Health Translation SA
>RESEARCH >ACTION >IMPACT

>>>

Continuity of Care Across the Primary and Acute Care Interface

The consumer perspective

>>> Background

Health Translation SA is working with our partners in education, research and healthcare services to address a significant health system challenge. We want to better use the rich supply of healthcare data in South Australia to enhance and improve continuity of care as people transition between our hospitals and the community (known as the 'primary/acute care interface')

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'. Continuity of care is multifaceted, consisting of three interrelated types of continuity:

Relational continuity (an ongoing therapeutic relationship between a patient and one or more providers)	**Informational continuity** (provision and use of information on past events and personal circumstances to make current care appropriate for each individual)	**Managerial continuity** (consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs)

This is a significant and multi-faceted challenge to address so HTSA's focus is on one key aspect:

Access to and timely flow of accurate information between care providers and the patient.

Early key objectives of the Primary/Acute Care Interface Data Project are to complete a situational analysis to understand:

a. current issues and barriers to continuity of care across the primary/acute care interface and

b. existing data assets, projects and expertise in South Australia that we can build on to improve care as people transition between the hospital and community setting.

The analysis will ensure we have a comprehensive understanding of patient and clinician needs as well as current activities and gaps.

During this analysis it became clear that there was little publicly available information available on the healthcare experience of patients and carers when transitioning between care settings.

In order to better understand this consumer experience HTSA undertook two key activities:

1. Analysis of relevant responses from the SA Consumer Experience Surveillance System (SACESS) survey

2. Consumer focus groups

Responses from the SACESS were analysed and used to inform the focus group discussions. Although the findings from both sources align, this report presents data and findings from the two Consumer Focus Groups held in October 2020 only.

The findings of this report will be presented and analysed alongside the perspective and needs of clinicians and healthcare providers in the 'Situational Analysis' (available online in late Nov 2020). However, this report can be read as a stand-alone document.

>>> Focus Groups

Aim

The expected outcomes for these focus groups were to:

- Gain an understanding of the current gaps in continuity of care between primary and acute care services

- Gain an understanding of what consumers find important and think might improve continuity of care

- Generate ideas for the purpose of devising recommendations

Method

As the project aims to understand the current issues on continuity of care, it was important to seek the perspective of those who have had a lived experience in transitioning between care settings. An analysis of SACESS data was undertaken to inform the process for the consumer focus groups (SACESS data is not included in this report).

Two focus groups were held to obtain first-hand accounts of consumer experience navigating between primary and acute care and to identify what key information pieces would greatly improve continuity of care.

HTSA recruited eight (n=8) consumers with a lived experience of healthcare as they moved between care in the hospital setting and care in the community. Consumers were recruited via email and social media

across HTSA consumer engagement and other stakeholder networks.

Participants selected to attend either an in-person session at the South Australian Health and Medical Research Institute (SAHMRI) or an online session. The online session was planned to assist those unable to attend SAHMRI (e.g. rural participants, reduced mobility etc).The structure and process for each was identical After brief introductions and an overview of the project, consumers were asked to share the following:

a. a significant healthcare experience they had as a patient or carer transitioning between care in the community and care in a hospital setting

b. what could have been done differently to ensure they experience smooth and seamless progression of care across these transitions

c. what was done well

Responses were mapped into major themes by a notetaker and reflected to the group at the conclusion. An opportunity was provided to clarify, correct or amend interpretations. Stand out comments were also noted by a second note-taker and were used to reflect themes that emerged. Focus group participants were also invited to provide written responses on the day or to email any relevant additional information. Participants were provided a copy of the draft report to for final confirmation of the content.

Results

Focus Group Participants

A total of 8 participants joined the focus groups, 5 at the in person session and 3 online. All participants were from the Adelaide metropolitan region. Six were between 40-64 years old, and two were above 65. Only one was below 40 years old. Most were of Australian, English speaking background, with only two participants from other countries. Experiences of care were varied. Four presented experience as carers for a loved one, two were patients themselves, and two had experience as carers and a patient. The type of stories shared varied as well. From the eight experiences, four described experiences with transfers within and between care settings, three discussed an experience with discharge and follow-up care, and one described an experience with difficulties accessing specialist care.

Table 1 Focus Group demographic data

| Age group		Country of origin	
25 - 39	1	Australia	6
40 - 64	6	India	1
65 +	2	Sri Lanka	1
Gender		Language spoken at home	
M	2	English	7
F	6	Hindi	1
		Italian	1
Experience			
Patient	2		
Carer	4		
Both	2		

Focus Group Process

The focus group sessions were identical in structure. A brief project background was provided to participants, which provided context for the focus group sessions. For both sessions, participants were sent the questions beforehand and were able to prepare their answers on a worksheet. Three questions were asked to participants, and each person had the opportunity to tell their story before moving onto the next participant. A timekeeper monitored progress and prompted participants to refine their answers or provide more information. Both sessions were recorded for the purpose of data analysis and complementing notes.

Below is a summary of the main themes that have emerged from these discussions.

Themes from Consumer Focus Groups

Focus group notes and recordings were coded into the themes. Themes and sub-themes are listed below with examples of participants comments, as well as summarised graphically in Figure 1. Communication and central co-ordination of care were identified as the two main underpinning pillars of continuity of care. The importance and value of the relational context was also found to be of paramount importance.
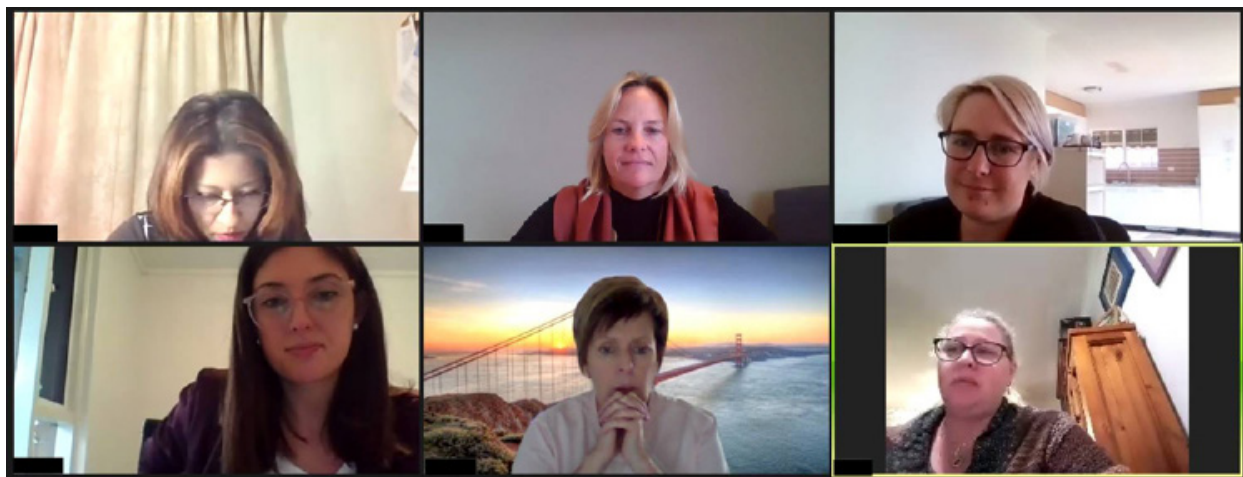
Theme 1: Communication

Communication was consistently reported as the most significant issue for consumers. Within this theme were topics such as communicating effectively at discharge, acknowledging the role of carers, and increasing the information exchange between services and wards.

(a) Discharge planning

The information provided at discharge was seen to be essential for a smooth transition to home respite, home care or other community specialist services. Clear and effective communication played an important role in maintaining the patient's and carer's confidence in the care they'd received.

> " *Access to a home support package makes a real difference – can get all sorts of assistance.*

(b) Role of carers, Value of carers

Acknowledging the presence and the role of family members and carers was also identified as critical to facilitating continuity of care - particularly in emergency situations and where complicated information is being communicated. Consumers highlighted that carers should be recognised as advocates for patients and partners in ensuring no information is lost between health professionals and across transitions. Some consumers found family meetings between carers, patient and medical/allied health staff to be very beneficial to ensuring continuity of care.

> " *I'm my mother's advocate and I carry a booklet with her medical history and medication lists.*
>
> *The catalyst for me was when the specialist told my mother "Hey, your son doesn't need to be here" This was the tip of the iceberg…. She was exhausted. I went away for a few hours and the team discharged her without my knowledge.*

(c) Communicating between wards and services

Another barrier to continuity of care identified by the consumers was the lack of communication between-hospital transfers. This included incomplete handover notes, lack of clarity once the patient arrived at the next hospital (why are they here?) and having to repeat their story multiple times.

> " *Communication loops were unclear and wrong instructions were given by the hospital staff.*
>
> *Hospital transfers created further confusion for everyone as the data was not entered into the systems because a diagnosis report wasn't created for the patient at XXX hospital.*

(d) Capturing the right information

Capturing the right information on admission and throughout the patient journey was also very important to consumers. Focus group participants mentioned that medical notes that are missing key pieces of information cause potentially significant issues.

> " *If it is not in the notes then it didn't happen*
>
> *Hospital transfers created further confusion for everyone as the data was not entered into the systems because a diagnosis report wasn't created for the patient at XXX hospital.*

Providing patients or carers access to proofread might prevent key pieces of information being missed from their care records.

> " *Consistency is important and case notes should be comprehensive and shared by both staff and the primary carers.*

Similarly, patients and carers reflected on whether enough information is collected at admission. Consumers worried that information that provides a full understanding or appreciation of the broader clinical and social context of the patient and their carers is often neglected. The high value placed on 'knowing and treating the whole person' is discussed under the 'siloed care' subtheme of Theme 2. Participants expressed that information such as whether a patient can make decisions, if they have carer or advocate or whether they currently have home support, should be captured on admission and help inform care. Consumers' experiences highlighted that these questions are often omitted when arriving at hospital. Providing background information would determine the type of care or discharge to plan.

(e) Sharing data between healthcare providers

Patients and carers alike expressed their frustration at having to repeat their story to every new clinician. One question asked by the focus group participants is

> " *Why is it (the information) not documented in one central and accessible place?*

Consumers would like their health plans written in partnership with their care provider to ensure all necessary information for discharge and continuity of care is included. Continuity of care was regarded as impossible without complete information about a patient being communicated between clinicians. Suggestions to address this were to create a universal digital platform accessible to all care providers and patients.

Theme 2: Coordination

Consumers found the health system to be complex and difficult to navigate. Patients and carers expressed the desire for better support in navigating the system and coordinating care. They identified that this should be provided by a key member of their healthcare team, whether it's their GP, a case manager or a patient liaison.
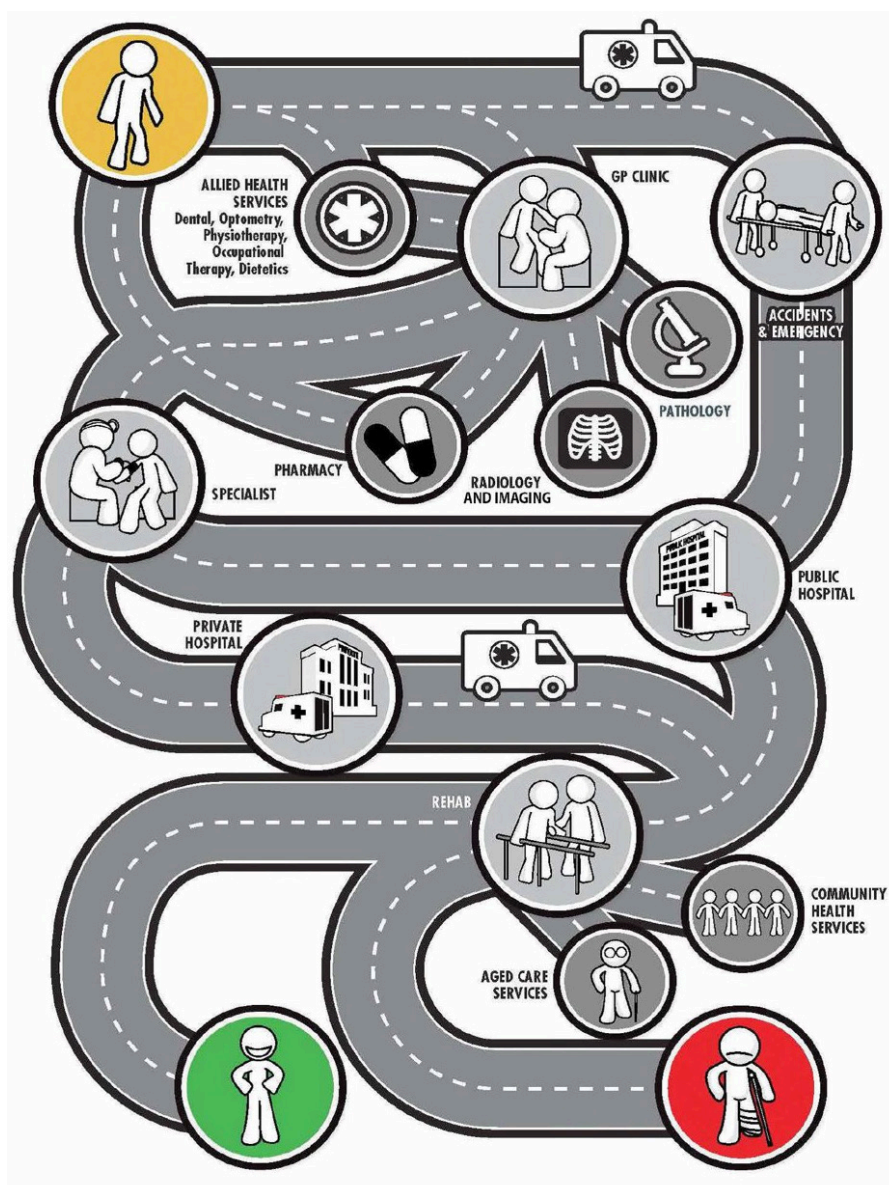
The Consumer Journey (Flying Blind, 2016)

(a) Siloed care

Focus group participants indicated that personalised holistic care across their entire journey through the health system was most important to them. A key failure point for continuity experiences was when clinicians only treated within their specialty areas (siloed care) without a full understanding or appreciation of the broader clinical and social context of the patient and their carers.

(b) Central coordination: GP, case manager, patient liaison

Focus groups revealed that having one central contact coordinating care with hospital is key to maintaining continuity of care. This one person, whether they be a GP, a case manager, patient liaison or coordinating specialist team, would have access to all information and ensure that proper care and follow-ups are organised. The best experiences of continuity of care were identified as those where one clinician, practice or medical team "took initiative and advocated for them" in the identification, arrangement and follow-up of care needed (generally post-discharge, but not exclusively). One consumer relied on one particular team of specialists to coordinate her daughter's care throughout the system and they followed up on her progression and healthcare journey routinely. This participant found this team's help essential as "transfers between wards are not explained well."

Continuity of care begins with the proper coordination of a patient's journey across the health system. Enabling GPs to obtain all relevant information could be a catalyst for providing holistic care, appreciating of the broader clinical and social context in which the patient is navigating.

" *A communicative and knowledgeable GP essential.*

This clinician would have the ability to be present and a great listener and offer "personalised" care.

Care coordination needs improvement, where health care plans are designed using patient input, primary care input and collaborating with patients.

It's hard to find a good GP that can liaise with hospital.

In addition, health system access would be simplified if consumers are guided by their central coordinator. Certain consumers stated that access to certain specialists is complex and takes time. It is important to have a strong advocate or carer to help navigate a very complex health system, particularly post discharge. When patients and carers are supported along their care journey, then continuity of care and satisfaction with the care received would be maintained.

Theme 3: Relational value

Building trust with the health professionals caring for patients was seen by consumers to be a key enabler of continuity of care. They regarded continuity as something that can only truly be experienced in the context of a relationship and an appreciation of the full context of that person.

The value placed on continuity of relationship was highlighted when participants shared their experiences with frequent home care staff turnover. Most would appreciate having a regular nurse or small nurse team for home care patients, as this would allow that personal connection that underpins the experience of healthcare being smooth and coordinated.

Summary of Themes

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
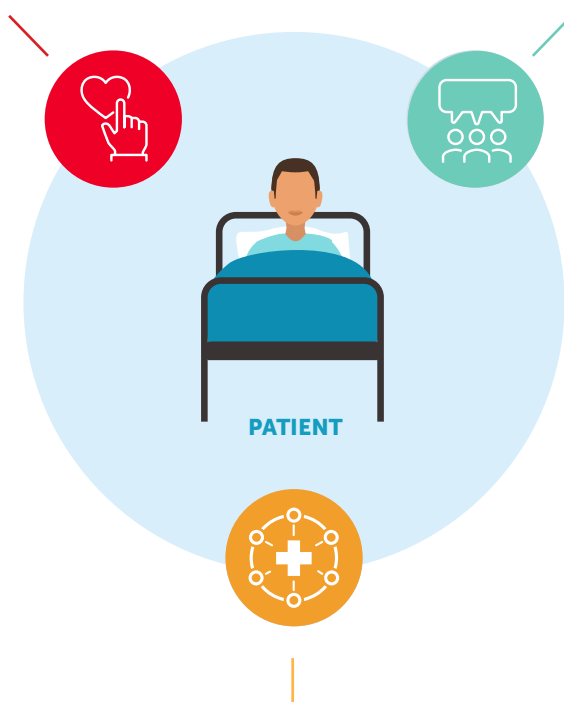
COMMUNICATION

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)

PATIENT

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

When discussing with consumers, it was also noted that different information needs are felt at different moments within a transition in care. The figure below illustrates the identified themes from both the Focus Group Sessions specifically as they fit within the care journey.
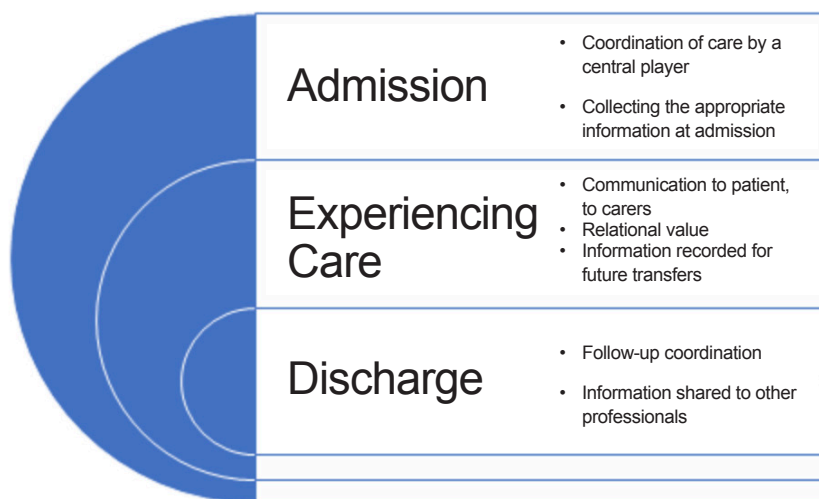

Admission	• Coordination of care by a central player • Collecting the appropriate information at admission
Experiencing Care	• Communication to patient, to carers • Relational value • Information recorded for future transfers
Discharge	• Follow-up coordination • Information shared to other professionals

Figure 2. Themes by phase of care

Themes could also be categorised by identifying the key information holders during an experience of care. As the objective of this project is to identify how continuity of care can be improved with the data readily available in South Australia, it is worth identifying who the key information holders are.

Information across specialists in the system	Information to external health professionals (GPs, community care, social supports)	Information to patients and carers

Table 3 Key information holders

Information across specialists in the system

This seemed to be a significant point of concern for consumers in the Focus Group sessions. The notion of data being collected electronically but different specialists not having access was a worry.

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

> *I had to go all the way back home to the hills to get a medication list for the doctor.*

Information to external health professionals (GPs, community care, social supports)

Consumers highlighted the importance of having a single point of contact coordinating care for them. Navigating the healthcare system is complex and having a representative, a GP, or a case manager

would help patients ensure all the information is kept by at least one person. This central coordination would be the key to maintaining continuity of care.

> " *The GP was left behind - only had part of the picture.*

Information to patients and carers

This category includes providing information about the care a patient is receiving, what next steps need to be taken, and planning for discharge.

> " *I still don't know who I'm supposed to contact about my healing process or my check-ups.*

Key Findings

Feedback from the consumer focus groups revealed that 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.

In addition, one key aspect of care that was highlighted by consumers was the building of trust and establishing and maintaining a caring relationship with health professionals over the course of their care. Continuity of care can only truly be experienced in the context of a relationship with a full picture of the person.

Key Consumer Recommendations

Three recommendations emerged from the combination of the focus group data to improve continuity of care.

1. Ensuring one key health professional or case manager has access to a universal medical record for each patient to coordinate care and establish a key relationship

2. Acknowledging carers and family members as part of the care team for patients

3. Creating a digital platform containing all details of care for all health specialists to avoid siloed care.