

UNDERSTANDING PATIENT AND PROVIDER EXPERIENCES WITH RELATIONSHIP, INFORMATION, AND MANAGEMENT CONTINUITY

August 2016

Promoting and improving patient safety and health service quality across Alberta

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EXECUTIVE SUMMARY

Since 2003, the Health Quality Council of Alberta (HQCA) has been monitoring patient experiences with healthcare services through the biennial Satisfaction and Experience with Healthcare Services (SEHCS) survey. The findings consistently showed a direct link between coordination of care, an aspect of continuity of care, and healthcare outcomes, in that better coordination is linked to good outcomes; the reverse is also true.

Continuity of care refers to "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's healthcare needs and personal context".¹ Continuity of care captures quality of patient care over time² and how an individual's healthcare is connected across healthcare events and between healthcare providers. Three major subtypes of continuity across healthcare settings are discussed in the literature: relationship, information, and management continuity.^{1,3,4,5}

Relationship continuity refers to a trusting relationship with one or more healthcare providers that helps to bridge healthcare episodes over time.¹ *Information continuity* concerns the timely availability of relevant information through shared medical records, but also includes accumulated knowledge about the patient's preferences, values, and context.¹ *Management continuity* involves the communication of patient-related information across healthcare teams, institutional and healthcare professional boundaries, as well as between healthcare professionals and patients.⁶

Given the critical role continuity of care plays in the healthcare system, the HQCA conducted an in-depth study to understand the conceptualization and measurement of continuity of care by determining the factors that influence both seamless and fragmented patient journeys.

Methodology

This study employed a dynamic mixed-methods approach of qualitative and quantitative research, beginning with an extensive review of literature on continuity of care. The findings informed the development of the interview guides for key informant interviews, interactive feedback sessions, and focus groups with 40 patients, the HQCA's Patient/Family Safety Advisory Panel, more than 50 primary care physicians and allied health professionals, and 10 individuals in leadership roles in Alberta's healthcare system.

Findings from the qualitative research informed the question content of the continuity of care measures, which were added to the HQCA's 2014 Satisfaction and Experience with Healthcare Services survey. In it, 4,424 Albertans were asked about their experiences with the healthcare system during the previous 12 months.ⁱ This enabled investigation into the associationsⁱⁱ⁽⁷⁾ between continuity and patient experience measures of access, quality, safety, satisfaction, and self-reported health status.

¹ Full details of the 2014 Satisfaction and Experience with Healthcare Services survey methodology and data can be found in the HQCA's *Satisfaction and Experience with Healthcare Services: A Survey of Albertans 2014* technical report, which can be accessed on the HQCA's website www.hqca.ca.



Statistical modelling was undertaken to understand how continuity of care relates to these aspects of patient experience and outcomes. Models for those individuals with or without a regular family doctor, and for those individuals with different levels of healthcare needs, were also examined (see Appendix I for details).

This report presents both the qualitative and quantitative results of this in-depth study. Opportunities for improving continuity of care are presented based on the interviews and focus groups with patients and providers.

Key findings

From the patient perspective, relationship continuity is most valued and is foundational for experiencing information and management continuity. A trusting, patient-centred, and respectful relationship with a family doctor is central to this. An excellent relationship can compensate for poor management continuity, as it still results in better patient-reported outcomes (i.e., patient satisfaction with healthcare services received, self-reported health status, and perceived safety).

From the provider perspective, information continuity is most important, and primary care providers get frustrated if information is withheld or delayed, particularly when other providers change treatment plans or medications. From the patient perspective, timely access to their own information is highly valued, as is having enough time during an appointment with a family doctor who listens and communicates effectively. The results further show that relationship and information continuity result in better management continuity, which in turn improves patient-reported outcomes.

Both patients and providers value and benefit from management continuity, which ideally includes a partnership or shared responsibility for managing and coordinating healthcare services. The survey results show that management continuity improves patient-reported outcomes. This is true also for those who experience difficulties accessing healthcare services – that even though access was difficult patients still saw improved outcomes because they experienced management continuity. Both access to healthcare services and excellent management continuity are substantially more important for those who don't have a family doctor, as they are precluded from experiencing the benefits of relationship and information continuity. For those who have a family doctor, excellent management continuity can compensate for a poor relationship with that family doctor, still resulting in better patient-reported outcomes.

Examined together, these critical elements of relationship, information, and management continuity make up a 'continuity of care hub'ⁱⁱⁱ that, when present, results in better ratings for perceived quality, patient satisfaction, self-reported health status, and perceived safety. All three types of continuity can

ⁱⁱ Structural equation models (SEM) were used to identify the relationship between continuity of care and patient-reported outcomes. All postulated associations among the survey measures are represented by a series of simultaneous regression (or structural) equations.

[&]quot;Those who experience a "continuity of care hub" experience a very good relationship with their family doctor, high levels of information continuity and excellent management continuity.



compensate for difficulties accessing healthcare services. They are particularly important for Albertans with serious or chronic health issues.

Obstacles to continuity of care

Both patients and providers perceive primary care as too disconnected from the rest of the healthcare system (i.e., community, hospital, specialist, and continuing care). In addition, they also recognize that the healthcare system itself creates problems for providers trying to deliver good care. Among some patients and healthcare providers there is a perception that problems with continuity are more a consequence of how the healthcare system is structured than the practice of individual healthcare providers. Healthcare providers were more likely to mention the system-level issues that affect continuity, such as funding models and lack of system accountability for providing continuity of care. Patients, more so than providers, note there is often nowhere for patients and families to seek help if they are experiencing a lack of continuity.

The quantitative findings provide evidence that not having or rarely visiting a family doctor is a structural barrier to relationship, information, and management continuity. In particular, Albertans without a family doctor and those who rarely visit their family doctor have fewer supports (i.e., relationship and information continuity) that when present can improve perceived quality of the healthcare system and consequently patient-reported outcomes. In addition, having a poor relationship with a family doctor is implicitly an obstacle to experiencing good information and management continuity, especially for those with serious or chronic health issues.

The extensive modelling undertaken in this study shows that these obstacles to continuity of care are more likely experienced by Albertans who use the healthcare system frequently.

Opportunities for improvement from the patient and provider perspective

Lessons from the patient and provider experiences suggest structuring primary care practices and processes to function as a 'continuity of care hub'. Built around a single most responsible doctor, the hub is an integrated group of resources designed to support continuity of care.

Relationship continuity can be improved by improving patient access to family doctors and to teambased care, especially for those with serious ongoing health issues, and by improving coordination and teamwork between family doctors and specialists.

A single universal electronic health record, that includes a patient portal which facilitates shared responsibility and thus management continuity, will enable improved information continuity.

Management continuity can be improved through the use of coordinators/navigators for vulnerable patients such as those with complex health issues and/or limited family support and through the implementation of a standardized referral system to improve coordinated and timely care.

The HQCA will continue to measure continuity of care through:

- ongoing use of the HQCA's newly established continuity of care scales to measure and track continuity of care experience at the Alberta population level, and
- establishing measures of continuity at the primary care practice level.



1.0 INTRODUCTION

The Health Quality Council of Alberta (HQCA) captures and listens to Albertans' voices through various sector-specific and general-population patient experience surveys^{iv} and through the studies and reviews^v it undertakes.

Since 2003, the HQCA has been monitoring patients' experiences with healthcare services through the biennial Satisfaction and Experience with Healthcare Services (SEHCS) survey. Over those years, the HQCA's findings consistently demonstrated a direct link between coordination of care, an aspect of continuity of care, and healthcare outcomes: better coordination is linked to good outcomes, and poor coordination is linked to poor outcomes. Given the critical role continuity of care plays in the healthcare system, the HQCA conducted an in-depth study to understand the conceptualization and measurement of continuity of care by determining the factors that influence both seamless and fragmented patient journeys.

The objective of this report is to present both the qualitative and quantitative results of this in-depth study of continuity of care. In addition, continuity of care quality-improvement strategies are presented from interviews and focus groups with patients and providers, as well as from current literature. Two important characteristics distinguish this study from other continuity of care work: (1) detailed results on continuity of care are based on scales (survey questions) developed for Alberta; and (2) provincial data is used as evidence to support the link between continuity of care, primary healthcare, and healthcare experience outcomes.

1.1 Methodology

This study employed a dynamic mixed-methods approach and each stage informed the next. The study began with an extensive review of the literature on continuity of care. The literature review informed the development of the interview guides for key informant interviews, interactive feedback sessions, and focus groups with:

- 40 individuals identified as having broad exposure to Alberta's healthcare system
 - Individuals were recruited through the previous SEHCS survey (Albertans who had used a variety of different healthcare services and had indicated a willingness to participate in further interviews)
- The HQCA's Patient/Family Safety Advisory Panel

^{iv} For more information, see: <u>http://hqca.ca/surveys/</u>

v For more information, see: <u>http://hqca.ca/studies-and-reviews/</u>



- More than 50 physicians and allied health professionals working in a primary care setting
 - The HQCA used two strategies to recruit healthcare professionals working in primary healthcare. The first was to attend three Alberta Access Improvement Measures (AIM)^{vi} training sessions to seek informal feedback from primary care physicians and from allied health professionals working in primary care clinics, public health, and other community settings (e.g., home care, mental health clinic). The second was to conduct four formal focus groups recruited from four primary care networks: three focus groups were solely with allied health professionals including registered nurses, a nurse practitioner, pharmacists, and a proactive office encounter technician;^{vii} and one focus group involved only primary care physicians.
- 10 individuals in leadership roles in Alberta's healthcare system (including the HQCA, Alberta Health (AH), Alberta Health Services (AHS), Alberta AIM, etc.)
 - Individuals were recruited through the HQCA's professional contacts

Findings from key informant interviews and feedback sessions/focus groups with primary care providers, as well as feedback from the HQCA's Patient/Family Safety Advisory Panel, informed the question content of the continuity of care measures. Existing validated instruments were reviewed and used to inform possible question wording and survey response options. An initial continuity of care item set was developed by the HQCA consisting of 74 questions. Of these 74 questions, 29 were chosen to be cognitively tested based on ratings ranging from high (1) to low (3) priority given by three evaluators independent of one another (members of the HQCA's analytics team). The remaining 45 questions from the initially proposed item set were dropped.

Cognitive interviewing^{viii} was applied to further refine one self-categorization question around healthcare system involvement and to test alternatives for the wording of questions and different formats of response options for the 29 questions. Before collecting survey data in Alberta, 15 of the 29 questions deemed to be the clearest and most meaningful to Albertans were pre-tested to evaluate their measurement performance (i.e., psychometric testing) and ensure accurate and reliable assessment. Based on the pre-test, the response scale for relationship continuity was modified. The final continuity of care scales showed excellent psychometric properties both on scale level (i.e., set of questions) and individual question level. Once complete, the continuity of care scales were added to the HQCA's 2014 Satisfaction and Experiences with Healthcare Services survey, where 4,424 Albertans were asked about their experiences with the healthcare system during the previous 12 months.^{ix} This enabled

vi Alberta AIM is a provincially funded organization focused on healthcare access improvement measures.

^{vii} A Proactive Office Encounter Technician (POET) is charged with managing patient data and getting patients prepared for their appointments with their family physician (taking blood pressure, etc.). The POET works closely with the referral coordinator to help patients navigate the health system (e.g., make sure referrals haven't been lost; provide patients with an estimated wait time).

vⁱⁱⁱ Two rounds of cognitive testing were conducted with 20 Albertans in total, using a scheduled interview guide. Items were ordered logically to reflect the order in which they would be asked in a cohesive survey.

^{ix} Full details of the 2014 Satisfaction and Experience with Healthcare Services survey methodology and data can be found in the HQCA's *Satisfaction and Experience with Healthcare Services: A Survey of Albertans 2014* technical report.



investigation into the associations^{x(7)} between continuity and the following patient experience measures:

- access to healthcare services
- quality of healthcare services
- safety of healthcare services
- patient satisfaction with healthcare services
- health status

Statistical modelling was undertaken to understand how continuity of care relates to various aspects of patient experience and outcomes (see Appendix I). Models were based on the literature and qualitative findings; multiple models were tested to determine the optimal one. The quality of various competing hypothesized models (the so-called goodness-of-fit) was evaluated by simultaneously analyzing the entire suite of measures of satisfaction and experience with healthcare services and determining the extent to which the model was consistent with the data. Additionally, models for those individuals with or without a regular family doctor, and for those individuals with different levels of healthcare need, were also examined (see Appendix I for further details).

[×] Structural equation models (SEM) were used to identify the relationship between continuity of care and patient-reported outcomes. All postulated associations among the survey measures are represented by a series of simultaneous regression (or structural) equations.



2.0 WHAT IS CONTINUITY OF CARE AND WHY IS IT IMPORTANT?

Continuity of care refers to "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's healthcare needs and personal context."¹ It emphasizes healthcare users', caregivers', and healthcare providers' perspectives on smooth and integrated care over time,^{2,5} care that is of high quality, and is cost-effective.⁸ In other words, continuity of care captures quality of patient care over time² and how an individual's healthcare is connected across healthcare events (i.e., various interactions with the healthcare system) and between healthcare providers. It entails a smooth progression of care from the patient's point of view.⁵ In previous projects, the HQCA has explored the relationship between continuity of care and outcomes (patient experience,⁹ healthcare service utilization,¹⁰ and health outcomes¹¹).

Traditionally, continuity was conceptualized as a relationship between a patient and an identified provider who is the sole source of care and information for the patient. Today, however, healthcare is more complex; patients' healthcare needs over time are changing and can rarely be met by a single healthcare professional. Consequently, multi-disciplinary pathways of continuity are a way to achieve both quality of care and patient satisfaction.¹² The concept of continuity of care aligns with concepts of coordination, case management,¹³ and patient-centredness^{14,15,16,17} as well as with the ideals of a medical home model.^{18,19,20,21,22,23} Reviews of international literature have identified three major subtypes of continuity across healthcare settings: relationship, information, and management continuity.^{1,3,4,5}

Relationship continuity, sometimes known as longitudinal²⁴ or personal²⁵ continuity, refers to a trusting relationship with one or more healthcare providers that helps to bridge healthcare episodes over time.¹ It is most valued in primary and mental healthcare as it fosters improved communication, trust, and sense of personal responsibility.²⁶ Within complex healthcare settings, such as hospitals and long-term-care facilities, ongoing relationships (i.e., longitudinal) may be difficult to establish as care is provided by a diverse team of healthcare professionals who work in shifts. As such, a consistent core of staff may provide the patient with a sense of predictability and coherence, and may help establish trusting relationships with multiple care givers.¹

Information continuity concerns the timely availability of relevant information through shared medical records, but also includes accumulated knowledge about the patient's preferences, values, and context.¹ Appropriate care is supported through synthesis of information on past medical events and personal circumstances, and the acting on this information in the delivery of care.²⁷

Management continuity involves the communication of patient-related information across healthcare teams, institutional and healthcare professional boundaries, as well as between healthcare professionals and patients.⁶ This covers continuity across the secondary-primary care interface; for example, when referring from generalist care to specialist care, or when planning discharge from specialist care or hospital care to generalist care. It is especially important in both chronic disease management and complex healthcare episodes (that may not be chronic). Such patients benefit most from care that is integrated across sectors of the health system, and where multiple healthcare providers deliver care in a coherent, logical, and timely fashion, using shared management plans or care protocols.²⁸



The value of continuity of care, and its three subtypes, is that it greatly improves many aspects of quality of care, and patients' and providers' experiences in the healthcare system. Current research has found that continuity of care:

- Increases trust between the healthcare provider and the patient (this research looked at the effects of relationship continuity specifically).^{22,28,29}
- Reduces errors and adverse events.^{11,30}
- Increases patient satisfaction with care.^{5,6,29,31}
- Reduces patients' psychological distress and/or improves mental health.^{5,29}
- Improves patients' health and quality of life.⁵
- Reduces long-term mortality among older adults.³²
- Decreases mental and physical healthcare needs.⁵
- Decreases utilization of healthcare services.^{10,33}
- Lowers healthcare costs.^{33,34}

Literature on continuity of care suggests a strong link to primary healthcare generally, and primary care medical homes more specifically.^{18,19,20,21,35,36,37} Haggerty,³⁸ for example, identifies six essential attributes of primary healthcare (i.e., accessibility, interpersonal communication, comprehensiveness, relational continuity, management continuity, and respectfulness), which align with the concept of continuity and its three subtypes. In addition, the College of Family Physicians of Canada's (CFPC) current definition of a medical home aligns with the concepts of continuity discussed so far, and the definition is meant to provide a patient-centred strategy for improved access and better health outcomes. Many authors describe coordinating and integrating care as a key responsibility of primary care providers.^{18,36,39} Others argue that what matters most in primary care is the quality and strength of the therapeutic relationship, and that relational continuity is part of the process by which a therapeutic relationship can be achieved.^{22,23} Some authors have noted that access is most closely linked to relationship continuity but also affects management and information continuity. Patients sometimes have to trade timely access to services for relationship continuity (i.e., seeing a familiar doctor).^{5,40,41,42,43,44,45} Management and information continuity are compromised by poor access and after-hours care.xi(46) Having a 'medical home' that is accessible and that coordinates care leads to improved access to needed care, to routine preventive screening, and to management of chronic conditions⁴⁷ and generally more positive healthcare experiences.⁴⁸ In short, the medical home is an entry point and central hub for providing and coordinating care including needed access to healthcare services.

^{xi} The College of Physicians and Surgeons of Alberta has recently amended and approved the *Continuity of Care* standard of practice, formerly *After-Hours Access to Care*. The standard outlines requirements for physicians to have arrangements in place for after-hours triage of patients and to receive critical diagnostic test results. This will ensure patients are informed that a qualified service provider is always available for them to contact and will provide clear guidelines to them and all members involved in their care about how to adequately access services. However, the implementation requires good collaborative practices among professionals where good communication is paramount to ensure continuity of care.



In summary, continuity of care is the product of patients and healthcare providers working together to provide coherent, connected, and consistent care. Therefore, the value placed on continuity, and its subtypes, differs according to the setting, healthcare provider, and the context of care. In order to achieve better clinical, functional, experiential, and cost outcomes, an integrated healthcare system is needed with a strong primary healthcare foundation – one that would allow for patient-centred, coordinated care over time. Thus, this study is focused on understanding continuity of care from the patient perspective. Continuity can be experienced in the context of the patient and his or her immediate healthcare professional (i.e., 'continuous caring relationship') or indirectly in the context of the wider organization (i.e., 'seamless service' or 'integrated care').



3.0 QUALITATIVE RESULTS

The following section highlights key findings from the in-depth interviews with patients and interactive feedback sessions as well as focus groups with primary healthcare providers.

3.1 Relationship continuity

Patients described good relationships with healthcare providers as patient-centred, including characteristics such as trust, mutual respect, good two-way communication, and being caring. They spoke very highly of healthcare providers who treated them "as people" and not "as numbers".

"There are some doctors I would trust with my life and some [I would run from]... The doctors that care about you are on the ball."

[Senior living with diabetes]

Patients recognized that trusting relationships take time to develop, and they talked about the importance of having enough time in appointments and seeing the same healthcare provider over time. Patients also talked about appreciating healthcare providers who are knowledgeable but who also recognize they don't know everything (i.e., healthcare providers who welcome the knowledge that patients and their caregivers possess about what is normal for them, and what treatment options would work best for them in the context of their lives).

In addition, patients talked about how the structure of the healthcare system contributes to a lack of relationship continuity. For instance, healthcare providers were perceived as being disconnected because when patients are admitted to hospital, they have little or no contact with their family doctor, physician specialists, and/or other healthcare providers they may have seen previously in the community.

"There's a huge disconnect between specialists and the family doctors."

[Young woman with extensive healthcare experience as a patient]

Even within the hospital itself, particularly large urban hospitals, patients often stated they saw many different doctors (specialists and hospitalists), many different nurses, and numerous other healthcare providers, which they said made it difficult to establish a relationship. This was exacerbated when the patients were moved to different units.

Patients also spoke of having a trusting relationship permanently severed because either their healthcare provider moved away or retired, or the patient moved to a different town or city or into a long-term-care setting. Finding a new healthcare provider and getting medical records transferred, they said, was often difficult.

In addition, some patients reported not having a trusting, ongoing relationship with a family physician or other healthcare provider, which led to experiences of being misdiagnosed and inappropriately treated, which then in turn led to poor physical and mental health.



In contrast, feedback from primary healthcare providers emphasized their working relationships with other healthcare providers in the healthcare system.

"At least ... I know somebody who knows somebody. Hey, can you do me a favour? And I've done that lots. I mean I do have some connections in the hospital and so I'll say I'm sending this patient and I know this is what your process is. And that goes to a trusting, working relationship with other people. This is really important. So what is it I need to do in order get that done faster?"

[PCN nurse]

Primary healthcare providers described these strong relationships with other providers as key to facilitating quicker access and thereby quicker care for patients (see further details in Section 3.4).

Interviews with both patients and primary healthcare providers identified relationship continuity as an important factor contributing to quality of care. Negative patient experiences – and in the worst case those resulting in adverse events – were often described involving many healthcare providers caring for the individual, and with no one clearly responsible for coordinating care or for communicating relevant health information.

"They don't have a history with you, so their perception of you only begins at the very moment they see you... Their lack of prior knowledge of your experience makes it so that most of the time any decision they try to make for your good is under-informed. So having them make any kind of decisions that could affect my health has turned out normally to be for the worse."

[Young man living with complex medical problems]

3.2 Information continuity

When asked about information continuity, patients talked about how online access to test results would be helpful for them in ensuring good information flow (i.e., information continuity). Specifically, patients talked about how online access helped doctors find and view test results the same or following day, regardless of where the test had been done in the province. Patients also talked about the value of the healthcare provider having enough time to discuss the patient's feelings and health, and to share information in a way that could be understood (e.g., possible diagnoses, test results, what to expect with a surgical procedure and post-op, etc.) as vitally important for good information continuity.

Patients and their caregivers were often described as the only source of continuity among healthcare providers and healthcare services. Consequently, valuable knowledge was said to be lost when healthcare providers did not listen to the patient or caregiver, such as what had already been tried, what had worked previously, and what had not.

"I find that when I see a new specialist what they do is they rely largely on me to get a sense of what my condition is. And then they only use my chart if they want to look something up or look at a previous test result... The chart is more of a record of the tests I've had done... It doesn't capture me or my problem really or my situation."

[Young man living with complex medical problems]



Primary healthcare providers talked about gaps in information continuity, especially between primary healthcare and acute care. For instance, staff or healthcare providers working in primary care networks (PCNs) often described not knowing when their patients received emergency department care or were admitted to a hospital.

"Well, that's the biggest thing. We don't know they've been in hospital... There is nothing from the hospital. No information and you don't know what medications were discontinued and you don't know what was done. And you don't know what they're taking."

[PCN pharmacist]

Patients reported that they didn't realize primary healthcare providers do not always have their hospital information. They are usually asked the name of their family doctor when admitted to hospital, and so they make the assumption that the hospital will send information to the family doctor about the care they received. Primary healthcare providers also talked about delays in receiving discharge summaries from the hospital or the emergency department, and the lack of information contained in these summaries was said to make follow-up care difficult. Primary healthcare providers talked about 'chasing down' the information, having to call the hospital or emergency department themselves to get information about a patient's care.

During one of the focus groups, a pharmacist spoke of the negative consequences of poor information continuity within a care team and across care teams. The pharmacist told a story about a patient who was on warfarin (an anticoagulant), was depressed (on an anti-depressant), and needed to gain weight. This patient ended up in hospital and wasn't given food for an extended period as the hospital team wasn't sure what tests or procedures were going to be ordered. The hospital team stopped the patient's anti-depressants, and left the patient on warfarin without consulting the primary healthcare providers involved in the patient's care. The pharmacist concluded the story by stating that the patient ended up with a bleed and was readmitted to hospital, all because of a lack of information flow among providers.

Primary healthcare providers also identified gaps between themselves and both community-based services (e.g., public health, home care, etc.) and other healthcare providers (e.g., podiatrists, physiotherapists, etc.). The flow of information was described as being particularly challenging when the patients made the appointments themselves. Primary healthcare providers talked about not receiving information if an appointment was made by a patient, and only receiving information if and when they, or someone in the office, made the referral.

"Communication with and feedback to the family doc is important, but who of these many physicians is going to take the responsibility to do this; and then how do they communicate with each other?"

[PCN nurse]

Additionally, the exchange of information between federally funded nurses on reserves and provincially funded primary healthcare providers was also said to be problematic. Reserve nurses, it was said, do not have access to Netcare because it is a provincial resource; consequently, this lack of access was said to hinder good information continuity among care providers.



3.3 Management continuity

When asked who has responsibility for managing and coordinating healthcare services, the overwhelming majority of patients described this as a shared responsibility among patients and healthcare providers. However, some patients described themselves as being 100 per cent responsible for managing and coordinating their own healthcare, while others (specifically the elderly) said a healthcare provider was entirely responsible.

"I would say I'm more the driving force of getting things done and following it through and making sure that I'm getting looked after. My family doctor was most helpful, definitely but I would have to go in and talk with him and ask him – if he could write out the letter to this doctor and say this."

[Middle-aged woman living with serious mental health issues]

It was generally younger patients, and those knowledgeable about their health condition and how the healthcare system works, who expected and wanted to play a greater role in managing and coordinating their own healthcare.

Some patients reported barriers involved with a shared-responsibility model. Patients spoke of feeling dismissed and ignored, and said their previous healthcare experiences were not considered valuable knowledge. They also talked about a lack of communication and listening skills in healthcare providers, being given insufficient time to discuss healthcare management issues with a healthcare provider, and consequently developing a non-trusting relationship with the provider. Others talked about how patients or caregivers are often required, but ill prepared, to assume the responsibility for managing and coordinating healthcare.

Primary healthcare providers talked about a lack of coordinator/navigator roles within the healthcare system, particularly to manage transitions in and out of hospitals and emergency departments. They described this need as critically important for complex patients and for those who have little support from family or friends.

In addition, a lack of social workers throughout the healthcare system meant there was little to no support for patients and families in understanding and accessing the complex network of social and financial supports available, thus impeding management continuity. As well, primary healthcare providers talked about the difficulty of facilitating access to mental health, pain management, publicly funded physiotherapy, and certain medical specialists. They also talked about the additional burden faced by patients needing to travel from rural settings to urban centres for care. This was said to be especially problematic and difficult for seniors and people with limited incomes, again compromising the experience of management continuity.

3.4 How primary healthcare providers bridge gaps in continuity of care

A number of primary healthcare providers described how they, as part of their everyday work, "sidestep normal processes" to ensure patients have access to healthcare services, thereby improving the experience of management continuity. Patients and caregivers recognized these "work-arounds" and talked about them as a means to deal with the limitations of the healthcare system. Specific sidestepping or work-around examples described by the primary healthcare providers included:

• Telling patients to go to the emergency department when they are unable to get the patient in to see a specialist and the patient needed help urgently.



- Phoning personal connections to facilitate quicker access for patients.
- Helping patients obtain costly drugs through pharmaceutical company compassionate drug programs.
- Helping patients obtain publicly funded physiotherapy services, when the patient had insufficient income and/or health plan coverage.

"But I definitely tell people if it's urgent and you're on the waitlist for this and it could take six months. If you have these symptoms just go to the ER and then they'll push you forward. So that's a terrible abuse of the ER, but what else can you do?

[PCN nurse]

Besides side-stepping normal processes, primary healthcare providers talked about teamwork and improved communication among themselves and physicians as strategies to bridge gaps in continuity of care. These improvements were described as helping to improve coordination of patient care. Also discussed was co-location of all healthcare providers at a clinic or practice, and how it enabled in-person communication and improved the sharing of complex patient histories.

"Not all of this stuff ends up in the chart, and it would just take too much time to put it all in there. It's much easier to have a brief conversation."

[PCN nurse]

The use of "warm hand-offs" within a care team was also talked about as a strategy used to bridge continuity. Personally introducing the patient and/or caregiver to another individual on the team was described as being important in helping to establish trust between the patient and the new provider. It was felt that personal introductions help patients feel they can trust the new provider and was also said to provide the patient with some "peace of mind".

"I do things like warm hand-offs, which is something I learned from the mental health people. Where if I'm not going to be there, I'm going to say to this patient, I won't be here to give you your injection, but I'd like you to meet [name], who is the person who is going to give you your injection next time."

[PCN nurse]

Other strategies used by primary healthcare providers were discussed, including:

- Having a referral coordinator on staff to make and track referrals, provide information to
 patients and caregivers about likely wait times, and to follow up. This role was described as
 essential for facilitating coordination between primary healthcare providers and medical
 specialists.
- Placing nurses in the emergency department to improve follow-up with patients about test results and referrals to healthcare services, and to improve follow-up and communication back to practices and programs supported by the PCN.



- Having nurses visit long-term care and assisted-living facilities on their own and jointly with the PCN-associated physicians. In one example given, a doctor and a registered nurse were described as working together to care for 30 patients living in an assisted-living facility. The nurse visited the assisted-living facility weekly, and the doctor and nurse visited together biweekly.
- Developing their own after-hours care programs and other services, such as pain management, smoking cessation, women's health, healthy eating, or living with diabetes to overcome gaps in care coordination.

"I have no idea what the wait times are now, but I know from my perspective the wait times for us to go to Alberta Health Services is ridiculous... That's why our PCN started adding in these programs, because we were seeing these huge wait lists."

[PCN health management nurse]

 Developing multi-disciplinary navigation teams, particularly for patients with complex health issues. The team would conduct home visits, access other healthcare providers in the PCN, and deal with complex navigation issues (e.g., finding funding for physiotherapy services for clients living on Alberta Income for the Severely Handicapped). Patient navigators in the cancer care system were viewed as very positive and a model to build on.

3.5 Patient and provider perspectives on improving continuity of care

Interviews with both patients and primary healthcare providers concluded by asking interviewees to identify the one thing they would change about our current healthcare system to improve continuity of care for patients and families. Their suggestions are described in relation to the three subtypes of continuity.

3.5.1 Relationship continuity

Patients talked about a need for more family doctors and better access to them. They wanted to work with a trusted doctor and other healthcare providers, someone with whom they have a mutually respectful relationship, who cares about them and listens to them, who helps to manage their health and their healthcare, and whom they can see consistently. A number of patients wished that their trusted healthcare provider could also be involved in their hospital care (this was usually a family doctor but sometimes a specialist). Patients in communities with a shortage of family doctors were also concerned about what would happen if their key healthcare provider retired.

"You need a doctor that you can go to on a regular basis that knows who you are and gets to know your family, gets to know what the hell is going on in it. Not just always going to walk-in clinics, where they see you for five minutes... We need more physicians that are available to us on a regular basis and we need the support systems that back that up."

[Woman living with chronic health conditions]



Primary healthcare providers reported that many patients, particularly those with chronic health conditions, developed close relationships with them and the healthcare provider team. Primary healthcare providers talked about ensuring that specialists pass ongoing patient care back to them when appropriate to help them build and maintain relationships with their patients. This appropriate hand-off was said to have the added benefit of decreasing patients' need to travel for specialty services, which was described as creating significant hardships for many people (i.e., those living in more rural and/or remote areas).

Another area for improvement discussed in interviews was the need to change the way patients and healthcare providers work together in order to maximize the continuity of care experience. Patients and primary healthcare providers both talked about the ways that patients and their families work with healthcare providers, and how best to develop relationships whereby patients and their families are supported and trusted to make decisions. In one example a young mother of two kids, who suffers from chronic kidney stones, related that going to the emergency department had always been a nightmare for her. She described being stigmatized for drug-seeking behaviour, and having her symptoms dismissed and diagnoses delayed. These delays had resulted in her experiencing extreme pain, illness, and psychological distress; using more healthcare resources (i.e., emergency department visits and emergency surgeries); and, negatively affecting her and her family's quality of life. She talked about working collaboratively with a nurse practitioner, family doctor, and psychologist to develop a care plan for her hospital file, which informed hospital staff of her issues.

3.5.2 Information continuity

Patients discussed the importance of timely and up-to-date information that is easily accessible and potentially shareable online. They reported, for example, not getting enough information before procedures or being asked for their complete history at every hospital admission even though they assumed that there would be an updated record. Patients also emphasized their need for time to process information and to talk to their healthcare providers about it. In particular, they wanted to be able to ask questions and have healthcare providers be open and encouraging of patient involvement. They also wanted healthcare providers to be updated as a matter of routine and to be aware of what was going on with their healthcare; they felt these updates should not have to come from the patient all of the time.

"Whenever you do a nursing history that is on the system or readily available for that hospital or the next hospital or the nursing unit wherever you went to ... it would be nice for your family doctor to be automatically flagged and made aware of if you were admitted. Like made aware of why you were admitted and what happened for your treatment. Even if it was a summary. So that at least he would know to talk to you about it the next time you saw him or maybe call you to request an appointment for you to come in."

[Senior living with diabetes and chronic back pain]



As part of improving the information flow among healthcare providers, primary healthcare providers talked about the importance of having a single, universal electronic health record (potentially a furtherevolved Netcare system), one that is available to all providers, with integrated links to physician and clinic electronic medical records. As part of this universal electronic health record, a patient portal was also said to be vital – a system that would allow patients and caregivers to see medical information. Primary healthcare providers suggested that an initial step could be to make improvements to Netcare by including more information, and by organizing the information in a more user-friendly way. Suggestions included having automatic alerts to providers when patients are admitted to hospital, when patients visit an emergency department, or when patients pass away.

3.5.3 Management continuity

Many patients said they would like to have access to someone to help them navigate the healthcare system. Particularly those patients with chronic and complex conditions wanted their healthcare providers to work on their behalf and to involve them in final decisions.

"I actually have said many times over the last five years that the Alberta healthcare system needs some---oh, kind of like a guardian---advocate, a senior advocate to go with, because there's a lot of older people, or really ill people ... who don't have family. So there really ought to be positions doing what I did. And people paid to do those things."

[Senior living with a number of chronic health issues]

Patients also discussed a need for better management continuity experiences with providers helping them to coordinate access to services/specialists and to avoid travelling long distances to get needed follow-up care. Some patients expressed concerns about services such as mental healthcare and physiotherapy, which are not directly managed by the healthcare system and often require patients to manage on their own and to pay out of pocket.

There were mixed perspectives on how much responsibility patients and families could take on with respect to the difficult job of managing their own health and healthcare, limited in part because of how confusing the system is to navigate. Some healthcare providers felt very strongly that patients had to take on more responsibility. Others felt that it would be challenging for patients and their families to be responsible for managing care because of the lack of access they currently have to their own healthcare information. Ultimately, primary healthcare providers said that patients and caregivers needed to be actively supported in co-managing health and the coordination of healthcare services (e.g., better education, access to relevant information) because it is a shared responsibility.

"Engaging patients more in their own care, which is that whole shared-responsibility piece ... how do we actually have a system that helps patients be more involved and also ensures that there are supports in the system to support people. Because the system is so darn confusing, you can't leave people out there trying to navigate it on their own."

[PCN nurse]



In addition, primary healthcare providers said that for patients with complex health issues, and potentially limited family support, having community-based care coordinators/navigators was essential. Primary healthcare providers felt that if care was not coordinated between multiple services and left to patients to manage, including those who may not have the capacity to do so, then management continuity would suffer and the primary healthcare provider would not be fully connected.

"I think we should start there with the patients who don't have key family or caregivers; the ones that are kind of falling through the cracks. They need to have someone who is assigned to them."

[PCN nurse]

The current referral processes for specialists were described by patients and primary healthcare providers as being extremely variable and confusing. Primary healthcare providers suggested standardized referral processes for specialists as one important strategy for improving continuity of care in the healthcare system.

"I think the long-term goal of the government to have a centralized referral system alone would improve in some ways, at least communication with continuity of care. So that more of the family physicians have a clue of what's happening, where are my patients sitting in the system."

[PCN family physician]



4.0 QUANTITATIVE FINDINGS

Since 2003, the Health Quality Council of Alberta (HQCA) has conducted the biennial Satisfaction and Experience with Healthcare Services (SEHCS) survey to capture Albertans' experiences and perceptions concerning a range of healthcare services. The most recent survey, conducted in 2014, included for the first time continuity of care scales developed by the HQCA, which allowed for the quantitative assessment of relationship, information, and management continuity and their associations with patient-reported access, perceived quality and safety, satisfaction, and self-rated health. Extensive modelling (i.e., structural-equation modelling) was undertaken to fully understand the associations between healthcare attributes, such as access and perceived quality as well as patient experience. The following sections highlight the findings of the HQCA's quantitative analyses of continuity of care, primary care (i.e., those who don't have a family doctor compared with those who do), and patient-reported outcomes such as safety, satisfaction, and functional health status.

4.1 Continuity of care bridge

An initial step in the quantitative analysis process was to propose a conceptual pictogram of continuity of care (see Figure 1) on which modelling would be framed. The qualitative data collected in the study (Section 3) and the information obtained from the research literature (Section 2) provided the basis for the conceptual pictogram. The essence of continuity is that it occurs over time and between discrete events, and among providers and locations.^{xii} Figure 1 shows the conceptual pictogram as an unstable bridge that connects healthcare access with patient-experience outcomes; that is, from the start of the patient's journey in the healthcare system to the outcome of that journey. Representing the healthcare system, the bridge is made of disconnected and parallel broken planks, symbolizing the multitude of healthcare sectors and providers in the system. These planks link haphazardly to the overall bridge supports of relationship, information, and management continuity, and provide a means for the patient to move from the point of access to services to the outcomes of those services. The planks are not connected to all parts of the support structure, so informal "ad-hoc" repairs or side-stepping and work arounds^{xiii} are used to make the connections. Beneath the bridge is a safety net, comprising social and community services, which has many holes.

xⁱⁱ While continuity is not static or limited to a single episode of care, it is helpful to understand the experience and effects of continuity as a single snapshot in time, as is the case with the twice-yearly survey. Ongoing measurement should ultimately focus on the effect of continuity on outcomes over time, and this further suggests that measurement occur in a cohort of patients who are assessed at different points in time.

xiii Workarounds are a legitimate way to get things done in the absence of other necessary factors.



Figure 1: Continuity of care bridge



In-depth interviews with patients showed that they rely heavily on their family doctor and that this relationship is fundamental for experiencing continuity of care. Therefore, it was hypothesized that individuals without a family doctor might have different experiences than those who have a family doctor. Similarly, among those who have a family doctor, different experiences might arise depending on the individuals' health issues and frequency of interaction with the healthcare system.

Thus, survey respondents were categorized initially into two groups:

- 1. Those with a family doctor
- 2. Those without a family doctor

Respondents with a family doctor were further subcategorized based on their self-assessed involvement with the healthcare system (see Figure 2):

- 1. No health issues/never or rarely use healthcare services
- 2. Minor health issues, resolved quickly/use routine healthcare services
- 3. More serious acute health issue/hospitalization, require specialist, surgery/intense use of healthcare services over a short period of time
- 4. Chronic serious health issues/frequent ongoing use of healthcare services





Figure 2: Survey respondents' involvement with the healthcare system

Based on the survey results, significant differences exist between respondents with and without a family doctor, as well as between those within the four groups of patients with a family doctor (see Appendix II, Table 1 and 2).

As expected, those with a family doctor and with increased healthcare needs have more self-reported health service use and see significantly more providers in the system, have more chronic conditions, and take more prescription medication. What this suggests in light of the healthcare bridge is that Albertans with serious and/or chronic health issues have to cross the bridge more often using many different services and are more likely to experience gaps in their care.

4.2 Newly developed continuity of care survey questions

Interviews and focus groups were used to gather data on the factors that influence individuals' experiences with continuity of care in the healthcare system. The literature and qualitative information was then used to inform the HQCA's SEHCS survey questions. Before newly developed questions were added to the survey, they were cognitively tested with a sample group of 20 Albertans to ensure that the questions were clear and meaningful. All three newly developed continuity of care scales (set of questions) showed excellent psychometric properties at the level of scale and individual question.

The following 15 questions, measuring the three subtypes of continuity, were added to the HQCA's SEHCS survey. Three composite measures are computed as an average of all questions in each of relationship, information, and management continuity. These are presented for all Albertans, for those without a family doctor (where applicable), and for those with a family doctor according to different levels of involvement with the healthcare system.



Relationship continuity (nine questions)

For Albertans, the qualitative findings show that the family doctor is central to patient care and emphasize that the relationship with the family doctor is fundamentally important for a seamless patient journey. A set of nine questions reflecting the 'quality of the patient-family doctor relationship' was developed for use in this study. Albertans were asked to rate their family doctor for the following attributes using a five-point Likert-type response scale with response options of 1='poor'; 2='fair'; 3='good'; 4='very good'; 5='excellent':

- 1. Explaining things to you
- 2. Making sure of your understanding
- 3. Amount of time spent with you
- 4. Listening to you
- 5. Treating you with dignity/respect
- 6. Understanding your personal healthcare choices
- 7. Allowing you to participate in your healthcare
- 8. Caring for you as a person, and
- 9. Your trust in your family doctor

As shown in Figure 3, about 80 per cent of surveyed Albertans rate the quality of their relationship with their family doctor as very good or excellent (composite score^{xiv} greater than 3.5 out of 5). Among the four different health groups of respondents with a family doctor, 77 to 82 per cent rate the quality of their relationship with their family doctor as very good or excellent. On the other end of the scale, however, 10 per cent of those with chronic health issues rate the relationship with their family doctor as poor or fair (with a composite score less than 2.5 out of 5), while in the other groups only 4 per cent to 5 per cent give a rating of poor or fair (representing a significant difference).

^{xiv} In order to arrive at a composite score assessing the quality of the patient-doctor relationship, scores for each single question are summed and divided by nine, thus assigning a score between 1 and 5 to each respondent. Those who score less than 2.5 are classified as having a poor or fair relationship with their family doctor, while those who score greater than 3.5 out of 5 are classified as having a very good or excellent relationship. Those who score between 2.5 and 3.5 in their composite score are classified as having a good relationship with their family doctor. The scoring intervals are based on the five-point Likert scale for all questions.



Figure 3: Among survey respondents with a family doctor, percentage with a composite score across nine questions indicating a poor/fair, good, or very good/excellent patient-family doctor relationship



When comparing the 'quality of patient-doctor relationship' composite score and mean scores for each single question, results show that:

- Those with chronic health issues and those with no health issues score lower on the quality of their patient-family doctor relationship composite (4.1 out of 5.0) than those with serious (4.3 out of 5.0) or minor health issues (4.2 out of 5.0).
- Those with chronic health issues score lower on *'the amount of trust in their family doctor'* and on *'understanding personal healthcare choices'* compared with the other three health groups.
- All four health groups (no, minor, serious, chronic) score highest on *'family doctor is treating you with respect and dignity'*.
- All four health groups (no, minor, serious, chronic) score lowest on *'the amount of time spent with the family doctor'*. xv

Information continuity (two questions, asked for multiple services)

The second scale concerned information continuity. Questions were developed to assess if patients thought the family doctor was informed about care they received from other providers, as well as about changes in medication recommended by another provider, such as walk-in clinic staff, emergency

xv See Appendix III, Table 3 for statistical testing of mean differences between the four health groups with a family doctor.



department staff, specialists, or mental health specialists. This was a methodological challenge, insofar as not all respondents experienced all of these services. However, to preserve sample size, a mean score based on the specific healthcare services used by each respondent was generated. All questions used a five-point Likert-type response scale with response options as follows: 1='strongly disagree'; 2='disagree'; 3='neither disagree/agree'; 4='agree'; 5='strongly agree'.

It is important to note that these two continuity scales – relationship and information – apply only for respondents with a family doctor. This is based on the findings of the earlier qualitative interviews, which identified the family doctor as the predominant focus for relationship continuity.

As shown in Figure 4, about 70 per cent "agree" that information is shared with their family doctor (i.e., composite score^{xvi} across information continuity questions was greater than 3.5 out of 5). Moreover, for Albertans with chronic health issues, nearly two in 10 (16%) "disagree" that information is shared, similar to the other three health groups.

Figure 4: Among survey respondents with a family doctor, percentage with a composite score across information continuity questions indicating disagreement, neither agreement nor disagreement, or agreement that information is shared with their family doctor



^{xvi} In order to arrive at a composite score assessing information continuity, scores for each single question are summed and divided by the number of questions answered. The number of questions answered ranged from two to six (as one of the two information continuity questions was asked in general as well as relative to four different healthcare services used). The composite score assessing information continuity assigned as a result a score between 1 and 5 to each respondent. Those who score less than 2.5 are classified as disagreeing with information being shared with their family doctor, while those who score greater than 3.5 out of 5 are classified as agreeing with information being shared. Those who score between 2.5 and 3.5 in their composite score are classified as neutral (i.e., neither agreeing nor disagreeing that information was shared). The scoring intervals are based on the five-point Likert scale for all questions.



When comparing the 'information continuity' composite score (i.e., score across the answered information continuity questions) and mean scores for each single question, results show that:

- All four health groups score similarly on the information continuity composite (3.9 to 4.0 out of 5.0).
- All four health groups score lowest on the family doctor being informed about medication changes recommended by walk-in clinic staff compared with other settings.
- Compared with those having no health issues, the three groups with health issues (minor, serious, chronic) score lowest on informing the family doctor about medication changes recommended by the walk-in clinic and emergency department staff.^{xvii}

Management continuity (four questions)

The third continuity of care scale concerned management continuity, which comprised four questions that were asked of all survey participants (i.e., including those with and without a family doctor). The first question asked: *'How would you describe how well all of the healthcare professionals coordinated their efforts to serve your needs?'* All questions used a five-point Likert-type response scale with response options as follows: 1='poor'; 2='fair'; 3='good'; 4='very good'; 5='excellent'.

The remaining three questions focused on specific aspects of management continuity, and used a fivepoint Likert-type agreement response scale with response options of: 1='strongly disagree'; 2='disagree'; 3='neither disagree/agree'; 4='agree'; 5='strongly agree'. The specific items were: 'getting enough help from healthcare providers to coordinate or manage care', 'care was coordinated or managed in a timely manner', and 'healthcare providers follow up on healthcare'.

As shown in Figure 5, about 60 per cent of Albertans scored very good or excellent on the management continuity composite and agree with specific aspects of getting enough help in a timely manner with follow-up care (i.e., composite score^{xviii} across all four questions greater than 3.5 out of 5). Moreover, for Albertans with serious and/or chronic health issues, about two in 10 (15% and 18% respectively) score poor/fair on the management continuity composite (i.e., score less than 2.5). This increases to one in four respondents (24%) for those Albertans who don't have a family doctor.

xvii See Appendix III, Table 3 for statistical testing of mean differences between the four health groups.

^{xviii} In order to arrive at a composite score assessing management continuity, scores for each single question were summed and divided by the number of management continuity questions. Response options range from 1 to 5 for each question even though a quality response scale is used for the general questions, whereas an agreement scale is used for the three specific questions. Those who score less than 2.5 are classified as perceiving poor / fair management continuity and disagreeing with questions, whilst those who score greater than 3.5 out of 5 are classified as perceiving very good / excellent management continuity and agreeing with specific questions. Those who score between 2.5 and 3.5 in their composite score are classified as perceiving good management continuity and neither agreeing nor disagreeing with questions. The scoring intervals are based on the five-point Likert scale for all questions.



Figure 5: Percentage of survey respondents with a composite score across four questions indicating poor/fair, good, or very good/excellent management continuity



When comparing the 'management continuity' composite score (i.e., score across four questions) and mean scores for each single question, results show that:

- Those who don't have a family doctor report the lowest management continuity composite score (3.4 out of 5) compared with the four patient groups with a family doctor.
- Those who don't have a family doctor score lowest on all four single questions compared with the four health groups with a family doctor.
- Those with serious and chronic health issues score lower on the management continuity composite (3.7 out of 5) than those with no or minor health issues.
- Those with serious and chronic health issues score lower on *'healthcare professionals coordinated their efforts'*, as well as *'care was coordinated or managed in a timely manner'* than those with no or minor health issues.
- Those with chronic health issues score lower on *'getting enough help from healthcare providers to coordinate or manage care'* than those with no, minor, or serious health issues.^{xix}

xix See Appendix III, Table 3 for statistical testing of mean differences between the four health groups with a family doctor and those without a family doctor.



In summary, when comparing the composite scores for all three continuity of care scales, the experience of management continuity is the least positive (59% - Figure 5) compared with both the perceived quality of the patient-family doctor relationship (i.e., relationship continuity) (80% - Figure 3) and the experience of information continuity (67% - Figure 4).

4.3 Patient experience and outcome survey questions

The HQCA's SEHCS survey questions traditionally measure access to healthcare services, quality and safety of healthcare services, patient satisfaction, and self-reported health status. Newly developed continuity of care scales (i.e., set of questions) were embedded within the flow of traditionally asked questions, which are discussed in this section.

As the conceptual pictogram 'continuity of care bridge' illustrates (see Figure 1), and as the literature demonstrates, continuity affects outcomes and perceived quality of care in a number of quality dimensions. The Alberta Quality Matrix for Health includes six dimensions, one of which is 'accessibility'. *Access* to needed health services is often described as being closely linked with aspects of continuity, particularly relationship continuity. Some authors describe patients as sometimes having to choose timely access to services over the relationship continuity associated with seeing a familiar doctor. Caremanagement gaps also occur when patients have to seek after-hours care in urgent care centres or emergency departments. Moreover, obtaining access to information such as test results can be challenging for providers, which often requires repeated testing. The HQCA's SEHCS survey measures access by asking how difficult or easy it was to obtain needed healthcare services. Questions used a fivepoint Likert-type response scale, ranging from 1='very difficult' to 5='very easy'. The provincial average for access is 3.4 on this response scale (see Appendix IV, Table 4).

Another quality dimension of the Alberta Quality Matrix for Health is 'acceptability'; acceptability here is defined as: "Health services that are respectful and responsive to user needs, preferences and expectations".^{xx} The 'acceptability' dimension ('patient-centred care' in the US⁴⁹ and 'responsiveness' in Europe⁵⁰) is often measured as *overall quality of care* and *patient satisfaction*. Perceived quality of care is measured in the SEHCS survey by asking respondents how they would describe the overall quality of healthcare services using a four-point Likert-type response scale of 1='poor', 2='fair', 3='good', 4='excellent'. Satisfaction is measured by asking to what degree the respondent is satisfied or dissatisfied with received healthcare services on a five-point Likert-type response scale, ranging from 1='very dissatisfied', 2='dissatisfied', 3='neither satisfied/dissatisfied', 4='satisfied', 5='very satisfied'. Previous SEHCS survey findings indicate that access and coordination of care are strong predictors of quality and satisfaction.^{xxi} Additionally, both Albertans with chronic health issues and those who don't

xx For more information see: http://hqca.ca/about/how-we-work/the-alberta-quality-matrix-for-health-1/

xxi For more information see: http://hqca.ca/surveys/satisfaction-experience-with-healthcare-services/



have a family doctor experience poorer-quality healthcare services and lower patient satisfaction (see Appendix IV, Table 4).

The impact of continuity on *perceived safety* and *self-reported health status* is examined in this section, as these are important outcomes identified in the key informant interviews. Perceived safety represents the 'safety' dimension of the Alberta Quality Matrix for Health and was measured by asking to what degree the respondent is concerned that unexpected harm could occur in the course of care and treatment as a patient, using a five-point Likert-type response scale: 1='very concerned', 2='concerned', 3='neutral', 4='a bit concerned', 5='not at all concerned'. Self-reported health status represents the 'effectiveness' dimension of the Alberta Quality Matrix for Health and was assessed using the EQ VAS,^{xxii} which records the respondent's self-rated health on a vertical, visual analogue scale where the endpoints are labelled 'Best imaginable health state' (score 100) and 'Worst imaginable health state' (score 0). Survey results show that those with serious and chronic health issues are more concerned that unexpected harm could happen when receiving healthcare services and their self-rated health status is lower, both compared with those lacking a family doctor, as well as compared with those who have a family doctor and who rarely or routinely utilize healthcare services (i.e., those with no or minor health issues respectively) (see Appendix IV, Table 4).

xxxii EuroQol visual analogue scale. This information can be used as a patient-reported outcome measure (PROM) as assessed by the individual respondent.



4.4 Statistical modelling

The final step was to understand the interplay of continuity of care with the patient experience and outcome questions described above, guided by the conceptual pictogram of continuity of care (Figure 1). The wording for all questions and response options included in the modelling process (as described in the previous sections) are summarized in Appendix V.

4.4.1 The role of management continuity

In this section, the scores for management continuity are examined in association with the rating for overall quality of healthcare services among the general population. The impact of this association on patient-reported outcomes (i.e., patient satisfaction, self-reported health status, and perceived safety) is also examined.

Figures 6 to 8 illustrate the influence of management continuity on overall quality as follows:

- Very good or excellent management continuity (composite score across four questions greater than 3.5 out of 5) enhances the rating of quality of healthcare services received (rating of 3 or 4 out of 4).xxiii
 - Very good or excellent management continuity combined with very good or excellent quality of healthcare services result in the highest scores for:
 - patient satisfaction^{xxiv} (4.4 out of 5 in Figure 6)
 - self-reported health^{xxv} (79.8 out of 100 in Figure 7)
 - perceived safety^{xxvi} (4.1 out of 5 in Figure 8)
- Very good or excellent management continuity (composite score across four questions greater than 3.5 out of 5) offsets the effect of poor- or fair-quality healthcare services (rating of 1 or 2 out of 4).
 - Similar patient experience scores are seen for very good or excellent management continuity combined with poor- or fair-quality healthcare services, and the inverse: very good or excellent quality healthcare services but poor or fair management continuity for:
 - patient satisfaction (3.3 vs. 3.3 out of 5 in Figure 6)
 - self-reported health status (75.8 vs. 74.3 out of 100 in Figure 7)
 - perceived safety (3.4 vs. 3.6 out of 5 in Figure 8)

xxiii Single question assessing how respondents would describe the overall quality of healthcare services

xxiv Single question assessing respondents' satisfaction with healthcare services

 $^{^{\}mbox{\tiny XXV}}$ Single question assessing respondents' worst to best imaginable health state

xxvi Single question asking to what degree the respondent is concerned that unexpected harm could occur in the course of care and treatment as a patient



- Poor or fair management continuity (composite score across four questions less than 2.5) worsens the impact of poor- or fair-quality healthcare services (rating of 1 or 2 out of 4):
 - Poor or fair management continuity and poor or fair quality (lowest bar on the right) result in the lowest scores for:
 - patient satisfaction (2.3 out of 5 in Figure 6)
 - self-reported health (69.4 out of 100 in Figure 7)
 - perceived safety (2.9 out of 5 in Figure 8)

Figure 6: The association between management continuity scores, overall rating of quality of healthcare services, and patient satisfaction with healthcare services









Figure 8: The association between management continuity scores, overall rating of quality of healthcare services, and perceived safety




The structural equation modelxxvii.(7) in Figure 9 highlights the associations between management continuity and perceived quality (0.46), as well as their impact on patient-reported outcomes. Overall, the associations among the measures are all positive and significant (indicated by an asterisk); as one measure goes up the result is an increase in the subsequent measure(s), and likewise if the measure goes down, so do the subsequent measure(s).

The model indicates that management continuity:

- Directly^{xxviii(51)} affects patient satisfaction (0.23) and safety (0.15)
- Mediates the effects (i.e., indirect effect^{xxix(51)}) on patient satisfaction (0.39), self-reported health status (0.12), and safety (0.16) through its association with quality (0.46)
- Mediates the effect (i.e., indirect effect) of access on patient-reported outcomes (i.e., patient satisfaction, self-reported health status, and perceived safety)
 - Despite the influence of access on management continuity (0.56), management continuity still directly increases ratings of quality (0.46), patient satisfaction (0.23), and perceived safety (0.15). This indicates that management continuity can compensate for difficulties experienced when accessing healthcare services.

xxvii The unique effects of all measures in relation to each other were examined estimating a series of simultaneous regression (or structural) equations. One major advantage of structural equation modelling is that it allows the examination of multiple outcomes in one model (as opposed to one outcome using regression analysis).

xxviii The direct effect (i.e., impact) measures the extent to which a measure changes when the preceding measure increases and a third measure (i.e., mediator) remains unaltered.

xxix The indirect effect (i.e., impact) measures the extent to which a measure changes when the preceding measure is held fixed and a third measure (i.e., mediator) changes by the amount it would have changed had the preceding measure increased.





Figure 9: Overall model with standardized path coefficients

Note: All participants (N=3,809); Fit indices (see Appendix VI): Chi-square=60(4), *p*<.01; Normed Fit Index=.99; Comparative Fit Index=.99; Goodness of Fit Index=.97; RMSEA=.06; Standardized RMR=.02 *statistically significant association

The impact of having a family doctor

The association between access and management continuity is itself influenced by whether a person has a family doctor (see Figure 10).^{xxx}

As illustrated, the effect of having a family doctor on management continuity is that:

- Having a family doctor enhances the benefits of very easy or easy access^{xxxi} to healthcare services (rating of 4 or 5 out of 5)
 - Having a family doctor, and rating access as very easy or easy, results in the highest composite score for management continuity (4.3 out of 5)
- Having a family doctor offsets the consequences of very difficult or difficult access to healthcare services (rating of 1 or 2 out of 5)
 - Having a family doctor, and rating access as very difficult or difficult, results in a management continuity composite score (3.2 out of 5) similar to those without a family doctor who rate access to healthcare services as very easy or easy (3.3 out of 5)

xee Results from the HQCA's 2014 Satisfaction and Experience with Healthcare Services survey show significant differences between respondents with a family doctor and those without. For further information, please refer to Appendix II, Table 1.

xxxi Single question assessing the degree of difficulty when accessing healthcare services



- Not having a family doctor worsens the effect of very difficult or difficult access (rating of 1 or 2 out of 5)
 - Not having a family doctor and experiencing very difficult or difficult access results in the lowest management continuity composite score (2.0 out of 5)

Figure 10: The association between management continuity score, having a family doctor, and rating of access to healthcare services



The models in Figures 11a and 11b illustrate the associations between access, management continuity, perceived quality, and patient-reported outcomes for those with a family doctor and those without.

The differences between the two groups are:

- Management continuity has significantly more influence on quality ratings (i.e., stronger direct effect of 0.60 versus 0.43) and patient satisfaction (i.e., stronger direct effect of 0.25 versus 0.22) for those without a family doctor compared with those who have a family doctor.
- The effect of access on management continuity becomes substantially stronger for those without a family doctor as shown in Figure 11b, compared with those with a family doctor as shown in Figure 11a (i.e., stronger direct effect of 0.65 versus 0.55).
- For Albertans with a family doctor, easier access increases ratings of perceived safety (0.13) (see Figure 11a). This is not the case for those who do not have a family doctor, however, as there is no significant direct effect between access and safety (see Figure 11b).
- For those with a family doctor, greater management continuity increases safety ratings (0.16), but the same direct effect is not significant for those without a family doctor.



In summary, Albertans without a family doctor are more dependent on access to healthcare services and management continuity to achieve positive patient-reported outcomes (i.e., patient satisfaction, self-reported health status, and perceived safety). Patients without a family doctor have fewer supports that contribute to their positive outcomes, as compared with those who have a family doctor and who thereby receive the additional benefits of relationship and information continuity.

Figure 11a: Overall model with standardized path coefficients for those who currently have a family doctor



Note: Participants who currently have a family doctor (N=3,310); Fit indices (see Appendix VI): Chi-square=56(4), *p*<.01; Normed Fit Index=.99; Comparative Fit Index=.99; Goodness of Fit Index=.99; Adjusted Goodness of Fit Index=.97; RMSEA=.06; Standardized RMR=.02

*statistically significant association



Figure 11b: Overall model with standardized path coefficients for those who do not currently have a family doctor



Note: Participants who do not currently have a family doctor (N=494); Fit indices (see Appendix VI): Chi-square=12(4), p<.05; Normed Fit Index=.99; Comparative Fit Index=.99; Goodness of Fit Index=.99; Adjusted Goodness of Fit Index=.96; RMSEA=.06; Standardized RMR=.02

*statistically significant association

4.4.2 The role of relationship and information continuity

The next set of analyses considers the influence of relationship and information continuity on management continuity, ratings of quality, and patient-reported outcomes. Relationship continuity is measured by assessing the quality of the relationship with a family doctor.^{xxxii} Information continuity is measured as the patient's experience of whether the family doctor is informed about changes to treatment or medications.

Figures 12 and 13 illustrate the association between having a very good or excellent relationship with a family doctor (composite score greater than 3.5 out of 5), access and information continuity, and management continuity.

The effect of the quality of the family doctor relationship is that:

- Having a very good or excellent relationship with a family doctor enhances the benefit of easy or very easy access (rating 4 or 5 out of 5) and patients are more likely to agree that information is shared with their family doctor (composite score greater than 3.5 out of 5).
 - Having a very good or excellent relationship combined with easy or very easy access results in the highest management continuity composite score (4.3 out of 5 in Figure 12).

^{xxxii} A very good or excellent relationship reflects a composite score greater than 3.5 out of 5 across nine questions. These questions include: explaining things to you, sufficient time spent, the doctor listening, being treated with respect and dignity, respecting the patient's choices, being encouraged to participate in care, caring for the patient as a person, and a trusting relationship.



- Having a very good or excellent relationship as well as good information continuity (composite score greater than 3.5 out of 5), too, results in the highest composite score for management continuity (4.3 out of 5 in Figure 13).
- Having a very good or excellent relationship with a family doctor offsets the effect of very difficult or difficult access (rating 1 or 2 out of 5), but not the consequences of poor information continuity (composite score less than 2.5).
 - Having a very good or excellent relationship results in a relatively high composite score for management continuity regardless of access ratings. As shown in Figure 12, those who rate access as easy or very easy have a management continuity composite score of 4.3 out of 5, whereas those who rate access as very difficult or difficult have a score of 3.9.
 - Easy or very easy access does not compensate for having a poor or fair family doctor relationship on the management continuity composite score (2.6 out of 5 in Figure 12).
 - Having a very good or excellent relationship with a family doctor and experiencing good information continuity results in a high management continuity composite score (4.3 out of 5 in Figure 13). Those who experience poor information continuity have a correspondingly lower management continuity composite score (3.3 out of 5 in Figure 13).
- Having a poor or fair relationship with a family doctor (composite score less than 2.5) worsens the effect of poor access and of poor information continuity.
 - Having a poor or fair relationship results in the lowest composite score on management continuity for those with poor access (2.3 out of 5 in Figure 12) and for those experiencing poor information continuity (2.0 out of 5 in Figure 13).

Figure 12: The association between management continuity scores, scoring on the quality of the relationship with a family doctor, and rating of access to healthcare services









Furthermore, the model in Figure 14 illustrates the increasingly complex associations between all three types of continuity,^{xxxiii} access, perceived quality, and the patient-reported outcomes of patient satisfaction, self-reported health status, and perceived safety.

In terms of benefits to patients, effective relationship, information, and management continuity:

- Can compensate for experiencing poor or fair access to healthcare services.
- Directly and indirectly affect (i.e., have a positive influence on) ratings of quality of received healthcare services, patient satisfaction with healthcare services received, self-reported health, and perceived safety.
- Indirectly mediate poor or negative results:
 - If access to healthcare services is experienced as very difficult or difficult (rating of 1 or 2 out of 5), patients' ratings of quality of received healthcare services would still increase with any improvement in either management continuity or relationship continuity. This in turn would still result in more positive patient satisfaction with healthcare services, self-reported health, and rating of perceived safety.

xxxxiii The model illustrates positive associations amongst the measures; as one measure goes up the resulting impact is an increase in the preceding measure(s).



- Both relationship and information continuity would contribute to improvements in management continuity even for those Albertans who experience access as very difficult or difficult.
- Management continuity could compensate for having a poor or fair relationship with the family doctor, and a very good or excellent relationship could compensate for poor or fair management continuity. This is because improvements in either management or relationship continuity influence quality ratings of healthcare services received.

In summary, Albertans who have an excellent or very good relationship with their family doctor, and who have good information continuity, experience positive management continuity; that is, they experience coordinated, timely care with enough help from providers to manage and coordinate their care, and follow-up care. This results in more positive patient satisfaction, selfreported health status, and perceived safety.

Figure 14: Overall model with standardized path coefficients for all Albertans who currently have a family doctor



Note: Participants who currently have a family doctor (N=2,175); Fit indices (see Appendix VI): Chi-square=48(9), *p*<.01; Normed Fit Index=.99; Comparative Fit Index=1.00; Goodness of Fit Index=.99; Adjusted Goodness of Fit Index=.98; RMSEA=.04; Standardized RMR=.02

*statistically significant association



4.4.3 The continuity of care hub

As has been shown, management continuity results directly and indirectly (i.e., mediated via quality) in better patient-reported outcomes for Albertans with and without a family doctor. Moreover, Albertans who have a family doctor with whom they have a very good relationship and with whom information is shared across providers experience excellent or very good management continuity.

Together all three subtypes of continuity represent a 'continuity of care hub'. The 'continuity of care hub' is analyzed here in the context of primary care, as all three subtypes – relationship, information, and management – are recognized as critical elements of a health home.⁸ Providing a health home for every Albertan is one of three strategic directions set out in Alberta's Primary Health Care Strategy (2014), with the goal of delivering integrated and coordinated primary healthcare. It is essentially a 'home base' where Albertans can access and be connected with health, social, and healthcare services; it is where Albertans receive team-based primary care services connected with other services, as well as support by the team to coordinate and manage the entire patient journey. Central to the health home is an ongoing and trusting relationship between the patient and family doctor (or sometimes a team), which enables better information-sharing, as well as planning and managing care.

It is assumed that the 'continuity of care hub' is founded within primary care with the patient-provider relationship being most valued by patients, as was shown in the qualitative results. In contrast, primary care providers most value sharing information regarding changes to medications and treatment details.

Albertans are classified as experiencing a 'continuity of care hub' when they score on average greater than 3.5 out of 5 for relationship, information, and management continuity. In contrast, those who score on average less than 2.5 out of 5 on all three continuity scales are classified as lacking a 'continuity of care hub'. In total, 47 per cent of respondents are classified as having a 'continuity of care hub'; 2 per cent are classified as not having a 'continuity of care hub'; and 51 per cent are in the middle as having some degree of management, information, and relationship continuity (Figure 15).



Figure 15: Per cent of respondents classified as having or not having a 'continuity of care hub' as determined by how they score on the three continuity scales of relationship, information, and management



It was hypothesized that scoring high on all three types of continuity results in better patient-reported outcomes. This is confirmed in the SEHCS survey data, as respondents who experience a 'continuity of care hub' give significantly higher ratings for perceived quality, patient satisfaction, self-reported health status, and safety as compared with those who do not experience a 'continuity of care hub' (see Figure 16).





Figure 16: Impact of experiencing a 'continuity of care (CofC) hub' on patient-reported outcomes



Relationship, information, and management continuity across different patient groups

Based on patient and provider experiences shared in qualitative interviews and focus groups, it was hypothesized that the role of information, relationship, and management continuity in influencing perceived quality and patient-reported outcomes could be uniquely different for individuals with different healthcare needs.

The HQCA's 2014 SEHCS survey asked Albertans to self-classify themselves into one of four groups (see Appendix II, Table 2):

- 1. No health issues rarely using healthcare system
- 2. Minor health issues routine use of the healthcare system
- 3. Serious health issues intense use of the healthcare system
- 4. Chronic health issues frequent and ongoing use of the healthcare system

As mentioned previously, in the context of the 'continuity of care bridge', there are significant differences between these groups (see Appendix II, Table 2). Those with increased healthcare needs use health services more often and see significantly more providers in the system, have more chronic conditions, and take more prescription medication. Due to the differences in their healthcare needs, the next set of structural equation models examines the associations between the different subtypes of continuity and patient-reported outcomes for these four groups. As shown as arrows in Figures 17a to 17d, there are significant differences in the magnitude of the associations between the four groups.^{xxxiv} These models examine if all four groups benefit from a 'continuity of care hub', how this works, and how the 'continuity of care hub' affects patient-reported outcomes, potentially in different ways.

Respondents with no health issues

For Albertans who reported 'no health issues', a very good or excellent relationship with the family doctor results in improved information and management continuity (see Figure 17a). Moreover, for this group of respondents, access has the strongest bearing on perceived quality (stronger than management continuity). Contrary to the other three groups of respondents who reported health issues (Figures 17b, 17c, 17d), very good or excellent management continuity results in higher ratings of patient satisfaction for respondents who reported no health issues, regardless of experiencing excellent quality of care.

xxxiv All of the models showed extremely good fits (see Appendix VI) regardless of the group.





Figure 17a: Overall model with standardized path coefficients for those who reported no health issues

Note: Participants who reported no health issues (N=193); Fit indices (see Appendix VI): Chi-square=107.58(18), *p*<.01; Normed Fit Index=.99; Comparative Fit Index=.99; Goodness of Fit Index=.99; RMSEA=.07; Standardized RMR=.02 *statistically significant association

Another unique characteristic for those who reported no health issues (Figure 17a), and for those without a family doctor (Figure 11b), is the absence of a significant direct effect^{xxxv} between perceived quality and self-reported health status. Only a very good or excellent relationship with the family doctor results in better ratings of self-reported health status. Relationship and management continuity play unique roles in influencing patient satisfaction and self-reported health in this model versus the other three models (see Figures 17b, 17c, and 17d).

Essentially, Albertans with no health issues experience better outcomes when access to healthcare services is very easy or easy and/or when they experience good management continuity. However, difficulties obtaining access to healthcare services, and poor or fair management continuity, can be compensated for by a very good or excellent relationship with the family doctor and subsequently better information continuity, but not through perceived excellence in the quality of care as is the case for the other three groups with health issues.

xxxv These are represented by the dotted arrows and the 'ns' notation.



Respondents with minor, serious, and chronic health issues

Relationship and management continuity either directly or indirectly affect ratings of quality, patient satisfaction, self-reported health status, and perceived safety for Albertans with minor (Figure 17b), serious (Figure 17c), and chronic health issues (Figure 17d). For all three groups, a very good or excellent relationship with the family doctor (relationship continuity) increases scores for information continuity, which contributes directly to increases in scores for management continuity. This was also the case for those who reported no health issues (see Figure 17a). That means the 'continuity of care hub' benefits everyone who has a family doctor. One substantive similarity across the three groups of respondents with health issues is how relationship and management continuity can compensate for difficulties obtaining access to healthcare services. When access is rated as very difficult or difficult, increases in scores on relationship and/or management continuity would still have a positive effect on ratings of patient satisfaction, self-rated health status, and perceived safety. However, the magnitude of the effect of access on information and management continuity is different. Better ratings of access result in improved information continuity to a similar extent for those with minor health issues and those with ongoing serious health issues (0.14 and 0.13), but access has a larger direct effect on information continuity for those with serious health issues (0.20). Likewise, access has a similar effect on management continuity for those with serious and ongoing chronic health issues (0.48 and 0.46), but the direct effect is reduced for those with minor health issues (0.37).

Unique differences arise across the models and between measures in magnitude and whether the effects are significant. What these differences illustrate are the unique ways in which relationship, information, and management continuity (i.e., 'continuity of care hub') xxxvi affect ratings of quality, patient satisfaction, self-reported health status, and perceived safety within each of the three groups of patients with health issues. Uniquely, those who reported minor health issues and a very good or excellent relationship with their family doctor also rate higher on patient satisfaction. As well, Albertans who reported chronic health issues feel less concerned about unexpected harm while using healthcare services when they experienced management continuity.

Essentially, for Albertans with minor, serious, and chronic health issues, relationship, information, and management continuity are critical and either directly or indirectly contribute to better ratings for quality, patient satisfaction, self-reported health status, and perceived safety. The positive effects of experiencing a 'continuity of care hub' on patient-reported outcomes are strongest for those with serious and chronic health issues.

xxxxvi Excellent relationship with family doctor who is informed about medication changes or changes to treatment details by other providers, as well as the experience of coordinated, timely care with enough help from providers and follow-up care.



Figure 17b: Overall model with standardized path coefficients for those who reported minor health issues



Note: Participants who reported minor health issues (N=1,050); Fit indices (see Appendix VI): Chi-square=18.09(18), *p*=.45; Normed Fit Index=.99; Comparative Fit Index=1.00; Goodness of Fit Index=1.00; RMSEA=.00; Standardized RMR=.02 *statistically significant association





Note: Participants who reported major serious acute health issues (N=504); Fit indices (see Appendix VI): Chi-square=22.50(18), *p*=.21; Normed Fit Index=1.00; Comparative Fit Index=1.00; Goodness of Fit Index=1.00; RMSEA=.02; Standardized RMR=.02 *statistically significant association



Figure 17d: Overall model with standardized path coefficients for those who reported chronic health issues



Note: Participants who reported ongoing serious chronic health issues (N=404); Fit indices (see Appendix VI): Chi-square=15.62(18), *p*=.62; Normed Fit Index=1.00; Comparative Fit Index=1.00; Goodness of Fit Index=1.00; RMSEA=.00; Standardized RMR=.02 *statistically significant association



4.4.4 Summary

It has been shown that in the general population of Albertans who participated in the HQCA's SEHCS survey, those who score high in management continuity and give high ratings for quality of care, have correspondingly better patient-reported outcomes, including patient satisfaction, safety, and self-reported health status. Those who rate the quality of healthcare services they received as very good or excellent can compensate for poor or fair management continuity and still experience better patient-reported outcomes. Very easy or easy access to healthcare services improves management continuity scores, particularly for those who don't have a family doctor. Both access and management continuity have the strongest effect on patient-reported outcomes for those who don't have a family doctor.

Albertans with a family doctor who experience additional supports (i.e., high scores for relationship and information continuity) also have higher management continuity scores. These additional supports can offset the effect of poor or fair access on management continuity. Very good or excellent management continuity can compensate for very difficult or difficult access (for those with and without a family doctor) and either directly or indirectly affect patient-reported outcomes through higher ratings for quality of healthcare services. Moreover, a very good or excellent relationship with the family doctor can compensate for poor or fair management continuity, and still result in improved patient-reported outcomes.

Albertans who experience a 'continuity of care hub' (relationship, information, and management continuity) have significantly higher ratings for perceived quality, patient satisfaction, self-reported health status, and perceived safety as compared with those without a continuity of care hub. The effects of a continuity of care hub on patient-reported outcomes are strongest for those with serious and chronic health issues.



5.0 STUDY CONCLUSIONS

Continuity of care encompasses quality of patient care over time and how an individual's healthcare journey is connected across healthcare events and providers.² In essence, continuity of care is the product of patients and healthcare providers working together to provide coherent, connected, and consistent care. Continuity can be directly experienced in the context of the patient and his or her immediate healthcare professional (i.e., 'continuous caring relationship') or indirectly in the context of the wider organization (i.e., 'seamless service' or 'integrated care').⁵²

From a patient perspective, the gaps in continuity suggest that healthcare services do not function as a system; it may be asserted that healthcare services have never been designed from a systems perspective. Importantly, this study confirms that continuity of care is most at risk at transition points and many of these occur across organizational boundaries, particularly transitions within and between primary, specialist, hospital, and continuing care. As a result, patients experience confusing or conflicting messages from different places and providers. Often, patients report that they and their families provide needed continuity by tracking and following up on their care. This means that Alberta's healthcare system is actually a patchwork of disconnected processes that fail to "communicate" with each other, as depicted in the conceptual pictogram, the 'continuity of care bridge'. Future conversations about health system design should focus on how all providers and services can work together and codesign a system that is managed around patient-centred relationships.

Throughout the patient journey, primary care is usually the first point of contact. Primary care is provided in community settings such as doctors' offices, community health centres, ambulatory care, and urgent care and walk-in clinics. As has been shown by this study's findings, primary care providers can often play a crucial role in managing their patients' care, as they build trusting, ongoing relationships over time, refer patients to other healthcare services, coordinate care and information received from other providers, and provide follow-up and ongoing care for their patients. Moreover, the family physician is often viewed as the central hub, responsible for coordinating access to healthcare services, including specialized care, rehabilitation, and mental health services.⁵³

Through the literature review, as well as qualitative and quantitative study findings, it has been shown that continuity of care is founded on three key concepts of relationship, information, and management continuity. Relationship and information continuity are measured only where patients have a family doctor; management continuity is measured for those with and without a family doctor. Literature and the qualitative and quantitative results from this study show that:

1. Relationship continuity refers to a trusting relationship with one or multiple providers.¹ From the patient perspective, relationship continuity is most valued and is foundational for experiencing information and management continuity. Most positive relationships are built with the family doctor. The quality of these relationships is described as being patient-centred, with an emphasis (among other quality characteristics) on being treated with respect and as a person, not as a 'case number'. Patients recognize that it takes time to build these relationships. From the provider perspective, working relationships with other providers are described as often being key to providing timely access for their patients and thus improve the experience of management continuity.



Nine characteristics of an excellent patient-family doctor relationship were embedded in the Health Quality Council of Alberta's Satisfaction and Experience with Healthcare Services (SEHCS) survey. Of these nine characteristics, respondents are least satisfied with the amount of time a family doctor spends with the patient. The survey results clearly show that an excellent relationship with the family doctor has a significant and positive influence on information and management continuity, perceptions of quality, and patient-reported outcomes. Furthermore, an excellent relationship with the family doctor can compensate for poor management continuity, as it still results in better patient-reported outcomes.

2. Information continuity concerns the timely availability of information, including patient's preferences, values, and context.¹ From the provider perspective, information continuity is most important, and primary care providers get frustrated if information is withheld or delayed, particularly when other providers change treatment plans or medications. From the patient perspective, timely access to their own information is highly valued and they recognize that their providers have online access to their test results. Patients feel that information continuity requires patient-centred relationships, in which the provider offers enough time during an appointment, listens to the patient to assess what has been tried previously and what has worked well or not, and provides clear communication with the patient, such as what to expect from a certain procedure.

Questions were added to the SEHCS survey to measure whether changes made to treatment plans or medications by other providers had been passed along to the family doctor. The survey results show that patients agree this generally occurs. The results further show that both relationship and information continuity result in better management continuity scores, which in turn improve patient-reported outcomes.

3. Management continuity involves the communication of patient-related information across healthcare teams, organizational, and professional boundaries, as well as between healthcare professionals and patients.⁶ Both patients and providers value and benefit from management continuity, which ideally includes a partnership or shared responsibility for managing and coordinating healthcare services. However, some patients, particularly young people with complex conditions, prefer a more active role in their care management; others prefer a more passive role, particularly elderly people. Patients and providers felt that shared responsibility is enabled through coordinated and timely access to healthcare services, as well as enough help from providers to coordinate and manage their care, and planned follow-up care. This was also reflected in the SEHCS survey responses.

The survey results show that management continuity either directly or indirectly (via quality of care) improves patient-reported outcomes. This is true also for those who experience difficulties accessing healthcare services. Both access to healthcare services and excellent management continuity are substantially more important for those who don't have a family doctor, as they can't experience the benefits of relationship and information continuity. For those who have a family doctor, excellent management continuity can compensate for a poor relationship, still resulting in better patient-reported outcomes.



In examining the role of relationship, information, and management continuity together, it becomes apparent that these critical elements make up a 'continuity of care hub' that improves the patient experience and patient-reported outcomes. All three types of continuity can compensate for experiencing difficulties accessing healthcare services. They are particularly important for Albertans with serious or chronic health issues. These findings underline the importance of developing primary care processes that optimize all three types of continuity to achieve a 'continuity of care hub'.

5.1 Obstacles to continuity of care

Both patients and providers perceive primary care as too disconnected from the rest of the healthcare system (i.e., community, hospital, specialist, and continuing care). Healthcare providers and many patients recognize that the healthcare system itself creates problems for providers trying to deliver good care. Among some patients and healthcare providers there is a perception that problems with continuity are more a consequence of how the healthcare system is structured than the practice of individual healthcare providers. Healthcare providers were more likely to mention the system-level issues that affect continuity, such as funding models and lack of system accountability for providing continuity of care (e.g., putting incentives and disincentives in place). Providers suggest that in the current healthcare system, acute care and primary care do not interact well or consistently. Patients, more so than providers, note there is often nowhere for patients and families to seek help if they are facing difficulties caused by a lack of continuity.

Patients report that relationship continuity is jeopardized when a family doctor moves away or retires, or when the patient moves away or into a long-term-care setting. Finding a new family doctor and getting medical records transferred, they say, is often difficult. Another barrier to relationship continuity is experienced in the hospital setting where patients see multiple providers who work in shifts. Poor continuity is a consequence of there being no one clearly responsible for coordinating care or communicating relevant information.

Information continuity is at risk when primary care providers are not informed of patients' admissions to hospital or to the emergency department, even though patients are usually asked at admission for their family doctor's name. Moreover, providers are frustrated when discharge summaries are delayed or withheld, which interferes with providing appropriate follow-up care. If patients take on a more active role and make referrals themselves, information is less likely to flow back to the family doctor than when primary care staff make the referral.

Poor management continuity is perceived when patients see a family doctor they don't trust, because they feel the family doctor is not listening and has insufficient time to discuss their health issues. Moreover, patients and caregivers often feel ill prepared to take on more responsibility for their own health and healthcare. It is felt that there are too few coordinator and navigator roles in the system to help manage care, especially for those with complex health issues and for those without any support from friends or family. In addition, a reported lack of available social workers makes it hard on vulnerable people to navigate the complex network of available social and financial supports. Another barrier to management continuity is that primary care providers often deal with a comprehensive range



of physical, mental, and behavioural health issues for which access to programs and specialists is difficult to facilitate (e.g., pain management, behavioral health consultant or psychologist, physiotherapy, or certain specialists). Finally, the cost and travel from rural or remote areas associated with specialist visits is particularly burdensome for seniors and those with low incomes.

The quantitative findings provide evidence that not having or rarely visiting a family doctor is a structural barrier to relationship, information, and management continuity. In particular, Albertans without a family doctor and those who rarely visit their family doctor have fewer supports (i.e., relationship and information continuity) that improve perceived quality of the healthcare system and consequently patient-reported outcomes. In addition, having a poor relationship with a family doctor is implicitly a barrier to experiencing good information and management continuity, especially for those with serious or chronic health issues.

Moreover, extensive modelling shows that all these barriers to continuity of care are more likely experienced by those who use the healthcare system frequently and therefore require a strategy to bridge these gaps (i.e., the 'continuity of care bridge'). These frequent users are Albertans who report serious acute health issues or hospitalization and require specialists, surgery, and intensive use of healthcare services over a short period of time, or those who report chronic serious health issues and use healthcare services on continuing basis.

5.2 Opportunities for improvement from the patient and provider perspective

Key opportunites to leverage lessons from the patient and provider experiences suggest structuring primary care practices and processes to function as a 'continuity of care hub'xxxvii where relationship, information, and management continuity work together to ensure a seamless healthcare experience. These are all critical elements of the patient-centred health or medical home (i.e., providing longitudinal and coordinated care).¹⁸ Built around a single most responsible family doctor (or very rarely a specialist), the hub is an integrated group of resources designed to ensure continuity of care.

Primary care physicians and their teams often have strategies in place to improve teamwork and communication among theselves in order to help bridge gaps in continuity. However, they often feel the need to side-step normal primary care practices and processes to facilitate coordinated and timely access to healthcare services for their patients.

xxxvii Those who experience a "continuity of care hub" experience a very good relationship with their family doctor, high levels of information continuity and excellent management continuity.



Both patients and providers suggest the following to improve continuity of care:

- 1. Relationship continuity a patient-centred trusting relationship between a family doctor or care team and a patient and family
 - Improve patient access to family doctors and to team-based care, especially for those with serious ongoing health issues, as these individuals in particular see the benefit of building close relationships to health teams.
 - Improve coordination and teamwork between the family doctor and a specialist.
- 2. Information continuity consistent and effective transfer of relevant information among everyone involved in a patient's healthcare journey
 - Ensure access to and user-friendly organization of information through the implementation
 of a single universal electronic health record with integrated links and updates of electronic
 medical records used in primary care practices.
 - Facilitate active patient engagement through, for example, a patient portal^{xxxviii} as part of a single, universal electronic health record system, which was described by patients and primary healthcare providers as being vital for enhanced patient engagement and for enabling shared responsibility (i.e., management continuity).
- 3. Management continuity the communication of patient-related information across care teams, organizational and professional boundaries, and between providers and patients
 - Assign primary care or community-based coordinators/navigators to vulnerable patients such as those with complex health issues and/or limited family support, as they are most at risk of falling through gaps in continuity. Primary care teams (including social workers) could take on this role.
 - Implement a standardized referral system to improve coordinated and timely care (management continuity).
 - Enable primary care to play a more extensive role in facilitating comprehensive care in areas such as mental health and physiotherapy, especially when the patient has insufficient income and/or health plan coverage, as this is often managed and payed for by patients and their families.

The HQCA will continue to measure continuity of care through:

- ongoing use of the HQCA's newly established continuity of care scales to measure and track continuity of care experience at the Alberta population level, and
- establishing measures of continuity at the primary care practice level.

xxxxviii A system which allows patients and caregivers to access, monitor and manage their health information.



APPENDICES

Promoting and improving patient safety and health service quality across Alberta



APPENDIX I: MODEL BUILDING STEPS

The method used to arrive at the final model and measures used were informed by the literature, qualitative results, and the Health Equity Measurement Framework from Alberta Health. Traditional models regarding patient satisfaction, based on the literature, have presumed that when the patient interacts with the healthcare system, access is highly important, as is the perceived quality of services received. Coordination of care was viewed as an additional concept that, along with access and quality, should impact patient satisfaction. Using this as a basic framework, *access* was placed at the front of the model and predicted the other measures in the model. Placement of relationship and information continuity, as well as additional measures assessing perceived quality and relevant outcome measures available in the survey, such as patient satisfaction, perceived safety, and self-rated health status, were also added. How these measures relate to each other is explained below and shown in subsequent figures.

A first step was to build on the Health Equity Measurement Framework in recognition of potential synergies (as Alberta Health focuses on health determinants whereas the Health Quality Council of Alberta's (HQCA) survey focuses on patient experience measures). In the proposed framework by Alberta Health, "health state" was a measure serving as a link between several socio-demographic characteristics and utilization of the healthcare system (also assessed by the HQCA's survey). Thus, the potential of including two measures (number of encounters with the healthcare system in the past year, and the number of chronic conditions reported by patients) into the model was explored. However, while these two measures were correlated with each other (a standardized coefficient of about 0.22), they did not relate to the access measure in the model, and were therefore not included. However, based on previous analysis of provincial survey data, it was reasonable to hypothesize a relationship between a measure of self-reported health status and various measures of patient experience; thus, this was included in subsequent models.

While self-reported health status is a measure that theoretically can be placed 'at the beginning' of a model (i.e., people who are less healthy would access services more frequently), perceptions of one's own health (as assessed by the EQ VAS^{xxxix}) are also viewed as an outcome measure of healthcare, and could therefore be placed 'at the end' of a model. The way this paradox was handled was to use the VAS measure of health status as an outcome measure and then assess and compare the proposed model according to four major self-reported categories of healthcare service need.^{xi} This is a shortcoming in the modelling process, as health status is still a factor at both the front and back. It would be better to model changes in health status over time; however, the available data do not provide longitudinal information.

xxxix 'On a scale from 0 to 100, where would you put your own state of health today?'

^{xl} Involvement with healthcare system: (1) No health issues/never or rarely use healthcare services; (2) Minor health issues, resolved quickly/use routine healthcare services; (3) Serious acute health issue/hospitalization, require specialist, surgery/intense use of healthcare services over a short period of time; (4) Chronic serious health issues/frequent ongoing use of healthcare services



In light of the work done on the Health Equity Measurement Framework, as well as the level of concern reported in the absence of continuity of care, an additional measure of patient safety^{xli} was incorporated into the model. Moreover, the traditional measure of patient satisfaction was also deemed to be an important but high-level healthcare system performance measure for Alberta Health.

Fleshing out the continuity of care concept into its three subtypes (i.e., relationship, information, and management) was an important step. While related to each other, these are somewhat unique constructs that do not completely overlap. The positioning of variables in the model was driven by theory/literature, key informant interviews with Albertans, as well as discussions with stakeholders. Through these interviews and discussions, it was theorized that the *quality of a patient's relationship* with his/her family doctor (explaining things, information is understood, amount of time spent, listening, respect and dignity, respecting care choices, help to participate, caring for you as a person, and amount of trust) would have a primary impact on patient interaction and experience with the healthcare system. Thus, this measure was placed at the beginning of the model. The quality of that relationship, then, would be expected to affect patients' perceptions of how well information flowed to the family doctor, the management of their care, the quality of that care, patient satisfaction, and perceptions of one's personal health status. The degree to which information about changes to treatment or medications is perceived to flow to the family doctor should also affect overall perceptions of management continuity. Management continuity (coordinated and timely care with enough help from providers and follow-up care) was then expected to predict quality, patient satisfaction, and perception of safety expressed by low levels of concern that harm could occur in the course of care and treatment.

While these paths are built on theory and literature, it was empirically examined whether or not management continuity would be better predicted by quality than the reverse. This was not the case. In addition, it was examined whether the direction of the paths *going to* management continuity from access, family doctor-relationship, and information continuity would be better if the paths *went from* management continuity to these three measures. In each instance, it was found that management continuity was better placed as being impacted by access, family doctor relationship, and information continuity.

The relationship between access and family doctor relationship was also discussed. The correlation between these measures is low to moderate, but whether there is a clear directionality between them was debatable. One might argue that a better relationship with one's family doctor should facilitate easier access to services. On the other hand, if patients experience good access to healthcare services, they may then rate the quality of their relationship with their family doctor better. Given the interest in seeing how both access and family doctor relationship affected subsequent measures in the model, especially across demographic groups, the model simply allowed them both to be exogenous variables and the correlation between them was left unanalyzed. Future research into predictors of these measures would provide a fuller understanding of the patient experience of the healthcare system.

x^{li} 'To what degree are you personally concerned that unexpected harm could occur in the course of your care and treatment as a patient?'



As noted, not all of the respondents had a family doctor, which meant that they would not have meaningful assessments of relationship and information continuity as it was measured in the survey. This gave rise to examining those with and those without a family doctor as unique samples. Those without a family doctor (and the entire sample as a whole which included these individuals) then, required a different model for analysis of their data.

For those respondents with no family doctor and for analyses using the entire sample the model took the following form (see Figure 18) and explores the role of management continuity:xlii



Figure 18: The role of management continuity

x^{lii} Four items were asked of all participants (i.e., those with and without a family doctor). The first item, is general and asks 'How would you describe how well all of the healthcare professionals coordinated their efforts to serve your needs?' (five-point Likert-type response scale, 'poor' to 'excellent'). The remaining three items focused on specific aspects of management continuity, and used a five-point Likerttype agreement response scale, 'strongly disagree' to 'strongly agree'. The specific items were: 'getting enough help from healthcare providers to coordinate or manage care', 'care was coordinated or managed in a timely manner', and 'healthcare providers follow up on healthcare'.



For those respondents who have a family doctor, the model included two additional variables (relationship^{xliii} and information continuity^{xliv}) and took the following form (see Figure 19):





x^{liii} Albertans were asked to rate their family doctor on (1) explaining things to you, (2) making sure of your understanding, (3) amount of time spent with you, (4) listening to you, (5) treating you with dignity/respect, (6) understanding your personal healthcare choices, (7) allowing you to participate in your healthcare, (8) caring for you as a person, and (9) your trust in your GP. Responses for all items were captured on a five-point Likert-type scale, 'poor' to 'excellent'.

x^{liv} Two items were developed to assess generally the degree to which the family doctor appears to have been automatically given details about care received from other providers, as well as about changes in medication that another provider recommended. Responses for all items were captured on a five-point Likert-type scale, 'strongly disagree' to 'strongly agree'.



APPENDIX II: SURVEY RESPONDENT CHARACTERISTICS

	All	"Having a family doctor" (84%)	"Not having a family doctor" (16%)	Test for significant group differences
Age in years (SD)	46.1 (16.96)	47.5 (17.07)	38.7 (14.41)	F(1,4416) = 163.052, <i>p</i> <.001
Gender Male Female	50.1% 49.9%	47.3% 52.7%	64.8% 35.2%	$\chi^2(1) = 71.32,$ p < .001
Utilization of healthcare services	3.9 (2.26)	4.1 (2.21)	2.5	F(1,4416) = 327.763, p <.001
Preferred GP Other GP	83.6% 26.6%	84.4% 26.1%	49.4% 50.6%	<i>p</i> < .001 <i>p</i> < .001
Other primary care provider Walk-in clinic	13.0% 30.8%	12.7% 26.9%	25.9% 51.4%	<i>p</i> < .001 <i>p</i> < .001
Specialist Diagnostic testing	43.9% 47.1% 66.9%	47.4% 50.4% 70.0%	25.4% 29.7%	p < .001 p < .001
Emergency department Hospital overnight	45.5% 11.4%	46.5% 12.2%	40.3% 7.4%	p < .001 p < .05 p < .001
Hospital day Mental health	22.5% 13.3%	23.2% 13.4%	18.6% 12.6%	p < .05 p = .560
Chronic Conditions	1.5 (1.81)	1.6 (1.87)	0.9 (1.33)	F(1,4416) = 87.533, <i>p</i> <.001
Diabetes	7.6%	8.5%	2.9%	<i>p</i> < .001
COPD	2.4%	2.6%	1.3%	<i>p</i> < .05
Asthma	8.7%	9.2%	6.3%	<i>p</i> < .05
High blood pressure	18.8%	20.8%	8.5%	<i>p</i> < .001
High cholesterol	12.0%	13.4%	4.6%	<i>p</i> < .001
Sleep apnea	7.6%	7.8%	6.4%	<i>p</i> = .226
Congestive heart failure	1.0%	1.1%	0.3%	<i>p</i> < .05
Obesity	9.4%	10.0%	6%	<i>p</i> < .05
Depression or anxiety	16.3%	16.4%	15.5%	<i>p</i> = .543
Chronic pain	17.2%	17.7%	14.3%	<i>p</i> < .05
Arthritis	21.8%	23.7%	11.9%	<i>p</i> < .001
Heart disease	5.0%	5.8%	1.1%	<i>p</i> < .001
Stroke	1.4%	1.5%	0.9%	<i>p</i> = .168
Cancer	4.0%	4.5%	1.6%	<i>p</i> < .001
Kidney disease	2.0%	2.1%	1.6%	<i>p</i> = .345
Bowel disorder/Crohn's disease	4.7%	5.0%	3.1%	<i>p</i> < .05
Other	12.4%	13.2%	8.0%	
Prescriptions	2.3 (2.73)	2.4 (2.79)	1.3 (1.89)	F(1,4416) = 65.057, <i>p</i> <.001

Table 1: Survey respondent characteristics for those with and without a family doctor



	"Have a family doctor"				
	(84.2%)				
	"No	"Minor	"Serious	"Chronic	
	health issues"	health issues"	health issues"	health issues"	
	(14.1%)	(42.6%)	(15.7%)	(11.3%)	
	never/rarely use of	routinely use of	intense use of	frequent/ongoing use of	
	healthcare services	healthcare services	healthcare services	healthcare services	
Age and gender	• 44 ± 17 years old	• 47 ± 17 years old	• 51 ± 16 years old	• 51 ± 16 years old	
Age and genuer	• 57.3% male	• 55.2% female	• 56.1% female	• 51.4% female	
	 two services on average 	 four services on average 	 six services on average 	 six services on average 	
	 58% saw preferred family 	 87.3% saw preferred family 	 94.6% saw preferred family 	 94.1% saw preferred family 	
	doctor	doctor	doctor	doctor	
	• 25.3% ED*	• 43.8% ED*	• 63.6% ED*	• 59.6% ED*	
Utilization of healthcare	• 6.4% MH**	• 10.2% MH**	• 16.3% MH**	• 30.8% MH**	
services over past 12 months			• 78.7% Specialist	• 79.1% Specialist	
			 77.3% Diagnostic testing 	 68.4% Diagnostic testing 	
			• 83.1% Pharmacy	• 87.9% Pharmacy	
			• 34.3% Hospital	• 24.7% Hospital	
			 45% Hospital - outpatient 	• 41.2% Hospital - outpatient	
	• One	• One	• Two	Three or four	
Chronic condition on average	• Top three conditions: arthritis	• Top three conditions: arthritis	• Top three conditions: arthritis	• Top three conditions: chronic	
	(11.9%); high blood pressure	(20.7%); high blood pressure	(30.3%); high blood pressure	pain (45.1%); arthritis	
	(9.5%); depression or anxiety	(19.9%); depression or	(25.8%); chronic pain	(40.6%); depression or	
	(8.7%)	anxiety (13%)	(25.1%)	anxiety (36.4%)	
Prescription medications on	• One	• Two	• Three	• Five	
average					

Table 2: Survey respondent characteristics for differing healthcare needs

*ED = Emergency Department utilized for themselves or for close family member over the past year

**MH = Mental Health



APPENDIX III: SCORING ON CONTINUITY OF CARE SCALES

Table 3: Mean and standard deviation (SD) for all continuity of care measures comparing the four health groups for those with a family doctor (GP) with those without a family doctor

Descriptives	Don't have a family doctor	No health issues	Minor health issues	Serious health issues	Chronic health issues	Test for significant group differences
Quality of family doctor relationship (SD)	-	4.1 (0.88)	4.2 (0.83)	4.3 (0.83)	4.1 (0.99)	F(3,3142) = 3.016,
Explaining things	-	4.2 (0.99)	4.3 (0.91)	4.4 (0.89)	4.2 (1.05)	p < .05
Information is understood	-	4.2 (0.99)	4.2 (0.99)	4.2 (0.97)	4.3 (0.93)	Serious >
Amount of time spent	-	3.9 (1.10)	3.9 (1.13)	4.0 (1.10)	3.9 (1.26)	Chronic
Listening	-	4.0 (1.07)	4.1 (1.04)	4.1 (1.04)	4.0 (1.20)	
Respect and dignity	-	4.4 (0.93)	4.5 (0.83)	4.5 (0.83)	4.4 (0.98)	
Respecting care choices	-	4.2 (0.98)	4.3 (0.93)	4.3 (0.94)	4.1 (1.08)	
Help to participate	-	4.1 (1.05)	4.1 (0.99)	4.2 (1.01)	4.0 (1.12)	
Caring for you as a person	-	4.2 (0.97)	4.2 (0.97)	4.3 (0.96)	4.2 (1.08)	
Amount of trust	-	4.2 (0.99)	4.2 (1.00)	4.2 (1.00)	4.0 (1.02)	
Information continuity (SD)	-	4.0 (1.01)	3.9 (1.15)	4.0 (1.08)	3.9 (1.10)	F(3,2698) =
Medication changes recommended by:						1.395, <i>p</i> = .242 No = Minor =
Other provider	-	4.1 (0.96)	4.1 (1.06)	4.2 (1.12)	4.1 (1.13)	Serious =
Walk-in clinic	-	3.8 (1.35)	3.2 (1.54)	3.4 (1.57)	3.2 (1.58)	Chronic
Emergency department	-	4.4 (0.60)	3.5 (1.43)	3.5 (1.53)	3.8 (1.49)	
Specialist	-	3.9 (1.25)	4.1 (1.19)	4.0 (1.30)	3.8 (1.54)	
Mental health specialist	-	3.8 (1.31)	3.9 (1.50)	3.6 (1.54)	3.5 (1.45)	
Family doctor has been given details about care received from other provider	-	3.9 (1.16)	3.9 (1.26)	4.0 (1.20)	4.0 (1.25)	
Management Continuity (SD)	3.4 (1.04)	3.9 (0.84)	3.8 (0.85)	3.7 (0.96)	3.7 (1.05)	F(1,3933) = 89.987,
Coordinated efforts	3.3 (1.16)	3.7 (1.00)	3.6 (1.05)	3.5 (1.13)	3.4 (1.25)	<i>p</i> <.001
Help from providers	3.4 (1.19)	4.0 (0.95)	4.0 (0.96)	3.9 (1.04)	3.8 (1.19)	No GP < GP
Timely management	3.4 (1.32)	3.9 (1.03)	3.8 (1.06)	3.6 (1.25)	3.6 (1.32)	
Followed up on care	3.4 (1.32)	4.0 (1.03)	3.9 (1.08)	3.9 (1.19)	3.9 (1.19)	F(3,3387) = 7.416,
						<i>p</i> < .001
						No = Minor < Serious = Chronic

Note: Global F-tests are used to compare variance between groups with variance within groups; Contrast comparisons (i.e., independent samples *t*-tests) are used to investigate statistical differences between two groups (i.e., no health issues versus minor health issues; minor versus serious health issues; serious versus chronic health issues)



APPENDIX IV: SCORING ON PATIENT EXPERIENCE SURVEY MEASURES

Table 4: Mean and standard deviation (SD) for all other patient experience measures used for statistical modelling comparing the four health groups of those with a family doctor (GP) with those who do not have a family doctor

Descriptives	Don't have a family doctor	No health issues	Minor health issues	Serious health issues	Chronic health issues	Test for significant group differences
Access (SD)	3.3 (1.29)	3.7 (1.19)	3.6 (1.12)	3.3 (1.31)	3.2 (1.34)	F(1,4056) = 6.790, p < .05
						No GP < GP
						F(3,3467) = 26.703, p < .001
						No > Minor > Serious = Chronic
Perceived quality	2.8 (0.90)	3.1 (0.78)	3.1 (0.74)	3.1 (0.80)	2.9 (0.92)	F(1,4099) = 32.677, p <.001
(SD)						No GP < GP
						F(3,3500) = 9.505, p < .001
						No = Minor = Serious >
						Chronic
Satisfaction (SD)	3.6 (1.18)	4.0 (0.95)	3.9 (0.94)	3.8 (1.07)	3.6 (1.17)	F(1,4093) = 39.228, p < .001
						No GP < GP
						F(3,3496) = 19.299, p < .001
						No = Minor > Serious >
						Chronic
Perceived safety	3.8 (1.31)	3.9 (1.28)	4.0 (1.24)	3.6 (1.35)	3.4 (1.40)	F(1,3908) = 0.328, p = .567
(SD)						No GP = GP
						F(3,3359) = 31.911, p < .001
						No = Minor > Serious >
						Chronic
Self-rated health	80.0	83.4	81.4	74.7	61.3	F(1,4390) = 11.895, p < .05
status (SD)	(14.64)	(12.89)	(12.18)	(15.93)	(21.10)	No GP > GP
						F(3,3643)=291.605, p < .001
						No > Minor > Serious > Chronic



APPENDIX V: QUESTION WORDING OF MEASURES INCLUDED IN THE MODELLING PROCESS

Table 5: Wording of the Health Quality Council of Alberta's Satisfaction and Experience with Healthcare Services Survey Questions

Access	Continuity of care experiences	Patient-reported outcomes
<u>Access</u>	Relationship	Perceived quality
How difficult or easy was it for you to actually obtain needed healthcare services in Alberta? (five-point Likert- type response scale, 'very difficult' to 'very easy')	Responses for all items were captured on a five-point Likert-type scale, 'poor' to 'excellent'. Thinking of the past year, how would you rate your family doctor: 1. explaining things to you in a way you can understand 2. making sure you understand all the important information 3. amount of time your family doctor spends with you to address your issues 4. listening to you 5. treating you with respect and dignity 6. understand all the important information 9. amount of trust you have in your healthcare choices 7. helping you to participate fully in your healthcare 8. caring for you as a person 9. amount of trust you have in your family doctor Information All items used a five-point Likert-type response scale, 'strongly disagree' to 'strongly agree'. Thinking of the past year, how much do you agree that your family doctor appears to know about changes in your medication: 1 that another provider recommended? 2 that the <u>walk-in clinic</u> recommended? 3 that the <u>specialist</u> recommended? 3 that your <u>mental health specialist</u> recommended? 3 that fue great year, how would you describe how well all of the healthcare professionals coordinated their efforts to serve your needs? (five-point Likert-type response scale, 'por' to 'acellent') The remaining three items focused on specific aspects of care coordination management, and used a five-point Likert-type agreement response scale, ranging from 'strongly disagree' to 'strongly agree': Thinking of the past year, how much do you agree that your family doctor appears to have been automatically given details about care your needs? (five-point Likert-type response scale, 'por' to 'acellent') The remaining three items focused on specific aspects of care coordination famagement, and used a five-point Likert-type agreement response scale, ranging from 'strongly disagree' to 'strongly agree'	How would you describe the overall quality of healthcare services in Alberta? (four-point Likert-type response scale, 'excellent' to 'poor') <u>Perceived safety</u> To what degree are you concerned that unexpected harm could occur in the course of care and treatment as a patient in Alberta? (five-point Likert- type response scale, 'very concerned' to 'not at all concerned') <u>Self-reported health status</u> Assessed using the EQ VAS, which records the respondent's self-rated health on a vertical, visual analogue scale where the endpoints are labelled 'Best imaginable health state' (score 100) and 'Worst imaginable health state' (score 0) <u>Patient satisfaction</u> To what degree are you satisfied or dissatisfied with received healthcare services in Alberta? (five-point Likert- type response scale, 'very dissatisfied' to 'very satisfied')



APPENDIX VI: MODEL FIT INDICES

Goodness-of-fit indices reported include:54,55

- 1. Chi-square minimum fit function. If the model "fits" the data (the model's paths can accurately reproduce an estimated correlation matrix that is not different from the observed correlation matrix) then the chi-square will be NON-significant. Large sample sizes have an unfortunate effect on the chi-square, making it likely to be significant. So, a rough "rule of thumb" is that of the chi-square value/degrees of freedom ratio. If the ratio is less than 3:1 then the model is a good fit.
- 2. Root mean square error of approximation (RMSEA) assesses the discrepancy of the hypothesized model with optimally chosen parameter estimates. Values range from 0 to 1, with smaller values (less than .10) indicating a good fit.
- 3. Standardized root mean residual (SRMR) is the square root of the discrepancy between the observed correlation and estimated correlation matrices. Values range from 0 to 1, with smaller values (less than .08) indicating a good fit.
- 4. Goodness of fit (GFI) measures the fit between the estimate and observed correlation matrices. Values above .90 are considered good fits.
- 5. Adjusted goodness of fit (AGFI) corrects the GFI by 'penalizing' models with many paths. Fewer paths that can reproduce the correlation matrix are considered important for the AGFI. Values above .90 are considered good fits.
- 6. The normed fit index (NFI) assesses the discrepancy between the chi-square associated with the hypothesized model with the chi-square of the null model (no paths specified). Values above .95 are considered good fits.
- 7. The comparative fit index (CFI) assesses the discrepancy between the data and the chi-square associated with the hypothesized model while adjusting for sample size. Values above .90 are considered good fits.



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