But a lot of doctors didn't know even what we were talking about. Int 41	41 Total = 1
MyHR 8. Software difficult to use - passwords	
I joined ages ago and I can't remember the password so I haven't bothered. You know a lot of people can't remember the password so they don't bother to access the My Health Record and see what it says. Int 48 *I would like to see it fixed and that it was easier to access. Make it simple. Well, I've tried to register for health reasons you know but I can't get into it because I've gotta have a password and because I am already in Centrelink and it's just crazy. It's unbelievable! It says to go to another site because they are trying to link them all. Because I don't have a password I can't get in to the next one so I gave up. I tried and I tried but I thought it's too hard. I can't. I'll have to give up. It's as simple as that. Int 45*	45, 48 Total = 2
MyHR 9. Unable to manage records for children	
I had to go recently on the My Health Record in relation to my daughter having some surgery and we had to go in and deal with some stuff. The health records are linking Medicare… at the federal level and we had to go in because my daughter is now technically an adult even though she's only 14. Medicare sees her as an adult so we have had issues in terms of not being able to look at her records. Int 02	02 Total = 1

Appendix G lower triangular proximity matrices for identification of relationships in concept maps

Table 11 Lower triangular matrix – relationship between themes and participant IDs - barriers

Themes	T1	T2	T3	T4	T5	T6	T7	T8	T9	T10	T11	T12	T13	T14	T15
T1	13 14 16 22 26 28 33 35 36 37 39 42 45														
T2	26 28	01 04 05 06 09 23 26 28 29 40													
T3	13 28 33	01 28 29	01 05 13 28 29 33 47												
T4	39	04		04 12 19 38 39 50											
T5		05 23 38	05	38	02 03 05 23 38										
T6		06 23			23	06 07 10 23 30									
T7	22 28 33	28	28 33		03		03 11 18 22 24 25 28 33 48 49								
T8	26 35 37 41	26 40					11	11 20 26 31 35 37 40 42							
T9	13 26 33 42	04 26 40	13	04			25 33	26 40 42	04 13 25 26 33 40 41 42						
T10	39 42	40		38 39	38		49	31 40 42	40 42	27 31 38 39 40 42 49					
T11	14		47	50			11	11	40 42		08 11 14 15 27 47 50				
T12	45						25 48	31	25 41		08	08 25 31 41 45 48			
T13	14	04		19 50			49			49	14 15		14 15 19 49 50		
T14		04		04	02		48		04		48			02 04 10 48	
T15	37			12			48	37			48			48	12 37 48

Table 12 Lower triangular matrix – relationship between themes and participant IDs - enablers

Themes	T16	T17	T18	T19	T20	T21
T16	03, 07, 08, 11, 14, 17, 18, 20, 21, 22, 26, 27, 28, 31, 33, 34, 35, 36, 37, 42, 43, 46, 48, 49					
T17	07 11 17 20 34	06, 07, 11, 13, 17, 19, 20, 30, 34, 41				
T18	07 18	06 07	01, 02, 06, 07, 09, 10, 18, 24, 50			
T19	18 22 34 36 37	19 34	18	18, 19, 22, 34, 36, 37, 39, 45		
T20	03 21 33	06	06		03, 05, 06, 12, 21, 33	
T21	26 36 43	06 19	02 06 09 50	19 36	05 06	02, 05, 06, 09, 19, 25,26, 32, 36, 38, 43, 44, 50

Appendix H Additional tables from CATI data

Table 13 Participant demographics

		N (%)
Sex		
	Women	536 (54)
	Men	462 (46)
Age		
	18 to <25	15 (2)
	25 to <30	7 (1)
	30 to <35	11 (1)
	35 to <40	14 (1)
	40 to <45	39 (4)
	45 to <50	41 (4)
	50 to <55	75 (8)
	55 to <60	83 (8)
	60 to <65	136 (14)
	65 to <70	166 (17)
	70 to <75	177 (18)
	75 to <80	114 (11)
	80 to <85	75 (8)
	85+	45 (5)
Speaks English at home		
	Yes	990 (99)
	No	8 (1)
Aboriginal or Torres Strait Islander		
	Yes	18 (2)
	No	980 (98)
Education level		
	Did not complete primary school	2 (0)
	Primary school	89 (9)
	Year 10	218 (22)
	Year 12	136 (14)
	Trade, apprenticeship, Diploma or TAFE	246 (25)
	University	307 (31)
ARIA+ (2011) score		
	Accessible (ARIA+ value 0.2 to 2.4)	954 (96)
	Moderately Accessible (ARIA+ value 2.4 to 5.92)	44 (4)

Table 14 Self-rated health, chronic diseases and conditions and contact with health professionals.

	N (%)
Self-rated health	
Excellent	170 (17)
Very good	270 (27)
Good	293 (29)
Fair	165 (17)
Poor	76 (8)
Very poor	24 (2)
Number of conditions or illnesses	
0	428 (43)
1	338 (34)
2	161 (16)
3	49 (5)
4	12 (1)
5	5 (1)
6 or more	5 (1)
Number of contacts with a health professional in the last 12 months	
>12	269 (27)
7 to 12	196 (20)
2 to 6	446 (45)
1 or none	87 (9)
>12	269 (27)

Table 15 Use of the internet to access health-related information

	N (%)
Use of internet to access health-related information	
Once a week or more often	76 (8)
Several times a month	61 (6)
Approximately once a month	102 (10)
Approximately once every two months	71 (7)
A few times within the past year	268 (27)
No, never	412 (41)
Don't know/NA	8 (1)
How internet is accessed* (among internet users)	
Smartphone	194 (33)
Tablet	203 (35)
Computer	396 (68)
Why internet is not used to access health-related information* (among non-internet users)	
I don't know how to	74 (18)
I don't know what's out there	5 (1)
I don't want to	92 (22)
I'm not sure I'd get what I need	17 (4)
I can't afford it	1 (1)
I don't have the right technology (equipment)	88 (21)
I'm not confident enough to use computers/smartphones/iPads	39 (9)
I'm not confident I'd be able to understand the information by myself	8 (2)
I prefer face-to-face interaction with health services	170 (41)

* Participants selected all options that applied to them

Table 16 Comparison of CATI participants with the Western Victoria Primary Health Network (PHN) population

	CATI sample (%)	Western Victoria PHN (%)
Sex		
Women	54	51
Men	46	49
Age		
<55 years	20	68
55 to 70	39	19
>70 years	41	13
Aboriginal or Torres Strait Islander		
Yes	2	1
No	98	93
Not stated		6
Highest educational attainment		
Year 10 or below	31	
Year 12	14	
Trade certificate, apprenticeship, Diploma or college/TAFE certificate	25	24
Tertiary education	31	14
Not stated		9

Source of data (15)

Table 17 Awareness, engagement and use or intention to use My Health Record for the total population and by demographics of interest

	N	Not sure if have	Don't have	Have MyHRand use it	Have MyHR don't use it but intend to	Have MyHRdon't use it and don't intend to	Have MyHRdon't use it and not sure if intend to
		% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Total	998	36 (33, 39)	32 (29, 35)	6 (5, 8)	10 (9, 12)	9 (7, 11)	7 (5, 9)
Sex							
Men	462	41 (36, 45)	28 (24, 33)	6 (4, 9)	9 (7, 12)	10 (8, 13)	6 (4, 8)
Women	536	32 (28, 36)	35 (31, 39)	7 (5, 9)	12 (9, 15)	7 (5, 10)	8 (6, 10)
Age							
Age <55 years	202	40 (34, 47)	26 (21, 33)	8 (5, 13)	9 (6, 14)	7 (4, 11)	9 (6, 14)
Age 55 to <70 years	385	34 (30, 39)	29 (25, 34)	7 (5, 10)	14 (10, 17)	10 (7, 13)	6 (4, 9)
Age >=70 years	411	36 (31, 40)	38 (33, 43)	5 (3, 7)	8 (6, 11)	8 (6, 11)	6 (4, 9)
Aboriginal or Torres Strait Islander							
Yes	18	39 (62, 0)	22 (47, 0)	22 (47, 0)	11 (35, 0)	6 (31, 0)	0 (0, 0)
No	980	36 (33, 39)	32 (29, 35)	6 (5, 8)	10 (9, 12)	9 (7, 11)	7 (5, 9)
Highest educational attainment							
Year 9 or below	91	38 (29, 48)	39 (30, 49)	4 (2, 11)	5 (2, 12)	9 (4, 16)	4 (2, 11)
Year 10	218	37 (30, 43)	35 (29, 41)	5 (2, 8)	9 (6, 14)	11 (7, 16)	4 (2, 8)
Year 12	136	36 (28, 44)	32 (25, 41)	5 (2, 10)	9 (5, 15)	9 (5, 15)	9 (5, 15)
Trade certificate, apprenticeship, Diploma or college/TAFE certificate	246	36 (30, 42)	32 (26, 38)	7 (5, 11)	9 (6, 13)	9 (6, 13)	7 (5, 11)
Tertiary education	307	35 (30, 41)	28 (23, 33)	8 (5, 11)	14 (11, 19)	7 (4, 10)	8 (6, 12)

Table 18 Awareness, engagement and use or intention to use My Health Record by self-rated health, chronic diseases and conditions, and contact with health professionals

	N	Not sure if have	Don't have	Have MyHRand use it	Have MyHR, don't use it but intend to	Have MyHR, don't use it and don't intend to	Have MyHR, don't use it and not sure if intend to
		% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Number of contacts with a health professional in the last 12 months							
>12	269	35 (29, 40)	30 (25, 36)	9 (6, 13)	10 (7, 15)	8 (5, 12)	8 (5, 12)
7 to 11	196	37 (30, 44)	29 (23, 36)	7 (4, 12)	10 (7, 15)	9 (5, 14)	8 (5, 13)
2 to 6	446	36 (32, 41)	32 (28, 37)	5 (3, 8)	11 (8, 14)	9 (6, 12)	7 (5, 9)
1 or none	87	38 (28, 49)	43 (33, 53)	2 (1, 9)	7 (3, 15)	9 (5, 17)	1 (0, 8)
Self-rated health							
Excellent	170	36 (29, 43)	34 (27, 41)	7 (4, 12)	9 (6, 15)	8 (5, 13)	6 (3, 11)
Very good	270	37 (31, 43)	30 (25, 36)	6 (3, 9)	12 (9, 16)	7 (5, 11)	8 (5, 12)
Good	293	35 (30, 41)	33 (27, 38)	7 (4, 10)	9 (7, 13)	9 (6, 13)	7 (5, 11)
Fair	165	33 (26, 40)	32 (25, 40)	7 (4, 12)	9 (6, 15)	12 (7, 17)	7 (4, 12)
Poor or Very Poor	100	42 (33, 52)	33 (24, 43)	4 (2, 10)	12 (7, 20)	6 (3, 13)	3 (1, 9)
Number of conditions							
0	428	36 (32, 41)	34 (30, 39)	7 (5, 9)	10 (7, 13)	7 (5, 9)	7 (5, 10)
1	338	35 (30, 40)	33 (29, 39)	6 (4, 9)	9 (7, 13)	11 (8, 14)	7 (4, 10)
2	161	37 (30, 45)	27 (21, 35)	7 (4, 12)	11 (7, 16)	9 (5, 14)	9 (6, 15)
3+	71	38 (28, 50)	24 (15, 35)	7 (3, 16)	17 (10, 27)	11 (6, 21)	3 (1, 11)
Asthma							
No	956	36 (33, 39)	32 (29, 35)	6 (5, 8)	10 (9, 12)	9 (7, 11)	6 (5, 8)
Yes	42	33 (21, 49)	29 (17, 44)	2 (0, 15)	10 (4, 23)	10 (4, 23)	17 (8, 31)
Cancer							
No	945	36 (33, 39)	33 (30, 36)	6 (5, 8)	10 (8, 12)	8 (7, 10)	7 (5, 9)
Yes	53	34 (23, 48)	19 (10, 32)	6 (2, 16)	17 (9, 30)	17 (9, 30)	8 (3, 18)
Cardiovascular disease							
No	869	36 (33, 39)	33 (30, 36)	6 (5, 8)	10 (8, 12)	8 (6, 10)	7 (6, 9)
Yes	129	38 (30, 47)	26 (19, 34)	9 (5, 15)	11 (7, 18)	12 (8, 19)	5 (2, 10)

Diabetes

No	914	36 (33, 40)	32 (29, 35)	6 (5, 8)	10 (9, 13)	9 (7, 11)	7 (5, 9)
Yes	84	31 (22, 42)	37 (27, 48)	7 (3, 15)	10 (5, 18)	10 (5, 18)	6 (2, 14)

Mental health condition

No	942	36 (33, 39)	32 (29, 35)	6 (5, 8)	10 (9, 13)	9 (7, 11)	7 (5, 8)
Yes	56	34 (23, 47)	32 (21, 45)	9 (4, 20)	7 (3, 18)	7 (3, 18)	11 (5, 22)

Musculoskeletal condition

No	804	36 (33, 40)	33 (30, 36)	6 (4, 8)	10 (8, 12)	8 (7, 10)	7 (5, 9)
Yes	194	34 (28, 41)	28 (22, 35)	8 (5, 13)	12 (8, 18)	10 (6, 15)	8 (5, 12)

Other' disease or condition

No	701	36 (32, 39)	33 (29, 36)	7 (5, 9)	9 (7, 11)	9 (7, 11)	8 (6, 10)
Yes	297	37 (31, 42)	30 (25, 35)	5 (3, 8)	14 (11, 19)	9 (6, 13)	5 (3, 8)

Note: Musculoskeletal condition refers to arthritis and/or chronic pain

Table 19 Use of My Health Record by use of the internet to access health-related information

	N	Not sure if have	Don't have	Have MyHR and use it	Have MyHR, don't use it but intend to	Have MyHR, don't use it and don't intend to	Have MyHR, don't use it and not sure if intend to
		% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Use of internet to access health-related information							
Once a week or more often	76	25 (16, 36)	32 (23, 44)	8 (4, 16)	14 (8, 24)	6 (3, 15)	14 (8, 24)
Several times a month	61	34 (47, 0)	30 (42, 0)	11 (22, 0)	13 (24, 0)	0 (0, 0)	11 (22, 0)
Approximately once a month	102	37 (28, 47)	25 (18, 35)	12 (7, 20)	13 (8, 21)	5 (2, 11)	8 (4, 15)
Approximately once every two months	71	39 (28, 51)	25 (16, 36)	10 (5, 19)	13 (7, 22)	7 (3, 16)	7 (3, 16)
A few times within the past year	268	32 (26, 38)	30 (25, 36)	6 (4, 10)	15 (11, 20)	11 (8, 16)	6 (4, 10)
No, never	412	40 (35, 45)	36 (32, 41)	4 (2, 6)	5 (4, 8)	10 (7, 13)	5 (3, 7)
Don't know/NA	8	50 (20, 80)	38 (13, 72)	0 (0, 0)	0 (0, 0)	0 (0, 0)	13 (2, 54)
How internet is accessed* (among internet users)							
Smartphone users	253	32 (26, 38)	30 (24, 35)	8 (5, 12)	11 (7, 15)	11 (7, 15)	9 (6, 14)
Tablet users	325	34 (29, 39)	28 (24, 33)	9 (6, 12)	17 (13, 21)	6 (4, 9)	7 (5, 11)
Computer users	194	38 (31, 45)	22 (17, 29)	9 (6, 14)	17 (12, 23)	6 (3, 10)	9 (6, 14)
Computer only	203	31 (25, 38)	31 (25, 38)	9 (6, 14)	17 (13, 23)	6 (4, 11)	5 (3, 9)
Multiple devices	396	32 (28, 37)	27 (23, 32)	8 (6, 11)	15 (11, 18)	10 (7, 13)	9 (6, 12)
Why internet is not used to access health-related information* (among non-internet users)							
I don't know how to	74	36 (26, 48)	43 (32, 55)	3 (1, 10)	1 (0, 9)	11 (5, 20)	5 (2, 14)
I don't know what's out there	5	60 (20, 90)	20 (3, 69)		20 (3, 69)		
I don't want to	92	36 (27, 46)	38 (29, 48)	4 (2, 11)	4 (2, 11)	11 (6, 19)	7 (3, 14)
I'm not sure I'd get what I need	17	29 (13, 54)	24 (9, 49)	6 (1, 32)	24 (9, 49)	18 (6, 43)	
I can't afford it	1	1					
I don't have the right technology (equipment)	88	32 (23, 42)	44 (34, 55)	2 (1, 9)	3 (1, 10)	11 (6, 20)	7 (3, 14)
I'm not confident enough to use computers/smartphones/iPads	39	54 (38, 69)	31 (18, 47)			13 (5, 27)	3 (0, 16)
I'm not confident I'd be able to understand the information by myself	8	38 (13, 72)	25 (6, 62)	13 (2, 54)	13 (2, 54)	13 (2, 54)	
I prefer face-to-face interaction with health services	170	43 (36, 50)	32 (26, 40)	4 (2, 8)	6 (3, 11)	10 (6, 16)	5 (3, 10)

Table 20 Demographic predictors of My Health Record awareness^

	N	Not sure mean or proportion (95% CI) N=359	Sure mean or proportion (95% CI) N=639	Odds Ratio (95% CI)	p-value
Sex					
Men	462	40 (36, 45)	60 (55, 64)		
Women	536	32 (28, 36)	68 (64, 72)	1.4 (1.1, 1.9)	0.006
Age					
Years of age (continuous)	998	64 (63, 66)	65 (64, 66)	1 (1, 1)	0.284
Highest educational attainment*					
Completed yr 11 or below	309	37 (32, 42)	63 (58, 68)		
Completed year 12	136	36 (28, 44)	64 (56, 72)	1.1 (0.7, 1.7)	0.707
Completed a trade certificate, apprenticeship, Diploma or college/TAFE certificate	246	36 (30, 42)	64 (58, 70)	1.1 (0.8, 1.5)	0.652
Completed a university degree or above	307	35 (30, 41)	65 (59, 70)	1.1 (0.8, 1.6)	0.513
Number of long-standing illnesses or disabilities*					
No conditions	428	36 (32, 41)	64 (59, 68)		
1 condition	338	35 (30, 40)	65 (60, 70)	1 (0.8, 1.4)	0.773
>=2 conditions	232	38 (31, 44)	63 (56, 69)	0.9 (0.7, 1.3)	0.593
Self-rated health*					
Excellent	170	36 (29 ,43)	64 (57, 71)		
Very good	270	37 (31, 43)	63 (57, 69)	0.9 (0.6, 1.4)	0.773
Good	293	35 (30, 40)	65 (60, 70)	1 (0.7, 1.5)	0.865
Fair	165	33 (26, 40)	67 (60, 74)	1.1 (0.7, 1.8)	0.616
Poor or Very Poor	100	42 (33, 52)	58 (48, 67)	0.8 (0.5, 1.3)	0.299
Use of the internet to access health-related information*					
No, or NA	420	40 (36, 45)	60 (55, 64)		
Yes	578	33 (29, 37)	67 (63, 71)	1.5 (1.1, 2)	0.003
Number of contacts with a health professional over the past 12 months*					
12 or more	269	35 (29, 40)	65 (60, 71)		
7 to 11	196	37 (30, 44)	63 (56, 70)	0.9 (0.6, 1.3)	0.648
2 to 6	446	36 (32, 41)	64 (59, 68)	0.9 (0.7, 1.3)	0.702
1 or none	87	38 (28, 49)	62 (51, 72)	0.9 (0.5, 1.5)	0.681

^Participants were asked 'Do you have a My Health Record?'; those categorised as 'not sure' responded 'not sure'; those categorised as 'sure' responded 'yes' or 'no'. * Analyses were adjusted for age

Table 21 eHealth literacy and health literacy predictors of the participant's My Health Record awareness^

	Not sure mean (95% CI) N=359	Sure mean (95% CI) N=639	Odds Ratio (95% CI)	p-value
eHealth Literacy scales (range 1 to 4)				
1. Using technology to process health information.				
(continuous score)	2.21 (2.15, 2.28)	2.41 (2.37, 2.46)	1.77 (1.42, 2.22)	<0.001
2. Understanding of health concepts and language.				
(continuous score)	2.91 (2.87, 2.95)	2.95 (2.92, 2.98)	1.28 (0.92, 1.77)	0.14
3. Ability to actively engage with digital services.				
(continuous score)	2.35 (2.27, 2.42)	2.52 (2.47, 2.56)	1.53 (1.25, 1.89)	<0.001
4. Feel safe and in control.				
(continuous score)	2.51 (2.46, 2.57)	2.64 (2.60, 2.68)	1.47 (1.17, 1.85)	0.001
5. Motivated to engage with digital services.				
(continuous score)	2.28 (2.21, 2.35)	2.47 (2.43, 2.51)	1.75 (1.40, 2.19)	<0.001
6. Access to digital services that work.				
(continuous score)	2.41 (2.36, 2.47)	2.57 (2.53, 2.60)	1.99 (1.51, 2.63)	<0.001
7. Digital services that suit individual needs.				
(continuous score)	2.28 (2.21, 2.34)	2.44 (2.40, 2.49)	1.63 (1.30, 2.04)	<0.001
Health literacy				
Health Literacy Questionnaire scales (range 1 to 4)				
1. Feeling understood and supported by healthcare providers.				
(continuous score)	3.14 (3.08, 3.19)	3.18 (3.14, 3.22)	1.15 (0.90, 1.48)	0.263
3. Actively managing my health.				
(continuous score)	3.03 (2.99, 3.08)	3.01 (2.98, 3.04)	0.89 (0.66, 1.20)	0.455
5. Social support for health.				
(continuous score)	3.04 (2.99, 3.09)	3.05 (3.01, 3.09)	1.02 (0.78, 1.33)	0.889
Health Literacy Questionnaire scale (range 1 to 5)				
7. Navigating the healthcare system				
(continuous score)	3.91 (3.84, 3.99)	3.96 (3.91, 4.02)	1.10 (0.92, 1.31)	0.292

^Participants were asked 'Do you have a My Health Record?'; those categorised as 'not sure' responded 'not sure'; those categorised as 'sure' responded 'yes' or 'no'. Analyses were adjusted for age

Table 22 Demographic predictors of My Health Record engagement^

	N	No, I don't have MyHR mean or proportion (95% CI)	Yes, I have MyHR mean or proportion (95% CI)	Odds Ratio (95% CI)	p-value
Sex					
Men	275	48 (42 ,54)	52 (46 ,58)		
Women	364	52 (47 ,57)	48 (43 ,53)	0.9 (0.6, 1.2)	0.315
Age					
Years of age (continuous)	639	67 (66 ,69)	63 (62 ,65)	1 (1, 1)	<0.001
Highest educational attainment*					
Year 11 or below	195	57 (50 ,64)	43 (36 ,50)		
Year 12	87	51 (40 ,61)	49 (39 ,60)	1.1 (0.6, 1.8)	0.75
Trade, apprenticeship, Diploma or TAFE	158	49 (42 ,57)	51 (43 ,58)	1.2 (0.8, 1.9)	0.397
University	199	43 (36 ,50)	57 (50 ,64)	1.5 (1, 2.3)	0.054
Number of long-standing illnesses or disabilities*					
No conditions	273	53 (47 ,59)	47 (41 ,53)		
1 condition	221	51 (45 ,58)	49 (42 ,55)	1.2 (0.8, 1.7)	0.303
>=2 conditions	145	42 (34 ,50)	58 (50 ,66)	1.8 (1.2, 2.7)	0.006
Self-rated health*					
Excellent	109	52 (43 ,61)	48 (39 ,57)		
Very good	170	48 (40 ,55)	52 (45 ,60)	1.2 (0.8, 2)	0.382
Good	191	50 (43 ,57)	50 (43 ,57)	1.2 (0.7, 1.9)	0.463
Fair	111	48 (39 ,57)	52 (43 ,61)	1.3 (0.8, 2.3)	0.305
Poor or Very Poor	58	57 (44 ,69)	43 (31 ,56)	0.9 (0.5, 1.7)	0.71
Use of the internet to access health-related information*					
No, or NA	251	61 (55 ,67)	39 (33 ,45)		
Yes	388	43 (38 ,48)	57 (52 ,62)	1.8 (1.3, 2.6)	0.001
Number of contacts with a health professional over the past 12 months*					
>12	176	46 (39 ,53)	54 (47 ,61)		
7 to 12	124	46 (37 ,55)	54 (45 ,63)	1 (0.6, 1.6)	0.996
0 to 6	339	53 (48 ,59)	47 (41 ,52)	0.7 (0.5, 1)	0.061

^Participants were asked 'Do you have a My Health Record?' those categorised as 'No, I don't have MyHR' responded 'No', those categorised as 'Yes, I have MyHR' responded 'Yes' * Analyses were adjusted for age

Table 23 eHealth literacy and health literacy predictors of My Health Record engagement^

	No, I don't have MyHR mean (95% CI) N=319	Yes, I have MyHR mean (95% CI) N=320	Odds Ratio (95% CI)	p-value
eHealth Literacy scales (range 1 to 4)				
1. Using technology to process health information.				
(continuous score)	2.33 (2.27, 2.39)	2.50 (2.44, 2.56)	1.80 (1.34, 2.42)	<0.001
2. Understanding of health concepts and language.				
(continuous score)	2.88 (2.84, 2.92)	3.02 (2.97, 3.06)	2.62 (1.70, 4.02)	<0.001
3. Ability to actively engage with digital services.				
(continuous score)	2.39 (2.33, 2.45)	2.64 (2.58, 2.71)	2.12 (1.60, 2.81)	<0.001
4. Feel safe and in control.				
(continuous score)	2.57 (2.51, 2.63)	2.71 (2.65, 2.77)	1.61 (1.20, 2.14)	0.001
5. Motivated to engage with digital services.				
(continuous score)	2.37 (2.32, 2.43)	2.57 (2.51, 2.63)	2.00 (1.48, 2.71)	<0.001
6. Access to digital services that work.				
(continuous score)	2.50 (2.46, 2.55)	2.63 (2.58, 2.68)	1.90 (1.33, 2.70)	<0.001
7. Digital services that suit individual needs.				
(continuous score)	2.35 (2.29, 2.41)	2.53 (2.47, 2.59)	1.89 (1.40, 2.55)	<0.001
Health Literacy Questionnaire scales (range 1 to 4)				
1. Feeling understood and supported by healthcare providers.				
(continuous score)	3.11 (3.06, 3.17)	3.24 (3.19, 3.29)	1.63 (1.19, 2.22)	0.002
3. Actively managing my health.				
(continuous score)	2.99 (2.94, 3.04)	3.03 (2.98, 3.08)	1.25 (0.87, 1.80)	0.236
4. Social support for health.				
(continuous score)	2.98 (2.93, 3.04)	3.11 (3.06, 3.16)	1.74 (1.25, 2.42)	0.001
Health Literacy Questionnaire scale (range 1 to 5)				
7. Navigating the healthcare system.				
(continuous score)	3.93 (3.85, 4.01)	4.00 (3.92, 4.08)	1.15 (0.93, 1.42)	0.201

^Participants were asked 'Do you have a My Health Record?' those categorised as 'No, I don't have MyHR' responded 'No', those categorised as 'Yes, I have MyHR' responded 'Yes'
*Analyses were adjusted for age

Table 24 Demographic predictors of using or intending to use My Health Record ^

	N	No, I don't intend to use MyHR mean or proportion (95% CI)	Yes, I use MyHR or intend to mean or proportion (95% CI)	Odds Ratio (95% CI)	p-value
Sex					
Men	117	41 (32 ,50)	59 (50 ,68)		
Women	135	28 (21 ,36)	72 (64 ,79)	1.8 (1, 3)	0
Age					
Years of age (continuous)	252	66 (63 ,68)	62 (60 ,64)	1 (1, 1)	0.1
Highest educational attainment					
Year 11 or below	71	45 (34 ,57)	55 (43 ,66)		
Year 12	93	37 (27 ,47)	63 (53 ,73)	1.3 (0.7, 2.5)	0.4
Trade, apprenticeship, Diploma or TAFE	88	23 (15 ,33)	77 (67 ,85)	2.5 (1.2, 5)	0
University					
No conditions	99	28 (20 ,38)	72 (62 ,80)		
1 condition	86	42 (32 ,53)	58 (47 ,68)	0.6 (0.3, 1.1)	0.1
>=2 conditions	67	33 (23 ,45)	67 (55 ,77)	1 (0.5, 1.9)	0.9
Self-rated health					
Excellent or very good	109	31 (23 ,40)	69 (60 ,77)		
Good, fair, poor, or very poor	143	36 (29 ,45)	64 (55 ,71)	0.9 (0.5, 1.5)	0.6
Use of the internet to access health-related information					
No, or NA	78	53 (42 ,63)	47 (37 ,58)		
Yes	174	26 (20 ,33)	74 (67 ,80)	3 (1.6, 5.4)	0
Number of contacts with a health professional over the past 12 months					
>6	125	31 (24 ,40)	69 (60 ,76)		
<=6	127	37 (29 ,46)	63 (54 ,71)	0.7 (0.4, 1.2)	0.2

^Participants categorised as 'No, I don't intend to use MyHR' responded 'Yes' to the question 'Do you have a My Health Record', 'No' to the question 'Do you use your My Health Record' and 'No' to the question 'Do you intend to use your My Health Record'. Participants categorised as 'Yes, I use MyHR or intend to' responded 'Yes' to the question 'Do you have a My Health Record', and either responded 'Yes' to the question 'Do you use your My Health Record' or responded 'No' to the question 'Do you use your My Health Record' and 'Yes' to the question 'Do you intend to use your My Health Record'

Table 25 eHealth literacy and health literacy predictors of using or intending to use My Health Record ^

| | No, I don't intend to use MyHR | Yes, I use MyHR or intend to | | |
	mean (95% CI) N=86	mean (95% CI) N=166	OR (95% CI)	p-value
eHealth Literacy scales (range 1 to 4)				
1. Using technology to process health information.				
(continuous score)	2.31 (2.21, 2.41)	2.68 (2.60, 2.76)	4.14 (2.34, 7.31)	<0.001
2. Understanding of health concepts and language.				
(continuous score)	2.96 (2.89, 3.03)	3.07 (3.01, 3.13)	2.25 (1.08, 4.69)	0.031
3. Ability to actively engage with digital services.				
(continuous score)	2.38 (2.26, 2.50)	2.81 (2.73, 2.89)	4.44 (2.55, 7.75)	<0.001
4. Feel safe and in control.				
(continuous score)	2.57 (2.44, 2.69)	2.82 (2.74, 2.89)	2.36 (1.43, 3.88)	0.001
5. Motivated to engage with digital services.				
(continuous score)	2.38 (2.28, 2.49)	2.74 (2.67, 2.82)	4.24 (2.36, 7.61)	<0.001
6. Access to digital services that work.				
(continuous score)	2.55 (2.46, 2.65)	2.72 (2.66, 2.79)	2.49 (1.32, 4.69)	0.005
7. Digital services that suit individual needs.				
(continuous score)	2.36 (2.25, 2.48)	2.67 (2.60, 2.75)	3.48 (1.97, 6.15)	<0.001
Health Literacy scales (range 1 to 4)				
1. Feeling understood and supported by healthcare providers.				
(continuous score)	3.17 (3.07, 3.26)	3.32 (3.24, 3.4)	1.89 (1.10, 3.27)	0.022
3. Actively managing my health.				
(continuous score)	2.97 (2.89, 3.05)	3.11 (3.04, 3.18)	2.28 (1.18, 4.38)	0.014
4. Social support for health.				
(continuous score)	3.03 (2.93, 3.13)	3.18 (3.11, 3.24)	2.10 (1.15, 3.84)	0.015
Health Literacy scales (range 1 to 5)				
7. Navigating the healthcare system.				
(continuous score)	3.92 (3.73, 4.10)	4.03 (3.93, 4.13)	1.24 (0.87, 1.75)	0.234

^Participants categorised as 'No, I don't intend to use MyHR' responded 'Yes' to the question 'Do you have a My Health Record', 'No' to the question 'Do you use your My Health Record' and 'No' to the question 'Do you intend to use your My Health Record'. Participants categorised as 'Yes, I use MyHR or intend to' responded 'Yes' to the question 'Do you have a My Health Record', and either responded 'Yes' to the question 'Do you use your My Health Record' or responded 'No' to the question 'Do you use your My Health Record' and 'Yes' to the question 'Do you intend to use your My Health Record'

Table 26 eHealth literacy for the total population and by demographics of interest

	1. Using technology to process health information mean (95% CI)	2. Understanding of health concepts and language mean (95% CI)	3. Ability to actively engage with digital services mean (95% CI)	4. Feel safe and in control mean (95% CI)	5. Motivated to engage with digital services mean (95% CI)	6. Access to digital services that work mean (95% CI)	7. Digital services that suit individual needs mean (95% CI)
Total	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Sex							
Men	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.4 (2.4, 2.5)	2.6 (2.5, 2.6)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.4)
Women	2.4 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.7)	2.4 (2.3, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Age							
Age <55 years	2.6 (2.5, 2.7)	3 (2.9, 3.1)	2.8 (2.7, 2.9)	2.6 (2.5, 2.7)	2.6 (2.5, 2.6)	2.6 (2.5, 2.7)	2.6 (2.5, 2.6)
Age 55 to <70 years	2.4 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.5)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Age >=70 years	2.2 (2.2, 2.3)	2.9 (2.9, 2.9)	2.3 (2.2, 2.3)	2.7 (2.6, 2.7)	2.3 (2.3, 2.4)	2.5 (2.4, 2.5)	2.3 (2.3, 2.4)
Aboriginal or Torres Strait Islander							
Yes	2.6 (2.4, 2.8)	2.9 (2.8, 3.1)	2.5 (2.4, 2.7)	2.8 (2.6, 3)	2.6 (2.5, 2.8)	2.8 (2.6, 2.9)	2.6 (2.4, 2.8)
No	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Highest educational attainment							
Year 9 or below	2.1 (2, 2.2)	2.8 (2.7, 2.9)	2.1 (2, 2.2)	2.7 (2.7, 2.8)	2.2 (2.1, 2.3)	2.5 (2.4, 2.6)	2.4 (2.2, 2.5)
Year 10	2.2 (2.2, 2.3)	2.8 (2.8, 2.9)	2.2 (2.2, 2.3)	2.7 (2.6, 2.7)	2.3 (2.2, 2.4)	2.5 (2.4, 2.6)	2.4 (2.3, 2.5)
Year 12	2.4 (2.3, 2.5)	2.9 (2.9, 3)	2.5 (2.4, 2.6)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)
Trade certificate, apprenticeship, Diploma or college/TAFE certificate	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.6)	2.6 (2.5, 2.7)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.5)
Tertiary education	2.5 (2.4, 2.5)	3 (3, 3.1)	2.7 (2.6, 2.7)	2.5 (2.5, 2.6)	2.5 (2.4, 2.6)	2.5 (2.4, 2.5)	2.4 (2.3, 2.4)

Table 27 eHealth literacy by self-rated health, chronic diseases and conditions, and contact with health professionals

	1. Using technology to process health information	2. Understanding of health concepts and language	3. Ability to actively engage with digital services	4. Feel safe and in control	5. Motivated to engage with digital services	6. Access to digital services that work	7. Digital services that suit individual needs
	mean (95% CI)	mean (95% CI)	mean (95% CI)	mean (95% CI)	mean (95% CI)	mean (95% CI)	mean (95% CI)
Number of contacts with a health professional in the last 12 months							
>12	2.4 (2.3, 2.5)	2.9 (2.9, 3)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.5)
7 to 11	2.4 (2.3, 2.5)	3 (2.9, 3)	2.5 (2.4, 2.6)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.5)
2 to 6	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.5, 2.6)	2.4 (2.3, 2.4)	2.5 (2.5, 2.6)	2.4 (2.3, 2.4)
1 or none	2.2 (2.1, 2.3)	2.9 (2.8, 3)	2.4 (2.3, 2.6)	2.4 (2.3, 2.6)	2.3 (2.2, 2.4)	2.4 (2.3, 2.5)	2.3 (2.1, 2.4)
Self-rated health							
Excellent	2.3 (2.2, 2.4)	3 (3, 3.1)	2.6 (2.5, 2.7)	2.7 (2.6, 2.7)	2.4 (2.3, 2.5)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)
Very good	2.4 (2.3, 2.4)	3 (2.9, 3)	2.5 (2.4, 2.6)	2.6 (2.5, 2.6)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.4, 2.5)
Good	2.4 (2.3, 2.4)	2.9 (2.9, 2.9)	2.4 (2.4, 2.5)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.4)
Fair	2.3 (2.2, 2.4)	2.9 (2.8, 2.9)	2.4 (2.3, 2.5)	2.6 (2.5, 2.7)	2.3 (2.2, 2.4)	2.4 (2.4, 2.5)	2.3 (2.2, 2.4)
Poor or Very Poor	2.3 (2.2, 2.4)	2.9 (2.8, 3)	2.3 (2.1, 2.4)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)	2.4 (2.3, 2.5)	2.3 (2.2, 2.4)
Number of conditions or illnesses							
0	2.4 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.5, 2.6)	2.6 (2.5, 2.6)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.4, 2.5)
1	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.5, 2.7)	2.4 (2.3, 2.4)	2.5 (2.5, 2.6)	2.4 (2.3, 2.4)
2	2.3 (2.2, 2.4)	3 (2.9, 3)	2.3 (2.2, 2.4)	2.6 (2.5, 2.7)	2.4 (2.3, 2.5)	2.5 (2.4, 2.6)	2.4 (2.3, 2.5)
3+	2.3 (2.1, 2.5)	2.9 (2.8, 3)	2.3 (2.1, 2.5)	2.5 (2.4, 2.7)	2.4 (2.2, 2.6)	2.4 (2.3, 2.6)	2.2 (2.1, 2.4)
Asthma							
No asthma	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.4, 2.4)
Asthma	2.4 (2.2, 2.5)	3 (2.9, 3.1)	2.4 (2.2, 2.6)	2.5 (2.3, 2.7)	2.4 (2.2, 2.5)	2.5 (2.3, 2.6)	2.3 (2.1, 2.4)
Cancer							
No	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Yes	2.4 (2.2, 2.5)	3 (2.9, 3.1)	2.4 (2.2, 2.6)	2.7 (2.5, 2.8)	2.5 (2.3, 2.6)	2.6 (2.5, 2.7)	2.5 (2.3, 2.6)
Cardiovascular disease or heart problems							
No CVD	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.5, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
CVD	2.4 (2.3, 2.5)	2.9 (2.9, 3)	2.4 (2.3, 2.5)	2.7 (2.6, 2.8)	2.5 (2.4, 2.6)	2.6 (2.5, 2.6)	2.4 (2.3, 2.5)

Diabetes

No Diabetes	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.5)	2.4 (2.3, 2.4)
Diabetes	2.3 (2.2, 2.5)	3 (2.9, 3.1)	2.4 (2.3, 2.5)	2.6 (2.5, 2.7)	2.5 (2.4, 2.6)	2.6 (2.5, 2.7)	2.5 (2.3, 2.6)
Mental health condition							
No	2.3 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.4)	2.5 (2.5, 2.6)	2.4 (2.4, 2.4)
Yes	2.3 (2.1, 2.5)	2.9 (2.7, 3)	2.3 (2.1, 2.5)	2.6 (2.4, 2.8)	2.3 (2.1, 2.5)	2.4 (2.2, 2.6)	2.2 (2, 2.4)
Musculoskeletal condition							
No	2.4 (2.3, 2.4)	2.9 (2.9, 3)	2.5 (2.4, 2.5)	2.6 (2.6, 2.6)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.4, 2.4)
Yes	2.3 (2.2, 2.4)	2.9 (2.9, 3)	2.3 (2.2, 2.4)	2.6 (2.5, 2.7)	2.3 (2.3, 2.4)	2.5 (2.4, 2.5)	2.3 (2.2, 2.4)
Other disease or condition							
No other NCD	2.4 (2.3, 2.4)	2.9 (2.9, 2.9)	2.5 (2.4, 2.5)	2.6 (2.6, 2.7)	2.4 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.4, 2.4)
Other NCD	2.3 (2.3, 2.4)	3 (2.9, 3)	2.4 (2.3, 2.5)	2.6 (2.5, 2.6)	2.4 (2.3, 2.4)	2.5 (2.4, 2.5)	2.3 (2.3, 2.4)

Note: Musculoskeletal condition refers to arthritis and/or chronic pain

Table 28 eHealth literacy by use of Internet and My Health Record

	1. Using technology to process health information mean (95% CI)	2. Understanding of health concepts and language mean (95% CI)	3. Ability to actively engage with digital services mean (95% CI)	4. Feel safe and in control mean (95% CI)	5. Motivated to engage with digital services mean (95% CI)	6. Access to digital services that work mean (95% CI)	7. Digital services that suit individual needs mean (95% CI)
Use of internet to access health-related information							
Once a week or more often	2.9 (2.8, 3)	3.2 (3.1, 3.3)	2.9 (2.8, 3)	2.6 (2.4, 2.7)	2.8 (2.7, 2.9)	2.6 (2.5, 2.8)	2.6 (2.5, 2.8)
Several times a month	2.8 (2.7, 3)	3.1 (3, 3.2)	2.9 (2.8, 3)	2.7 (2.5, 2.8)	2.8 (2.7, 2.9)	2.7 (2.5, 2.8)	2.6 (2.5, 2.8)
Approximately once a month	2.7 (2.6, 2.8)	3.1 (3, 3.2)	2.8 (2.7, 2.9)	2.6 (2.5, 2.7)	2.7 (2.6, 2.8)	2.6 (2.6, 2.7)	2.6 (2.5, 2.7)
Approximately once every two months	2.6 (2.5, 2.7)	3 (2.9, 3.1)	2.8 (2.7, 2.9)	2.6 (2.5, 2.7)	2.6 (2.5, 2.8)	2.6 (2.5, 2.7)	2.5 (2.4, 2.6)
A few times within the past year	2.4 (2.4, 2.5)	2.9 (2.9, 3)	2.6 (2.5, 2.6)	2.5 (2.5, 2.6)	2.5 (2.4, 2.5)	2.5 (2.5, 2.6)	2.4 (2.3, 2.5)
No, never	2 (1.9, 2)	2.8 (2.8, 2.9)	2.1 (2, 2.2)	2.6 (2.6, 2.7)	2.1 (2.1, 2.2)	2.4 (2.4, 2.5)	2.2 (2.1, 2.3)
Don't know/NA	1.6 (1.3, 1.9)	2.7 (2.4, 3)	1.8 (1.3, 2.3)	2.6 (2.2, 2.9)	1.9 (1.4, 2.3)	2.1 (1.8, 2.4)	2.1 (1.6, 2.6)
How internet is accessed* (among internet users)							
Computer Only	2.5 (2.5, 2.6)	3 (2.9, 3)	2.6 (2.6, 2.7)	2.5 (2.4, 2.6)	2.5 (2.5, 2.6)	2.5 (2.5, 2.6)	2.4 (2.4, 2.5)
Multiple devices	2.7 (2.6, 2.7)	3 (3, 3.1)	2.8 (2.7, 2.8)	2.6 (2.6, 2.7)	2.7 (2.6, 2.7)	2.6 (2.6, 2.7)	2.6 (2.5, 2.6)
Smartphone	2.7 (2.6, 2.8)	3.1 (3, 3.1)	2.8 (2.8, 2.9)	2.6 (2.6, 2.7)	2.7 (2.6, 2.8)	2.6 (2.6, 2.7)	2.6 (2.5, 2.7)
Tablet	2.7 (2.6, 2.7)	3 (3, 3.1)	2.8 (2.7, 2.8)	2.6 (2.6, 2.7)	2.7 (2.6, 2.7)	2.6 (2.6, 2.7)	2.6 (2.5, 2.7)
Computer	2.6 (2.6, 2.7)	3 (3, 3.1)	2.7 (2.7, 2.8)	2.5 (2.5, 2.6)	2.6 (2.5, 2.7)	2.6 (2.5, 2.6)	2.5 (2.4, 2.5)
Why internet is not used to access health-related information* (among non-internet users)							
I don't know how to	1.8 (1.7, 1.9)	2.8 (2.7, 2.9)	1.8 (1.7, 1.9)	2.7 (2.6, 2.8)	2 (1.8, 2.1)	2.3 (2.2, 2.4)	2.1 (2, 2.2)
I don't know what's out there	2 (1.5, 2.4)	2.6 (2.5, 2.8)	2.1 (1.6, 2.6)	2.2 (1.7, 2.7)	2.2 (1.6, 2.7)	2.3 (1.9, 2.8)	2.2 (1.8, 2.6)
I don't want to	1.9 (1.8, 1.9)	2.9 (2.8, 2.9)	2 (1.9, 2.1)	2.6 (2.5, 2.7)	2 (1.9, 2.1)	2.3 (2.2, 2.4)	2.1 (2, 2.2)
I'm not sure I'd get what I need	1.9 (1.7, 2.1)	2.8 (2.6, 3)	2.2 (1.8, 2.5)	2.6 (2.3, 2.8)	2 (1.8, 2.2)	2.3 (2.2, 2.5)	2 (1.8, 2.3)
I can't afford it*	2.2 (0, 0)	2.6 (0, 0)	2.2 (0, 0)	2 (0, 0)	2 (0, 0)	2.3 (0, 0)	2 (0, 0)
I don't have the right technology (equipment)	1.9 (1.8, 2)	2.8 (2.8, 2.9)	1.8 (1.7, 1.9)	2.7 (2.6, 2.8)	2.1 (1.9, 2.2)	2.4 (2.3, 2.5)	2.1 (2, 2.3)
I'm not confident enough to use computers/smartphones/iPads	1.8 (1.6, 2)	2.8 (2.7, 2.9)	1.7 (1.5, 1.9)	2.5 (2.3, 2.7)	2 (1.7, 2.2)	2.3 (2.1, 2.4)	2 (1.8, 2.2)
I'm not confident I'd be able to understand the information by myself	1.9 (1.4, 2.3)	3 (2.8, 3.1)	2 (1.5, 2.5)	2.6 (2.2, 2.9)	2.1 (1.5, 2.6)	2.3 (1.8, 2.8)	2 (1.5, 2.5)
I prefer face-to-face interaction with health services	2 (1.9, 2.1)	2.9 (2.8, 2.9)	2.1 (2, 2.2)	2.6 (2.5, 2.7)	2.1 (2.1, 2.2)	2.4 (2.4, 2.5)	2.3 (2.2, 2.4)

My Health Record, access and use or intention

Not sure if have	2.2 (2.1, 2.3)	2.9 (2.9, 3)	2.3 (2.3, 2.4)	2.5 (2.5, 2.6)	2.3 (2.2, 2.3)	2.4 (2.4, 2.5)	2.3 (2.2, 2.3)
Don't have	2.3 (2.3, 2.4)	2.9 (2.8, 2.9)	2.4 (2.3, 2.5)	2.6 (2.5, 2.6)	2.4 (2.3, 2.4)	2.5 (2.5, 2.6)	2.4 (2.3, 2.4)
Have **MyHR** and use it	2.7 (2.6, 2.9)	3.1 (3, 3.3)	2.9 (2.8, 3)	2.9 (2.7, 3)	2.8 (2.7, 2.9)	2.8 (2.7, 2.9)	2.8 (2.7, 2.9)
Have **MyHR**, don't use it but intend to	2.6 (2.5, 2.7)	3 (3, 3.1)	2.8 (2.7, 2.9)	2.8 (2.7, 2.9)	2.7 (2.6, 2.8)	2.7 (2.6, 2.8)	2.6 (2.5, 2.7)
Have **MyHR**, don't use it and don't intend to	2.3 (2.2, 2.4)	3 (2.9, 3)	2.4 (2.3, 2.5)	2.6 (2.4, 2.7)	2.4 (2.3, 2.5)	2.6 (2.5, 2.6)	2.4 (2.3, 2.5)
Have **MyHR**, don't use it and not sure if intend to	2.3 (2.2, 2.4)	2.9 (2.9, 3)	2.6 (2.4, 2.7)	2.6 (2.5, 2.8)	2.4 (2.2, 2.5)	2.5 (2.4, 2.6)	2.4 (2.3, 2.5)

* Note that, as only one participant selected 'I can't afford it', we were unable to calculate 95% CI's for this subgroup

Table 29 Health literacy for the total population and by demographics of interest

	1. Feeling understood and supported by healthcare providers mean (95% CI)	3. Actively managing my health mean (95% CI)	4. Social support for health mean (95% CI)	7. Navigating the healthcare system mean (95% CI)
Total	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
Sex				
Men	3.1 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (3.0, 3.1)	4.0 (3.9, 4.0)
Women	3.2 (3.1, 3.2)	3.1 (3.0, 3.1)	3.1 (3.0, 3.1)	3.9 (3.9, 4.0)
Age				
Age <55 years	3.1 (3.1, 3.2)	3.0 (2.9, 3.0)	3.1 (3.0, 3.1)	3.8 (3.7, 3.9)
Age 55 to <70 years	3.1 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (2.9, 3.0)	3.9 (3.8, 3.9)
Age >=70 years	3.2 (3.1, 3.2)	3.0 (3.0, 3.1)	3.1 (3.0, 3.1)	4.1 (4.0, 4.2)
Aboriginal or Torres Strait Islander				
Yes	3.2 (2.9, 3.4)	3.0 (2.9, 3.1)	3.0 (2.8, 3.2)	4.1 (3.7, 4.5)
No	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
Highest educational attainment				
Year 9 or below	3.2 (3.1, 3.3)	3.0 (2.9, 3.0)	3.1 (3.0, 3.2)	4.1 (3.9, 4.2)
Year 10	3.2 (3.1, 3.3)	3.0 (2.9, 3.0)	3 (3.0, 3.1)	4.0 (3.9, 4.1)
Year 12	3.1 (3.0, 3.2)	3.0 (3.0, 3.1)	3.0 (2.9, 3.1)	3.9 (3.8, 4.1)
Trade certificate, apprenticeship, Diploma or college/TAFE certificate	3.1 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
Tertiary education	3.2 (3.1, 3.3)	3.1 (3.0, 3.1)	3.1 (3.0, 3.1)	3.9 (3.9, 4.0)

Table 30 Health literacy by self-rated health, chronic diseases and conditions, and contact with health professionals

	1. Feeling understood and supported by healthcare providers	3. Actively managing my health	4. Social support for health	7. Navigating the healthcare system
Number of contacts with a health professional in the last 12 months	mean (95% CI)	mean (95% CI)	mean (95% CI)	mean (95% CI)
>12	3.2 (3.2, 3.3)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
7 to 11	3.2 (3.2, 3.3)	3.0 (3.0, 3.1)	3.1 (3.0, 3.1)	4.0 (3.9, 4.1)
2 to 6	3.1 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	4.0 (3.9, 4.1)
1 or none	2.9 (2.8, 3.1)	3.0 (2.9, 3.1)	3.0 (2.9, 3.1)	3.9 (3.7, 4.0)
Self-rated health				
Excellent	3.2 (3.1, 3.3)	3.2 (3.1, 3.3)	3.2 (3.1, 3.3)	4.2 (4.1, 4.3)
Very good	3.2 (3.1, 3.3)	3.1 (3.0, 3.1)	3.1 (3.1, 3.2)	4.0 (4.0, 4.1)
Good	3.2 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (3.0, 3.1)	4.0 (3.9, 4.0)
Fair	3.1 (3.0, 3.1)	2.9 (2.9, 3.0)	2.9 (2.8, 3.0)	3.7 (3.6, 3.8)
Poor or Very Poor	3.2 (3.1, 3.3)	2.9 (2.8, 3.0)	3.0 (2.8, 3.1)	3.6 (3.4, 3.8)
Number of conditions or illnesses				
0	3.1 (3.1, 3.1)	3.0 (3.0, 3.1)	3.1 (3.0, 3.1)	4.0 (3.9, 4.0)
1	3.2 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
2	3.3 (3.2, 3.4)	3.0 (2.9, 3.1)	3.1 (3.0, 3.2)	4.1 (4.0, 4.2)
3+	3.1 (3.0, 3.3)	3.0 (2.9, 3.1)	3.0 (2.8, 3.1)	3.7 (3.5, 4.0)
Asthma				
No asthma	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
Asthma	3.2 (3.1, 3.4)	2.9 (2.8, 3.1)	3.0 (2.9, 3.2)	3.9 (3.6, 4.1)
Cancer				
No	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
Yes	3.3 (3.1, 3.5)	3.1 (2.9, 3.2)	3.2 (3.0, 3.3)	4.1 (3.9, 4.3)
Cardiovascular disease or heart problems				
No CVD	3.2 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
CVD	3.2 (3.1, 3.3)	3.0 (2.9, 3.0)	3.0 (2.9, 3.1)	4.0 (3.9, 4.1)
Diabetes				
No Diabetes	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	3.9 (3.9, 4.0)
Diabetes	3.3 (3.2, 3.4)	3.1 (3.0, 3.1)	3.0 (2.9, 3.1)	4.1 (3.9, 4.2)
Mental health condition				
No	3.2 (3.1, 3.2)	3.0 (3.0, 3.0)	3.1 (3.0, 3.1)	4.0 (3.9, 4.0)
Yes	3.2 (3, 3.4)	3.0 (2.9, 3.1)	2.8 (2.6, 3.1)	3.7 (3.4, 4.0)
Musculoskeletal condition				
No	3.1 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	4.0 (3.9, 4.0)
Yes	3.2 (3.1, 3.3)	3.0 (2.9, 3.1)	3.1 (3.0, 3.1)	3.9 (3.8, 4.0)
Other disease or condition				
No other NCD	3.1 (3.1, 3.2)	3.0 (3.0, 3.0)	3.0 (3.0, 3.1)	4.0 (3.9, 4.0)
Other NCD	3.2 (3.2, 3.3)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)

Note: Musculoskeletal condition refers to arthritis and/or chronic pain

Table 31 Health literacy by use of internet and My Health Record

	1. Feeling understood and supported by healthcare providers mean (95% CI)	3. Actively managing my health mean (95% CI)	4. Social support for health mean (95% CI)	7. Navigating the healthcare system mean (95% CI)
Use of internet to access health-related information				
Once a week or more often	3.1 (3.0, 3.3)	3.2 (3.1, 3.3)	3.0 (2.9, 3.1)	3.8 (3.6, 4.0)
Several times a month	3.2 (3.1, 3.4)	3.1 (3.0, 3.2)	3.2 (3.0, 3.3)	3.8 (3.6, 4.0)
Approximately once a month	3.2 (3.1, 3.3)	3.1 (3.0, 3.1)	3.1 (3.0, 3.2)	3.9 (3.7, 4.0)
Approximately once every two months	3.2 (3.1, 3.3)	3.1 (3.0, 3.1)	3.1 (3.0, 3.2)	4.0 (3.8, 4.1)
A few times within the past year	3.1 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
No, never	3.2 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (3.0, 3.1)	4.0 (4.0, 4.1)
Don't know/NA	3.2 (2.7, 3.7)	3.2 (2.9, 3.6)	3.0 (2.5, 3.6)	3.7 (2.9, 4.5)
How internet is accessed* (among internet users)				
Computer only	3.1 (3.0, 3.2)	3.0 (3.0, 3.1)	3.0 (2.9, 3.1)	3.8 (3.8, 3.9)
Multiple devices	3.2 (3.1, 3.3)	3.1 (3.0, 3.1)	3.1 (3.0, 3.1)	3.9 (3.9, 4.0)
Smartphone	3.2 (3.1, 3.2)	3.1 (3.0, 3.1)	3.1 (3.0, 3.1)	3.9 (3.8, 4.0)
Tablet	3.2 (3.1, 3.2)	3.1 (3.0, 3.1)	3.1 (3.0, 3.1)	4.0 (3.9, 4.1)
Computer	3.1 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
Why internet is not used to access health-related information* (among non-internet users)				
I don't know how to	3.1 (3.1, 3.2)	2.9 (2.9, 3.0)	3.0 (2.9, 3.2)	4.0 (3.8, 4.2)
I don't know what's out there	3.1 (2.8, 3.4)	2.8 (2.6, 3.0)	3.0 (2.8, 3.1)	3.9 (3.2, 4.7)
I don't want to	3.3 (3.2, 3.4)	3.0 (2.9, 3.1)	3.1 (3.0, 3.2)	4.2 (4.1, 4.3)
I'm not sure I'd get what I need	3.1 (2.9, 3.3)	2.9 (2.7, 3.1)	3.0 (2.7, 3.3)	3.7 (3.3, 4.1)
I can't afford it	2	2.6	2.6	2.2
I don't have the right technology (equipment)	3.2 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (2.9, 3.1)	4.0 (3.9, 4.1)
I'm not confident enough to use computers/smartphones/iPads	3.2 (3.0, 3.3)	3.0 (2.9, 3.1)	2.9 (2.8, 3.1)	3.9 (3.7, 4.1)
I'm not confident I'd be able to understand the information by myself	3.2 (3.0, 3.5)	3.1 (2.7, 3.5)	2.9 (2.6, 3.2)	4.1 (3.9, 4.4)
I prefer face-to-face interaction with health services	3.2 (3.2, 3.3)	3.0 (2.9, 3.1)	3.1 (3.0, 3.2)	4.1 (4.0, 4.2)
My Health Record, access and use or intention				
Not sure if have	3.1 (3.1, 3.2)	3.0 (3.0, 3.1)	3.0 (3.0, 3.1)	3.9 (3.8, 4.0)
Don't have	3.1 (3.1, 3.2)	3.0 (2.9, 3.0)	3.0 (2.9, 3.0)	3.9 (3.8, 4.0)
Have **MyHR** and use it	3.4 (3.2, 3.5)	3.1 (3.0, 3.2)	3.2 (3.1, 3.3)	4.1 (3.9, 4.3)
Have **MyHR**, don't use it but intend to	3.3 (3.2, 3.4)	3.1 (3.0, 3.2)	3.2 (3.1, 3.2)	4.0 (3.9, 4.1)
Have **MyHR**, don't use it and don't intend to	3.2 (3.1, 3.3)	3 (2.9, 3.0)	3.0 (2.9, 3.1)	3.9 (3.7, 4.1)
Have **MyHR**, don't use it and not sure if intend to	3.1 (3.0, 3.3)	2.9 (2.8, 3.0)	3.1 (2.9, 3.2)	4.0 (3.9, 4.2)

Table 32 12 cluster analysis with demographics and eHealth Literacy Questionnaire (eHLQ) data

12 Cl #	Cl ord	Num people	Av Age	% Female	% use internet last year for health	Av Freq use internet	% have MyHR	% use or plan to use MyHR	ATSI%	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
3	1	37	58.9	54.1%	78.4%	2.2	59.5%	48.6%	5.4%	3.17	3.60	3.26	3.65	3.37	3.57	3.43
12	2	53	56.7	52.8%	96.2%	3.0	35.8%	30.2%	1.9%	3.25	3.66	3.45	2.66	3.20	2.80	2.83
2	3	123	62.9	52.8%	73.2%	2.0	41.5%	24.4%	4.1%	2.90	3.04	2.87	3.00	2.95	2.96	2.95
8	4	135	60.9	56.3%	80.7%	1.9	42.2%	27.4%	2.2%	2.63	2.90	2.81	2.46	2.67	2.60	2.56
10	5	179	67.3	54.7%	49.7%	1.0	34.6%	15.6%	1.7%	2.30	2.88	2.35	2.96	2.47	2.71	2.64
7	6	117	61.1	49.6%	81.2%	1.9	33.3%	12.0%	0.0%	2.45	2.92	2.75	1.92	2.46	2.31	2.13
5	7	121	69.8	59.5%	25.6%	0.4	20.7%	8.3%	2.5%	2.00	2.72	2.10	2.78	2.01	2.36	2.04
6	8	96	64.6	50.0%	60.4%	1.2	24.0%	8.3%	1.0%	2.15	2.69	2.30	2.16	2.13	2.22	2.10
9	9	39	71.7	53.8%	20.5%	0.3	20.5%	5.1%	0.0%	1.56	2.90	1.41	2.86	1.75	2.29	1.92
4	10	41	65.4	51.2%	46.3%	1.1	14.6%	2.4%	0.0%	1.75	2.87	1.89	1.74	1.75	1.92	1.60
1	11	38	75.2	52.6%	0.0%	0.0	15.8%	5.3%	0.0%	1.07	2.99	1.13	2.79	1.09	1.79	1.18
11	12	21	69.6	47.6%	14.3%	0.1	9.5%	0.0%	0.0%	1.16	2.48	1.29	1.50	1.23	1.44	1.25

Table 33 Health Literacy Questionnaire (HLQ) data by cluster

12 Cl #	Num people	HLQ1 Feeling supported by health care providers	HLQ3 Actively engaged with health	HLQ4 Social support	HLQ7 Navigating health services
3	37	3.70	3.46	3.65	4.23
12	53	3.49	3.38	3.33	4.09
2	123	3.18	3.08	3.08	4.14
8	**135**	**3.09**	**2.95**	**2.98**	**3.93**
10	179	3.18	2.97	3.06	4.17
7	**117**	**2.96**	**2.95**	**2.91**	**3.64**
5	121	3.07	2.89	2.96	3.92
6	96	2.90	2.91	2.89	3.64
9	39	3.38	3.06	3.30	4.04
4	41	2.99	3.07	2.89	3.52
1	38	3.49	3.23	3.31	4.17
11	21	3.07	2.93	2.73	3.63

Table 34 Clusters and the proportion of people who use or plan to use MyHR

12 Cl Num	Ord Cl	Number of people	% use or plan to use MyHR
3	1	37	48.6%
12	2	53	30.2%
2	3	123	24.4%
8	4	135	27.4%
10	5	179	15.6%
7	6	117	12.0%
5	7	121	8.3%
6	8	96	8.3%
9	9	39	5.1%
4	10	41	2.4%
1	11	38	5.3%
11	12	21	0.0%

Table 35 Clusters and health conditions

12 CI #	Number in CI	Av Age	# Fem	% Fem	Av # conds	# Cancer	# CVD	# diab	# ment hlth	# musc-skel	% Cancer	% CVD	% diab	% ment hlth	% musc-skel	Av Freq HP	Av SR Health	# use internet last year	% use internet last year	Av Freq int	# have MYHR	# use/ plan MYHR	% have MYHR	% use or plan to use MYHR	ATSI	ATSI%
3	37	58.9	20	54.1	1.0	2	6	4	5	9	5.4	16.2	10.8	13.5	24.3	2.6	4.5	29	78.4	2.2	22	18	59.5	48.6	2	5.4
12	53	56.7	28	52.8	0.9	3	7	5	1	8	5.7	13.2	9.4	1.9	15.1	2.8	4.5	51	96.2	3.0	19	16	35.8	30.2	1	1.9
2	123	62.9	65	52.8	1.0	10	20	11	7	23	8.1	16.3	8.9	5.7	18.7	2.8	4.3	90	73.2	2.0	51	30	41.5	24.4	5	4.1
8	135	60.9	76	56.3	0.7	8	9	8	2	21	5.9	6.7	5.9	1.5	15.6	2.6	4.4	109	80.7	1.9	57	37	42.2	27.4	3	2.2
10	179	67.3	98	54.7	1.0	5	32	20	12	31	2.8	17.9	11.2	6.7	17.3	2.6	4.1	89	49.7	1.0	62	28	34.6	15.6	3	1.7
7	117	61.1	58	49.6	0.9	6	13	7	5	19	5.1	11.1	6.0	4.3	16.2	2.5	4.4	95	81.2	1.9	39	14	33.3	12.0	0	0.0
5	121	69.8	72	59.5	0.8	3	12	9	8	24	2.5	9.9	7.4	6.6	19.8	2.6	4.1	31	25.6	0.4	25	10	20.7	8.3	3	2.5
6	96	64.6	48	50.0	0.8	5	10	9	3	16	5.2	10.4	9.4	3.1	16.7	2.6	4.2	58	60.4	1.2	23	8	24.0	8.3	1	1.0
9	39	71.7	21	53.8	1.1	5	6	3	2	11	12.8	15.4	7.7	5.1	28.2	2.7	4.0	8	20.5	0.3	8	2	20.5	5.1	0	0.0
4	41	65.4	21	51.2	1.0	1	5	4	2	11	2.4	12.2	9.8	4.9	26.8	2.4	3.6	19	46.3	1.1	6	1	14.6	2.4	0	0.0
1	38	75.2	20	52.6	1.4	4	6	1	4	14	10.5	15.8	2.6	10.5	36.8	2.9	4.2	0	0.0	0.0	6	2	15.8	5.3	0	0.0
11	21	69.6	10	47.6	1.5	1	3	3	5	7	4.8	14.3	14.3	23.8	33.3	2.2	4.1	3	14.3	0.1	2	0	9.5	0.0	0	0.0

Appendix I Table of Recommendations Template

Table 36 cross references the recommendations in the report with consumer education, consumer access, healthcare provider education, and systems/policy, which were categories requested by the Australian Digital Health Agency (ADHA) in feedback to the draft report. This table will be populated by WVPHN and the ADHA.

In the report, the recommendations are structured into two categories and are underpinned by four fundamental principles.

Box 1 Two categories of recommendations that seek to ensure coverage of all Australians

Category 1 recommendations address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)

Category 2 recommendations for actions at specific levels including actions required at the individual, family/community, practitioner/professional and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR.

Box 2 The four principles underpinning the recommendations.

Principle A: Actions to promote the use of digital health technologies including MyHR need to be guided by a principle of equity and to recognise that the people who have the greatest need for a system like MyHR are often the people facing the greatest barriers to engagement. Therefore, in planning for improvement, strategies should aim to maximise the benefits for people with the greatest needs and health systems should be developed with the flexibility to allow for this.

Principle B: Achieving acceptable population-wide implementation and community engagement in digital health technologies and MyHR will require action at multiple levels of government and organisations and implementation in an integrated and synergistic manner across these levels. In considering the recommendations, it is necessary to always reflect on how the whole may be more than the sum of the parts. (See Recommendations 1 to 4 as examples of synergistic sets of interventions.)

Principle C: It is necessary to recognise that the introduction of digital health technologies, including MyHR, is perceived by many people as a change that poses a threat to systems of care that are comfortable and familiar to them. People's expectations are coloured by past experiences with new technologies that have promoted self-service and are associated with a reduction in services, especially services where contact with a person is preferred. Such a scenario is a source of anxiety to many people when it relates to their health and health care. All actions to promote digital health technologies, including MyHR, must recognise and take systematic and proactive action to manage people's expectations and anxieties.

Principle D: There is no one-size-fits-all approach to education and communication. In particular, approaches that depend solely on mass media and/or uniform printed materials will not engage all the different groups of people in a community. An extensive and diverse suite of approaches are needed to address the diverse needs of different groups, and these approaches will very often need to involve community members having opportunities to discuss potential benefits, concerns, and what is required of them with peers and/or health professionals. Promotional materials must reflect an understanding of the core concerns of community members, and what different groups of people are likely to consider a significant and practical benefit to engagement in digital technologies such as MyHR.

Table 36 Recommendations Cross Reference (Template)

How to read the table:

1. Recommendations from the report are written in **black** text in the left column. The red text has been copied from ADHA draft report feedback.
2. The types of recommendations are grouped by Consumer Education (**CE**), Consumer Access (**CA**), Provider Education (**PE**), System and Policy (**S&P**), as requested by ADHA in the draft report feedback.
3. The table is intentionally left blank in order for ADHA to input their own text and ticks around each recommendation in terms of the type of recommendation and the current level of implementation.

Recommendation 1

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 1 Recommendations: address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)							
1.1 Assist people to understand potential benefits, the relevance of possible benefits, and to weigh benefits against possible risks.							
Recommendation 1 There is a need for an integrated and synergistic strategy to help people **understand the potential benefits** of MyHR and other digital technologies in a way that is relevant to their life circumstances, perceived health risks, and preferences for receiving healthcare services. This strategy should consider both the intellectual and experiential aspects of understanding (where experience can be personal or gained vicariously through the experiences of others). It needs to facilitate the ability of people to assess perceived benefits against perceived risks and should, ideally, allow for people to choose a level of engagement that maximises their perceived benefit while minimising their							

perceived risks. Some components of an integrated and synergistic approach could include: Consumers need to understand the potential benefits and potential risks that are relevant to their situation, choosing their level of engagement based on their individual situation. The benefits should be both practical and relevant to consumers:								
g. [A comprehensive taxonomy of potential benefits of MyHR with an emphasis on the types of benefits experienced and desired by consumers]. • Taxonomy of benefits and risks, dependent on engage, provided in a visual format								
h. Description and presentation of potential benefits in terms of the user not the health system (e.g., reduced need to tell the same information repeatedly, reduced waiting times, less chance of an accident, convenience in accessing services or purchasing health products, advantages for travel). • Description of benefits should be described in terms of the consumer, not the health system. Examples include: - Safety benefits for emergency situations - Convenience and reduced waiting times in emergency departments - Healthcare while traveling - Reduced paperwork when using new services - Reduced need to explain things to new doctors or services.								
i. Sharing simple, true and positive stories in the community (as well as negative stories, which are already widely shared). For this to occur, people need to know when their MyHR has been accessed and how it has streamlined and benefited the services that they have received. Providers who access and use a person's MyHR should be encouraged to, and given a process to, share this fact with their patient. • Need to share positive stories of My Health Record in the community, for this to occur, consumers need to know when their record has been								

	accessed and how the services have benefits from this access. Providers could be encourage to share this with their patients							
j.	Simple, true stories of how people have benefited need to be made widely available in a range of formats. • Simple, true stories could be made available in a range of formats							
k.	Simple tools and processes that assist people to assess potential benefits of MyHR against potential risks, and to choose a level of utilisation that suits them. For example, a GP says 'how about I just upload your medications and allergies in case you have to go to hospital sometime?'; or a chart displaying different levels of engagement with MyHR and potential uses and benefits of each level (similar to the charts presented for many software products). • In addition several people requested a tool that would enable them to easily see the possible benefits and risks							
l.	Regular communication/promotion to people to increase awareness of the things that don't exist or don't happen in the current system but that they believe already happen (e.g., a belief that emergency departments somehow already know their history and medications). • [Many participants in the workshops were unaware of what the benefits could be and emphasised that the benefits need to be explained in very concrete ways, illustrated by stories of real people and circumstances.]							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 2

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 1 Recommendations: address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)							
1.2 Address concerns about the potential impact of developments in digital health on familiar and valued processes of care (see next row down)							
Recommendation 2 General practices are the first point of care for most Australians and the primary source of health data about patients. There needs to be an integrated and systematic approach to enabling GPs and practices to support their patients in the most appropriate way to engage with MyHR. This approach requires action at multiple levels in a practice. [Consumer Education] Address concerns about the potential impact of developments in digital health on familiar and valued processes of care. These concerns include: [Consumer Access] There needs to be an integrated and systematic approach to enabling GPs and practices to support their patients in the most appropriate way							
f. Fully engaging general practice in the design of the system [and ensuring that it integrates with all clinical software systems]. • Fully engaging general practice in the design of the system, ensuring that it integrates with all clinical software systems							
g. Providing training and resourcing to GPs and practice nurses for approaches to introduce MyHR in a gentle and minimally burdensome manner that builds on the patient's belief that the doctor is in control of							

their care. This should include options that do not require the patient to use technology at all but that still support patients to understand what information a doctor uploads on their behalf. • Providing training and resourcing to GPs and practice nurses in approaches to introduce MyHR in a gentle and minimally burdensome manner that *builds on the patient's belief that the doctor is in control of their care*							
h. Providing materials that make it easy for doctors or practice nurses to easily discuss what data can be uploaded and what the patient does and does not want uploaded, as well as potential benefits of use including both health and convenience benefits. • Provide materials that make it easy for doctors or practice nurses to easily discuss what data can be uploaded and what the patient does and doesn't want uploaded							
i. Ensure that it is easy for the doctor to only upload data agreed with the patient. • Same							
j. Supporting practices to provide computers that patients can access within the practice that include easy access to MyHR and high quality information sites. • Same							
• **[from p.56 of report]** My Health Record may be forcing people to engage in a new process of 'self-service' care that may undermine the personal care that they are used to							
• **[from p.56 of report]** This was also expressed as a concern that in order to effectively interact with the healthcare system people will need to learn computer skills and organise computer access or else they will be at a disadvantage							
• **[from p.56 of report]** Many participants were unaware that the system could be used, and provide benefits to them, without them needing to							

engage with the technology at all just by discussing with the doctor what would be uploaded							
• **[from p.56 of report]** For these people the relatively passive components of MyHR were thought to be already occurring while their perception of the active features of MyHR was seen as frightening or burdensome and a possible intrusion into the face-to-face, personal care that they prefer.							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 3

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 1 Recommendations: address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)							
1.2 (continued) Address concerns about the potential impact of developments in digital health on familiar and valued processes of care							
Recommendation 3 Where possible, utility should be built into the MyHR system to transparently enhance processes of care that people value. Utility should be built into the My Health Record, enhancing processes of care that consumers value, leading to an increase in the value and the trust in the My Health Record system							
a. Integration with other systems such as systems at pharmacies, [community health centres], hospitals/emergency centres and the medical practices. Particular potential benefits/conveniences that were identified include streamlined prescription filling, better reminders and appointment making with the medical practice, reduced time waiting at emergency departments, and less need to spend time completing forms and repeating information when referred to other services. • Integration with other systems such as systems at pharmacies, community health centres, hospitals/emergency centres and the medical practices • Benefits/conveniences that were identified included: - streamlined prescription filling - better reminder and appointment making with the medical practice							

- reduced time waiting at emergency departments and less need to spend time completing forms and repeating information when referred to other services							
b. As with Recommendation 2, there should be methods available for people who do not want to, or who are not able to, interact with MyHR to have it set up for them. • There should be methods available for people who are not interested or able to interact with the system themselves to have these systems set up for them							
These conveniences will only help to increase the extent to which people value and trust MyHR if they are made aware of them, both as potential benefits and when they experience these benefits. Many consumers assume that integration of these supports, services and systems is already in place.							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 4

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 1 Recommendations: address the major issues requiring an integrated synergistic approach (in general these tend towards longer-term, structural solutions)							
1.3 Providing opportunities to people who experience substantial barriers to engagement but who also have high capacity to benefit (Note: Recommendation 2 is also particularly important for this issue)							
Recommendation 4 A flexible and multi-level approach will help people facing barriers to access and engagement to participate at the level of their interest, and to achieve benefits equitably with those who face fewer barriers. This approach should consider the stages that people go through in engaging with digital health technologies, and the barriers that different groups of people might face. Figure 25 shows some of the issues and points of action that should be considered at each stage of a person's journey to engage with digital health technologies and MyHR. Some of the components of a flexible, integrated approach identified in the workshops were: There is a need for a flexible, multi-level approach to help people facing different barriers to access and engagement, considering the user journey when engaging in digital health technologies:							
f. Implement Recommendation 2.							
g. To facilitate access to important health websites, including MyHR, provide computers in community settings such as libraries, neighbourhood houses, medical practices, pharmacies, centres providing University of the Third Age (U3A), and Men's Sheds. This is especially important in areas with poor Internet connections and for people without personal access to computers and good Internet services. There							

will be additional benefits if there are people at these places who can provide some guidance about how to access and use these websites.								
• Provide access to computers that are set up to provide easy access to important health websites, including MyHR, in community settings such as libraries, neighbourhood houses, medical practices, pharmacies, centres providing U3A, men's sheds. This is especially important in areas with poor internet connections and for people without personal access to computers and good internet services….								
h. Engage organisations like U3A, neighbourhood houses, libraries, and Men's Sheds in providing simple training to use computers for practical purposes. • Same								

i. Make systems easily accessible through alternative technologies such as tablets and phones.
    • Ensure that MyHR can be accessed through simple smartphone applications.
    • Same
    • Implement a system where people who don't have smartphones can interact through a mix of sms and phone calls [e.g. a summary of what information is uploaded, notifications of access, who to call to discuss concerns].
    • Same
    • Ensure that all promotional and informational materials contain a phone number to call, not just a web address.
    • Same
    • Ensure that complaints and problem-solving processes allow people to talk to an actual person.
    • Same								

j. Provide all services and interfaces in multiple languages.								

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 5

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR **This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.**							
2.1 Health practitioner/professional roles							
Recommendation 5 There should be clear guidelines [and training] for health professionals who access and use MyHR data for an individual in their care. These should include: There should be clear guidelines and training for health professionals who access and use My Health Record data for an individual in their care. These should include:							
e. Circumstances in which access and use is or is not appropriate and permissible • Same							
f. Communicating with and engaging the patient whose record is being accessed, including: • Informing the person that they have accessed the data • Allowing the person to make any comments or clarifications that they wish							

• Reassuring the person, where appropriate, that the practitioner will undertake their own assessment and provide an independent opinion • If the MyHR data have proved useful in any way, explaining this to the person • Discussing any data that will/could be uploaded as a result of the episode of care • Procedures if data are found to be out of date or incorrect (see point c in next row)							
g. Procedures if data are found to be out of date or incorrect (see point b in row above)							
h. How to access problem solving support • Same							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 6

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.							
2.1 (continued) Health practitioner/professional roles							
Recommendation 6 There is a need to ensure that all health professionals have an accurate and consistent understanding of MyHR and that they understand the potential benefits. This has been difficult to achieve due to ongoing changes during the MyHR roll out. Some health professionals feel that they have been bombarded with procedural information but still don't have an overall sense of what MyHR is really going to achieve: *'As health professionals we are bombarded but still don't know much about what it is'*. It was also noted frequently in the workshops that health professionals have high opt-out rates although the evidence for this was not cited. At the earliest possible time the following should be implemented. Ensure that all health providers have an accurate and consistent understanding of My Health Record and that they understand the potential benefits. Some health providers feel that they have been provided with procedural information but don't have an overall sense of what My Health Record is going to achieve. An approach to fully inform health providers should be implemented that includes:							

c. As a priority, Recommendation 1 should be fully implemented for health professionals.							
d. Provision of simple up-to-date resources and training for health professionals with a focus on the following points as soon as the components of the MyHR system are sufficiently settled: • Exactly what MyHR is and is not • Same • Specific benefits of MyHR • Same • Safeguards for security, quality, appropriate use • Same • How MyHR can synergise with and enhance normal care • Same • Options for engaging patients as per Recommendations 2 and 5 • Same • Resources and financial support that are available • Same							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 7

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.							
2.2 Community engagement/outreach strategies Recommendation 7 presents many of the ideas from the workshops about options for increasing access to and support for the use of computers and of digital health technologies, including MyHR, in community settings.							
Recommendation 7 The workshops produced many suggestions for opportunities and contexts where people may learn about MyHR other than from a health professional or the media. Some of these contexts may make it easier to highlight particular potential benefits and for people to develop their understanding in a shared and reflective manner: '*… social engagement is credible really because if you can find a small increase of people that do understand or can use that, that can easily permeate out into their social circles and get gradual exposure to the thing. It does not matter if they are homeless or otherwise if you can get a couple of people who are advocates that can permeate through their social circles. Often when you are presenting there will be two that really get it and the others will trickle in after talking to people and start to understand bits of it.*'							

Strategies and resources should be developed to encourage and enable community facilities and organisations to discuss digital health resources, including MyHR, as part of activities that already engage people in learning about and discussing related issues. These could include: Explore opportunities and contexts where people may learn about My Health Record other than from a health professional or the media. Some of these contexts may make it easier to highlight particular potential benefits and allow people to develop their understanding in a shared and reflective manner, these include:							
• Health education and promotion events • Computer training activities (see also Recommendation 4) • U3A and other lifelong education activities • [Retirement and financial planning activities] • Activities that engage people in using computers for other important tasks in life such as MyGov • Travel planning and sharing events • Farming events and other business planning and management events • Same for all of these							
To take advantage of such opportunities, it would be highly desirable to have materials available that present potential benefits in practical, relevant ways as discussed in Recommendation 1.							
It would also be useful to ensure that there are links to MyHR or relevant information about MyHR on web pages and materials related to the activities listed above.							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 8

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.							
2.3 Strategies for engaging families and individuals The recommendations that have already been presented include many recommendations to support flexible implementation of MyHR to support a wide diversity of individual needs and preferences within the community. This section has a focus on suggestions that were made in workshops about engaging families and about families supporting each other.							
Recommendation 8 A significant finding of both the semi-structured interviews and workshops was that in many families one person was substantially more engaged in digital health technologies, and likely to be more interested in MyHR, than other family members. This can have both positive and negative aspects. It can be positive because the strengths of one person can help other family members. It can be negative if that person becomes unable to continue that role and other family members do not have the knowledge of what has been done for them or the ability to be engaged on their own behalf. Digital health technologies, including MyHR, should be implemented in such a way that engages participation of different family members where possible. Specific suggested actions include:							

• Develop resources that assist families to discuss MyHR together or people to discuss with elderly parents, possible as part of other discussions about future health planning [e.g. Advanced care planning] • Educate adolescents about MyHR (schools, online) • Provide simple materials to guide parents through how they can control MyHR for their children • Consider the role of parents making decisions for children in implementing all other recommendations. A significant finding of both the semi-structured interviews and workshops was that in many families one person was substantially more engaged in digital health technologies and likely to be more interested in MyHR than others. • Digital health technologies, including MyHR should be implemented in such a way that engages and reaches individuals as well as families. • Teaching about MyHR in schools						

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 9

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.							
2.4 Design and features of digital health technologies Recommendations 2 to 4 emphasised the need to provide options for people who do not wish to or who are unable to directly engage in the IT interfaces of MyHR. The recommendations in this section are about supporting individuals who do wish to interact with and control their MyHR but who, in order to engage, need the design and features of digital health technologies to be easy to access and navigate.							
Recommendation 9 Many participants in the workshop expressed desired characteristics of the system to do with the simplicity of the MyHR interface, the reliability of the system (even with poor Internet connections), and the ease of solving problems within the system. While many community members reported having experienced difficulties with these issues in the past, their negative experiences may not have related to MyHR but may reflect other negative past experiences including trying to interact with MyGov services. None-the-less both consumers and health professionals indicated that the following would be required for ease of use: Same							

f. Extremely simple language used throughout. • Same							
g. Ensure short loading times for MyHR web pages and minimum need to load new pages. • Same							
h. Available on multiple platforms including phones and tablets. • Same							
i. Options for people who can't remember passwords (fingerprint, retina, [face]). • Same							
j. Ability to easily solve most problems online or with support that is quick and involves the option to talk to a real person. • Same							

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy

Recommendation 10

Recommendation and actions	Type of recommendation				Current level of implementation: technical and promotion		
	CE	CA	PE	S&P	In place	In progress	Future
Category 2 Recommendations: actions at specific levels including actions required at the individual, family/community, practitioner/professional, and system levels (including design of digital health technologies) to increase uptake of eHealth technologies and MyHR This section contains additional recommendations based on the levels of action that have not already been included in Recommendations 1 to 4.							
2.4 Design and features of digital health technologies Recommendations 2 to 4 emphasised the need to provide options for people who do not wish to or who are unable to directly engage in the IT interfaces of MyHR. The recommendations in this section are about supporting individuals who do wish to interact with and control their MyHR but who, in order to engage, need the design and features of digital health technologies to be easy to access and navigate.							
Recommendation 10 For some people, it is important that the MyHR system enables them to check and correct the information that is uploaded, including making sure that the information has sufficient context to be correctly interpreted by future users. These people are also likely to want to exert control over what information is uploaded and to be able to add comments or information of their own. The MyHR system should make it as easy as possible for users to:							

The My Health Record should make it as easy as possible for users to exert control over what information is uploaded and to be able to add comments or information of their own:						
g. Identify and read all information that is uploaded, and identify who uploaded it • Same						
h. Have the ability to block particular information from being visible to other users • Same						
i. Add notes of comment or explanation to provide context to any particular uploaded information • Same						
j. Add general notes of their own • Same						
k. Select a set of information that they want available for a particular purpose (e.g., travel) • Same						
l. Print out an extract of selected information for overseas travel or for other purposes • Same						
Many of these points would only be effective if health professionals who upload information are easily contactable and have the time, willingness, and technical capability to explain about information that has been uploaded, correct errors, and/or remove uploaded information. Same						

CE, Consumer education; CA, Consumer Access; PE, Provider Education; S&P, System and Policy
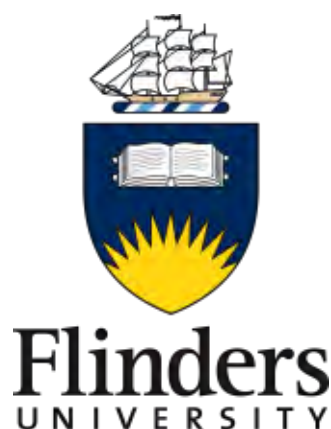
My Health Record: A South Australian General Practice Case Study

Final report

Discipline of General Practice
Flinders University

Authors: Cecilia Moretti, Richard L Reed & Tania Shelby-James

November 2018

Contents

Executive summary

Background

The Australian Digital Health Agency commissioned the Flinders University College of Medicine and Public Health to research perceptions and use of My Health Record by GPs, practice staff and patients in a single site primary care setting in South Australia.

Tailored My Health Record training was delivered at ▉s47G▉ ▉s47G▉ in June 2018, as part of the practice's continuing professional development program. The research case study examined whether GP and practice staff perceptions and use of My Health Record changed after receiving the training, leading to greater engagement.

The study also canvassed the views of patients who are registered My Health Record users to determine whether the system has delivered value to consumers as a useful health resource.

▉s47▉ case study

▉s47▉ is a leading general practice in ▉s47G▉, with an excellent tradition of research and innovation and awards for the quality of their care. The surgery offers a comprehensive range of services including both acute and preventive services. ▉s47G▉ ▉. One GP partner ▉s47G▉ ▉s47G▉ has been taking a lead role in encouraging practice-wide uptake of the technology. Therefore, ▉s47▉ is both a receptive and well-positioned primary care setting to test professional readiness and factors that influence the uptake of My Health Record.

Study context

Contextual factors of note included:

- the relative immaturity of the My Health Record system in South Australia; principally, the insufficient connection of primary, secondary and tertiary care data flow across the health system
- the unanticipated introduction of the My Health Record opt out period between 16 July and 15 November 2018, coinciding with the completion of the training.

Research method

Twenty face to face interviews with health professionals were conducted pre-training on site at ▉s47▉ in May 2018. Of these, 16 participated in the post-training interviews in August 2018.

Findings – GPs and practice staff

Understanding of My Health Record

Members of the ▉s47▉ team ranged along a spectrum of awareness, understanding and acceptance of My Health Record as a digital health tool, with most expressing some ambivalence but an open mind to using it.

The practical training was successful in giving participants the knowledge, skills and confidence to navigate My Health Record and reassured them that My Health Record is quick and easy to navigate.

Perceived benefits of My Health Record

The main perceived benefits associated with a well-designed and properly functioning My Health Record system were relatively consistent across the pre- and post-interviews and included:

- the ability to share health information seamlessly across the primary, secondary and acute sectors and thereby reduce medication errors, aid in informed diagnoses and enable GPs and practice staff to receive timely directions about follow up treatments
- potential workflow efficiencies, not having to chase up test results and discharge summaries or having to probe for patient histories
- patient empowerment through increased access to their health information and involvement in their care.

Utilisation of My Health Record in s47

My Health Record uptake was low before the training with minimal change after the training. The main reasons for the lack of change – in spite of recognising the many potential benefits – included:

- data privacy and security concerns associated with the opt out debates
- limited wider health provider buy in and unavailability of information such as pathology and diagnostic imaging results and hospital discharge summaries
- perceived unreliability of My Health Record information (e.g. incomplete, not up to date, edited by patients)
- lack of time in pressured consultations and other priorities taking precedence
- patients not asking for My Health Record and lack of other triggers for use.

However, training and the wider dialogue surrounding My Health Record activated interest in and uptake of My Health Record among several s47 team members.

Key facilitating factors for the uptake of My Health Record

Uptake would be facilitated by:

- comprehensive buy-in from providers across the health sector and systematic uploading of relevant health information
- demonstrable evidence of clinical benefits, workflow efficiency and patient satisfaction
- practice-level support to ignite and maintain momentum, e.g. encouraging ongoing conversation and promoting, recognising and rewarding the use of My Health Record.

Reflections on the training

GPs reflected upon the need for:

- hands on training, rather than an overhead screen demonstration walk through of My Health Record.
- opportunities to practice – 'to play' – with the technology during and after training, preferably with a dummy patient or equivalent
- more training specifically addressed to non-GP participants' roles and expectations in administering My Health Record
- follow up training after the closure of the opt out period, to regain the momentum, refresh their practical skills, and to knowledgably respond to patient concerns about data privacy, security and other contentious components of My Health Record.

Findings – s47 patients

The patients interviewed were an older cohort, 70 years of age on average – some with complex health conditions while others were in reasonably good health – who were targeted because they had reasonable IT literacy and a keen interest in charting their health journey.

Reasons for signing up to My Health Record
Most signed up on the advice of their GP and considered it a good idea that their health information could be shared/accessed anywhere, anytime, by any health provider involved in their care.

Many were experiencing a growing sense of vulnerability associated with ageing, and My Health Record was seen as a valuable health management tool (e.g. for mitigating memory loss/cognitive decline), particularly the event of health emergencies (providing on the spot, accurate health information).

Patient interaction with My Health Record
Patients ranged from actively interacting with their My Health Record to a passively allowing the tool to be managed by their GPs and practice nurses.

Direct interactions involved accessing and monitoring information and reports uploaded by their GPs (most common), discussing their records with their GP (relatively common) and entering their own information into the record (least common).

My Health Record gave these patients a sense of confidence, autonomy and control over their health management. In particular they valued:
- the increased transparency in the health exchange between patient and GP offered by My Health Record
- the ability to access information and results independently, without having to go directly through their health provider.

Issues and concerns raised about My Health Record
Patients were concerned by:
- technical issues experienced while trying to sign up or activate their records
- insufficient information in the record, e.g. the lack of test results
- the need for information that is relevant, easy for patients to read, interpret and manage.
- privacy and security; however, most believed that the health-protecting and potential life-saving benefits of My Health Record outweighed any privacy and security risks.

Real life benefits of My Health Record
No patients provided an explicit example of My Health Record delivering a life-changing health impact, as none of them had yet had a critical health event or emergency necessitating its use.

Two respondents described adverse situations where a My Health Record, had it been operative at the time, could have made a key difference to their health encounters.

Recommendations

Recommendations for supporting increased uptake of My Health Record – in s47G SA general practice more widely and the SA patient community – relate to four key focus areas.

1. **Build confidence in primary, secondary and tertiary My Health Record connections in South Australia**

   Recommendation 1: Continue to fast track My Health Record connections (noting key developments scheduled for 2019) and ensure that GPs, practice staff and patient users of My Health Record **are well informed** about progress in bringing diverse health providers and data/test results into My Health Record (e.g. pathology, radiology, SA Health, and allied health).

2. **Develop targeted training and education**

   Recommendation 2: Design and deliver My Health Record training and education:
   - equipping GPs and practice staff with the **practical knowledge and skills** to navigate My Health Record
   - providing more **hands on training**, incorporating laptops and a dummy patient or equivalent to practice on
   - improving health practitioner knowledge and confidence **to discuss the privacy and security issues** raised in the opt out debates and associated protections built into the tool
   - equipping GPs and practice staff to **assist and advise patients about how use** the tool;
   - specifically addressing **non-GP practice staff roles and functions**
   - providing the s47 team with **follow up training** after the opt out period has concluded to address the issues raised, refresh practical skills and reignite the momentum lost following the opt out experience
   - exploring avenues for **peer-to-peer education** both within the s47 GP and practice staff team and in broader a cross-general practice context.

   Recommendation 3: Develop a stronger focus on patient community information and education through:
   - a **positive public awareness campaign** to engage the interest of the wider community and counter the negative messaging produced in much of the opt out media
   - **targeted information resources** (online and brochures) for patients, addressing privacy and security concerns and how to apply protection mechanisms built into the tool.

3. **Maximise features which will support rollout of My Health Record**

    Recommendation 4: Select and prepare key general practices for successful uptake of – and a leadership role in promoting – My Health Record in South Australia, noting the following facilitating factors:
    - having one or more **digital health champions** within the practice to drive and support the process
    - projecting a **positive practice culture** that encourages and supports staff uptake of My Health Record

    Recommendation 5: Recognise and reward health practitioners for committing the extra time and effort required to clean data in preparation for setting up a patient's My Health Record. This could include:
    - considering a **non-attendance based My Health Record set-up rebate**; potentially time limited until sufficient momentum is underway
    - **exploring other mechanisms** (e.g. practice-based) to minimise and account for the time involved in setting up a My Health Record with clean and adequate data.

    Recommendation 6: **Address technical issues** in My Health Record and **make the tool as user-friendly** as possible, by:
    - streamlining and simplifying **patient activation and login procedures**
    - resolving **interface issues** between My Health Record and s47G software (e.g. problems in the medication view)
    - developing swift resolution processes to **rectify data errors** in My Health Record (e.g. incorrect medications).

4. **Leverage the progress of s47 to encourage broader acceptance of My Health Record**

    Recommendation 7: Assess the change readiness of general practices in South Australia and **develop a diffusion strategy** to grow regional and state-wide momentum. The strategy should:
    - maximise the digital health strengths and advancement of s47 to establish it as **a lead South Australian practice** in the utilisation of My Health Record
    - build a **digital health network** to diffuse the capabilities of s47 to other receptive practices and beyond.

1. Background

My Health Record is a national digital health record system that provides a secure online summary of individuals' key health information, which can include a patient's health summary, medication prescribing and dispensing history, pathology reports, diagnostic imaging reports and discharge summaries[1]. My Health Record is designed to share this information quickly and easily among the range of health-care providers involved in an individual's health care. Registered health care providers can upload a range of clinical documents Medicare and the Pharmaceutical Benefits Scheme add information about episodes of care or prescribed medications and registered users can add any personal health-related information they deem relevant. Information on an individual's record can be accessed by the registered user, registered health professionals and the user's nominated or authorised representatives[2].

The Australian Digital Health Agency commissioned the Flinders University College of Medicine and Public Health to research perceptions and use of My Health Record by GPs, practice staff and patients in a single site primary care setting in South Australia. s47G ███████ s47G ███ was selected as the target site as it is an innovative and forward-thinking practice s47G ███████ s47G ███████████. The surgery offers a comprehensive range of services including both acute and preventive services. s47G ███████████████████████ ███████████████████████████. s47G ███████ ███████████████████████████████ ███████████████████████████████ ███████████████████████████████ ███████████████████████████ ███████████████████

Tailored My Health Record training was delivered at s47 ██ in June 2018, as part of the practice's continuing professional development program. The research case study examined whether GP and practice staff perceptions and use of My Health Record changed after receiving the training, leading to greater engagement with the tool. The study also canvassed the views of patients who are registered users of My Health Record to determine whether the system has delivered value to consumers as a useful health resource.

Some key contextual notes

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[1] https://www.myhealthrecord.gov.au/for-healthcare-professionals/what-is-my-health-record
[2] Walsh, L., et al. (2017) 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* 47(3) 106-115.

s47B

The introduction of the My Health Record opt out period coinciding with the completion of s47 training

The original intention of the My Health Record case study was to examine changes in attitudes and behaviour relating to the uptake of My Health Record by s47 GPs and practice staff, after receiving tailored training. The change focus has remained a consistent research objective; however, the unanticipated introduction of the My Health Record opt out period between 16 July and 15 November 2018, coinciding with the completion of the training, has exerted a significant impact on GP and practice staff thinking about the technology. Unless Australians actively opt out, they will automatically receive a My Health Record as of January 2019 there has been significant and frequently heated debate about the relative merits of an opt in or opt out approach. A proliferation of media highlighting data privacy and security risks coincided with s47 GPs and practice staff completing the training. In the context of the present study, participant responses to My Health Record training must be understood in light of this context.

2. The research study

The aims the research study were to:

⇒ identify current attitudes toward and uptake of My Health Record by GPs and practice staff, in a single general practice setting s47G and assess whether this changed after receiving tailored My Health Record training
⇒ better understand s47 patients' direct experience with My Health Record and identify associated benefits, barriers and facilitators, from the consumer perspective.

2.1.   Research methodology

Permission was granted by s47 for the Flinders University College of Medicine and Public Health to undertake the My Health Record: A South Australian General Practice Case Study research project using s47 as the single site case study after obtaining approval by the Flinders University Social and Behavioural Ethics Committee. The surgery is a larger practice with a shared medical record and exclusively uses the s47G medical software package.

All s47 GPs and practice staff were invited to participate in a pre- and post-training interview. A pre-prepared email invitation from the Flinders research team was circulated to all GPs and practice staff by the s47 Business Manager. A project information sheet and consent form were included in the email.

Twenty s47 primary care practitioners participated in the pre-training interviews in May 2018. This included 13 GPs, 1 registrar, 3 RNs, 1 specialist (located a day a week at the surgery), 1 pharmacist and the business manager. Three training sessions were delivered in June 2018. The study allowed a period of four weeks for the training to settle before conducting post-training interviews in August 2018. Sixteen s47 primary practitioners participated in the post-training interviews, with four withdrawing from the original group on the grounds they did not do the

training. s47G ████████████████████████████████
s47G ████████████████. Data was collected via one-on-one interviews using a semi-structured interview schedule (see Appendix 1).

Purposive sampling was used to recruit patients identified by s47 as registered and active users of My Health Record. Twenty potential participants were identified from the s47 patient database. The Flinders Research team prepared an invitation letter, which was mailed to them together with the project information sheet and consent form by the s47 Business Manager. Fourteen s47 patients consented to participate in the study over August and September 2018. Data was collected via telephone interviews using a semi-structured interview schedule (see Appendix 2).

2.1.1. GP and practice staff interviews

A trained interviewer from Flinders University conducted the pre- and post-training interviews. The majority of interviews were conducted face-to-face onsite at the s47 premises. Two post-training interviews were conducted by telephone to accommodate the work schedules and requirements of these participants. All participants gave informed consent with all interviews digitally recorded with participants' permission. The recordings were backed up with reflective notes taken by the researcher during the interviews. Participants were able to withdraw from the study at any time. Interviews focused on:

- baseline knowledge of My Health Record
- perceptions of the utility and value of My Health Record
- whether participants are using My Health Record:
  - if yes, how is it being used and do they mention it to patients they see during consultation?
  - if no, what are the reasons for not using it?
- whether there are particular groups of patients they believe get more benefit from My Health Record
- anticipated benefits/drawbacks of My Health Record, including implications for work flow efficiency.

GPs and practice staff received a $50 payment for their involvement in the study interviews, which were undertaken during work hours on-site at s47G Payment was disbursed to s47G which distributed individual payments to study participants.

2.1.2. Patient interviews

A trained interviewer from Flinders University conducted the patient interviews by telephone. All participants gave informed consent with all interviews digitally recorded with participants' permission. The recordings were backed up with reflective notes taken by the researcher during the interviews. Participants were able to withdraw from the study at any time. Interviews focused on:

- how and why patients signed up for My Health Record, including how they found out about it
- how much do they know about My Health Record and what they think it is principally designed to do

- how long they have been registered and how much they use My Health Record as a health self-management tool (e.g. regularly in health consultations, intermittently, rarely and the reasons for this)
- how they would describe the role of the GP and other practice staff in mediating their experience of My Health Record – encouraging and supporting their use of it (or otherwise)
- what, if any, specific benefit they gain from being My Health Record users
- whether they have any concerns about using My Health Record andany aspects of My Health Record they don't like.

Patient participants received a $50 shopping voucher to compensate for their time. The vouchers were provided to s47 which posted them to participants at the conclusion of the interview process.

2.2. Data analysis

All GP and practice staff interviews were transcribed by the researcher, with the patient interviews transcribed by a professional transcription service. Interviewee contributions were de-identified, with names replaced by number codes. Transcripts were analysed using thematic (inductive) analysis, which is a qualitative method for identifying, analysing, organizing, describing, and reporting themes found within a data set, informed by grounded theory methodology.

3. Findings

3.1. GPs and practice staff perspectives on My Health Record pre- and post-training

Members of the s47 team range along a spectrum of awareness, understanding and acceptance of My Health Record. At one end are a small number of digital health enthusiasts and deep engagers with the My Health Record technology. At the other end were several team members who maintained a resistance to My Health Record over the course of the project. Most respondents occupied a middle ground, drawn to some elements of My Health Record and deterred by others.

While the current study has sought to gauge positive changes in s47 team member attitudes to My Health Record following training, the unanticipated implementation of the My Health Record opt out period, which happened immediately after the training, was a key confounding factor. The negative messaging about data privacy and security made a deep impression on many of the practice team, winding back some of the attitudinal gains achieved by the training. However, while some of the respondents lamented the timing, others considered that the debates were important to recognise and address early in the process.

3.1.1. Awareness and understanding of My Health Record

Prior to receiving My Health Record training, s47 GPs and practice staff were asked to rate their current level of understanding about the tool and where it fits into modern medical practice. Most

respondents rated their understanding about My Health Record as slight to somewhat, with the few My Health Record enthusiasts rating their understanding as moderate to extremely good. After the training most respondents reported greater awareness and knowledge about My Health Record; however much of the credit for increased awareness was attributed to the heightened media and debates surrounding the commencement of the opt out period. In rating their level of understanding at this point in time, most had shifted from slight or somewhat to moderate or greater understanding.

Respondents had a competent grasp of My Health Record as an electronic database for the centralised storage of people's health information, intended as a platform for communicating and sharing information across the health sector. My Health Record was conceptualised in ideal rather than realistic terms, as containing an overall summary of people's health status, including detailed patient histories, medications, allergies, immunisation histories, hospital discharge summaries, pathology and radiology results and specialist and other external health provider reports: 'All info that you want to know when you meet a patient for the first time'. Many went on to express uncertainty about what, if any, of this information is currently available in My Health Record, who is able to upload and view information and when My Health Record in South Australia will be fully functional.

3.1.2. Perceived benefits of My Health Record

There was widespread agreement – both pre- and post-training - that a properly designed, configured and executed system would have the potential to deliver key benefits to patients and providers in the South Australian health system.

Seamless sharing of health information

My Health Record's greatest potential is in the seamless sharing of individual patient health information across primary, secondary and acute care sectors. The s47 experience is that patients assume that information is automatically communicated between hospitals and specialists and their local GPs, whereas this is rarely the case. There is frustration that the GP role is pivotal in following up care to external health interactions and yet they are rarely looped into the process in a timely manner. If My Health Record was able to provide access to relevant real time or near real time patient health information, fed in by all providers involved in the care of a patient – then everybody would be much more likely to use it.

Specific benefits to flow from seamless information sharing across health sectors include:

- **improved clinical decision-making**, drawing on comprehensive medical histories/notes including external health interactions, for example hospital admissions, and diagnoses and health treatments provided by other doctors

    Patients often forget or disregard crucial details about past health interactions in discussions with their primary care provider. The ability to source these on the spot has key potential to influence healthcare decisions.

    'The fact that people can fly in from interstate, which they frequently do, and appear on your doorstep for a script or appear on your doorstep with a urinary infection and we don't know what they're allergic to. It's just being able to freely

access that information. Or the patient [with dementia] that comes in and you don't know a thing about them and they are very poor historians; you can grasp a bit of what's being going on for them just by looking up their record. When you've got your regular patients that come through it doesn't matter, you don't need the My Health Record because you already know what's going on, but it's the new patients that out of the blue come in and [you] don't have a clue or anything about their medical background. And then there are the things that nobody thinks is important, they don't bother to tell you: you know I've actually got a genetic problem, but I didn't bother to tell you because I didn't think it was important for this when it is very important. And so, having that accessible and saying oh you've got this – ok that changes this, it's really quite helpful.'

- **improved patient safety and clinical benefit** particularly in reducing/avoiding medication errors and adverse allergic reactions

A priority is having access to patient medication lists updated by all health providers involved in the care of a patient (including hospitals, specialists and other GPs) who may have prescribed new medications or changed the dosages of existing medications.

- the ability to **identify and action follow up treatments** recommended by specialists and/or hospitals on patient discharge, where it is important that these treatments are implemented without delay

Some respondents commented that an alert system within My Health Record would be a valuable feature, to prompt GPs to call patients into the surgery and commence recommended treatments.

'It's going to improve that continuity of care – if you've had a hospitalisation, for example, so that we can see what's happened in hospital, what medications might have been altered, what procedures they've had, any of that type of information, what follow up is required, from an outpatient side of things, what blood tests need to be ordered, are they potentially at risk in their own home, do they need follow up in the community.'

- **enhanced team care arrangements and communication**, which was of particular concern to practice nurses

'I think there's limitations in [My Health Record] from my understanding at the moment of what information is on there… Practice nurses can upload shared care plans but if patients saw a physio or a podiatrist or an optometrist, for chronic disease management, that's the information that I would love to be able to link in there and say yep you've seen your optometrist, you've seen your podiatrist and it's all on there or you've seen your specialist.'

Workflow efficiencies

A number of respondents identified efficiencies that could flow from using My Health Record. These included:

- **time savings** from the ability to access new patient medical histories, removing the need to probe for historical details, and including details the patient may forget or omit during the consult

  'You don't have to ask the patient twenty questions if it's all there. You just quickly confirm if Dr Smith, your GP in Queensland put this up on your My Health Record.'

- not needing to **chase up test results or discharge summaries** which can be prohibitively time consuming

  'Now, we're writing to people for a medical request of information where the patient has to sign, we fax it off, we then wait for the hospital to find the records and send it back. So it can be really long and sometimes never happens and sometimes we don't want to do it because it's just hard and doesn't happen so if we could just find it quickly that would be much more efficient and better patient outcomes.'

- **streamlined communication with other health providers**, such as referrals to specialists, without need for paper and faxing, which are seen by many as increasingly anachronistic

  'Down the track it would be good if we could use it as a referral base so we didn't have to send referrals, you know the referral's on My Health Record … Put it all in one spot and then they can access it, would be fantastic.'

- reduced **duplication of testing**, which saves cost to the broader health system, inconvenience, and over-exposure for the patient.

Enhanced patient self-management of health care
While most GPs focused on potential clinical benefits associated with My Health Record, a few highlighted the engagement of patients in their own health care as a potential strength of the tool. This also tended to be a heightened focus of non-GP practice staff.

My Health Record is well-positioned to facilitate:
- **patient empowerment and control over their health journey**, as they can access and review their health histories and results, add further information they see as relevant to their health experience, and better manage their health behaviours
- **greater transparency** of the doctor–patient interaction, whereby patients have a right to know what doctors have written/reported about them, patients can have confidence that the doctor is aware of their issues, and more proactive patients may take it a step further and provide the doctor with feedback.

3.1.3. Utilisation of My Health Record

Utilisation of My Health Record among GPs prior to training ranged from one GP who reported consistently uploading *'the lion's share'* of shared health summaries, a couple of GPs who uploaded shared health summaries in the dozens, several reporting limited use, to the remainder not using My Health Record at all.

Pre-training reasons for not using My Health Record more consistently included:

- **insufficient knowledge about/familiarity with the features of My Health Record** and how to navigate through registration and implementation

    'I think that comes down to me not understanding it completely. I think that's a big thing of it. I need to sit down and spend time with it and know exactly what I can access, how to. Because I've only done it a few times I feel like at the start, when I was doing a few uploads, I felt a bit uncomfortable signing people up through s47G *but then I haven't signed anyone up for a few months.'*

- **perceived limitations in the utility of My Health Record in the South Australian context -** respondents were not aware of any useful information currently worth looking up in My Health Record and considered it futile to upload information if nobody else was referring to it (limited clinical value)

- concerns about **the amount of time it would take** to implement My Health Record, on two levels:
    - the s47G – My Health Record interface would be clunky, difficult and time-consuming to navigate
    - the amount of time it would take to explain My Health Record to patients and step them through the registration process.

- My Health Record is **not seen as part of routine practice**; in the context of busy work schedules and complex consultations, practitioners do not think of raising the topic of My Health Record unless they are specifically 'triggered' to do so, for example by a patient asking for it (which is rare), or patients raising travel plans where the GP thought a My Health Record would be warranted

- while there is encouragement at the practice level for non-GP practice staff (practice nurses and the pharmacist) to take a more hands on role in implementing My Health Record, they were **uncertain about the specifics of their role and expectations around their involvement.**

Many respondents considered the training helped in addressing a number of these concerns. The practical training sessions increased most participants' confidence in engaging with My Health Record, particularly in accessing and navigating their way around it, and uploading shared health summaries (i.e. the nuts and bolts, what buttons to press).

The training sessions helped them to understand what information is currently available and how to access useful functions (e.g. the medications view), what information is pending (e.g. pathology and radiology results) and more general intentions of bringing other health providers into the frame (e.g. SA Health, specialists). Respondents were reassured that the process is not overly complicated, onerous or time consuming.

The training flagged limitations in currently available information for users to be aware of (e.g. incomplete or non-updated prescription/dispensing data). Post-training, many respondents

indicated confidence that they would be able to set up and use a My Health Record if required (from a 'how to' perspective).

However, in spite of improving their practical knowledge and skills, and recognising the many benefits that could potentially flow from My Health Record, there was minimal change in utilisation rates after training.

The reasons why utilisation remained static among the majority of respondents included the following:

- **for some it was about entrenched resistance:** a small number of GPs and practice nurses who were resistant to My Health Record before training remained so after training

  This position tended to be aligned with a lack of confidence in computer and computer systems in general, a disinclination to change established practice, and a wariness of the 'big brother' aspects of My Health Record (i.e. a mistrust of data governance, and data being accessed for non-legitimate purposes).

- **negative media messaging associated with the My Health Record opt out period coinciding with the post-training period**

  Many participants emerged from the training with a positive mindset and intention to increase their engagement with My Health Record; however they were subsequently deterred by the surge of negative media associated with the opt out phase. A number of respondents reported pulling right back as a result.

  '*My feelings are mixed, probably. Immediately after the training they were good and then with all the media stuff, now it just raises some uncertainty, mainly because I don't necessarily know the answers to the issues raised about security and ease of opting out and things like that so if somebody asked me about it now in regards to those issues*.'

  One My Health Record supporter commented, '*we had them and then we lost them! I feel like we lost them. And that's a bummer*'.

  The main issues raised by the opt out debates included:

  - **concerns about privacy and data security**

    '*I'm still very on the fence about it, I love the concept of it, I think it's a fantastic concept but I have trust issues with it just the same as a lot of people I speak to in that you're putting an awful lot of your information online which is not hackable which is what they're saying which is utterly ridiculous in that everything is hackable if it's on the internet. I don't care how many times you tell me it's not, it is.*'

  - **potential misuse of the data**

    Participants had concerns about the government operating in 'big brother' mode,

providing access to other agencies such law enforcement or social security, and the information being accessed by employers, insurance companies and other private organisations. Some considered that the passing of proposed legislation to regulate access to My Health Record should help to allay these concerns.

- **lack of across-the-board health provider engagement and timely uploading of data, and compromised data quality**

Many continued to express a lack of confidence in the completeness, currency and accuracy of the information contained within My Health Record. This included:

  - **key gaps in clinical information**

    'How I really want to use it is for that medicines view, because that's where I think it would have been useful if I could have remembered how to do it and if it was actually giving me what I want and I don't think it's all got there. I can see why other GPs who are not quite as keen on it would think oh this is just crap, I'm not going to be bothered…. I do know the advantages of this, I know it's got lots of potential so I'm a bit of a convert anyway.'

  - **patient control over/self-editing of files**

    'Just knowing they can edit so much is a worry to me. To me it's going to come down to that time where you're like, ok can I treat this person with this or can I do this potentially risky thing, can I rely 100% on this record to provide me with the truth and all the facts I need to know about the patient – no. So would I make a life and death decision based on it – no. Because if there are things missing could you really give someone a treatment you're just not 100% sure about?'

- **continuing concerns about the amount of time and effort involved**

While pre-training concerns about the amount of time involved in navigating the My Health Record – s47G interface were generally allayed, post-training concerns focused on the amount of work and time involved in a) explaining and guiding patient engagement with My Health Record, and b) tidying up notes in preparation for uploading shared health summaries into My Health Record, particularly past medical history.

'We're going to have to tidy up absolutely everything that's on our notes. It's past history as well as active which strikes me as insane. When s47G first came out and everything everyone was putting on as part of their past history, colds, contraceptive pill, come in for a pap smear, we're going to have to actually delete all of that off the past history because you don't want that on My Health Record, so there's a lot of work, I see a lot of work, extra work in it.'

Some respondents are not currently raising My Health Record with patients because they believe that accounts will be automatically created post opt out, circumventing the need (and associated time and effort) to sign people up.

- **absence of a direct circumstance or compelling need to raise the subject of My Health Record with a patient in a consultation since training**
Some respondents observed that while they have no explicit objection to using My Health Record, they haven't been 'triggered' by patients going travelling or by a need to check the prescribing history of new patient or to source a hospital discharge summary. Even consistent s47 users of My Health Record only raise it with patients when they perceive a compelling reason or a clear associated benefit for the patient (rather than with everybody). This is compounded by the limited clinical information available in My Health Record.

  '*So that's probably good feedback, why didn't someone like me who's comfortable with using it not use the extra functions? I guess I haven't felt compelled to, I haven't felt that there was critical information for me on that record yet that I needed to know how to access. Yet.*'

- **not enough time to play and gain familiarity with the technology**

  One respondent noted that after the training his feelings about My Health Record basically stayed the same.

  '*I think purely that is me not putting the time in at the moment to play with it. It's not an instinctual thing. We're so used to the way this practice works, like our medical software, that that's where my comfort is. I can navigate my way through that really easily. But then seeing how My Health Record operates, it appears clunky. Like, it's not a straightforward thing for me. That's just me being, it's a new thing. So you need to spend time on anything new, and I haven't spent time with it yet.*'

- **confusion about how My Health Record will operate post opt out**

  For example, are all people who haven't opted out automatically activated when the opt out period ends, or is there still an activation process that needs to be performed (by the GP and/or patients)? Is it purely a case of clicking the green button and GPs can start uploading? Is there information that will upload automatically or is a manual process still required? Is it ethical to upload information without the direct consent (face-to-face) of patients? Some respondents report still feeling a little overwhelmed about how My Health Record will work once the opt out phase ends.

  '*I don't know what's going to happen after the opt in phase finishes, whether we can just upload a health summary willy-nilly with no consent from the patient whatsoever. That I can just be sitting here, say a summary has come in from the hospital about the patient and I think oh gee it might be useful for that person to have a shared health summary up on their My Health Record, do I do that because I'm happy to sit here and do it and the patient's not here and I just do it, but I'm assuming that I know what they want included and not included and I don't know whether I'm prepared to do that … and I don't want to be the one who has the patient ranting and raving because there's something on their health record that they didn't want on there.*'

A positive outcome for increased use of My Health Record

One GP who reported knowing very little about My Health Record and perceiving it as an administrative burden in the pre-training interview, was transformed into a My Health Record supporter and user by the time of the post-training interview. The interesting feature was that this particular GP was away from the practice and did not attend any of the training sessions, and so arrived at this position via an alternative route. In this case, it was the heightened profile of My Health Record within the practice by virtue of the study being promoted at practice level, the debates stimulated by the opt out media, and conversations among peers in the practice prompted by both. In essence, My Health Record went from invisible in his world to topical and relevant to his practice. It helped that he was technologically competent and curious, and confident within himself to follow up and explore the technology under his own steam. This particular case indicates that uptake of My Health Record can be a simple function of a heightened profile reinforced by messages of relevance to clinical practice:

> *I think my reservations at the time [pre-training] were just not having done it, and no experience in it, but I'm more comfortable using it now. Actually, I found it quite useful last week, I had a patient from another practice that came here for the first time and it was very useful to be able to get access to the patient's medications, they were already set up. A couple of times actually it's been really useful, so it was useful about six weeks ago, I saw a patient, she came in from [interstate] and she had a couple of discharge summaries… she went [interstate] for several years with her family and so during that time frame you know accessing mental health services and she went into hospital a few times so it was really helpful to read those and have access to those… so when the patient was here we went through it together to talk about it because it's obviously hard for patients to remember it all.*

The primary motivation for this GP to refer to My Health Record was the ability to source information not otherwise readily available; he commented that he would use it in any patient cases where there is a perceived information gap (i.e. not specifically targeted to older people or travellers): *'I think because you know you've got a lack of information in what you're doing and the patient doesn't know and then you raise well let's check the My Health Record.'*

3.1.4. Suggested approaches to accelerate the uptake of My Health Record

GPs and practice staff were asked what factors, supports or resources would encourage and facilitate their uptake of My Health Record. Their responses included the following:

- **fast-tracking the engagement of diverse health providers and ready availability of useful information** such as pathology and radiology results, hospital discharge summaries, and other health investigations on My Health Record would motivate health practitioners to use it

  Universal uptake of My Health Record is key to its success, namely confidence that all relevant parties are engaged and using it: SA Health, specialists, allied health and pharmacists.

'For me it was more the broader perspective on it, like what's the buy in going to be like, you know across all hospitals, specialties, where is it heading, how useful is all this? My big problem is it's an all in all out thing, if it's not 100% all in you can only use it as a little bit of a tool, as a supportive agent rather than The Record.

And according to another respondent:

'If I knew that it's not just GPs using, it if the hospitals are actually on board… at the moment it just seems to be GPs and you know I think the system is only as good as what's put into it and if the hospitals aren't putting anything into it like a discharge summary I don't see a lot of benefit for me.'

- **general practice needs to see clear and real benefits** associated with using My Health Record: these can be expressed on a professional basis for clinicians, on a health outcomes basis for patients and at practice level

'If there was something in it for us [GPs], something in it for them [patients] then we'd probably all be more on board with it'.

One respondent noted that trying to promote My Health Record to general practice solely on the basis of the benefit for patients may not be sufficient to win over reluctant GPs; however, facilitating access to specialists' reports, discharge summaries, investigations outside the public system and whether prescribed medications have been dispensed is likely to make the difference. Respondents recognised *in theory* the potential for workflow efficiencies, for example not having to probe for patient histories or chase up test results; however, they need to see how these time-savings work *in practice* to appreciate their real value. At a practice level, practice incentive payments for uploading shared health summaries is an important motivator, but more so for practice partners than associate GPs.

- **enhancing optimum user-friendliness**

While the interface between My Health Record and s47G is relatively seamless, elements of the s47G software data display are sub-optimal, for example the medications view interface with s47G : *'When a patient is on lots of medications it's quite confusing to look at, it's not clean.'* My Health Record needs to be designed in a way that requires minimum effort on the part of general practice users; any minor roadblocks encountered in using the technology will cause them to backtrack.

Several GPs set up their own My Health Record in order to play with it, to get a better grasp of what is involved. In this process, some were faced with problematic 'patient-side' access and information issues, particularly navigating through the MyGov website.

'The detail required of them to be able to remember which practitioner they saw on a particular day, it had to be, it was date specific – a month and a year was not sufficient and so I found that was hard, I could name the date but I couldn't name the practitioner. And then it just said you do not have sufficient information to proceed.'

- **recognising and/or compensating for the time it takes to set up My Health Record for patients** is a recurrent theme

  For example, a time or non-attendance-based rebate dedicated to setting up a record may help, rather than expecting doctors and patient to absorb this into their regular consultation time. The rebate could be applicable to an initial, one-off block of time to set up the record: '*because why wouldn't you want me to tidy up your file, and why do I have to do it with you sitting here, so why can't I just know that I could put aside this time or do it after hours or whatever it is to tidy up these files.*' This might potentially address the concerns of health practitioners who are daunted by the prospect of having to clean up their data for entry into My Health Record.

- **measures to keep My Health Record at the forefront of practitioners' minds** and **maintain enthusiasm/momentum**

  Some GPs and practice staff emerged from the training feeling energised but this fell rapidly away in light of '*too much other stuff to do*'. One GP commented that post-training he was '*More motivated [but] I'm still lacking time, and I think it's one of those skills that unless you do it a couple of times then you're quite likely to forget … I think we need to just do a few but we're not going to get the time to do the few you know what I mean?*'

  Recommended strategies:
  - **Identify the key triggers for doing My Health Record** in order to overcome the problem of practitioners not prioritising and/or simply forgetting to do it, e.g. patient plans to travel. Make uploading shared health summaries for all pending travellers a practice priority, in the process building familiarity and user comfort among health practitioners.
  - **Make My Health Record a routine part of regular patient health reviews**, for example when doing or reviewing a health care plan. These consultations are more conducive for using My Health Record as they are general in scope rather than addressing a specific problem on a given day.
  - **Maintain conversations and encourage and reward the use of My Health Record** within the practice team, e.g. regularly present My Health Record statistics to the team (e.g. rates of uploading); set, monitor and report on goals; offer more training, roundtables and awareness promotion activities; and promote My Health Record through the newsletter including good news stories to counter the negative publicity.

- **presenting a stronger case for how and why My Health Record can a positive force in general practice**

  Part of this involves the government driving a positive public awareness campaign:

  '*Frankly, and I'm sure I'm not the first to say it, the public awareness and information campaign has been woeful, it's been dreadful… they just need mums and dads, just need some proper advertising to reassure the everyday person that*

this is a great idea, just three or four different scenarios, you know your elderly father is in hospital and the emergency physician can pull up his notes; you're stressed, you can't remember what blood pressure medicine he's on and what antibiotic he's allergic to – it's all there. And the voice over, you know the federal government is making [a difference], you know its simple stuff like that. Patients will be drivers for change if they're educated well enough.'

- **maximising patient-driven demand for My Health Record**

Respondents often commented that patients are not coming into the practice and asking for a My Health Record. If patients do raise the subject, it is often focused on their fears and concerns rather than an interest in setting one up. There is a firm belief that if patients take a more proactive stance, then general practice would respond positively.

'One of the drivers has got to be patients and the patient education and reassurance. I think is critical … I have had one young couple come in and say that they'd organised their own My Health Record and they wanted some data uploaded, I thought that was cool. They were Gen Z Millennials and they were keen to use what was a very common technology, everyday technology, and they just assumed that the rest of the world would be on board with that. So I think one of the things that would drive me to use it more, start with the patients saying, if the patients can be reassured and educated that it is a useful, safe tool, they're going to be drivers for change as well.'

- **more information and education**
  - The **general community/patients** need to be better informed about the range of benefits associated with having a My Health Record, the protections and mechanisms that safeguard their electronically-stored data, and how to use the tool to best effect in monitoring and managing their own health status.
  - **GPs and practice staff** need to be better informed so they are able to advise their patients on the full range of issues and concerns. Many respondents commented that another My Health Record training session would be highly valuable, preferably after the conclusion of the opt out phase. The training session could double as a technical refresher and strengthen GP and practice staff confidence in responding to current debates about My Health Record, particularly around data privacy and security, and layers of consent within the tool.

- **targeted support and training for non-GP practice staff**

Practice nurses s47G specifically identified a need for:
  - greater clarity around roles and expectations and targeted training to build knowledge and confidence to perform their roles (i.e. less GP-focused); otherwise, their concerns and needs are similar to GPs – universal engagement, consistency and reliability of information, data privacy and security
  - My Health Record to facilitate team working (particularly with Allied Health providers), as this is their key area of focus.

Training played an important role for respondents in reinforcing the value and potential of My Health Record; however post-training there is a focus on the need to acquire skills and confidence, practicing with My Health Record, and nutting out accessibility glitches for nurses: *'We've got every opportunity, we do home health assessments, we do care plans so we've got the time, we've got the contact with the patient and so it really is being confident in setting it up and uploading.'* Practice staff are confident that if they are given the opportunity to access My Health Record and support to practice it a few times, it could become part of their routine practice.

GPs and practice staff more broadly identified a further range of facilitating factors, post-training:

- **having committed practice level support** - practice champions are crucial for engagement and confidence building; practice management plays a crucial role in encouraging and supporting uptake; and having people to ask for advice and technical support is important.

- **time and opportunity to play with My Health Record** - this could include a dummy patient to practice on (respondents observed that they cannot link the s47G test patient to My Health Record because it doesn't have a health identifier). Respondents stressed the importance of practicing within their own software system, quarantined from My Health Record. They will not do it if they are forced onto an off-site website/system. The practice team reiterate that *'It's just practice, with doing it'* and *'practice actually uploading a document, practice if there is a modification I can make to their medication, you know a summary that might be there, things like that.'*

- **practice software-specific training videos** would be useful.

- **information or resources** that the practice team can provide or refer patients to for additional information, support and guidance, for example a commonly asked questions/FAQ resource; support packs for GPs, Q&A resources for concerned patients; and an effective public awareness campaign.

3.1.5. Reflections on the training

At the time of delivery, s47 GPs and practice staff highlighted the need for a **more practical, implementation-focused approach to training**: *'What I needed was: how do we set a record up? How do we access medication lists?'* They were less interested in a high level, theoretical overview style of training as most felt they understood and appreciated the rationale for developing a digital health system.

Most participants emerged from the training with better awareness and understanding of My Heath Record generally and its functionality more specifically; it was described as a 'good basic intro'. Some GPs with already established My Health Record knowledge and skills found the training to be somewhat superfluous, but understood and appreciated that it was pitched at the right learning level for the majority of participants. That said, even the most advanced My Health Record users learned something new about the tool; for example, that information deleted from the record by patients can still (and only) be viewed by the practitioner who uploaded the summary. This was illuminating for the GP involved and made the training a worthwhile exercise.

Respondents identified a number of limitations in relation to the training including:

- a lack of guidance about **how to interact with patients around engagement and registering** for My Health Record; including how to explain My Health Record to them, walk them through its functionality from patient perspective

- a need to better acknowledge the experience of and **respond to the needs of non-GP practice staff**

  'Be nice to focus towards the practice nurses a little bit more, give us a little section of their time. And I guess steps as to actually how to do it, how would you engage with the patient about informing them firstly and then how to actually go about it on the computer.'

- a lack of opportunity **to consolidate learning post-training**, including opportunities to play and familiarise themselves with My Health Record and 'bed down the learning'.

In light of the opt out experience directly following the training, participants realised that they needed to **supplement their hands-on learning with a lot more information about the issues**. There was an appetite for follow up training with a focus on enabling health practitioners to respond with confidence to patients' concerns and enquiries; for example, being able to advise patients on the layers of consent built into the tool.

Recommendations for an effective training approach:
- Undertake a series of training sessions rather than a one-off session, targeting benefits and drivers, practical skills and implementation, and knowledge and confidence in promoting the tool.
- Target training to different practitioner groups, avoid a GP-centric approach.
- Give practitioners opportunities to go away and play with the tool post-instruction, followed by another group session to workshop issues and ideas arising from engagement.
- Plan a series of refresher sessions, practice level My Health Record updates.
- Focus on doctor-to-doctor, peer-to-peer learning as it is built on deep understanding of the logistics and issues faced by practitioners. This would be a way to structure ongoing training and development at the practice level.

3.2. The experience of patients with an activated My Health Record

Fourteen telephone interviews were conducted with s47 patients with an activated My Health Record. The ages of interviewees ranged from 54 to 84 years of age, with an average age of 70 years. This signals the propensity of s47 GPs to target older patients with accumulating health conditions as apt candidates for My Health Record. Eight males and six females participated in the study.

3.2.1. Perceptions of My Health Record

All of the patients interviewed understood My Health Record as a **system for storing people's health information in an online database that is able to be accessed by health providers from anywhere** in Australia, in the event that medical care is required when people are away from their regular providers.

> *'Well, the way I look at it is that patients' or a person's record is held in a database; probably the health records going back a couple of years, and if there was an emergency situation where a person was overseas or away from their own doctor, then the medical practitioner would be able to access that information which, in my opinion, could be life-saving.'*

Around a third of respondents had **limited awareness of the finer points of My Health Record** or how their GPs and other health providers are using it in their care. It is something that seems a good idea, and they are happy to have it working in the background of their health care, but they do not spend time thinking about or questioning its impact on their care. These patients emphasise the high level of trust they have in their doctors and nurses, and their preparedness to leave My Health Record in their hands to manage: '*It's just one of those things that's handy now, and I'm happy to have it in the background'.*

The remaining patients have a **good to excellent grasp of My Health Record**. These tended to be the more health and IT literate patients and described themselves as curious and inquiring when it comes to their health interactions with providers. They also spent some time doing inquiry into various dimensions of My Health Record (in conversation with their GP and through personal inquiry) to determine what value it could add to their health experience and whether it was safe and appropriate to use. One patient described when her GP signed her up:

> *'It was back in the time when [my GP] said, okay, this is coming on board; I don't know how many doctors are actually doing it, and how much data they've collected, but do you want to go in? My husband has Parkinson's, and at that stage I was going in with [him], and he said it to both of us, and we both said yes, that's good. Then, of course, [my husband's] thinking becomes a bit clouded and he doesn't get into everything, so I just took over and realised that, yes, we were in control, this was a good thing. It was safe for us.'*

3.2.2. Reasons for signing up to My Health Record

A few patients were unsure how long they had been signed up to My Health Record and had no clear memory of how the signing up happened. However, most recall **signing up on the advice of their GP**, who is a trusted agent of their care: '*We discussed it the other day when I said I wanted to put it on, and he said it's already there. I think he may have mentioned it a couple of times before but I didn't quite understand what it was, but it didn't really worry me. I trust him.'*

It is clear that GPs are promoting My Health Record as **a way for all relevant health providers to access people's key health information**, no matter where they are, which people generally think is an excellent idea from health safety perspective.

> *'Well, you can end up in hospital overseas which I did at one stage, and my MedicAlert was a great help. So if you had your health record with you plus all your medications and everything, it just makes it easier for the doctors. They can't give you something that's going to kill you.'*

'Well, I wanted to have the medical profession, all the different people that I see, the opportunity to know exactly where I stood health-wise. I thought it was a great tool, one that benefits everyone concerned.'

'I ring s47G *, it might be semi-urgent, and I can't see anyone there because they're booked out, right; well, I can go to another doctor up at where I live in* s47G *, for an emergency or semi-emergency, and it would be nice if they had a history of me on their computer.'*

One patient believed his GP targeted him for a My Health Record because he was *'a bit more organised than perhaps some other patients'*, which was tied up with being **highly engaged in his own health journey**. A couple of others noted that their GP targeted them because they are **reasonably IT literate** ('computer savvy') and therefore better able to manage the digital interface of My Health Record. One of these noted that for his age, his health is relatively good. So in this instance, the GP's motivation was less about using My Health Record to manage serious health conditions, and prompted more by the prospect that the patient might be interested and competent in interacting with the technology.

Other respondents were clearly targeted **to assist in better managing their health conditions**. For example, one respondent noted that her GP suggested My Health Record might be useful following a major health event:

'I felt that it was a brilliant idea that if I lobbed up again at s47G *, there would be some idea of what had gone before and some communication with my GP had sort of gone on in the interim as well in terms of my recovery and back-up and all that sort of stuff. I think it's very sensible and very worthwhile, given my circumstances.'*

Not every instance of signing up was at the suggestion of the GP. One respondent noticed the media about My Health Record and **self-initiated a conversation with his GP**; after it was explained to him, he indicated he would like to join.

Other reasons listed by patients for signing up to My Health Record included:

- **professional reasons**
  One patient with pre-existing medical conditions needed to keep meticulous health records in order to maintain his commercial vehicle licence.

- **personal convenience**
  A number of patients identified the ability to access details about their health status or history whenever needed, without having to visit the doctor. Notably, people tended to identify this is a valuable feature of My Health Record without having used it: *'Maybe because it's a bit high tech. I'm not sure if I'd be able to get it right. One day I might have a go'.* If people were more aware, confident in how to do this, they may make better personal use of the record.

- **interest in monitoring health reports/results**
  Some patients take a very active interest in following their health journey and want to be able to access shared health summaries and other test results without having to ring their

doctor/book health appointments. One respondent harbours curiosity about how health providers interpret her health conditions and experiences:

> 'Yes, I was just interested to see what was there and what sort of things – as a patient, you sort of have a reason for going to seek medical assistance. Sometimes it's translated in a different way and recorded in a different way, and I was interested to see what that might be.'

3.2.3. Patients interaction with My Health Record

Limited interaction

A number of patients were **neither actively interacting with their My Health Record themselves, nor greatly aware of what their GPs were doing with it**. Many do not discuss My Health Record with their doctor in consults, although a few report that the GP refers to their record on occasion, and shows/discusses record content with them in the course of a consultation. One respondent discussed his My Health Record in his six monthly health review and care planning process.

Although patients value the prospect of multiple health providers accessing and using their information (e.g. other doctors, specialists, allied health, hospitals) they are **not aware if anyone other than their regular GP has accessed their My Health Record** it (although one knew enough to say he doubted it otherwise he would have received an access alert).

Higher levels of interaction

A few patients were more personally engaged in their My Health Record. For some, this was **motivated by wanting to enter their own information into the record**. One respondent wanted to track his diet and exercise patterns, although he conceded that this activity trailed off over time: *'I did intend to do that, but all intentions are very good, but I'm a busy person, and I think it falls very low on the priority list.'* Others were interested in entering information such as personal information that the health provider may not deem important enough to include, family medical history, significant life events relating to their health, and non-PBS medications.

Patients were also engaging with My Health Record to **access information uploaded by their GP and other sources**. Often this was about curiosity to see what has been uploaded; for example, one patient set up the alert system to be notified when anyone altered his record. He reported accessing his record eight to ten times per year to check its content. Another respondent logged into her record around three to four times per year. Both respondents accessed their record to review what has been uploaded and both have prompted their GP to correct omissions. As one noted: *'obviously doctor puts a summary on my eHealth quite frequently and I go in and check that, and sometimes I find he's made an omission or two, but he corrects it'.*

One respondent was very keen to interact with his My Health Record but expressed frustration that it did not contain his full spectrum of test results, which is the information of value to him:

> *'What should be on it, for want of better words, is not just – I don't know if you've actually had a look at My Health Record; that's irrelevant – but after it was all set up and everything, the only thing that was available – and this is what really peed*

me off and peed a lot of doctors off – is the fact that all they had on there was all my illnesses from 1998 to current date, and the tablets I was on, and we were like, well, woo hoo!'

Some patients were very keen to interact with their My Health Records for a variety of reasons but had **no success when trying to login**. The access code failed for one respondent who was set up by her GP, and she basically never tried again:

'That is what I was hoping it was going to do, and that I had the ability to input as well. That, however, wasn't as successful as I thought it might be. When it was set up, I did come home and I set up a password which, since you've been in contact, I've actually found again, but I didn't ever have any success. So I have no idea what's on there, and that's basically the bottom line. You can call me a failure in that task.'

3.2.4. Perceived value of My Health Record

The majority of respondents described My Health Record as something they are not using much because they are not in a current state of medical or health crisis, but which **sits behind the scenes as an interim health monitoring, management resource**. The information collecting in their My Health Record is considered highly valuable because they have conditions that are likely to deteriorate over time, so when the need presents, the record will be there. Patients consistently identified the **feelings of confidence, comfort and security** conveyed by having a My Health Record that different health providers can access, anywhere and at any time. Patients frequently describe it as akin to having an insurance policy.

'I think it's more a useful thing to have insofar as if there's an emergency and people need to access it. Apart from that, just seeing [my GP] when I see him, it's enough, but outside of normal living, I feel it's great to have it there. I think that's the way people need to think about it. They think that they're home and they've got a doctor and that's always going to be the way things are; they're not. Life changes quickly. It's like having an insurance policy.'

Respondents consistently identified that My Health Record will be **useful if they travel**; of those who have travelled, none have yet experienced a need for medical treatment where My Health Record would have come into its own; however, they draw comfort from knowing it is there should they need it.

'We're hoping that next year we'll do a bit of travelling probably in the car up to Queensland, around there probably; when we do that sort of thing, it would be handy to know it's there, just in case. But I know it's there, and that's it.'

With the average age of respondents at 70 years, there was a heightened awareness of functional decline over time, with people looking for ways to take better care of themselves: '*Yes, I think it's coming to a time, and certainly, you know, I'm bloody not getting any younger, and every day becomes a* s47G *struggle'*. The interviews showed that **value of My Health Record becomes more apparent as people get older**:

'Well, if the various people that you see in the medical profession use it, they're going to be able to see immediately, without asking you questions, exactly what point your health is at. That's a good thing, because especially when you get to my age and older, we tend to forget. If someone asks you to relate, for example, what your medications are, and I think, well, I can't do that unless I refer to my records.'

'Yes, I suppose it does [have benefit], especially when you've had a number of different bits and pieces. It all becomes a big blur of appointments and operations and biopsies, and it all blurs into one, and you really just don't have any clue as to where you're at half the time.'

However, respondents also consider that **My Health Record could benefit younger people as well**, by ensuring that their critical health information can be easily accessed in times of need (some may have more need than others). The difference is that older people sense their vulnerability more and are therefore more inclined to rate the health benefits over the security concerns.

Some respondents saw value in the role My Health Record can play **in strengthening the connection between doctor and patient**. Some respondents see it as a way to keep the doctor informed about patients' daily health experience, as some of this information may be of use at a later time.

'I think so long as it provides me with somewhere to jot down stuff that I need to know, but also I guess that link between me, myself and the GP, probably that's probably important so the GP can go: yes, [the patient] says this, or, you know, I had a migraine this day and then I had a migraine the next day, then I had a migraine three days later, and then I had a migraine a week later; then the GP can say, ooh, geez, perhaps we should look at that.'

Patients also see value in the potential of My Health Record to **keep health providers on track and accountable**. It allows patients to review what their doctors have uploaded and helps them to know what doctors are thinking about their health status and treatment, and if they have left anything important out the patient can raise this with them. One respondent noted his doctor's response to this type of intervention: *"It's good to have this double check from you, [patient's name], because we make mistakes as well". I said, "well, you're only human, the same as everybody else"'*. Other patients saw value in being **able to review the shared health summaries** because they perhaps did not quite understand what was discussed in the consultation.

Some respondents flagged that My Health Record **can be the voice of the patient if the person and/or next of kin is not in a position to provide the level of detail being sought, for example in an emergency health encounter**, for example identifying allergies, health conditions and what medications people are on. Moreover, people do not always discuss their health wishes with their families; for example, do not resuscitate instructions. It would be useful if these instructions were stored on My Health Record in the event the patient is unable to speak for themselves.

'I think if you ended up in hospital and you had something like this and your children were asked anything about your health, which they might not know. There's always that possibility that you could end up in hospital unconscious and not be able to speak, and someone would need to know something about your health, your medications. So your next of kin has got to know something. Also, a good thing on My Health Record too would be if they have got it on there, whether people want to be resuscitated… that point is rarely discussed.'

None of the respondents to date was able to provide an **example of where My Health Record had contributed substantially to a positive health outcome.** A few however were able to cite circumstances where they believed My Health Record may have provided key benefit if it had been in place at the time and functioning properly.

- In one instance, a respondent was scheduled for an operation, but had a mini-stroke two weeks before. This information was not adequately linked within the hospital which almost led to an adverse outcome for the patient. If My Health Record was able to operate as an effective and efficient information sharing tool, this may have been avoided.

    'When I had a recent operation, two weeks before I had a mini stroke, a TIA, and the hospital records – this was all in the public system – the hospital records weren't married up, and they almost went ahead doing an operation on me which would have been catastrophic by all accounts. That was because the fact that I've had the TIA at the same hospital, hadn't been married up with the appointment for my operation… Well, I got to the pre-op appointment and spent all day in the waiting room only to be told it was far too dangerous to do the operation.

- A second respondent reflected on how My Health Record could have prevented a medication misunderstanding, which had serious personal consequences.

    But I'm 100% certain that [My Health Record] is a good thing. I remember going in – I had a major anxiety attack that resembled a heart attack, going back about, I don't know, eight years ago, and because [my GP] was overseas at the time, I presented myself, shopping and all, to s47G *and said, I'm in trouble… so they took my obs and rang an ambulance, and then sent me down to* s47G *, and I was in* s47G *s47G for a few days. Unfortunately for me they couldn't access my records, didn't believe the meds I was on. My husband brought down the wrong dosage of the OxyContin to cover the pain [for another condition], and the staff didn't believe I was on a higher dosage. As much as I tried to tell them that I needed that dosage to just dull the pain, they didn't believe me. Now, if they could have accessed my medical – the medications I was taking, that would have saved me from Friday night through to Monday in excruciating pain.*

One respondent raised the **lack of information uploaded by the diverse providers involved in his care as a key detractor f**rom the value of My Health Record. He wanted to be able to look up his test results, to bypass the need to ring health providers direct for results.

'I don't know if it's mundane, but you're ringing up reception, oh hello love, I just wondered, have you got those blood tests through yet? Have you got those x-ray results through yet? Have you got anything through yet? Well, if this My Health Record is set up correctly, taking patients' opinions, views and input in line, then that would eliminate annoying other people… Obviously I've still got to converse with the doctor and follow his procedure, but I also get to read the book at the same time.'

3.2.5. How could My Health Record better respond to the needs of patients?

Respondents in general expressed **few or no personal issues with My Health Record**. Many consider that health providers having access to vital health information, particularly when they are away from home, outweighs any privacy or security risks; some were not concerned about the risks at all.

'I couldn't care less, really. It's just nice that it's there if needed.'

'It was a bit of fuss in the media about the fact that it might be that other people could get hold of the information and that sort of thing, but I felt, well, I didn't think it was going to be a problem what should happen. If worst case scenario, it probably wouldn't worry me anyhow really. What are they going to worry about?'

However, a few respondents were deeply concerned about the **potential for privacy or security breaches** and called for stringent measure to be put in place, for example Centrelink level data security.

'I would hate for anyone else to be able to get into my record. I would have to be assured of the privacy of it all.'

'Now I've seen the publicity, also that there's quite a few other organisations that can look into this. Now I don't feel like the benefits are outweighing anything. I've gone right against it now. I thought the benefits would be, well, it's all centralised, it's controlled, but having read articles in the media and individuals voicing their concerns, I was happy if it was only doctors and hospitals looking at it, but I don't really want other individuals or government departments to be able to access it without my permission. You can put, I know, privacy details on it, but the article that I read about that said it's very involved and quite convoluted. You have to have PINS and things, so the fact is the government might come back with the argument, oh well, yes, you can set it up, but it's actually quite involved to do that.'

One respondent called for **more patient information and education** so that they better understand and feel reassured about protections built into My Health Record:

'I believe that people would be more accepting of it if they had more knowledge. I think at the moment, by what I hear from different people when this subject comes up, that they are fearful. They feel that every intimate detail of their medical or psychological life is going to be documented. They really aren't aware that they can go in and change things. They don't understand that they are in control.'

Technical difficulties signing up for and/or accessing an existing My Health Record proved a significant barrier and disincentive for some respondents, who insisted that it must be easy to set it up, access and use. Some patients tried multiple times to work out their problems to no avail, some gave up immediately, signalling the importance of a foolproof digital system that engages people at the moment they make contact.

> *'Well, the doctor said to me, you're computer literate; I'm going to give you a code to get into My Health Record, which I presumed was my records would be there so if at any time I wanted to look it up, that would be available to me. So he gave me the code, and I came home and I went through all the procedures and everything to get onto the My Health website, and when I got to the last page, it threw me out.*

> *'Because I've had that initial lack of success, it's not something that I have revisited or even thought about it, until this came through, and this recent media bits and pieces.'*

One respondent signed up for My Health Record and discovered her medications list to be **'riddled with errors'**. The incorrect medications listed in her record were eventually traced to a pharmacy linking medications to an incorrect Medicare card; however, this failure in process and the difficulty experienced in trying to rectify the problem profoundly shook the patient's confidence in the system.

Usability is another key concern for patients. One respondent was open to the notion of being able to look up his health information and test results, but was worried that it will be represented in technical terms that he will not understand.

> *'The only problem with that is if there's any technical terms. I'm not going to be able to read a report with, you know, like ratios and measurements; it's going to mean nothing to me… So if I'm going to look at it, I need it broken down to be easily understandable.'*

Another noted the **need for the notes in the record to be relevant and concise**, and not cluttered with incoherent and poorly organised data.

> *'When they first put the information in, it needs to be as concise as possible so that it does give an overall picture of the patient, not just little bits here and there. Try and give a good background. There may be things that have happened 10 years ago, just a few things that may crop up and cause a problem, so if the GP thinks that that could be so, pop it in. Make sure that they really think about the information they're putting in… If they put in the information that may be needed down the track, they could save a life. But if they just shove it in and think, oh well, that's done, maybe they haven't done it properly by the patient.'*

The same respondent connected with a theme raised by the GP and practice staff interviewees, namely the need to devise a way to ensure that GPs and patients are **not disadvantaged in terms of time or money** by attending to My Health Record matters during the consultation time.

'People are paying for their time. If it can be that if they're coming in, if the patient is coming in to have this done during their appointment, perhaps if it's going to be lengthy, they are not charged for a double appointment because people are mindful these days that they don't have the money for consultations. We read that people are missing out on going to the doctor because they can't afford it. So to spend the 15 minutes making sure that the information is going in correct, perhaps there should be a way of that being bulk billed.'

Two other features that respondents identified would improve My Health Record from the patient perspective included:

- ensuring that information such as 'do not resuscitate' instructions and advanced care directives can be entered in My Health Record, and if this is the case, ensuring that patients know about it.
- ensuring that both hospitals and paramedics can access My Health Record in the event of an emergency.

4. Discussion

4.1. s47G GPs and practice staff perspectives, pre- and post-training

The original intention of the My Health Record case study was to examine change in attitudes and behaviour relating to the uptake of My Health Record by s47 GPs and practice staff, prior to and after receiving tailored training. The change focus remained a consistent research objective; however, the unanticipated introduction of the My Health Record opt out period, coinciding with the conclusion of the training, was a significant factor influencing GP and practice staff thinking about the technology. However, as the study was not designed to evaluate the training per se, but to focus on the change in GPs and practice staff over the period between May and August 2018, the opt out factor provided additional scope for investigating the conditions that support or otherwise the uptake of My Health Record in primary care.

The impact of training on GP and practice staff engagement with, and uptake of, My Health Record
The GP and practice staff interviews indicated a spectrum of engagement with My Health Record with a couple of deep-rooted resistors at one end, a similar number of keen enthusiasts at the other, and the majority occupying the tentative middle ground – cautiously open to the technology but not entirely convinced by the product. The pre- and post-interviews revealed no change at either end of the spectrum in terms of engagement and use, and relative stability in the centre, with a few exceptions where a few GPs signalled positive advancements while several retreated somewhat, principally due to the controversy surrounding the opt out period.

In the context of entrenched resistors
For the more resistant GPs and practice staff, digital aversion, a disinclination to change existing work practices, concerns about additional work burden, and privacy and security concerns (more prevalent in the post-interview) were the main obstacles. As this was largely about preferred ways of working and a general lack of interest in digital health, encouraging uptake through practical training was unlikely to exert an impact. Furthermore, the arguments mounted by

opponents of opt out provided fertile ground for these respondents to cement their non-engagement. The wider view was that this small group is unlikely to change until broader momentum is so great that they will feel compelled to join in or risk professional irrelevancy.

In the context of tentative GPs and practice staff
For the GPs and practice staff occupying the middle ground, barriers to uptake *prior to training* included: lack of familiarity with, and confidence in, how to use the technology; My Health Record not figuring in their daily routine or being at the forefront of their minds; not having enough time in busy consults; an impression that My Health Record contains minimal useful information (either not uploaded and/or patchy and unreliable); and some privacy and security concerns. *Post-training*, most participants had increased their knowledge and confidence in how to use My Health Record on a practical level and felt they could set one up, upload into it and source available information from it with minimal difficulty.

However, in spite of this upskilling, most participants reported little or no appreciable increase in My Health Record activity after receiving training. Many continued to express reservations about inadequate provider engagement across the health sector, missing and unreliable information in the record, lack of time, and lack of time to prioritise My Health Record in busy consults. There were also heightened concerns expressed in the post-training interviews about privacy and security, and patient control over the data posing a risk to data quality. Some of these factors were outside the control of the training, noting that the concerns about privacy and security spiked post-opt out, which occurred after the training was delivered. There was a strong level of interest expressed in My Health Record among practice nurses and the pharmacist both before and after training; however, this was frustrated by a continuing lack of clarity about roles and expectations, and access to the tool which was not enabled for any of them.

A few GPs and practice staff bucked the trend by showing a much more positive response to My Health Record after the training, through increased engagement and use. Some developed enough confidence to discuss and promote My Health Record in their wider health networks; one GP moved from very low level of awareness and engagement to recognising its value and raising it much more consistently with patients. These members of the s47 team, together with the established advocates, represent the beginnings of a core within-practice group well set to lead through example and support wider practice engagement.

Why perceived benefits are not translating to active use of My Health Record
Notably, all GPs and practice staff identified a range of benefits attached to a properly designed and functioning My Health Record. These included scope to share information seamlessly and across the health system, which is extremely valuable both in terms of transferring and receiving key reports and results, in almost real time. Associated clinical benefits included the potential to reduce medication errors, improve diagnosis, and identify and action follow up treatments recommended by hospitals. Key workflow efficiencies were identified, particularly in the area of time savings; for example, not having to chase results or probe for patient histories.

The inherent problem in translating these *perceived* benefits into active use of My Health Record is that *realising* the benefits assumes that all health providers involved in a patient's care are engaged in the process and are systematically uploading and sharing information, whereas this

is not currently the case in South Australia. It is clear that the unevolved functional status of My Health Record makes it difficult to institute a meaningful program a change; however, a number of respondents insisted that change has to start somewhere and that s47 is better positioned than most to take the lead in South Australia.

Notably, key developments are underway to strengthen My Health Record connections across the health system, which should make a significant difference to practitioner engagement going forward. Key features to note in the South Australian context include (timeframes are indicative and subject to change):

- private pathology connections into My Health Record are currently at 21%, expected to increase to at least 90% by the end of December 2018
- private diagnostic imaging connections into My Health Record are currently at 3%, projected figures unknown
- SA Health is currently connected and can upload but it is not automated, and will have all facilities viewing by Jan 2019
- SA Health will be uploading pathology and diagnostic imaging beginning in March 2019 and adding a HIPS user interface into their ePAS to integrate with My Health Record (i.e. the hit of a button that will bring up a browser to view My Health Record) which will allow regional hospital sites to view it.

How to create and sustain My Health Record uptake, in s47 and more broadly

GPs and practice staff identified a range of facilitating factors for the incorporation of My Health Record into their regular practice, including the comprehensive engagement of (committed) health providers to contribute to the database and making the tool optimally user-friendly (including ironing out My Health Record – s47G interface issues). Respondents wanted to see demonstrable evidence of clinical benefits, workflow efficiencies, and patient empowerment and satisfaction. Many felt it is important to recognise the time and effort involved in tasks, such as a one-off My Health Record set up, and rebates to compensate for the time involved in cleaning data for uploading into patients' records. Some argued for maintaining momentum by keeping the My Health Record conversation alive, recognising the role of the practice in maintaining a practice-wide program of support and encouragement. More training and education was supported, for GPs, practice staff and particularly the wider patient community as it was emphasised that patient demand is a key motivator for primary care providers.

Finally, GPs and practice staff provided some reflection on the training and how it could be improved for future iterations. A consistent message was the need for practical, hands on training rather than theoretical overview-focused training. Moreover, hands on training means sitting in front of a computer and playing with a dummy record or equivalent, rather than watching an instruction 'walk through' the functions of My Health Record on an overhead screen. Some participants resorted to setting up their own My Health Record in order to 'play' with it, and these GPs recorded the greatest advancement in terms of attitudes and use among the group. However, not all GPs were prepared to take this route, as some still lack confidence in the system. In this context, a My Health Record-enabled dummy patient is the ideal solution for GPs and practice staff alike to practice with the technology. Practice staff further suggested the need

for non-GP focussed training tailored specifically to their roles and needs. There was a general need for more guidance on assisting patients to set up, activate, use and interpret their records.

There was a strong appetite expressed for a follow up training session, after the conclusion of the opt out period, to equip GPs and practice staff to address their own and patients' concerns about privacy and security, including understanding how to navigate the layers of consent and other protections built into the tool.

4.2. s47G patient perspectives on My Health Record

s47 patients were interviewed for the study to provide a complementary perspective on My Health Record. The patients interviewed were an older cohort, with an average age of 70 years, which reflects the general profile of patients targeted for a My Health Record in the surgery. Some patients reported having complex health conditions, while others were in reasonably good health but believed they were approached about My Health Record because they had reasonable IT literacy and an interest in charting their health journey. This aligns with GP and practice staff accounts of their target population for My Health Record.

Perceived value of My Health Record and why patients signed up

Most patients reported that their GP broached the subject of My Health Record with them, although two instigated the conversation themselves. This supports the general observation made by GPs and practice staff that patient-driven demand is not very apparent. However, patient receptiveness is apparent, if the GP brings it up and explains it in a manner that patients can relate to. It was clear from the way patients described their general understanding of My Health Record – as an online system for storing and sharing health information able to be accessed anywhere and anytime by any health provider involved in their care (subject to their consent) – that this is how GPs are communicating its value. Patients consistently identified this as an extremely valuable feature of the tool. Part of this can be attributed to an increasing sense of vulnerability associated with ageing and the sense that health complications could arise at any time or place, hence the value of readily accessible health information. Many patients are also very aware of impending signs of cognitive decline and memory loss, and value their My Health Record for containing critical information that they may struggle to remember or voice in a health encounter. Many shared the view that the health benefits provided by My Health Record in the context of ageing and/or increasing health vulnerability significantly outweighed the privacy and security risks highlighted in the media.

How patients interact with My Health Record

Patients related to having a My Health Record in variable ways. Some interacted with their record in a highly active and inquiring manner, while others were content for it to sit in the background, managed by their GPs and practice nurses, as a type of 'insurance' should something go wrong. These patients tended to emphasise the high level of trust they have in their GP; in other words, if their GP recommended My Health Record then they were open to considering it. This highlights the role that a GP who is confident and skilled with My Health Record plays in building engagement with My Health Record in the wider community. It also contrasts with the GP view that patient demand should drive the uptake of My Health Record; patients clearly see a role for their health practitioners in leading and guiding the process.

The more engaged users of My Health Record interacted with it two ways, most commonly by accessing and monitoring information and reports uploaded by their GPs and less frequently by entering their own information into the record. Patients who used My Health Record to monitor their health information were also likely to discuss their records with their GP, particularly if they felt that something significant had been left out of the health summaries. This monitoring activity contributed to patients' sense of confidence in and transparency around the health exchange between patient and GP. It also provided patients with a sense of autonomy and control over their health management, with a number of patients placing value on their ability to access information and results independently, without having to go directly through their health provider.

How My Health Record could be improved to enhance the patient experience

Patients raised a number of issues with My Health Record. Several reported technical issues while trying to sign up or activate their records, which aligns with the experience reported by some GPs who set their own record up to practice with. Patients and GPs both stressed that the system must be simplified and streamlined to facilitate the user experience. Another issue was the lack of valued information in the record such as pathology and radiology test results. There is a need to educate and inform the patient community/activated users of My Health Record about what to expect now and in the future regarding functionality, in order to moderate expectation and frustration. One highly engaged, interested and informed patient discovered medication errors and other information anomalies in her record and lost critical confidence in the system. While it is difficult to ensure perfect fidelity in a system that relies on human-mediated input, the risk of error can have an impact on community and professional confidence. Finally, some patients emphasised the need for My Health Record to contain information that is relevant, easy to read and interpret, and easy to manage if patients are to derive full value.

My Health Record making a difference to patients' lives

When asked, patients could not provide any examples of where My Health Record had delivered a life-changing health impact on their lives, as none of them had yet had a critical health event or emergency where it was used. However, two respondents were able to describe adverse situations where a My Health Record, had they had one at the time, might have made a major difference to their health encounters. Both incidences occurred within the hospital system, one where information about concurrent health conditions was not linked up in the hospital records and the other where the patient was unable to communicate important medication information to hospital staff resulting in inadequate pain relief for a separate health condition. The ability to quickly and easily access their health information on My Health Record would have saved both patients from adverse, or near adverse outcomes. While other patients did not relate to its value in the same intimate terms, they recognised and understood its potential life-saving and health preserving value in their lives.

5. Key messages and recommendations

Study findings reflect the singular timing of the project, coinciding with the very formative stage of the My Health Record rollout in South Australia and the introduction of the opt out period by the Australian government. s47 staff requested and received training with a highly practical focus, designed to build their skills and confidence in interfacing with the tool. While the training proved

valuable in terms of up-skilling GPs and practice staff in this respect, it was apparent that attitudinal and behaviour change in general practice depend on more than accomplished practical skills; what is required is a wider My Health Record support system to **inform**, **encourage**, **enable** and **sustain** change.

Recommendations for supporting increased uptake in s47G SA general practice more widely and the SA patient community relate to four key focus areas.

1. **Strengthen/build confidence in My Health Record Connections in South Australia**

   Recommendation 1: Continue to fast track My Health Record connections (noting key developments scheduled for 2019) and ensure that GPs, practice staff and the patient users of My Health Record **are well informed** about progress in bringing diverse health providers and data/test results into My Health Record (e.g. pathology, radiology, SA Health, and allied health).

2. **Developing a well-rounded training and education focus**

   Recommendation 2: Design and deliver My Health Record training and education targeted at:
   o Equipping GPs and practice staff with the **practical knowledge and skills** to navigate My Health Record (e.g. upload shared health summaries and access information stored on the record);
   o Providing more opportunity for **hands on experience** in training, incorporating laptops and a dummy patient or equivalent to practice on;
   o Improving health practitioner knowledge and confidence **to discuss the privacy and security issues** raised in the opt out debates and associated protections built into the tool;
   o Equipping GPs and practice staff to **assist and advise patients about how to interact productively** with the tool;
   o Specifically addressing **non-GP practice staff roles and functions**; ensuring that access to My Health Record is working for relevant practice staff;
   o Providing the s47 team with a **follow up training session** after the opt out period has concluded to address the issues raised, refresh practical skills that have lapsed during the period of uncertainty and reignite the momentum lost following the opt out experience;
   o Exploring avenues for **peer to peer education** within the s47 GP and practice staff team and in broader a cross-general practice context.

   Recommendation 3: Develop a stronger focus on patient community information and education through:
   o A **positive public awareness campaign** to engage the interest of the wider community and counter the negative messaging produced in much of the opt out media;
   o **Targeted information resources** (online and brochures) for patients, addressing privacy and security concerns and how to apply protection mechanisms built into the tool.

3. **Maximise enabling features/mechanisms to support the use of My Health Record**

Recommendation 4: Select/prepare general practice settings for successful uptake of and a leadership role in promoting My Health Record in South Australia, noting the following facilitating factors:
o Having one or more **digital health champions** within the practice to drive and support the process;
o Projecting a **positive practice culture** that encourages and supports staff uptake of My Health Record; noting the key role of practice management (particularly the business manager) in building and sustaining the profile of My Health Record in the team environment, providing encouragement and support, promoting conversations and debate, and continuing training and development opportunities.

Recommendation 5: Recognise and/or reward health practitioners for committing the extra time and effort required to clean data in preparation for setting up a patient's My Health Record:
o Investigate the potential for a **non-attendance based My Health Record set-up rebate**; possibly time limited until sufficient momentum is underway;
o **Explore other mechanisms** (e.g. practice-based) to account for/alleviate the time involved in setting up a My Health Record with clean and adequate data.

Recommendation 6: **Address technical issues** in My Health Record and **make the tool as user-friendly** as possible for users across professional and community groups:
o Streamline and simplify **patient activation and login procedures**;
o Resolve **interface issues** between My Health Record and s47G (e.g. problems in the medication view);
o Develop swift resolution processes to **rectify data errors** in My Health Record (e.g. incorrect listed medications).

4. **Leveraging the progress of s47 to encourage broader acceptance of My Health Record**

Recommendation 7: Assess the change readiness of general practices in South Australia and **develop a diffusion strategy** to grow regional and state wide momentum. The strategy should:
o Maximise the digital health strengths and advancement of s47 to establish it as **a lead South Australian practice** in the utilisation of My Health Record;
o Build a **digital health network** to diffuse the capabilities of s47 to other receptive practices and beyond.

Appendix 1

GP and Practice Staff interview questions

Baseline interviews

1. How would you rate your current level of understanding about My Health Record? Please describe what you know about the technology.

2. Are you currently using/have you ever used My Health Record?
   If yes:
   a. How long have you been using it?
   b. Do you mention it to patients you see during consultations?
   c. How are you using the technology as part of your work practice/work flow?

   If no:
   d. What are your reasons for not using My Health Record?

3. Do you think My Health Record is/could be a useful tool for managing client records? If yes how so, if no why not?

4. Are there particular groups of patients that are likely to receive more benefit from using My Health Record?

5. Can you pinpoint any specific benefits or advantages associated with using My Health Record? (e.g. workflow efficiency).

Post-training interviews

1. How would you rate your current level of understanding about My Health Record? Please describe what you know about the technology.

2. Are you currently using My Health Record?
   If yes:
   a. Do you mention it to patients you see during consultations?
   b. How are you using the technology as part of your work practice/work flow?

   If no:
   c. What are your reasons for not using My Health Record?

3. Do you think My Health Record is/could be a useful tool for managing client records? If yes how so, if no why not?

4. Are there particular groups of patients that are likely to receive more benefit from using My Health Record?

5. Can you pinpoint any specific benefits or advantages associated with using My Health Record? (e.g. workflow efficiency).

Appendix 2

Patient interview questions

1. How familiar are you with My Health Record? Can you describe what you think My Health Record is about or what it is designed to do? From your point of view, what do you think is its principal purpose?

2. Can you remember when you signed up for My Health Record? Around about how long have you been on it?

3. What were your reasons for signing up to My Health Record? How did you find out about it?

4. How often would you say you use My Health Record/refer to it? (E.g. regularly, intermittently, rarely, in health consultations and/or privately at home, and the reasons for this.)

5. Do you ever talk to your GP/other practice staff about My Health Record when you visit the Surgery? Do they ever bring it up, encourage and/or support your use of it (or otherwise)?

6. Do you think that My Health Record is/has the potential to be a useful tool in helping you to keep track of/manage your health conditions?
   a. If yes, how so?
   b. If no, why not?

7. Can you describe what, if any, specific benefit/assistance you get (or could get) out of using My Health Record?

8. Do you have any concerns about using My Health Record? Are there any aspects of My Health Record you don't like? Can you think of ways to make it a better tool/health resource from your point of view?