



# Continuity of Care Across the Primary and Acute Care Interface

Situational Analysis

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## **Acronyms and definitions**

Acronyms	
CEIH	Commission on Excellence and Innovation in Health
HTSA	Health Translation SA
EMR	Electronic Medical Record
SACESS	SA Consumer Experience Surveillance System
AIHW	Australian Institute of Health and Welfare
GP	General Practitioner
EDA	Enterprise Data and Information Data Asset
HARC	Health Analytics Research Collaborative
PAS	Patient Administration System
iRAD	Integrated Real-time Active Data
MBS	Medicare Benefit Scheme
PBS	Pharmaceutical Benefits Scheme
DVA	Department of Veteran's Affairs
SAHMRI	South Australian Health and Medical Research Institute
IHI	Individual Healthcare Identifier
PHN	Primary Health Network
AHHA	Australian Healthcare and Hospitals Association
Definitions	
Primary care	Generally the first point of contact people have with the health sys-tem and includes a broad range of activities and services that are de-livered outside the hospital setting—from health promotion and pre-vention, to treatment and management of acute and chronic condi-tions [1].
Acute care	Care in which the intent is to perform surgery, diagnostic or thera-peutic procedures in the treatment of illness or injury. Management of childbirth is also considered acute care.
Continuity of care	Describes the effective coordination and smooth progression of care over time as viewed from the perspective of the patient. It is the degree to which patients experience care over time as coherent and linked.
Data	Information, especially facts or numbers, collected to be examined and considered and used to help decision-making, or information in an electronic form that can be stored and used by a computer
Relational continuity	An ongoing therapeutic relationship between a patient and one or more providers.

## **Executive summary**

#### Context

Health Translation SA (HTSA) is working with our partners to better use the rich supply of healthcare data in South Australia to improve continuity of care; particularly as people transition between care provided in our hospitals and care provided within the community setting (across the primary/acute care interface).

The project commenced in July 2020 and will be completed by June 2022. This report outlines the major findings of the situational analysis conducted in Phase 2 the purpose of which is to

- understand the problems associated with continuity of care across the interface from the perspective of consumers, clinicians and the health system, and
- identify relevant data assets, projects, and expertise that can contribute to the development of a solution.

The situational analysis conducted by HTSA project staff, was informed by a series of discussions with health service decision makers, primary and acute care clinicians, as well as patients and carers.

Over 40 interviews were conducted with GPs, primary health networks, SA Health, researchers, Digital Health SA, Commission for Excellence and Innovation in Health, Australian Institute of Health and Welfare and Australian Healthcare and Hospitals Association. The report was originally intended to provide the basis for discussions at a Stakeholder Forum on 30th November 2020 and development of the next steps. However due to COVID-19 and the limited availability of critical clinical staff the decision was made to cancel this form and develop and alternate process for continued clinical engagement. Additional feedback on this report is welcomed from the healthcare sector and will assist in shaping this project. Further opportunities for clinicians and consumers to engage and partner with this project will be provided.

## **Key findings**

Focus groups with patients and carers revealed communication and central co-ordination of care to be key enablers of the smooth progression of care across the transitions between community and hospital care. They were surprised at the inability of the system to capture the appropriate information and provide it to all care providers (as well as themselves) and expressed frustration at the need to continually 'retell their story'. Specific types of information were identified as important to capture and communicate, particularly carer/advocate details, the need for home care, decision making capacity etc).

Patients and carers were largely unsatisfied with the transfer of their medical information across care providers -particularly upon discharge from hospital. However, of critical importance to their experience of continuity of care is the feeling that they are 'known' and treated as a whole person rather than within silos of disconnected care. All were keen to see data used to improve continuity of care but highlighted that this must supplement the establishment and maintenance of caring relationship with patients and carers, not become a substitute for such relationships.

For clinicians in both primary and hospital care settings the timely communication and transfer of clinical information is a significant, everyday problem. Clinicians expressed the need to be able to access current clinical information at point of care to aid in decision making, and to track and coordinate their patients' journey through the system. Such patient journey tracking was also regarded as critical to efforts to identify service gaps and improve healthcare services.

#### THE NEED

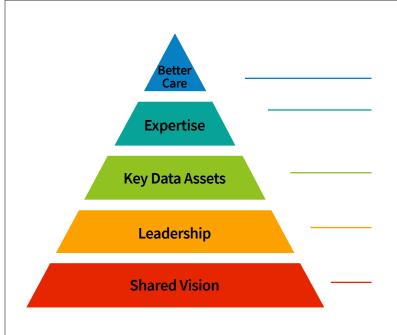
To provide real time transfer of healthcare information between primary and hospital care providers that is readily accessible at point of care to assist healthcare decision making.

To track the patient journey across the system to support coordination of care, identify gaps in care and ultimately improve services.

#### What is possible?

The advice of South Australian experts is that the technology exists to provide a solution that captures data once and uses it to support real-time transfer of clinical information at point of care and contribute to a multi-source enduring linked data asset that can inform service improvements.

Indeed, we are well positioned in SA to better use data to improve continuity of care, building on the current willingness for change, existing leadership and governance and significant infrastructure, data assets and expertise within the state.



#### **Improved Continuity of Care**

Real time health data exchange between primary care providers and hospitals to enable better clinical care and service improvement

- CEIH Clinical Informatics Directorate Digital Health SA HARC Digital Health CRC SA NT Datalink NPS MedicineInsights DVA Veteran's Mates Al<sup>2</sup> other research projects industry
- Clinical informatics database EMR EDA primary care practice software My Health Record MBS PBS radiology pathology, pharmacy
- Digital Health SA CEIH HTSA General Practices PHNs Wellbeing SA

Provision of real time healthcare information that is readily accessible through one platform across sectors to inform clinical decision making, management, coordination of care and follow-up and allows tracking of the patient journey across the interface.

Other states have developed projects that either support real-time transfer of clinical information or provide deidentified unit/aggregate level data for service improvement.

Whilst we recognise the breadth of the primary care sector, focusing GPs in the first instance, as the gatekeepers of healthcare, is recommended. Identified areas of need include:

- Information transfer to GPs and patients/carers following discharge from hospital
- Information flow between GPs and hospital Outpatient Departments
- Information available upon presentation to hospital Emergency Departments

As continuity of care requires partnership across 'the interface' this project should if possible, address two-way communication between these sectors. Consideration should be given to how this solution can also contribute to multisource enduring linked data asset such as SA Health's Clinical Informatics Database, and the National Primary Care Data Asset.

Once the project scope and shared information needs (data sources) are identified, it is recommended that a technical working group be established to develop the specifications for a technical solution with consumers and clinicians. A tendering process for technical build and pilot implementation is then recommended.

#### 1. Introduction

#### 1.1 Aim

Health Translation SA (HTSA) is working with our partners to better use the rich supply of healthcare data in South Australia to improve continuity of care; particularly as people transition between care provided in our hospitals and care provided within the community setting.

#### 1.2 Context

Continuity of care has been recognised as a long term and significant health system challenge in South Australia. Continuity of care across different healthcare providers and settings is critical. Vital information and time are lost, and patients' outcomes can be compromised at several points within the system, particularly when they are being referred or admitted into a hospital and upon discharge into the care of their regular doctor. Poor care continuity during such transitions carries a higher risk of preventable adverse events such as increased emergency department visits, hospital readmissions, and even disabilities or death [2].

Achieving coordinated and smoothly progressing care in the context of chronic disease, multiple healthcare providers and different care setting is a difficult and multifaceted challenge. However, one critical aspect underpinning continuity of care is the provision of timely and accurate information regarding the patient, and the communication and flow of this information across this interface [3] . This project will focus on this key aspect and will explore how we can build on current digital health initiatives and health service reform and more effectively use data to improve care as people transition between the hospital and community setting, or across the primary/acute care interface. For more information on the project please read our <u>Background Briefing Paper</u>.

## 1.3 Project plan

This project is supported by the Australian Government's Medical Research Future Fund (MRFF) as part of the Rapid Applied Research Translation program (MRF9100005). The project will be conducted in a series of phases over the next two years with a required completion date of June 2022.

PHASE 1	PHASE 2	PHASE 3	PHASE 4	PHASE 5
Establishment	Situational Analysis	Solution Scoping/ Identification	Solution Development	Solution Piloting
Project Team Steering Committee (SC)	Stakeholder Interviews     Consumer Focus     Groups     Draft Report	Stakeholder Feedback Final Report SC Recommendation HTSA Board Decision	Specifications     development     Tendering	
Jul - Aug 2020	Sep - Oct 2020	Nov - Dec 2020	Jan - Mar 2021	Mar 2021 - June 2022

Figure 1. Project plan

#### 1.4 Progress to date

#### 1.4.1 Phase 1

The first phase of the project saw the establishment of the Project Steering Committee that will drive the project reporting to the HTSA Board. This committee meets monthly and is comprised of health service decision makers, clinicians, researchers, data experts and community members (Appendix 1).

This report outlines the major findings of the situational analysis conducted in Phase 2 and aims to:

- understand the problems associated with continuity of care across the interface from the perspective of consumers, clinicians and the health system, and
- identify relevant data assets, projects, and expertise that can contribute to the development of the solution.

#### 1.4.2 Phase 2

The situational analysis was conducted by HTSA project staff and was primarily informed by a series of interviews with health service decision makers, and primary and acute care clinicians as well as focus groups with patients and carers. Initial interviewees were identified by the project staff and steering committee, with others identified and included as a result of these interviews. In total, 40 interviews were conducted with representatives from across primary (GPs, PHNs) and acute care (SA Health sectors), research, government (Digital Health SA, CEIH) and national bodies (AIHW, AHHA).

A full interviewee list is available in (Appendix 2). The consumer perspective was explored through two focus groups and analysis of the SA Consumer Experience Surveillance System (SACESS) survey conducted by SA Health [4]. This survey explored the experiences of people who received overnight hospital care from a South Australian metropolitan or country hospital 6 weeks following discharge.

#### 1.4.3 Preparing for phase 3

This situational analysis reports on the key themes and findings emerging from discussions with clinicians, consumers, and healthcare providers. Evidence available in other public reports has also been used to identify where themes align with findings reported elsewhere.

The report was originally intended to provide the basis for discussions at a Stakeholder Forum on 30th November 2020 and development of the next steps. However due to COVID-19 and the limited availability of critical clinical staff the decision was made to cancel this form and develop and alternate process for continued clinical engagement.

Additional feedback on this report is welcomed from the healthcare sector and will assist in shaping this project. The Project Steering Committee will define the project scope based on the findings outlined in this report and provide a recommendation to the HTSA Board for endorsement.

Additional feedback on this report is welcomed from the healthcare sector and will be taken into consideration. Further opportunities for clinicians and consumers to engage and partner with this project will be provided.

## 2. Key Findings of Situational Analysis

## 2.1 Understanding the problem

The first objective of the situational analysis was to understand the problems associated with continuity of care across the interface from the perspective of consumers and primary and acute care clinicians. This section outlines the key themes that emerged from these interviews.

#### 2.1.1 The need to clarify terminology and define the 'interface

An early key finding was the need to clarify what is meant by 'the primary/acute care interface' and to adopt clear and accurate terminology that facilitates building a shared vision and partnership to address this problem. Interviews revealed that all sectors required clarification on the phrase 'primary/acute care interface'. Understanding the scope of the 'interface' and relevant pain points across this interface is also necessary in order to identify and prioritise opportunities to use data to improve continuity of care.

We are defining 'the interface' for this project as being those points at which patients transition between receiveing health care in the community setting versus healthcare within a hospital setting (Figure 2).

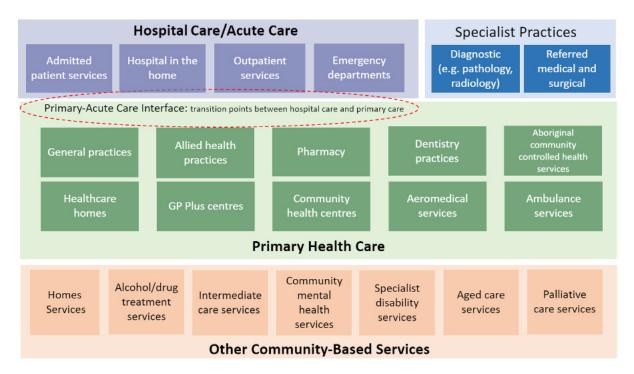


Figure 2. Primary health care and its interactions with the broader health care and community service sectors (adapted from [5])

Primary care is defined by the Australian Institute of Health and Welfare (AIHW) as the first point of contact people generally have with the health system. It includes a broad range of activities and services that are delivered outside the hospital setting—from health promotion and prevention, to treatment and management of acute and chronic conditions [1]. While general practice is the cornerstone of primary care in Australia, primary care can also include care provided through nurses (such as general practice nurses, community nurses and nurse practitioners), allied health professionals, midwives, pharmacists, dentists, and Aboriginal health workers. Primary care can be provided in the home or in community-based settings (e.g. general practices, community health centres, Aboriginal Community Controlled Health Services) [5]. It is important to recognise that primary care health professionals provide a variety of types of care including acute, subacute and non-acute care.

For this reason, the use of the term acute care to refer to care provided in the hospital setting is somewhat inaccurate and problematic. Although the Australian Government Department of Health uses acute care interchangeably with 'hospital care' [8], acute care is defined as care with the intent to cure the condition, alleviate symptoms or manage childbirth [6]. The interchangeable use of the term acute care to denote a) a specific type of care that may occur within any setting, and b) care provided in a hospital - is confusing. Additionally, in some instances this mispresents the breadth and importance of care provided by primary care providers. It is recommended that the terms 'hospital care' or 'hospital setting' are adopted instead of acute care. In fact, as the project develops, it is recommended that the paradigm of continuity of care be shifted from 'the interface' between 2 components of the system (primary and hospital care) to healthcare providers partnering together to provide quality care for their shared patients.

#### 2.1.2 The perspective of patients and carers

This section outlines the high-level findings of the consumer groups relating to the experience of patients and carers as they move between care occurring in the community and hospital care. The findings align with key themes emerging from the SACESS survey. The complete <u>Consumer Report can be viewed online</u> and is summarised below (Figure 3).

#### Theme 1: The system is complex and difficult to navigate

Focus groups with patients and carers confirmed they find the health system to be very complex and difficult to navigate. They often need to see multiple care providers in many different settings. Navigating this system is inherently more difficult when unwell and even more difficult for people with multiple comorbidities or chronic conditions. Both patients and carers describe frustration and exhaustion associated with this. These consumer experiences are consistent with the "Flying Blind -Australian Consumers and Digital Health" report of 2016 [15].

## Theme 2: Transfer of information between care providers is poor especially upon hospital discharge

Focus group participants were surprised at the inability of the system to capture the appropriate information and provide it to all of their care providers and themselves. They expressed frustration at having to 'retell their story' repeatedly. Although this was a common within

all care settings it was seen as more problematic across the transitions, where patients and carers were largely unsatisfied with the transfer of their medical information across care providers.



Surely there's an app for this?

Why can't we have a single accessible medical file with all our information?

.....Isn't that what My Health record was supposed to do?

Discharge from hospital was consistently identified as a critical transition point where patients were negatively affected by poor communication and transfer of information. Such information might include medications and after-care instructions, follow-up appointments, who to contact and when. A stand-out exception was the transfer of information from the SA Ambulance Service to hospital Emergency Departments.



Only one nurse came twice, otherwise it was a different nurse every day.

I was not their problem anymore and I was left wondering what to do next.



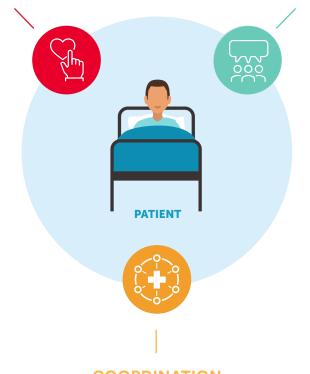
Why is it not documented in one central and accessible place?

...they only had part of the picture...

#### **RELATIONSHIP**

## Personalised, holistic care across the whole system

- Being aware of and understanding the broader clinical and social context of patients and their carers
- Providing care that is connected across the system (non-siloed care)
- Identifying and involving patient carers or their representatives
- Building trust, providing consistency in home-care providers



#### COMMUNICATION

Timely provision and communication of health information

- Keeping GPs up-to-date with hospital care
- Providing all health care providers access to complete and current medical records
- Provide patients and carers with clear information about medications, management, discharge and follow-ups, next steps, valuing role of carers, etc.
- Capture the right information on admission to hospital
   (e.g. decision making capacity, patient representative, home care requirements etc)

#### COORDINATION

#### Central co-ordination of care and advocacy for patients and carers

- Need for a strong advocate to help navigate a very complex health system
- One central contact person to arrange follow-up, community care, and provide medical advice
  - Recognising the critical role the GP/patient relationship plays



Figure 3. What consumers value regarding continuity of care between primary care and hospital care

## Theme 3: A central contact who can co-ordinate care is valued highly

The best experiences of continuity of care described were those where one clinician, practice or medical team "took initiative and advocated for" patients, identifying care required and organising and following up on this. Examples given of these key co-ordinators were GPs, discharge nurse, and hospital specialist medical units.

## Theme 4: Identifying and partnering with carers/patient representatives is often overlooked

The critical role carers or patient representatives play was a recurring theme in the focus groups. They identified a pressing need to identify whether a patient representative or carer is available or required and then to record and transfer that information throughout the patient journey. Carers viewed this as critical to facilitating the partnership with carers that is required to support continuity of care, and felt they were not recognised, valued and therefore underutilised by the system. Capturing their information at the beginning of a patient's journey would help validate this partnership.

66

I was treated like a ghost (carer)

There was just so much information and she couldn't take it all in (carer)

#### Theme 5: The relational context is critical

Another key contributor to poor continuity of care was the experience of care as being siloed and disjointed. Consumers often felt that each doctor or medical team treated them for the specific medical need (or condition) that fell within their specialty area without a full understanding or appreciation of the broader clinical and social context of the patient and their carers.

Patients were often left with the feeling that nobody is keeping the bigger picture in mind or understands who they are and what is important to them. Continuity of care for the focus group participants meant receiving personalised holistic care across the entire health system and throughout their whole healthcare journey.

Communication and central co-ordination of care are regarded by patients and carers as key enablers of the smooth progression of care across the transitions between community and hospital care. However, the relational context within which this occurs is paramount to consumers and cannot be ignored.

Healthcare data can be used to improve continuity of care. However it must supplement establishing and maintaining caring relationships with patients and carers, not substitute for these.



#### 2.1.3 The perspective of primary care and hospital clinicians

This section outlines the major themes that emerged from interviews with primary care clinicians, hospital clinicians and health care services in response to questions about their biggest needs when providing care for patients that are transitioning between the hospital and community setting.

## Theme 1: Timely communication and transfer of clinical information is a major, longstanding, everyday issue

Clinicians and hospital services highlighted poor access to timely patient information at the point of care as a major issue that leads to unnecessary repeated testing, medication errors and avoidable hospital readmissions.

It was noted that this problem is a longstanding one and an everyday issue – particularly for GPs.

"Communication of key information (also known as clinical handover) can takes place in 5 minutes however this often doesn't happen or is very delayed. For example, when a patient is discharged from a hospital, they often visit their GP afterward and find that their GP has no record of what they went to hospital for, what was done, or what the plan is. Likewise, we (GPs) write a summary of our consultations with patients, but this information is held within our clinical software and only conveyed if we send a referral. If a patient presents to a hospital emergency department the hospital clinicians cannot access their primary care information and therefore may not have an accurate picture of the patient's current care (such as medications, conditions etc.)".

Clinicians on both sides of this 'interface' expressed the necessity of data following the patient in either physical (letter) or digital form. The preference is to utilise digital solutions to capture and communicate this information as paper communication has clear limitations. For example, even if a referral or doctors' letter is received at the hospital the information contained within it does not necessarily get recorded in a patient's electronic medical record (EMR).

#### Theme 2: This is a shared problem

It was clear that the timely flow of accurate, up-to-date patient information between primary care and hospital providers is key to supporting continuity of care. The lack of communication of critical health information is a problem shared by both sectors. Therefore, solutions need to support the two-way flow of information across the interface.

#### Theme 3: My Health Record has not yet provided the solution

The consensus of participants is that My Health Record (a central repository of a patient's health information) has not yet been able to facilitate the flow of information required to assist clinical decision making. The use of My Health Record in primary care is variable with many records being incomplete. Despite the growing number of opt-ins and increasing type and number of information types uploaded, the data structure does not enable quick and easy content filtering, identification and communication of useful information. Most information is contained within documents and pdfs making it difficult to identify and digest relevant clinical information in a time-pressured healthcare setting. There is also considerable variability in whether and how My Health Record has been integrated into workflows throughout the state.

## Theme 4: Being able to track patients through the system is important – and currently impossible

GPs also expressed the importance of being able to not only identify the management plan for the patient, but to also track their progression and ensure all relevant follow up appointments, procedures and tests are completed. There is currently no ability for GPs to identify or track their patients' journey once they cross the interface into the hospital setting. From a system perspective this has also been flagged as a priority as it will enable the identification of gaps in care and opportunities to improve continuity of care across the system and within distinct areas (e.g. palliative care).

## Theme 5: Patients need to be included in the information flow

It is important to note that patients, carers and clinicians in both primary care and hospital settings have raised the importance of medical information being readily accessible to patients – putting them firmly at the centre of care.

#### Theme 6: The relational context is critical

GPs interviewed also stressed the importance of the relational context within which information flow occurs. Although the provision of timely and accurate information regarding the patient underpins continuity of care, the relationships between primary care and hospital clinicians and between GPs and patients is critical. The importance of this has been a consistent theme in interviews with patients, carers and GPs alike. Relational continuity is defined as an ongoing therapeutic relationship between a patient and one or more providers [10]. It conveys the sense that the whole person is known and is being treated.

GPs highlighted their role as the key relationship holder with the patient and co-ordinator of care. This was also confirmed in the consumer focus groups. Often it is the GP who retains this "understanding about the patient's preferences, values, and context through the development of a trusted care provider relationship. This relationship and retained knowledge is important for bridging separate care events and ensuring that services are responsive to needs" [17].

Clinicians expressed the view that improved data access and data flows can support better handover of clinical information, however accessible real time patient data is not a substitute for a clinical handover. This aligns with the viewpoints of consumer focus groups. In support of this, a recent article in MJA Insights asserts "the baton is passed between people not machines" [16].

"In the real world, GPs are grappling with being thrown links to hospital electronic records through systems such as "The Viewer". Investigations are likely to be uploaded (after a delay) to My Health Record. These are raw data, unfiltered and disorganised, and more of a throw than a handover. Being thrown raw data and being expected to catch them in this way is akin to a hospital doctor being given the login to the GP clinic's patient management system and being expected to extrapolate a referral" [16].

Timely communication and transfer of clinical information is an everyday, significant problem shared by clinicians in both primary and hospital care settings. Clinicians need the ability to access current clinical information at point of care to aid in decision making as well as being able to track and coordinate their patients' journey.

#### 2.1.4 Summary of the problem and needs of patients, carers and clinicians

Patients, carers and clinicians had specific views about what they needed to support improved continuity of care across the interface of primary and hospital care (as summarised below).

#### **THE PROBLEM**

The incomplete or delayed transfer of information to healthcare providers and patients as patients transition hospital and primary care settings impairs patient care

#### What patients and carers want

- For all their healthcare information to be captured and effectively communicated to all healthcare providers
- To have clear information about their care and follow up (particularly following discharge) provided to them
- A central contact who will track and coordinate their care and advocate on their behalf.

#### What clinicians want

- Provision of **real time** patient information that is readily accessible through one platform across sectors to inform clinical decision making.
- Ability to track patient their patient's journey across the interface.

## 3. The SA healthcare data landscape

In South Australia we are well positioned to better use data to improve continuity of care, building on the current willingness for change, existing leadership and governance and significant infrastructure, data assets and expertise within the state (Figure 4).

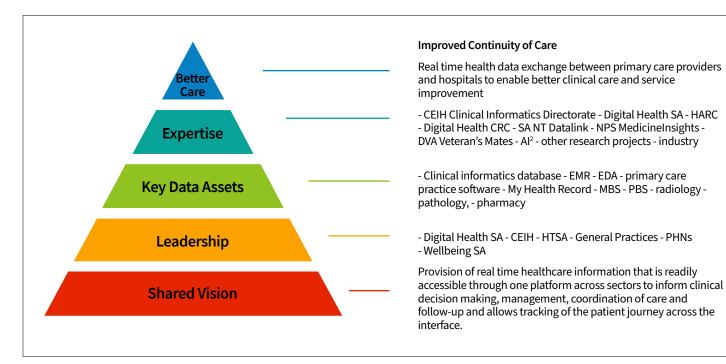


Figure 4. Building on South Australia's strengths for South Australia's future

## 3.1 A willingness for change

Historically, there have been seemingly insurmountable barriers to data sharing across the system, with challenges identified by patients, GPs and SA Health alike. However, the global COVID-19 pandemic of 2020 has brought a significant shift in our understanding and experience of what can be achieved (what barriers are not insurmountable) when these three sectors align out of necessity to overcome a significant shared problem.

Furthermore, there is a growing expectation among the general public that available data will be used to improve care whilst protecting individual privacy and security. In some instances, conversations are shifting from permission to use data to demand for data to be used more effectively.

Health care providers across SA are keen to build a learning health system that seeks to capture and generate knowledge from the data flowing from routine care and use it to produce continual improvement in care [18]. In 2019, there was significant interest across SA for a HTSA forum involving the UK #DataSavesLives team (https://datasaveslives.eu/). Data Saves Lives is working to build awareness and understanding of why data is important and how it can be responsibly shared to support health professionals provide safe and effective care.

#### 3.2 Leadership and governance

SA has significant leadership and governance found in SA Health's Digital Health SA and Enterprise and Data Information branch, the Commission on Excellence and Innovation in Health's Clinical Informatics Directorate, Adelaide and Country SA Primary Health Networks (PHNs) and Health Translation SA.

Leaders from these sectors are represented on our Project Steering Committee (Appendix 1) and involved in the development and implementation of SA's Data and Analytics Plan.

The <u>Data and Analytics Plan 2020–2023</u> will provide a roadmap to provide easier access to data and infrastructure to significantly improve the health and care of all South Australians and to build the world's

best health system [19]. The plan was established by the Commission on Excellence and Innovation in Health (CEIH) in response to SA Health and will be executed by SA Health's Digital Health team over the next 3 years with support from CEIH and the Data and Analytics Plan Project Board.

#### 3.3 Major infrastructure/data assets

There are many valuable data assets available in South Australia. This section includes only those which are likely to be able to support real-time data access and transfer. Details of other state and national data assets and initiatives can be found in Appendix 3.

#### 3.3.1 Electronic medical record (EMR)

South Australia is leading the way in Australia when it comes to implementing a state-wide EMR −(Sunrise™) in our public hospitals. The EMR is a critical data asset which can be used to support continuity of care between the primary care sector and hospitals. However, the information contained in patients EMRs is currently largely inaccessible by primary healthcare providers such as GPs. By far the biggest request from interviews

with GPs was to gain access to their patients EMRs in order to provide, co-ordinate and track patient care. It is important to note that most country SA public hospitals currently use Chiron EMR, except for Mount Gambier and Port Augusta (who use Sunrise™). The status of Sunrise™ rollout across SA is provided in Appendix 4. It will be necessary to build a solution that is EMR agnostic and able to connect information from disparate systems.

#### 3.3.2 Enterprise data and information data asset (EDA)

The EDA stores state-wide data from SA Health's patient administration systems to deliver a centralised and consistent source for clinical, operational and performance data in a useable format [20]. In contrast to EMRs (which contain medical information) patient

administration systems hold administrative data such as patient demographics and details all patient contact with the hospital system as both outpatient and inpatient. It is a valuable source of data to consider in this project and also the data source for national corporate reporting.

#### 3.3.3 Clinical informatics database

Digital Health SA is progressing work to establish an 'on premise' near real-time clinical informatics repository for raw, untransformed identified SA Health data which is accessible by Local Health Networks (LHNs) and clinical staff. It is envisaged that the SA Health Clinical Informatics Database will support clinical care across the public health system as well as service improvement activity and clinical trials. This will be an important asset to work with in the development of a solution to providing twoway real time access to patient data for primary care and hospital providers.

This initiative leverages the learnings from a platform proof of concept that was built to provide SA Health with near real time clinical data during COVID-19 to assist tracking and logistics. The aim is now to create a more

permanent platform considering all the different needs of the health system. Broad stakeholder engagement workshops are being conducted to consider current applications and data use across the system that are needed to provide patient care and solve real world health service problems. The physical architecture required to house the clinical informatics database is being completed currently. Whilst the initial asset will be an on-premise solution, SA Health is exploring the policy and digital health requirements to migrate to a cloudbased solution in the future. It is important to note that a cloud-based solution has been developed by Heart AI (see 3.4.6) and further consideration to aligning and leveraging the work done by both Digital Health SA and Heart AI is recommended.

#### 3.3.4 My Health Record

My Health Record was designed to provide an electronic summary of an individual's key health information that can be shared securely online to support improved decision making and continuity of care [21]. Although it does provide a central repository or secondary storage solution for a person's health information, most information is contained within documents and pdfs making it difficult to identify and digest relevant clinical information in a healthcare setting. There is also considerable variability in whether and how it has been integrated into workflows throughout the state.

"My Health Record is not a safe or effective communication tool for clinicians: it is a repository of information designed for the patient. While My Health Record can be a useful place to store a copy of a clinical handover, it cannot be used as a substitute for a clinical handover that occurs from one clinician to another. GPs are not notified of information you upload to My Health Record nor is My Health Record use universal across the breadth of primary care. The same goes for other online portals". [22]

Interviews with the Australian Digital Health Agency indicate the use of My Health Record is increasing, and the volume of pathology and radiology reports, prescriptions and shared summaries uploaded, and the types of information uploaded continues to expand. A growing amount of data is automatically uploaded as part of another medical process e.g. MBS/PBS, medication lists, resulting in near real-time data flows in some instances.

It is important to consider the role My Health Record can play in this project, as it is a large and important source of health data. Appropriate use of this data source can potentially enhance the usefulness and value of this resource. There are several examples of projects or products that are already utilising My Health Record as a source of data, linking it to other data and converting this into formats that support improved continuity of care (e.g. iRAD (3.4.7), Al<sup>2</sup> (3.4.8)) that should also be considered.

#### 3.3.5 Primary care clinical software

Across primary care, the most valuable health care data that is digitised and easily accessible is GP data. Currently primary care data sits within the clinical software of individual GPs and practices. There are a several existing instances in which this data is (or is planning to be) extracted and used from primary care sources in South Australia:

#### a. <u>Practice Incentives Program Quality</u> <u>Improvement Incentive (PIP QI)</u>

Practices are required to electronically submit the PIP Eligible Data Set from their general practice clinical information system to their local PHN on a quarterly basis to receive payment. The PIP Eligible Data Set comprises de-identified patient data collected against 10 specified Improvement Measures [23].

#### b. NPS Medicine Insights

Is the first large-scale, national primary-care data program in Australia that that extracts longitudinal de-identified patient health records from general practices to improve the post-marketing surveillance of medicine use in Australia and support quality improvement activities in general practices. The platform uses Grhanite as its data extraction tool.

Individual GPs and General Practices also often collaborate with researchers on projects of interest to provide de-identified patient data for research and service improvement purposes. Data is released in accordance with ethics and consent requirements. It should be noted that the most successful attempts to extract primary care data from general practice are those in which the project provides value back to the individual contributors.

#### 3.3.6 Individual healthcare identifier (IHI)

The IHI is a unique 16-digit number used to identify an individual for health care purposes. It helps health professionals access their patients' My Health Records to read their medical history and add new information. Anyone registered with Medicare or Department of Veterans' Affairs (DVA) has an IHI.

Interviewees flagged the IHI a key patient identifier enabler for data collection and sharing and tracking

patient journeys across the healthcare system. Poor adoption and implementation of IHI is prevalent across the entire health system [15]. Some regarded data linkage as being a work around for not implementing the IHI. It was recommended that a business case for the use of IHI to facilitate seamless real time connection of health data is needed. Further exploration of the feasibility and barriers of IHI implementation in SA is needed.

## 3.4 Expertise

South Australia has a broad set of experts working in this space across government, industry, academia and research institutes. These include (but are not limited to) the following:

#### 3.4.1 Digital Health SA

Digital Health SA (DHSA) is responsible for development of digital infrastructure and application development and maintenance, along with partnering with various Local Health Networks in developing digital health solutions. The Office of the Chief Medical Information Officer (OCMIO) is the clinical lead within DHSA that

assists in leading and prioritising key clinical digital health initiatives. DHSA and OCMIO also work closely with the Clinical Informatics Directorate, the Health Analytics Research Collaborative and other key stakeholders to deliver high quality clinical digital solutions.

#### 3.4.2 CEIH – Clinical Informatics Directorate

The Clinical Informatics Directorate works to enhance the way data and analytics are used to improve healthcare, building capability in clinical informatics, enhancing the data assets and providing better access to data across the

health system to inform the creation of better healthcare. This Directorate includes skilled data engineers, data architects, data scientists and user interface developers.

#### 3.4.3 <u>Health Analytics Research Collaborative (HARC)</u>

The HARC is a collaborative initiative between HTSA and CEIH that works closely with health services to consolidate and build upon the analytic expertise that is already available across the state and to mobilise and connect the expert analytic capability within the academic and research sectors.

The HARC Leadership Group, co-chaired by Prof Derek Chew (SAHMRI/Flinders University/SALHN) and Tina Hardin (CEIH) guides and governs the Collaborative, includes clinical researchers, registry analysts and data scientists, to boost collaboration and further develop the data analytic capacity in South Australia.

#### 3.4.4 <u>Digital Health Cooperative Research Centre</u>

The Digital Health CRC is a unique, multidisciplinary, collaborative taskforce of research, clinical, industry, government and educational organisations to focus research and development on combining individual and collective expertise with data, information and telecommunication technologies. They are also building a world-leading research and innovation centre, to

address identified industry issues. Over 70 organisations, including health funds, larger and small health and technology providers, and 17 universities, have joined this Australia-wide R&D consortium.

South Australia is well represented in this initiative.

#### 3.4.5 Primary Health Networks (PHNs)

PHNs are tasked with improving access to primary care and the patient journey. County SA PHN and Adelaide PHN, work closely with General Practice, including Aboriginal Community Controlled Health Organisations and Royal Flying Doctors Service on the Australian Governments Quality Improvement Practice Incentive Program (PIP-QI). This program is the main conduit for the collection of deidentified patient information from general practice, which stored in a central repository.

PHNs are also a conduit in the rollout of various national digital initiatives including ePrescribing, My Health Record etc and collect a variety of minimum data sets from their commissioned services. In addition, they support the implementation of secure messaging in primary care to improve the flow of patient information between providers.

#### 3.4.6 <u>Heart Al</u>

The Heart AI research team has developed the architecture that enables real time processing of health system data from multiple sources. This system has been designed to be deployed on the cloud and tested in a pilot environment. The Heart AI system hopes to generally support capabilities and capacities with data integration, data accessibility, performant and real-time data processing, and rapid analytics at the point-of-care. Initially the system aimed to improve audit and

monitoring capacity with the Department of Cardiology at Flinders Medical Centre, and with risk assessment of patients presenting to the emergency department at Flinders Medical Centre. However, they are looking to extend their capabilities across the broader South Australian health system. This work has been led by Lukah Dykes and Dr Derek Chew (Flinders University).

#### 3.4.7 Allscripts iRAD

Allscripts is a commercial provider of innovative products that facilitate the development of open, connected communities of care. Allscripts is the developer and provider of Sunrise™ EMR/PAS which is currently being rolled out across South Australia and has a base in Adelaide.

There was considerable knowledge and interest amongst people interviewed for this report, in the Allscripts platform dbMotion™. This is an interoperability solution to leverage and share data assets, achieve safer high-quality clinical outcomes and get a single, harmonised patient record that reflects actions taken in the community. It is the technical solution that has been

deployed in Israel and South West Sydney PHN (4.2.1) to connect disparate health records and systems and provide real time access to patient data.

Using the dbMotion™ platform, Allscripts have also worked with South Western Sydney Primary Health Network on an innovative Integrated Real-time Active Data (iRAD (4.2.1)) interoperability project that has enabled healthcare organisations to share patient-consented health records across the continuum of care. iRAD currently connects data across primary and specialist care and provides hospital view only ability. Connecting with hospital data in this pilot was delayed due to COVID-19 but is due to proceed in 2021. Consideration of this technology is also recommended.

#### 3.4.8 Actionable Intime Insights (AI<sup>2</sup>)

The Al<sup>2</sup> decision support application is the first ever application of machine learning on My Health Record in Australia and offers real-time digital updates on patient status to clinicians. The project is led by Flinders' Associate Professor Niranjan Bidargaddi.

It is a real-time monitoring system that pulls and stores consented patients' Medicare Benefit Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) data, such as medication prescriptions, from My Health Records into the Al<sup>2</sup> infrastructure. From there it, it uses machine learning algorithms to continuously monitor key

parameters of patients' mental health within the data. It provides clinicians with objective information about medication adherence for their patients to support early intervention from health services and identifies patterns that represent when a patient may be at risk of mental health relapse and hospitalisation. Together with their MINDtick technology, this group has developed both the mechanism to connect primary care data with SA Health data, and the tools to allow SA Health to push information back out to GPs. Consideration of this technology is recommended.

#### 3.4.9 SA NT Datalink

SA NT DataLink is the authorised linkage system for South Australia and the Northern Territory. Retrospective administrative, clinical and service datasets are linked (using privacy protected data linkage procedures) and de-identified and made available to approved statistical linkage projects.

It enables academics and policy makers to undertake research, policy, planning and evaluation. All output is population level and not individual based. The linked data are not used for direct service or clinical provision for individuals. The technology used does not support real time data linkage.

#### 3.4.10 <u>DVA Veterans Mates</u>

Veterans' MATES is the Veterans' Medicines Advice and Therapeutics Education Services program. It aims to improve the use of medicines and related health services in the veteran community. This program links administrative claims data from Commonwealth MBS, PBS, Aged Care and DVA with state data from hospitals and hospital pharmacies. The data linkage is near-real time with timeliness of linked data being dependent on the uploading processes of each data set. In general, the data lag is between 2-6 weeks for some data sets. Data are used to identify DVA clients who are at risk of medicine related problems and the health providers who treat them.

#### 3.4.11 NPS MedicineInsight

Established in 2011 to develop and manage a longitudinal general practice data platform to improve the post-marketing surveillance of medicine use in Australia and support quality improvement activities in general practices.

It is the first large-scale, national primary-care data program in Australia that that extracts longitudinal deidentified patient health records from general practices. The platform uses Grhanite as its data extraction tool.

#### 3.4.12 Registry of Senior Australians (ROSA)

ROSA monitors the health, service utilisation, medication use, mortality, and other outcomes of people receiving aged care services in South Australia. ROSA brings together diverse datasets collected by government subsidised aged care services throughout the country, to provide a whole picture of the ageing pathway. Data asset linking administrative data from hospitals, pharmacy, allied health, mental health, physiotherapy, dental services, MBS, PBS, and National Death Index.

Data linkage is performed by SA/NT Datalink and AIHW. Data is used to produce evidence to guide decision-making for quality, coordinated, efficient, innovative and age-friendly services and practices. Retrospective data with minimum 12-month lag time in data availability.

## 4. How other jurisdictions have used data to support continuity of care

It does not appear that any Australian jurisdiction has yet developed a single solution that facilitates the real-time transfer of clinical information between primary care and hospitals whilst also supporting deidentified unit/aggregate level analysis for service improvement. Instead solutions grant one-way viewing of hospital data by GPs, provide real time transfer of clinical information or develop multi-source enduring linked data assets to inform service improvement.

#### 4.1 Granting viewing rights

In 2017, Queensland Health provided GPs with secure, online read-only access to patient healthcare information from Queensland public hospitals through <u>'The Viewer'</u>. The Viewer is a web-based application that collates data from multiple Queensland Health systems, enabling

healthcare professionals, including general practitioners, to access patients' information quickly, without having to log in to different systems [24, 25].

## 4.2 Developing real-time health information exchanges for clinical care

#### 4.2.1 iRAD

SWSPHN, working with Allscripts has led the development and localisation of iRAD (integrated real-time active data) in an Australian first to achieve an integrated health system that is fit for purpose. iRAD uses AllScripts' dbMotion solution to deliver real-time, identified, patient information exchange between care providers who are connected to the system through conformant software (share and view information) or non-conformant software (view only). To achieve this, a patient level of consent is required. iRAD has gained appropriate consent from patients to share identified information between clinicians in real-time, and the

secondary use of data where insights can be published in de-identified reports. Currently, 35 primary care sites in South Western Sydney are connected to iRAD (GPs, after-hours services and specialists). Whilst primary care providers can 'share and view' information, at this stage the hospital system is only able to 'view'. A joint project is underway to enable 'sharing and viewing' form the hospital side. There is considerable interest in this technology in South Australia and further exploration of how this technology can support real time data capture and transmission plus feed data into SA Health's Clinical Informatics Database is warranted.

#### 4.2.2 RADCARD™

RADCARD™ is promoted as a premium, high capacity USB based data card that allows patients to carry their entire medical image and report history wherever they go in a secure and self-contained system. RadCard™ is integrated into a cloud based interoperable and backup environment to ensure that health care providers have access to critical patient diagnostic imaging and health information in a compact, reliable and convenient format. This multi-port microEMR has been developed by iDATAMAP with proof of concept piloted in Korea, Malaysia and the Philippines. It facilitates interoperability between the silos of general practice, specialists, and public and private hospitals.

Discussions with SA health services suggest that this is one of a number of similar products, however further exploration of these is outside the scope of this situational analysis.

Many interviewees highlighted the inevitable movement towards patients being custodians of their own data, and that products such as RadCard™ can facilitate this. However, they indicated that whilst patient custodianship of data is a long-term goal it is not feasible in the immediate future. Additionally, the acceptance of such 'plug and play' devices by both primary and hospital health care services in SA has been identified as a significant barrier and unlikely to be overcome in the short term.

## 4.3 Developing linked data assets for patient tracking and service improvement

#### 4.3.1 <u>LUMOS</u>

LUMOS is a NSW Ministry of Health project that links primary care data-set and Ministry owned/accessed data-sets (hospital, emergency, deaths etc). The software tools that extract, de-identify and send the data to the Centre for Health Record Linkage for this linkage are different data extraction tools to those used in iRAD and are also used to satisfy the Department of Health's PIPQI and PHN quality improvement programs. This data linkage between primary and Ministry of Health data

sets is de-identified, using a bloom-filter methodology of patient matching. Lumos data-linkage occurs twice a year (6-monthly) as opposed to real-time nature of iRAD. The de-identified nature of the data allows the linkage to occur without patient-level consent. The result is a novel, very large, de-identified data-asset that can used for developing health-system insights, however, has no application for an individual patient.

#### 4.3.2 VCCC Research Data Platform

The Victorian Comprehensive Cancer Centre (VCCC) Research Data platform links primary care data with hospital data for cancer patients. It builds upon an initial work connecting data extracted from primary care by NPS Medicine Insight (3.4.10) using GRHANITE (4.3.4). This platform was developed through a major collaboration between the University of Melbourne's GRHANITE team, VCCC alliance hospitals and BioGrid Australia.

The next step for this project is to link data from the Victorian Cancer Registry to all the identification and mapping of the health journeys of all cancer patients according to diagnosis to guide future care and service improvement.

#### 4.3.3 POLAR

POLAR has been developed by Outcome Health specifically for use by General Practice and Primary Health Networks. The system combines data extraction and reporting tools that enable analysis in a practical, user-friendly way. POLAR is a Population Level Analysis

and Reporting Tool that extracts and uses deidentified patient data from GP practice software to inform population level analysis. Outcome Health is working with Primary Health Networks in Victoria and New South Wales.

#### 4.3.4 <u>GRHANITE™</u>

GRHANITE™ is computer software that provides researchers, managers and health professionals with the means to collect data for the purposes of audit, clinical research and health surveillance. It allows data extraction and linkage at the unit or aggregate level. Identified data is not used, nor is this used for clinical care.

The advice of South Australian experts is that the technology exists to provide a solution that captures data once and uses it to both support real-time transfer of clinical information and multi-source enduring linked data assets to inform service improvements.



## 5. Key structural considerations moving forward

Discussions held with clinicians, consumers and healthcare services highlighted a number of key issues that need to be considered in the development and implementation of a data solution to continuity across the interface of primary and hospital care. These considerations also align with the findings from AIHWs National Primary Care Data Asset consultation workshops [26].

#### 5.1 Shared vision and resource

Continuity of care across the interface of primary and hospital care is a significant problem shared by patients, carers, primary care and hospital clinicians and health services alike. It is essential that the solution developed is for the betterment of everyone and a resource for South Australia. Development, piloting and implementation of a solution must be codesigned from the ground up with

these major stakeholder groups. This means that the business requirements for such a solution incorporate the needs of each of these groups. This is not just about 'pulling data' from primary care but enhancing the two-way flow of information between the primary and hospital care sector. It is therefore imperative that all those involved in providing data (consumers, primary care, hospitals) are engaged throughout.

## 5.2 Data considerations in Aboriginal Community Controlled Health Services

The interface and collaboration between the acute sector data and data held in the context of primary health care in Aboriginal Community Controlled Health Services is a critical consideration in order to improve the health outcomes related to Aboriginal communities in SA. This, however, requires further tailored consultation with the Aboriginal community-controlled health sector. This has not yet occurred to inform the present situational analysis. Further consultation is expected to reveal how the interface would need to design its solutions in line with the principles of Aboriginal data sovereignty,

and according to the varying characteristics and scope of practice of the Aboriginal Community Controlled Health Services. Of particular note is the capability of the interface in catering for the differences of the Aboriginal community-controlled health sector, and its ability to communicate with the patient information management system utilised in the Aboriginal community-controlled health sector: Communicare.

## 5.3 Transparency and accountability

Transparency of the project is important in order to build public, consumer and provider engagement and support for 'the solution'. Issues pertaining to data ownership, consent, and privacy must also be addressed in an open and transparent way.

Interviewees expressed that the final 'solution' should not be owned by anyone but rather be a South Australian resource for the whole state. However, it was also acknowledged that identifying the group/person ultimately responsible for ensuring the implementation of 'the solution' throughout SA was critical to the success of this project.

#### 5.4 Governance

There will need to be clear, robust, transparent governance arrangements for who can contribute to, and access the data. Governance should include representation from the major stakeholder groups.

### 5.5 Legislation and policy

There are several pieces of inconsistent legislation related to how we can streamline data access and use. The CEIH is currently looking at how to gain consistency of legislation regarding the regulations around data use and access. Scoping and recommendations are expected to be completed in 2020.

#### 5.6 Data security

It is essential that data handling and security be of the highest standard, and protected by trusted, independent sources.

#### 5.7 Data sources

Development of a solution should initially consider those data sources that are clean enough to link and are automatically captured in existing processed (e.g. MBS/PBS, pathology, practice software). When considering the use of healthcare data (both primary care and hospital care) data collection or extraction should not create additional burden to busy clinicians, and provision of data should be incentivised and resourced [26].

#### 5.8 Rural SA

Country SA generally use a different EMR and have varying levels of access to equipment and services that will underpin such a solution. Consumer and clinician representatives from rural and remote SA need to be engaged in the solution development to ensure inequities in healthcare are not inadvertently widened.

#### 5.9 Use of data standards

It is important that data standards, definitions (such as those in METeOR – the national metadata registry system) and codes (e.g. SNOMED CT) are used to facilitate linkage to data sets used for hospitals and other primary health care settings. These data standards promote comparability and consistency, facilitate sharing of data

and synergy amongst multiple data sources, and support efficient national data development through reduced costs and efforts. Use of recognised data standards will enable any data asset developed to be effectively incorporated into national data assets and used across jurisdictions.



#### 5.10 Implementation

Developing a technical solution has been identified as the 'easy part' of the process to improve continuity of care between primary and hospital care. The more critical part is the implementation process. This will require engagement on key stakeholders and champions from each of these sectors from the development stage

onwards. The solution will need to be forced to function if is to become meaningful. Being built into the system and clinical workflows is essential, and this will require significant engagement with primary care, as well as clinical leads, COOs and Department heads within SA Health.

#### 5.11 Financial sustainability

Funding to support the development and pilot of a proof of concept solution is available through Health Translation SA as part of the funding received from the Australian Government's Medical Research Future Fund (MRFF) as part of the Rapid Applied Research Translation program. (MRF9100005).

Longer-term funding to scale up the solution and implement the solution across SA will be required. A potential source of funding which should be considered is the MRFF 2020 Primary Health Care Research Data Infrastructure Grant Opportunity which closes on Feb 23rd 2021. This opportunity will fund infrastructure and tasks that will enable the better use of health and medical research data, including facilities, equipment, systems,

services, and data generation, manipulation curation and access. It also includes activities that help data to exchange securely, help data to be better understood and used with confidence, build the digital health capacity of the workforce within a primary healthcare setting.

It is also important to identify the timeline for what we ultimately want to achieve in terms of scale up, implementation and integration into clinical workflows in SA and the funding requirements and opportunities (Figure 6). System funding to embed the solution into clinical workflows will be critical.

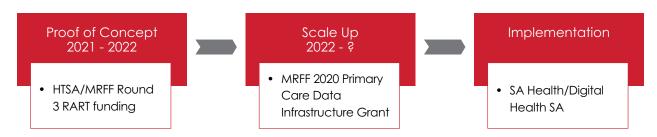


Figure 6. Funding opportunities for implementation and sustainability of the project

## 6. Where to from here?

#### THE NEED

There is a significant need to:

Provide real time transfer of healthcare information between primary and hospital care providers that is readily accessible at point of care to assist healthcare decision making.

Track the patient journey across the system to support coordination of care, identify gaps in care and ultimately improve services

#### THE SOLUTION

- The advice of South Australian experts is that the technology exists to provide a solution that captures data once and uses it to both support real-time transfer of clinical information and multi-source enduring linked data assets to inform service improvements.
- Indeed the Flying Blind report notes that "tapping into complete, current and 'fast flowing' datasets of healthcare providers is an alternative model that delivers more comprehensive and 'real-time' benefits to consumers and their carers **as well as** providing the richest possible environment to support system planning and management, and research" [15].

#### **DEFINING THE SCOPE**

- There is a need to define and contain the initial scope of a proof of concept project. Whilst we
  recognise primary care is a very broad area, GPs are the gateway to care across this sector and
  working with GP data in the first instance is recommended.
- Major areas of initial interest and within the hospital setting include:
  - a) Information transfer to GPs and patients/carers following discharge from hospital
  - b) Information flow between GPs and hospital Outpatient Departments
  - c) Information available upon presentation to hospital Emergency Departments
- As continuity of care requires partnership across the interface a pilot should if possible, look to address two-way communication between these sectors
- Consideration should be given to how this solution can also contribute to multisource enduring linked data assets such as SA Health's Clinical Informatics Database/National Primary Care Data Asset.

#### **DETERMINE TECHNICAL SPECIFICATIONS**

- Identify the essential shared information needs to enhance continuity of care across the primary care/ hospital interface (within the project scope)
- Consideration needs to be given to which data sources providing the information identified above are clean
  enough currently to link. A technical working group should be established to develop the specifications and
  requirement for a technical solution under the governance of the project Steering Committee

#### PILOT BUILD/TEST

- Need to identify the essential shared information needs to enhance continuity of care across the primary care/hospital interface.
- Consideration needs to be given to which data sources providing the information identified above are clean
  enough currently to link. A technical working group should be established to develop the specifications and
  requirement for a technical solution under the governance of the project Steering Committee

## **Appendix 1: Project steering committee members**

Ali Krollig (Co-Chair)	Prof Susan Hillier (Co-Chair)
Director-Health Policy Country SA Primary Health Network & Adelaide Primary Health Network	Dean of Research, Allied Health & Human Performance University of SA
Prof Tarun Bastiampillai	Dr Emily Kirkpatrick
College of Medicine & Public Health Flinders University, Southern Adelaide Health Network	Deputy Chief Public Health Officer Medical Advisor for Primary Care/COVID-19 GP Liaison Department for Health and Wellbeing
Tina Hardin	Adam Philips
Executive Director, Clinical Informatics Commission on Excellence and Innovation in Health	Clinical Informatics Specialist Allscripts Australia
Dr Santosh Verghese	Michele McKinnon
Chief Medical Information Officer Digital Health SA Department of Health and Wellbeing	Executive Director Commissioning and Performance Department for Health and Wellbeing
Chris Bollen	Lana Earle-Bandaralage
GP/Director BMP Healthcare Consulting	Community Representative
Wendy Keech	Dr Gokhan Ayturk
CEO Health Translation SA	Aboriginal Health Council of SA

## Appendix 2: Participants who provided information for the situational analysis

Person	Organisation/Project
Gokhan Ayturk	Aboriginal Health Council of SA
Raj Balasingam	Adelaide PHN
Dani Arousi	Allscripts
Ben Stevenson	Allscripts
Adam Phillips	Allscripts
Alison Verhoeven	АННА
Rebecca Haddock	АННА
Vicki Bennet	AlhW
Niall O'Connor	AIHW
Conan Liu	AlHW
Paul McRae	Australian Digital Health Agency
Kate Ebrill	CSIRO
Tina Hardin	CEIH
Keirstie Bull	CEIH
Peter Wilkinson	CEIH
Rama	CEIH
Clinical Informatics Advisory Group	CEIH
Clinical Network Chairs	CEIH
Colin Standing	Country SA PHN
Bernie Cummins	Country SA PHN
Bill Wilson	Digital Health SA
Santosh Verghese	Digital Health SA
Naranjan Bidargaddi	Flinders Uni
Chris Moy	GP; Australian Medical Association SA
Peter Del Fante	GP; Australian Digital Health Agency
Andrew Kellie	GP; The Healthy Collective
Chris Bollen	GP; BMP Consulting
Oliver Frank	GP
Derek Chew	HARC,Flinders University
Frank O'Neill	iDataMap
Michele McKinnon	SA Health, Commissioning and Performance
Rhys Parker	SA Health, Office of the Chief Medical Information Officer
Holly Smith	SA Health, Enterprise Data and Information
Emily Kirkpatrick	SA Health, Department for Health and Wellbeing
Pat Ranieri	SA Health, Safety and Quality
Chris Radbone	SA/NT Datalink
Gillian Caughey	ROSA
Barry Drake	UTS/LUMOS
Libby Roughead	UniSA, DVA Veterans Mates
Nicole Pratt	UniSA, NPS Medicine Insights

## **Appendix 3: State and national data sets**

#### **Aggregated Deidentified Unit Level Data Sets**

#### Practice Incentives Program Eligible Data Set

Deidentified unit level data across a set number of measures extracted from primary care clinical software and provided quarterly to Primary Health Networks (PHNs). Data is aggregated to the SA2/SA2 geographic levels and stored regionally by PHNs and Nationally by AIHW. Data collected is used to describe the proportion of patients with a given classification (e.g. current HbA1c result, smoking status, weight classification, immunisation status etc) for Quality Improvement purposes at a local, regional and national level.

#### National Minimum Data Sets

There are over ten NMDSs for admitted and non-admitted patient care in hospitals, elective surgery waiting times, as well as community and residential mental health care, public dental waiting times, perinatal data and others. The deidentified data contained in these NMDSs are aggregated and used variously for reporting, planning, policy development and program management. Data are used to describe the care provided by these services and the patients journey through the system. Data includes the number of service contacts provided, length of treatment period, principal diagnoses, type of services provided, patient characteristics. The PHNs are the data custodians for the mental health and alcohol and other drugs data. Identified patient level data can be accessed with appropriate ethics approvals and general practice/patient consent.

#### **Multisource Enduring Linked Data Assets**

#### National Integrated Health Services Information Analysis Asset (pilot testing stage)

National centralised Australian Commonwealth data set of deidentified data, from 2010–11 onwards, on admitted patient care services (in public and private hospitals where available); emergency department services; and outpatient services in public hospitals, for all participating states and territories, along with MBS data, PBS and RPBS data, residential aged care data and National Deaths Index data. SA is one of the first pilot sites, but access provisions have only been recently granted. It can be used to derive insights into a wide variety of situations ranging from healthcare in the home and management of chronic disease to the use of opioids. It does not include GP data.

#### National Primary Health Care Data Asset (early development stage)

The AIHW is developing the National Primary Care Data Asset. The purpose of this data asset is to inform the public and health consumers about the primary sector, support clinicians, improve services, support better planning, policy and supporting research on primary health care. It is envisaged that this enduring Data Asset will contain reliable, detailed, high-quality data about primary health care which will assist in the creation of a comprehensive understanding of the system and a patient's journey and experiences within it. Consultation concluded in 2019 and proof of concept exercises are underway to demonstrate the value of the Data Asset in the short term. Timing of the development of the asset will be determined by the variation in primary care data flows in different jurisdictions. There is strong support for the benefits of linked unit record data to enable understanding and investigation of the entire patient journey through the Australian health system [26].

If done well, our project should be able to be accessed as a resource for the National Primary Health Data Asset.

#### NPS MedicineInsight

Established in 2011 to develop and manage a longitudinal general practice data platform to improve the post-marketing surveillance of medicine use in Australia and support quality improvement activities in general practices. It is the first large-scale, national primary-care data program in Australia that that extracts longitudinal de-identified patient health records from general practices. The platform uses Grhanite as its data extraction tool.

#### Registry of Senior Australians (ROSA)

ROSA monitors the health, service utilisation, medication use, mortality, and other outcomes of people receiving aged care services in South Australia. ROSA brings together diverse datasets collected by government subsidised aged care services throughout the country, to provide a whole picture of the ageing pathway. Data asset linking administrative data from hospitals, pharmacy, allied health, mental health, physiotherapy, dental services, MBS, PBS, and National Death Index. Data linkage is performed by SA/NT Datalink and AIHW. Data is used to produce evidence to guide decision-making for quality, coordinated, efficient, innovative and age-friendly services and practices. Retrospective data with minimum 12-month lag time in data availability.

#### **DVA Veterans Mates**

Veterans' MATES is the Veterans' Medicines Advice and Therapeutics Education Services program. It aims to improve the use of medicines and related health services in the veteran community. This program links administrative claims data from Commonwealth MBS, PBS, Aged Care and DVA with state data from hospitals and hospital pharmacies. The data linkage is near-real time with timeliness of linked data being dependent on the uploading processes of each data set. In general, the data lag is between 2-6 weeks for some data sets. Data are used to identify DVA clients who are at risk of medicine related problems and the health providers who treat them.

#### **Data Linkage Service Provider**

#### **SA NT Datalink**

SA NT DataLink is the authorised linkage system for South Australia and the Northern Territory. Retrospective administrative, clinical and service datasets are linked (using privacy protected data linkage procedures) and de-identified and made available to approved statistical linkage projects. It enables academics and policy makers to undertake research, policy, planning and evaluation. All output is population level and not individual based. The linked data are not used for direct service or clinical provision for individuals. The technology used does not support real time data linkage.

## Appendix 4: Status of Sunrise™ electronic medical record roll-out in SA

#### **Full Clinical Solution Implemented**

CALHN Hospital Avoidance and Supported Discharge Service

The Royal Adelaide Hospital

Mount Gambier and Districts Health Service

Hampstead Rehabilitation Centre

Marion GP Plus Healthcare Centre

The Queen Elizabeth Hospital

Flinders Medical Centre services moved to Flinders Medical Centre

Port Augusta Hospital and Health Service

Noarlunga Hospital

Noarlunga GP Plus Super Clinic

#### **Patient Administration System**

St Margaret's Rehabilitation Hospital — administrative and read-only access

#### **Read Only Access**

Country Health Connect sites

SA Ambulance Headquarters (Extended Care Paramedics, MedSTAR and Mental Health Triage teams)

#### **Future Sites**

Flinders Medical Centre – planned early 2021

Elizabeth GP Plus Health Care Centre

Flinders Medical Centre

Glenside Hospital

Lyell McEwin Hospital

Modbury GP Plus Super Clinic

Modbury Hospital

Women's and Children's Hospital

Provided by SA Health

http://inside.sahealth.sa.gov.au/wps/wcm/connect/non-public+content/sa+health+intranet/it+systems/sunrise/about+sunrise

## **References**

- Health, A.G.D.o. 2020 28/10/2020]; Available from: <a href="https://www1.health.gov.au/internet/main/publishing.nsf/Content/primarycare">https://www1.health.gov.au/internet/main/publishing.nsf/Content/primarycare</a>.
- 2. Periera Gray D, S.-L.K., White E, Thorne A, Evans PH., Continuity of care with doctors A matter of life and death? A systematic review of continuity of care and mortality. BMJ Open, 2018. 8(6).
- 3. Tandjung, R., Rosemann, T., & Badertscher, N., *Gaps in continuity of care at the interface between primary care and specialized care: general practitioners' experiences and expectations. International journal of general medicine, 2011.* 4: p. 773–778.
- 4. Health, G.o.S.A.-S. *Consumer Experience.* [cited 2020 1st November]; Available from: <a href="https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/safety+and+quality/partner-ing+with+consumers+and+the+community/consumer+experience.">https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/safety+and+quality/partner-ing+with+consumers+and+the+community/consumer+experience.</a>
- 5. Welfare, A.I.o.H.a., Australia's health 2014, in Australia's health series. 2014, AIHW: Canberra.
- 6. (AIHW), A.I.o.H.a.W., Australia's hospitals 2016-2017 at a glance. Health services series, 2018. 85(Cat. no. HSE 204).
- 7. Welfare, A.I.o.H.a. *Hospitals info & downloads: Glossary. 28/10/2020]; Available from:* <a href="https://www.aihw.gov.au/reports-data/myhospitals/content/glossary">https://www.aihw.gov.au/reports-data/myhospitals/content/glossary</a>.
- 8. Health, A.G.D.o. Fact Sheet: Primary Health Care. 2018 28/10/2020]; Available from: <a href="https://www1.health.gov.au/">https://www1.health.gov.au/</a> internet/main/publishing.nsf/Content/Fact-Sheet-Primary-Health-Care.
- 9. Freeman, G.a.S., S., Continuity of Care: Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). 2000.
- 10. Reid, R., et al. Defusing the Confusion: Concepts and Measures of Continuity of Healthcare. 2002.
- 11. Pereira Gray, D.J., et al., Continuity of care with doctors-a matter of life and death? A systematic review of continuity of care and mortality. BMJ Open, 2018. 8(6): p. e021161.
- 12. Martin, D.J., M.K. Garske Jp Fau Davis, and M.K. Davis, *Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. (0022-006X (Print)).*
- 13. Griffith, S., A review of the factors associated with patient compliance and the taking of prescribed medicines. The British journal of general practice: the journal of the Royal College of General Practitioners, 1990. 40(332): p. 114-116
- 14. Association, A.M., AMA Position Statement. General practice/hospitals transfer of care arrangements. 2018.
- 15. Srinivasan, U., Rao, S., Ramachandran, D., & Jonas, D., Flying Blind: Australian Consumers and Digital Health, in Australian Health Data Series. 2016, Health Market Quality Research Program.
- 16. McLean, K., M. Rice, and N. Tellis GPs want clinical handovers, not discharge summaries. Insight Plus, 2018.
- 17. Haggerty, J.L., et al., Continuity of care: a multidisciplinary review. BMJ (Clinical research ed.), 2003. 327(7425): p. 1219-1221.
- 18. Project, T.L.H. *Building Blocks Healthcare Data. [cited 2020 30th October]; Available from:* <a href="http://www.learning-healthcareproject.org/section/building-blocks/healthcare-data">http://www.learning-healthcareproject.org/section/building-blocks/healthcare-data</a>.
- 19. (CEIH), C.o.E.a.I.i.H. *Data and Analytics Plan.* [cited 2020 30th October]; Available from: <a href="https://ceih.sa.gov.au/data-analytics-plan">https://ceih.sa.gov.au/data-analytics-plan</a>.
- 20. Australia, G.o.S., Enterprise Data and Information Data Requirements Bulletin 2020-2021, D.f.H.a. Aging, Editor.
- 21. Government, A., Benefits of My Health Record for healthcare professionals, A.D.H. Agency, Editor.
- 22. Mclean, K., M. Rice, and L. Leeuwenburg Clinical handover to primary care what GPs need.
- 23. Practitioners, T.R.A.C.o.G., Practice Incentives Program Quality Improvement Incentive (PIP QI) fact sheet
- 24. Health, Q.G.M.S. GP access to 'The Viewer'. 2017 05/06/2017 [cited 2020 30th October]; Available from: <a href="https://metrosouth.health.qld.gov.au/about-us/accessing-information/gp-access-to-the-viewer">https://metrosouth.health.qld.gov.au/about-us/accessing-information/gp-access-to-the-viewer</a>.
- 25. Health, Q.G.Q. *The Viewer. August 8th 2019 [cited 2020 30th October]; Available from:* <a href="https://www.health.qld.gov.au/clinical-practice/innovation/digital-health-initiatives/queensland/the-viewer">https://www.health.qld.gov.au/clinical-practice/innovation/digital-health-initiatives/queensland/the-viewer</a>.
- 26. Welfare, A.I.o.H.a., Developing a National Primary Health Care Data Asset: consultation report. . 2019: Canberra.



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