

## THE IMPACT OF MY HEALTH RECORD ON PRIMARY CARE

**Final report** 

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#### Ethics approval

Ethics (University of Melbourne HREC ID: 1750888) and Data Governance approval (ID 2017-022 and 2018-003) was obtained for the studies.

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### Introduction

In Australia, patient<sup>1</sup> 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<sub>1c</sub> 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.

<sup>1</sup> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> testing for people with type 2 diabetes

- A higher proportion of people with at least one HbA<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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.

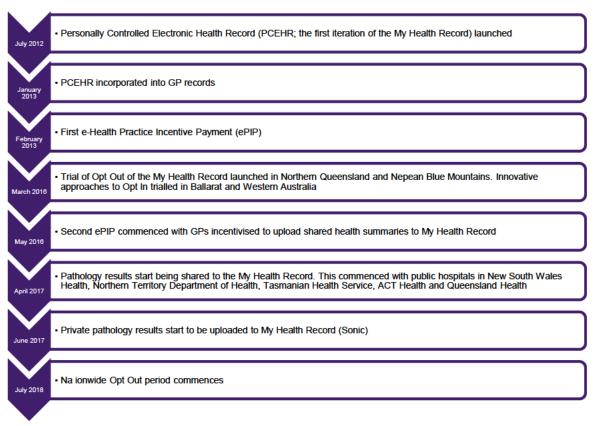
- 1. Improve integration of My Health Record with current GP clinical information systems to ensure optimum functionality and compatibility. Co-design with end users and simulation testing will be important to this work.
- 2. Continue to design patient engagement strategies for My Health Record based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



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

- explore whether My Health Record activity was associated with reduced: (1) HbA<sub>1c</sub> 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
- 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 deidentified 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<sub>1c</sub> 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<sub>1c</sub> 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 HbA1c pathology testing

Current Australian guidelines recommend that HbA<sub>1c</sub> tests be performed at 3-month intervals for patients with type 2 diabetes who are not pregnant. For this study, duplication of HbA<sub>1c</sub> pathology was defined as an HbA<sub>1c</sub> test that was reported less than 90 days from the preceding HbA<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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 HbA1c tests reported per patient
- the number of patients with at least one HbA<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> test results (average 4.4 HbA<sub>1c</sub> test results per patient, range 2 to 35 HbA<sub>1c</sub> results) over the 5-year study period.

# Figure 2: Identification of patients with at least two HbA<sub>1c</sub> tests recorded between 2013 to 2017

238 139 people with type 2 diabetes in dataset 51 757 people in dataset with at least one HbA<sub>1c</sub> recorded between 1/1/13 and 31/12/17 33 756 people in dataset with at least 2 HbA<sub>1c</sub> recorded between 1/1/13 and 31/12/17

#### Table 1.1.1: Characteristics of general practices (N=438)

Practice deta	ails	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	1	71 (16.5)
Quintiles#	2	70 (16.0)
	3	107 (24.5)
	4 and 5	189 (43.3)
	Major cities	259 (59.3)
Rurality^	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.

<sup>^</sup> 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<br/>cohort and who had at least two HbA1c tests recorded between 2013 and<br/>2017

Patient characteristics		All patients with d cohort	iabetes in the	Patients with at patholo	
		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	No	170672	(71.7)	32591	(96.5)
clinics	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.

<sup>^</sup> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> records for these patients, an average of 4.6 per patient, ranging from 2 to 20 HbA<sub>1c</sub> pathology tests per patient. The first occurrence of the HbA<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> records of which only one HbA<sub>1c</sub> test was repeated within a 90-day interval within a practice.

Results show that the percentage of HbA<sub>1c</sub> 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<sub>1c</sub> 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).

Variable	Tota	I 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 HbA1c test recorded within 90 days of a previous test	23579	(69.9)	1611	(6.8)	403	(1.7)	82	(0.35)
At least one HbA1c 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 HbA1c 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 HbA1c 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 <sub>1c</sub> 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 <sub>1c</sub> test recorded within 90 days of a preceding test within and across practices	37	(3.2)	3	(8.1)	3	(8.1)	0	(0)

### Table 1.1.3: HbA<sub>1c</sub> test results and My Health Record activity by practice attendance between 2013 and 2017 (N=33756)

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<sub>1c</sub> 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<sub>1c</sub> test results)

My Health Reco	ord	Total number of	$HbA_{1c}$ results with testing interval of < 90 days recorded							HbA <sub>1c</sub> results with testing interval of < 90 days recorded across different practices only			
		paired HbA <sub>1c</sub> tests recorded in CIS (N)*	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<sub>1c</sub> tests across practices in the CIS.

\*The first occurrence of the HbA<sub>1c</sub> 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<sub>1c</sub> tests recorded in CIS in each row; Diff – difference in percentage of HbA<sub>1c</sub> 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.<sup>2</sup>

#### 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;

<sup>#</sup> 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.

<sup>^</sup> 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.

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

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

\*Discrepancies in total due to missing responses;

<sup>#</sup> 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.

<sup>^</sup> 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 p	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)
Dne 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)
/ultiple 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 oractice 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 oractices 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)</td>

				Days between X-ray tests was less than 365 days (duplication)										
Type of My Health		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					
Record activ	vity	paired knee X-ray results recorded in CIS (N)	n	(row %)	Diff	(95 % C	21)	Median (range)	n	(row %)	Diff	(95 % C	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.<sup>3</sup>

#### 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

<sup>3</sup> 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

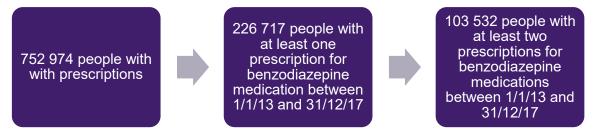


Table 1.3.1 shows the characteristics of the 494 practices attended by patients who had at least two prescriptions. Table 1.3.2 summarises the characteristics of the 226 177 patients who had at least one prescription between 2013 and 2017. The sex distribution was similar between patients with one prescription 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.

		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)

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

\*Discrepancies in total due to missing data;

<sup>#</sup> 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.

<sup>^</sup> 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<br/>for benzodiazepine medications recorded, in total and by the number of<br/>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.

<sup>^</sup> 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 personyear), 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 personyear by number of practices attended between 2013 and 2017

			Rate of benzodiazepine prescriptions/ person-	
	N (col %)	n	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-<br/>year by My Health Record activity for patients who attended multiple<br/>practices between 2013 and 2017

			Rate of benzodiazepine prescriptions/	
	N (col %)	n	person-year	RR (95% CI)
My Health Record activity recorded* (N=621	8)			
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<sub>1c</sub> tests with betweentest intervals of less than 90 days or fewer people with osteoarthritis having knee X-ray tests with betweentest 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<sub>1c</sub> 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<sub>1c</sub> 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<sub>1c</sub> 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 personyear 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<sup>4</sup> 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.

<sup>4</sup> ATC classes included in this study were D06AX, D06BX, D10AF, J01AA, J01CA, J01CE, J01CE, J01CF, J01CR, J01DB, J01DD, J01DD, J01DD, J01DH, J01EA, 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: Gen	eral practice characteristics	
Characteristics		n (%)
State	ACT	9 (1.8)
	NSW¥	167 (33.8)
	NT	10 (2.0)
	QLDŦ	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)

### Table 2.1: General practice characteristics

# 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

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

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)

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

# 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<br/>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 ir	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	
0.		

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:

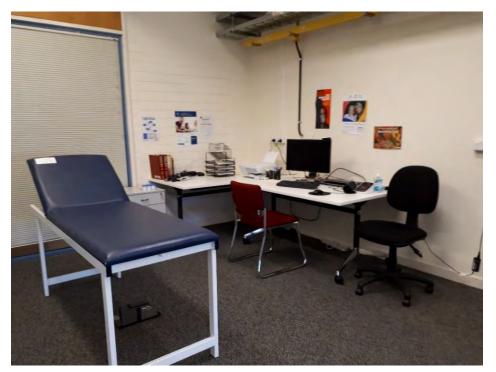
- Shared health summary documenting allergy to a previous antibiotic
- Pathology report documenting organism and sensitivities for a previous urinary tract infection
- Shared health summary accurately stating current medications and dosages.

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<sup>5</sup>. 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.

<sup>5</sup> 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: <u>https://www.nps.org.au/medicine-insight/using-medicineinsight-data</u>.

#### 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.

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)

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

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

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# **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 <sub>1c</sub> 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%

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# **APPENDIX 4: GP INTERVIEW PROTOCOL**



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?
- 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?

7.

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?
  - 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**



#### 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

3.

- 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?
  - 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?)
    - . 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

b.

- 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?
    - 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?

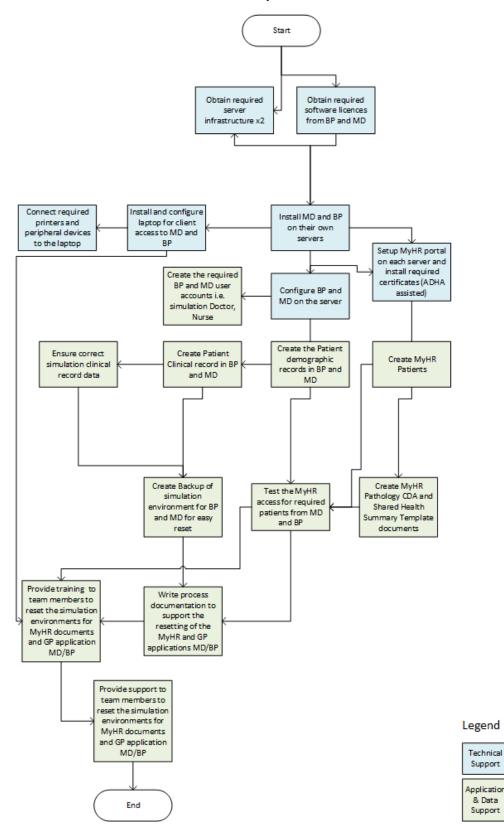
#### CONCLUSION

- $\triangleright$  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

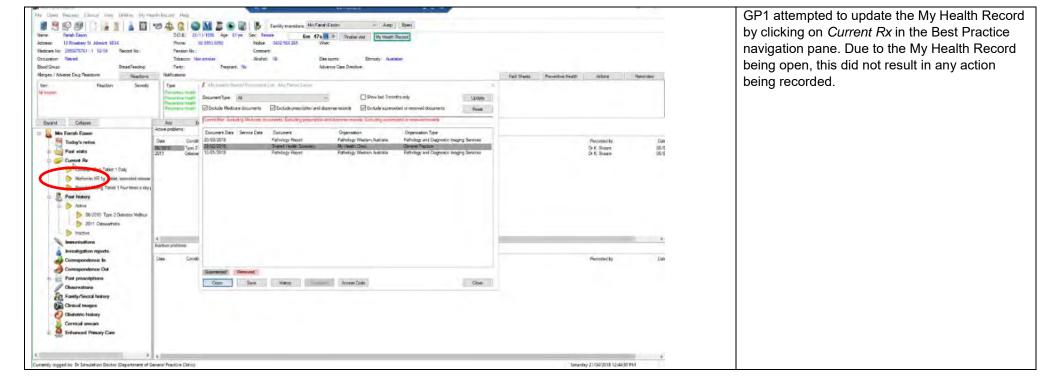
Creating the simulation data within BP, MD and My Health Record and training the team members on the project, including:

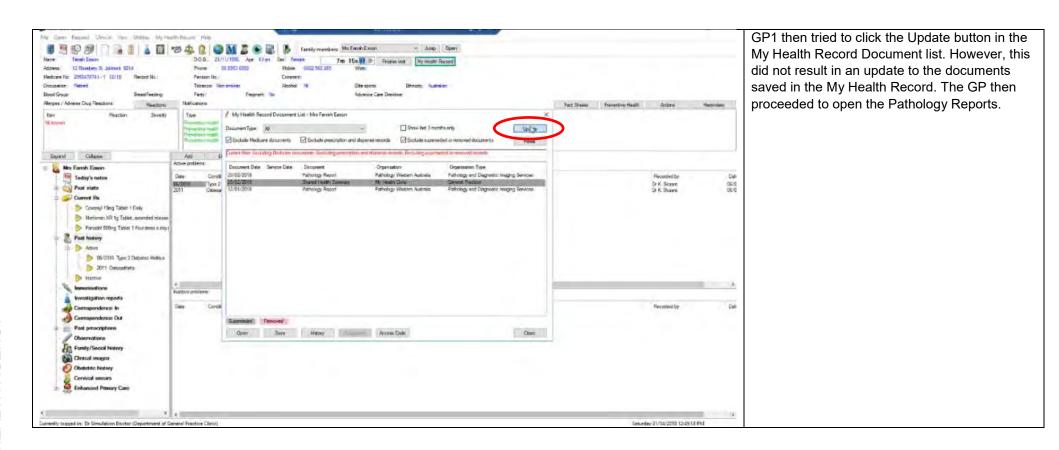
- Training from ADHA on how the My Health Record works and how to create the Shared Health Summary and Pathology reports
- Creation of the mock (simulated) patient record within BP and MD, ensuring all dates and information were included as required by the researchers to simulate a life-like patient 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

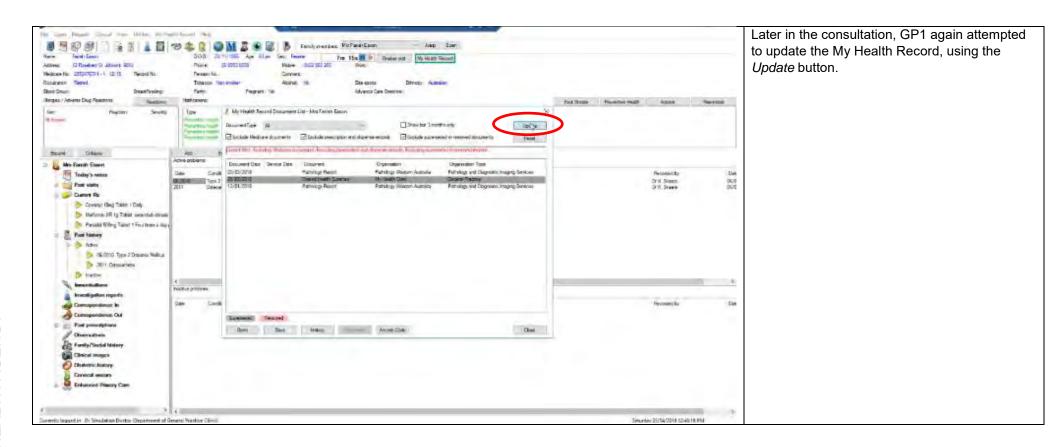
# APPENDIX 7: NAVIGATING MY HEALTH RECORD – SCREENSHOTS FROM THE SIMULATION LABORATORY

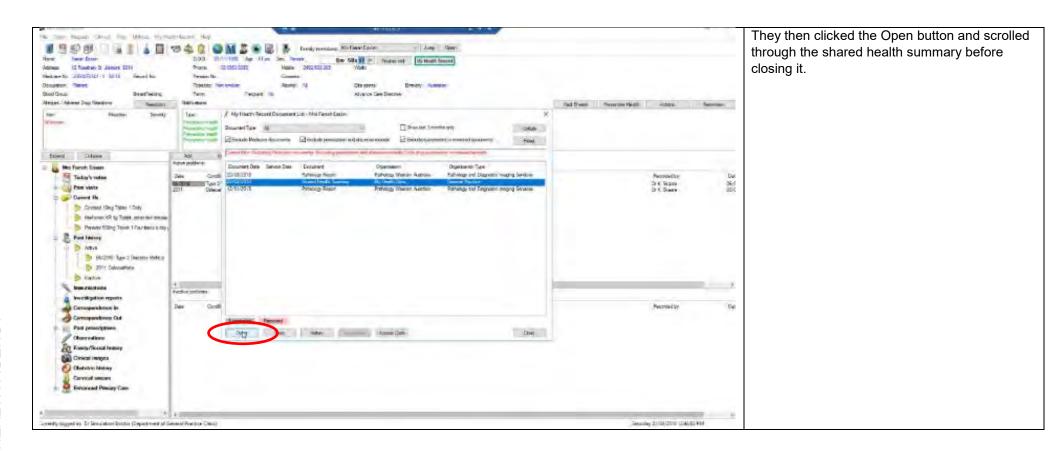
Screenshots and activities were recorded as GPs undertook the simulated consultation. Examples are provided which demonstrate how GPs tried to navigate My Health Record to achieve different tasks. These have implications for design of integration of My Health Record into clinical information systems/electronic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

GP1: Utilising Best Practice to try to upload a document to My Health Record.



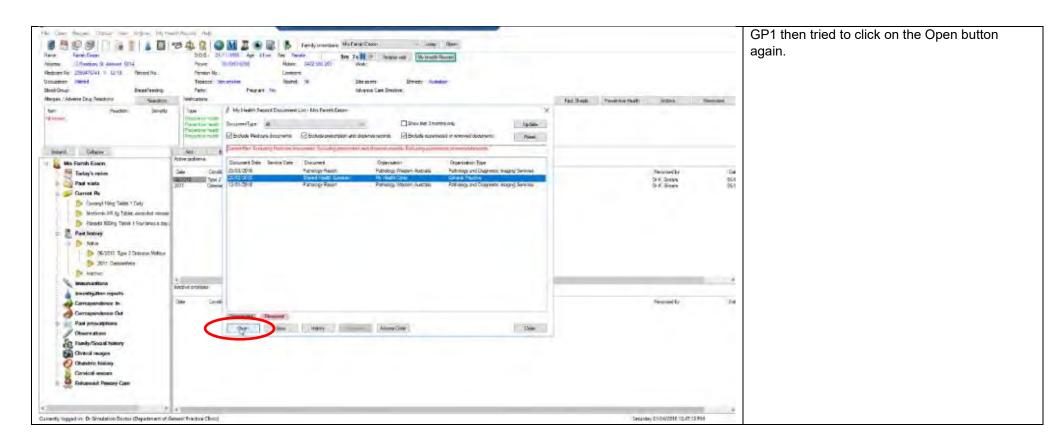






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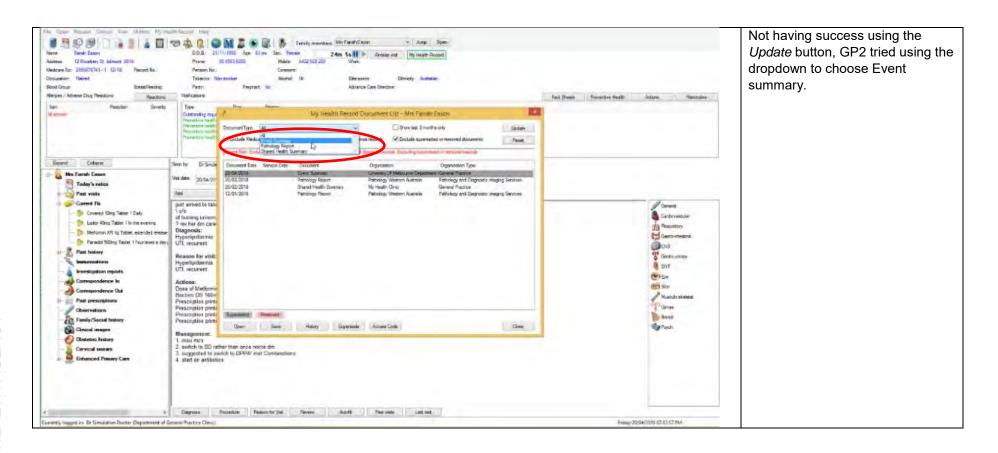




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