HEALTHCARE PRACTICE

Saskatchewan Patient First Review – Patient Experience

Final Report

Advisory Services

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1.0 Introduction

KPMG and Innovative Research Group Incorporated (know hereafter as the "KPMG Team"), is pleased to provide this final report summarizing the results and analysis of the Patient Experience component of the Patient First Review. The KPMG Team comprises KPMG Consultants from the Regina office and the KPMG National Healthcare Practice, along with research experts from Innovative Research Group, a national public opinion research and strategy firm.

Over the past 7 months, The KPMG Team has assisted the Province of Saskatchewan in the conduct of the Patient Experience Review. The Patient Experience Review is one of two initiatives within a large-scale system transformation project called ***The Patient First Review***. The other component of Patient First – The Administrative Review – examined health care administration with the goal of finding ways to optimize the way corporate services are managed and delivered.

The Patient First Review, and its two components, was launched by the Province in order to find out what Saskatchewan residents feel about the way health care services are delivered, and to explore ways to improve the patient experience in the Province. Both reviews hired consulting firms and an independent Commissioner to conduct the reviews, which provided an independent process for Saskatchewan residents, health providers and stakeholders to discuss their health care experiences and their thoughts on how the Saskatchewan health care system should develop in the future. The Patient First Review is a landmark study in Canada for the unique approach it took by asking Saskatchewan citizens, health care providers and stakeholders to explore health issues from the perspective of the patient journey rather then from the traditional system/provider perspective.

This report presents the detailed results of the review and captures the voices of the patients, health care providers, and system stakeholders from the research conducted by the KPMG Team. The voices heard in the research provide a Province-wide perspective on what the issues are with the system, what the causes of those issues are, and what potential solutions should be considered to address those issues. Also included within this report are KPMG's recommendations to The Commissioner of this review. These recommendations provide The Commissioner with plausible solutions that are based on leading practice and KPMG's health care industry experience on how the Province can shift its system to deliver patient-centred care, and also how to address some of the larger system issues (e.g. wait times, access) currently experienced within the Province.

Accompanying this detailed report is a separate document which contains an executive summary of our detailed report. This summary will be used by The Commissioner to author his final report on the Patient First Review with his final recommendations to the Province. The Commissioners report will also contain three (3) case studies prepared by KPMG which profile 3 negative experiences in more detail, and provide leading practice solutions for how the issues might be addressed.

1.1 The Patient Experience

Many patients, health care providers and stakeholders are very proud of the Saskatchewan health care system. From patients in particular, there was some reluctance to be critical of the health care that they have received based upon the respect they had for health care workers and the universal health care system available to them in the Province.

Most days, and in most ways the Saskatchewan health care system works. But when it doesn't, the consequences can be severe. Thousands of Saskatchewan residents come into contact with the health care system every year, either directly or through assisting family members or friends in their own journey. Disappointing even a small percentage of these patients equates to improperly serving a good proportion of the Province's population who rely on the services the health care system provides.

Too often the human price of these disappointments and failures are masked by the use of percentages in satisfaction surveys. General positive statistics can distance health providers and decision-makers from the often demeaning and dehumanizing experiences that lie beyond the numbers. A key purpose of this report is to use patient voices to document the need to do better so that all those involved in the system have a constant reminder of the cost of the status quo. It is critical to note that providers and stakeholders consulted in the Patient First Review were quick to validate the range of concerns identified by patients. There was little sense of defensiveness and little interest in indulging in a blame game. Providers and stakeholders are patients too, and they have no difficulty in seeing a gap between the level of service they would like to deliver and the level of service that is delivered. Their voices are also heard throughout this document building a consensus that when it comes to health care, Saskatchewan needs to protect the best and fix the rest.

The Patient First dialogue was not just about what was wrong with the system, but how to make it better. All participants, regardless of their role in the health system, were quick to move from an acknowledgment that there is room for improvement, to a discussion of what can be done to improve the system. That discussion began with dialogue about the underlying factors that have been driving both positive and negative experiences – that is, "causes" of experiences. The discussion then moved to a process of identifying ideas for improvement.

The "causes" discussion had some particularly interesting surprises. Concerns about funding and staffing were often mentioned, but a wide range of additional factors were also identified. Key among the critical success factors is strong leadership at all levels of the system.

The "ideas for improvement" discussion was particularly fruitful. The patient and provider discussions and workbooks generated 150 ideas for improvement, which were eventually boiled down to six key categories for improvement. When stakeholder groups addressed those six categories for improvement, another approximately 350 ideas were generated. With 500 ideas on the table for how to make improvements to the system, the patients, providers, and stakeholders were clearly not focused

merely on pointing out what ailed the system, but were very thoughtful and insightful about ways to make improvements.

There is a clear bias for action to improve the system so that it consistently delivers in practice what it promises in theory. Saskatchewan people are accepting and realistic; they want quality and safe care delivered within reasonable timelines and by health care professionals who treat them with the same care, kindness and respect any individual would wish for themselves, their family members or their friends. High standards and the continual pursuit of excellence should be par for the course when both quality and length of life are at stake.

Saskatchewan residents were appreciative of this process, one that allowed their voice to be heard on a topic/issue that is very close to home for many within the Province – health care. Patients were passionate in their input to the process, and were optimistic and hopeful that action would be taken by the government and that that their feedback would help bring about change and continued improvement.

1.2 Report summary

The KPMG Team final report summarizes the research findings from speaking with patients, providers, and system stakeholders about system issues, causes and potential solutions. The report is organized by the following five sections:

- Section 2 describes the methodology used to gather input during all phases of the Patient Experience component of the Patient First Review.
- Section 3 provides a detailed summary of the most common positive and negative patient experiences that arose from analysis of focus groups, telephone interviews, and patient workbooks. In total, there are 5 positive experience themes and 14 negative experience themes.
- Section 4 discusses the key themes pertaining to the "causes" of positive and negative patient experiences from our discussions with patient and providers. This discussion of "causes" revolved around the drivers of negative patient experiences and the enablers of positive patient experiences.
- Section 5 presents patient, provider and stakeholder thoughts on the "categories for improvement", which are solution ideas heard through the research process for maintaining good activity in the system and improving upon negative patient experiences.
- Section 6 provides validation of the working hypothesis that Saskatchewan's health care system is not patient-centred; KPMG's recommendations to the Commissioner on how the Province can achieve the desired "system shift" from the current model of delivery to a patient-centered model; and KPMG's recommendations to the Commissioner on how the Province could address system issues such as wait times in the Emergency Room and for surgeries/diagnostics – these

recommendations are based on what was heard in the research, combined with KPMG's experience in working with other health care systems and our knowledge of leading practices.

The appendices that accompany this report are a collection of the research tools that were used to gather data from the field. There are also a series of supplementary documents which provide the results of specific research tools used for this review, namely three workbooks and a province-wide survey.

2.0 Research Design and Methodology

The Patient First Review was designed to be about the patients, giving them a chance to have their voices heard on what they felt ailed the system, and also what they valued about it. Given this mandate, the patients were very deliberately given both the first word and the last word in the research process. Having spoken to the patients about their experiences, we then approached the Providers, the individuals that make the system work. The system stakeholders were next, those who represent various groups of patients, providers, institutions and interests. Finally, we completed our research process with the patients for final validation of what we heard in the prior stages of the research.

As we engaged these three groups, we always focused on three core/fundamental research:

1. What has been your experience in the Saskatchewan health care system?
2. What are the key factors that you feel drive that experience?
3. What ideas would you suggest to ensure good experiences are sustained and bad experiences are avoided?

2.1 Summary of research phases

The first phase of the Patient First Review began with patients and focused on documenting their experiences, both positive and negative. The primary objective of Phase 1 was for patients to "define" the problems with their experiences. Participants were also given an opportunity to identify the "causes" of negative and positive experiences, and to propose solutions for patient problems. A surprising number of each were generated.

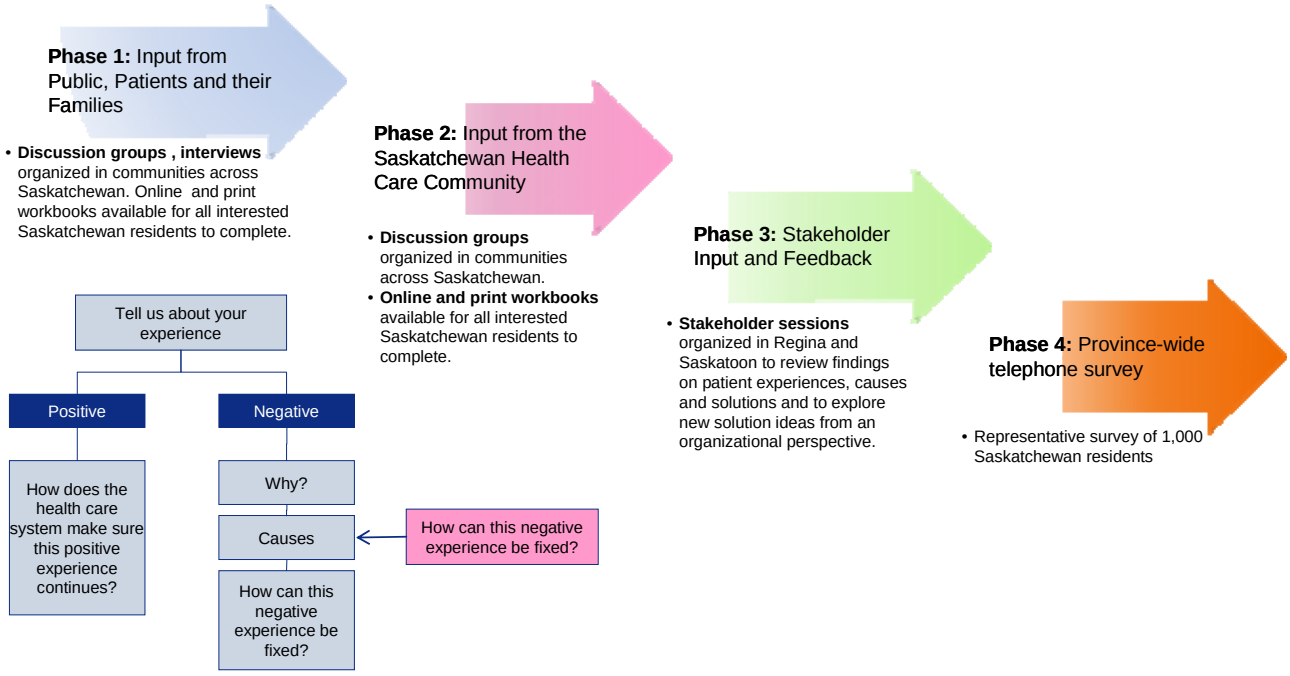
In Phase 2, health care providers were asked to respond to patient experiences – in essence, to validate patient experiences – and to discuss their point of view on the underlying "causes" of those experiences. The primary objective of Phase 2 was to identify the "causes" of negative patient experiences, as well as the enablers of positive patient experiences, in more depth. Providers were also given an opportunity to identify solutions for some of the "causes".

"Solutions" heard in Phase 1 and Phase 2 to address the causes of negative patient experiences were grouped into "categories of improvement". These categories of improvement can be thought of as separate buckets of solution ideas for improving patient experiences in terms of ***access*** to care, ***quality*** of care and ***efficiency*** of care delivery.

In Phase 3 of the research, stakeholders were invited to share ideas for bringing about meaningful improvement to patient experiences by focusing on what could be done within each of the "categories of improvement" identified.

Finally, in the fourth phase, we returned to the patients with a Province-wide telephone survey. The objective of this survey is to further "check" experiences – to quantify the prevalence of various facets of patient experiences documented in Phase 1 of the Patient First Review.

The following is a diagram of the research design methodology.



2.2 Phase 1: Patient Research Methodology

Phase 1 of the research included a series of exploratory focus groups (8-10 participants), triads (3-5 participants), and one-on-one phone interviews among target patient groups and their families in communities across Saskatchewan. In total, 265 Saskatchewan residents were consulted in-person or by telephone in Phase 1. In addition to these dialogues, input from approximately 2,500 Saskatchewan residents was collected through online and print workbooks. The patient experience workbook was an interactive survey tool designed to explore the experience of patients using the health care system for various usage needs.

2.2.1 Focus Groups

A total of 23 focus groups were held across the 12 Regional Health Authorities (including the Athabasca Health Authority) in Saskatchewan during the month of January. Focus groups ran hours in length and were held in the local hospital, regional health authority offices, or focus group facilities.

11 mixed demographic focus groups were held in major urban, regional, and rural centres and each group contained a representative mix of gender and age as well as First Nation/Métis participants. For each group, 10 participants were recruited for 8 to show. All mixed demographic groups were moderated by a Patient First Review researcher. Groups held included:

- 2 groups in Regina, 1 in Saskatoon, 1 in Prince Albert, 1 in Swift Current, 2 in Yorkton, 2 in Kipling, 1 in La Ronge, 1 in Ile a la Crosse

7 dedicated First Nations/Métis Focus groups were held; 4 in major urban centres and 3 on reserve. Again, approximately 10 participants were recruited for 8 to show. Dedicated First Nations/Métis groups were moderated by a Patient First Review researcher with experience leading First Nations and Métis consultations. Groups held included:

- 1 group in Saskatoon, 1 group in Regina, 2 groups in Fort Qu'Appelle
- 1 group on Standing Buffalo reserve, 1 group on Black Lake reserve, 1 group on Sandy Bay reserve

2 focus groups were held among new mothers who had accessed community support services. These groups were moderated by a Patient First Researcher and ran 2 hours in length. Groups held included:

- 1 group in Yorkton, 1 group in Regina

3 focus groups were held among the homeless or marginally housed. These groups were moderated by a Patient First Researcher and lasted approximately 1 hour each. Groups held included:

- 1 group in Saskatoon, 2 groups in Regina

All mixed demographic and dedicated First Nation/Métis focus groups in Fort Qu'Appelle, Saskatoon and Regina were recruited by random digit dialing in the local community. Respondents who work in the health care sector, in media, market research, advertising or communications - or who have immediate family working within those sectors – were eligible to participate.

On-reserve focus groups were recruited with the help of local on-reserve leaders. Focus groups with the homeless were recruited in collaboration with Saskatoon and Regina-based services for the homeless and marginally housed. Groups with new mothers who had accessed community support services were recruited with the assistance of those support services in Yorkton and Regina.

2.2.2 Triads

18 triads with patients who are in more regular contact with the health care system were held across the Province during the month of January in major urban, regional and rural centres. Triads were designed to target specific patient groups, and 5 participants were recruited for 3 to show. All triads were moderated by a Patient First Researcher and ran 2 hours in length. Six target patient groups were identified for the patient triad groups. Triads conducted included:

- Intense Episodic : 1 group in Saskatoon, 1 group in Prince Albert, 1 group in Rosetown
    - Screening question to recruit for this group: Have you personally relied upon the health care system in Saskatchewan to receive treatment for a serious medical incident such as a heart attack, a serious injury such as a motor vehicle accident, a major surgery, or a sudden serious illness?

- Chronic Illness : 1 group in Saskatoon, 1 group in North Battleford, 1 group in Assiniboia
    - Screening question to recruit for this group: Have you used the health care system to ask for medical advice or to receive treatment for one or more chronic illnesses such as diabetes, arthritis or asthma?
- Women of reproductive age: 1 group in Saskatoon, 1 group in Rosetown, 1 group in Melfort
    - Recruitment screening criteria for this group: Women both with and without dependent children, and between the ages of 18-44.
- Episodic 55+ : 1 group in Saskatoon, 1 group in North Battleford, 1 group in Assiniboia
    - Screening question to recruit for this group: Have you personally relied upon the health care system in Saskatchewan to receive treatment for a serious medical incident such as a heart attack, a serious injury such as a motor vehicle accident, a major surgery, or a sudden serious illness?
- Parents/Guardians of children who require full time care (screening question for recruit: 1 group in Regina, 1 group in Swift Current, 1 group in Canora
    - Screening question to recruit for this group: Does your child have an ongoing reliance on the Saskatchewan health care system for treatment and care of a serious chronic illness, a physical or developmental disability, or a mental health condition?
- Care of the Elderly : 1 group in Regina, 1 group in Canora, 1 group in Melfort
    - Screening question to recruit for this group: Do you currently have any adult members of your family over the age of 55 with a medical problem or disability for whom you are at least partially responsible for providing care in Saskatchewan?

Video recording was done at the discretion of the moderator. First Nation/Métis groups, and groups among, mothers who had accessed community support services, and groups among the Homeless were not recorded.

2.2.3 One-on-one Interviews

Eight one-on-one phone interviews were conducted in the month of January among 2 target patient groups. All one-one-one interviews were conducted by a Patient First Review Researcher and were voice recorded.

- 4 phone interviews with patients who have sought medical treatment for a mental health condition

- Screening question to recruit for this group: In the last three years, have you used the health care system in Saskatchewan to ask for medical advice or to receive treatment for one or more mental or emotional health conditions?

- 4 phone interviews with patients who have one or more chronic illnesses and have difficulty leaving home

  - Screening question to recruit for this group: Do you have one or more long-term medical conditions that have reduced the amount or kind of physical activity you can do at home, at work or at school?

Please see **Appendix A** for a comprehensive summary of the patient research process.

Please see **Appendix B** for a copy of the moderators guide used in all patient discussion groups.

2.2.4 Workbook

During the course of Phase 1, online and print workbooks were available for all interested Saskatchewan residents to complete at www.patientfirstreview.ca. A total of 2247 workbooks were completed, 1995 online, and 252 completed in print.

Please see **Appendix C** for a comprehensive summary diagram of the Patient Workbook.

Results from the Phase 1 Workbook are available in a supplementary document to this report.

2.3 Phase 2: Provider Research Methodology

Phase 2 of the research included a series of 10 focus groups with health care providers organized in communities across Saskatchewan in the month of March. In total, 94 Saskatchewan health care providers across the continuum of care were consulted during this phase.

Provider lists: Lists for recruiting providers were supplied to the research team by Saskatchewan health agencies. Names were provided on a confidential basis solely for the purpose of randomly recruiting a representative group of health providers. Lists were obtained from the Saskatchewan Association of Health Organizations (multiple provider types), the College of Physicians and Surgeons, Saskatchewan College of Paramedics, Saskatchewan College of Pharmacists and the All Nations Healing Hospital.

2.3.1 Bridge group

Phase 2 started with 1 'bridge' discussion group in Saskatoon. The 'bridge group' included Quality of Care Co-coordinators, patient advocates and volunteers from Saskatchewan health organizations. Due to their direct experience with patients, this session was designed to provide unique insight into the experiences of patients during their journey through the health care system. This group contained 12 participants and the session was moderated by a Patient First Review Researcher. Participants included:

- 7 Quality of Care Coordinators, 5 patient advocates and volunteers

2.3.2 Focus Groups

The bridge group was followed by 9 mixed provider focus groups held across the Province. All groups recruited 12 participants for 10 to show, and contained a mix of health care providers across the continuum of care. A total of 82 providers participated in these consultations and the groups were moderated by a Patient First Review Researcher. Provider focus groups were video recorded. The following provider types were recruited: General/Family Physicians; Physician-Specialists; Nursing Personnel; Pharmacists; Home care Aide/Special Care Aides; Environmental services, Housekeeping Staff; Psychologist/Social Workers; Rehabilitation/Therapists; Paramedics; Diagnostic Personnel; Health Care Administrator/High Level Supports; Dietician/Nutritionists; and Quality of Care Coordinators.

2 groups were held in Saskatoon, 1 in Prince Albert, 1 in La Ronge, 2 in Regina, and 1 in each of Swift Current, Weyburn and Yorkton.

Please see **Appendix D** for a comprehensive summary of the provider research process.

Please see **Appendix E** for a copy of the moderators guide used in all patient discussion groups.

2.3.3 Workbook

During the course of Phase 2, online and print workbooks were available for all interested health care providers and Saskatchewan residents to complete. The workbook was available online at www.patientfirstreview.ca until June 9, 2009. In total, 413 workbooks were submitted for further analysis on "causes", 351 from online submissions, and 62 printed workbooks.

Please see Appendix **F** for a comprehensive summary diagram of Workbook 2.

Results from the Phase 2 Workbook are available in a supplementary document to this report.

2.4 Phase 3: Stakeholder Research Methodology

A total of 82 stakeholders attended these Phase 3 sessions over the course of the two days in May, with two sessions being held in Saskatoon and one in Regina. Each session lasted 3 hours. Participants were split out into smaller "break out" groups within each session, each of which was moderator by a member of the Patient First Research team.

RHA Session: Stakeholders who participated in the first sessions consisted of the RHA Chairs, CEOs, Board Members and Senior Medical Officers.

- RHA Session in Saskatoon – 31 participants

Mixed Stakeholder Session: The second session in Saskatoon, and the session in Regina included representatives from health advocacy groups, regulatory bodies, educational institutes, unions and First Nations/Métis organizations.

- 1 Mixed Stakeholder Session in Saskatoon – 23 participants
- 1 Mixed Stakeholder Session in Regina – 28 participants

Prior to the sessions, stakeholders were provided with pre-reading materials, including background information on patient experience analysis, causes analysis and categories of improvement analysis. Participants were asked to prepare for the sessions by reviewing these documents.

Within breakout groups, stakeholders were tasked with an exercise which encouraged them to share ideas to improve the patient experience by focusing on the six categories of improvement.

Please see **Appendix G** for a diagram of the stakeholder break-out group format

Please see **Appendix H** for a copy of the discussion guide used during the sessions

2.4.1 Workbook

During the course of Phase 3, stakeholders were invited by the Commissioner to complete a targeted online workbook designed for stakeholder feedback. This workbook was also open to the general public. In total 168 workbooks were completed online.

Please see **Appendix I** for a comprehensive summary diagram of Workbook 3.

Results from the Phase 3 Workbook are available in a supplementary document to this report.

2.5 Phase 4: Province Wide Survey

Phase 4 consisted of a Province wide telephone survey among Saskatchewan residents conducted from June 8th - 28th, 2009. This survey was designed to provide quantifiable benchmarks and further check the patient "experience". Upon completion, 1,076 residents had participated in the survey. The respondents consisted of a regionally representative sample of Saskatchewan residents from across the province: 24% from the North, 19% from Regina, 22% from Saskatoon, 22% from the South and 13% from Central Saskatchewan. The participants were all 18 years of age and older, with a 48%/52% split between male and female respondents. The survey also successfully achieved its quota for First Nations and Métis respondents that are representative of the Province as a whole, representing 8% (82) and 7% (75) of sample respectively. Results from the Province-wide survey are available in a supplementary document to this report.

Please see **Appendix J** for a diagram of the survey flow and design.

Please see **Appendix K** for a copy of the survey questionnaire.

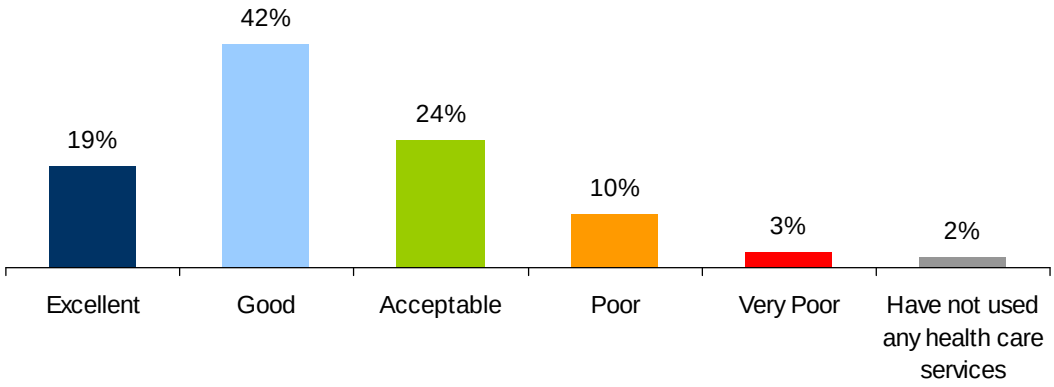
3.0 Exploring Patient Experiences

The Patient First Review has provided a refreshing opportunity for Saskatchewan citizens to voice their views on how they experience the health care system. The following section details the positive and negative patient experiences most commonly heard in focus groups, telephone interviews and in the Patient Experience workbooks collected from the public and target patient groups. In this chapter, there are 5 positive experiences presented in detail, and 14 negative experiences.

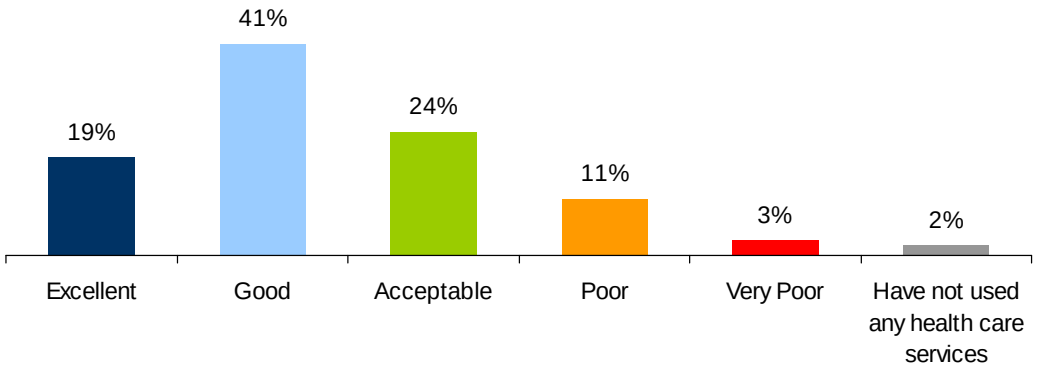
The relatively higher number of negative patient experiences does not suggest that negative experiences outnumber positive experiences 3:1. Instead, it suggests that negative experiences, even if they may be rarer for most patients than acceptable or positive experiences, are memorable and discussed with greater detail and specificity. Discussion of positive experiences tended to be more generalized.

In reading about the experiences of participants in the Patient First Review research process, it is important to remember that on most days, and in many ways, patients have positive experiences with the health care system. The results from the Province-wide survey of Saskatchewan residents show that when it comes to health care services for themselves and their own families, around half of residents have good or excellent descriptions of services. 55% say that the quality of health care services provided to their families and themselves is good or better, and 50% say the same for their ability to access health care services for themselves and their family.

Generally speaking, how would you describe the quality of the health care services provided to you and your family in the last 12 months? Is it excellent, good, acceptable, poor or very poor? (n=1,076)

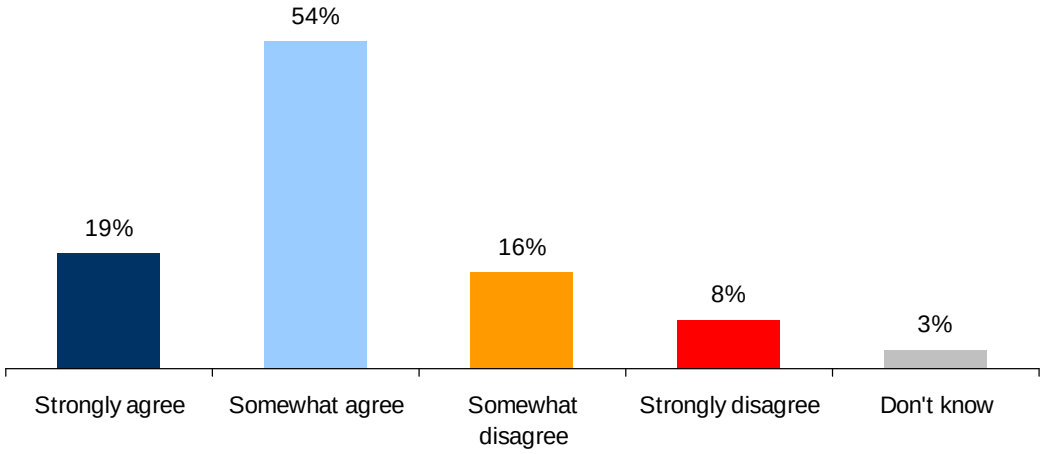


Q Generally speaking, how would you describe your ability to access health care services for yourself and your family in the last 12 months? Is it excellent, good, acceptable, poor or very poor? (n=1,076)



The survey also shows that over two-thirds (73%) of residents agree with the statement that "The Saskatchewan health care system puts patients first". While the overall level of agreement is good, the relatively small number of people who strongly agree as well as those who either don't know or who disagree indicates plenty of room for improvement.

Q The Saskatchewan health care system puts patients first? (n=1,076)



Although these survey results show positive patient feelings towards the health care system, not all experiences were positive. Saskatchewan residents have also told us the things they didn't like about the system, and have provided their thoughts on how to fix it. The following table summarizes the 5 positive and 14 negative experiences explored in detail in this chapter.

Summary of Positive and Negative Patient Experiences	
Positive patient experiences	**Negative patient experiences**
1 Good Two-Way Physician-Patient Communication 2 Feeling Connected to the System during a Health Episode 3 Encountering Genuine and Caring Attitudes from Staff (Non-Physician) 4 "Speed" in Accessing Needed Services and Providers 5 Access to Culturally Oriented Health Services	1 Feeling Lost in the System 2 Uncaring and Dismissive Attitudes from Health Care Workers 3 Feeling Inadequately Served in Hospital Emergency Rooms 4 Long Waits for Diagnostics and Surgeries 5 Difficulties Accessing Specialized Services 6 Poor Case Management/Communication with Physicians 7 Difficulties Accessing Appropriate Family Health Care 8 Limitations in Available Home Care Services 9 Feeling that the Province Seems Ill-Equipped to Meet the Care Needs of the Aging Population 10 Under-Supported by Maternal and Child Health Services 11 Difficulties Accessing Appropriate Mental Health Care and Addictions Services 12 Medically Required Transportation and Accommodation Issues for Remote/Rural Locations 13 Experience of Cultural Insensitivity Among Health Care Workers 14 Unexpected Out of Pocket Costs for Services

There is a clear bias for action to improve the system so that it consistently delivers in practice what it promises in theory. Patients are hopeful about action and that their stories will help bring about change and continued improvement.

Detailed reporting and analysis of patient experience survey results can be found in a supplementary document to this report.

3.1 Analysis of Patient Experiences

Focus group discussions, telephone interviews and patient workbooks were analyzed using thematic analysis. Similar experiences were clustered together into clearly defined clusters of themes – both positive and negative. Positive and negative experiences were analyzed to organize data into workable groupings, and to find basic areas of consensus and contradictions. The analysis involved three parts: coding and clustering comments, naming themes and developing a coding framework, and applying and revising the coding framework. The organization of data into themes described by basic codes provided enough of a framework to set up the analysis. These processes are explained below.

A note on the analysis:

- These experience clusters represent findings from qualitative research only and **cannot** be extrapolated to the population as a whole.

- "Experiences" articulate the patient perspective – not the system perspective. There was a decision by the researcher to remain loyal to the patient narrative.

- Positive and negative experiences shown in the following pages are those that came up with a high level of frequency.

3.1.1 Coding and Clustering

The coding process began with a thorough reading of focus group notes, flip charts and a review of tape recordings and workbook submission. Ideas in the text noted as "recurring" were assigned a code to describe the key characteristic or issue constituting the text. Like-coded comments were clustered with other text units having the same or similar code-tags. Different notations on comments were used for each focus group so that participants could be differentiated on the spreadsheet, aiding the researcher to identify similarities and differences between participants. In initial coding, similar codes were common and some difficulty was encountered in deciding which like-codes should be merged, and which should stand alone as separate clusters. Decisions were made based on the prevalence of each code-tag; however, in the early stages it was decided to err on the side of caution, and a fairly large number of small clusters were generated.

3.1.2 Naming themes

To help shape the data analysis, each code cluster was assigned a name, which described the main argument or idea grounded in the variety of codes. For instance, response code-tags such as "long waits for specialty consults" and "long wait for MRIs and other diagnostic procedures" grouped together into a cluster named: "Long waits for surgeries and diagnostics". As more and more notes were reviewed, some clusters were merged, while others were disbanded based on prevalence. Some code-tags that had been set aside in the first round of clustering found mates later in the workbook review and were bound into new clusters.

3.1.3 Coding Framework

Below we describe the themes in greater detail. Exemplary quotations are extracted from the focus groups, interviews and workbooks. Quotations are provided to "bring to life" the patient experience described in each code cluster. Patient stories are also provided to describe real patient experiences. The names are fictitious, but the stories are based on real experiences. As a supplement to this report, a quote bank from patient consultations (focus groups, triads and one-on-one interviews) is available.

3.1.4 Validation by Health Care Providers

The summary of Patient Experiences was shared with health care providers in focus groups. Two changes to cause themes were added after consultation with our first provider group. This first provider group in Saskatoon was set up specifically with health care providers who are directly engaged in the patient journey, including Quality of Care Coordinators and Patient volunteers from across the Province

to provide a 'bridge' between patients and providers. Two new stand alone themes were created that were separated from existing themes. These were "unexpected out of pocket costs for services" and "difficulties accessing specialized services".

Participants in the nine additional focus groups with front line providers were not surprised by patient experience themes shared from Phase 1 consultations so no further changes to the coding frame were necessary. Many explicitly remarked that the themes were what they had expected to see. While the patient experiences shared were "nothing new", many felt encouraged to see these ideas reinforced through the review process.

Quotations to illustrate provider agreement with the 14 negative experiences are provided in Section 3.3 of this chapter.

3.2 Positive Patient Experiences

When patients told us about their health care experiences in Saskatchewan, they described both positive and negative experiences. It is important to realize that among those patients who felt their experience was excellent, the Saskatchewan health system is already delivering the care they seek. They don't want a different experience; they just want more people to share their experience. With that in mind, when we look at positive experiences, we are actually seeing patients describe their vision for the Saskatchewan health care system, a vision where care is fast, effective and compassionate, transitions are facilitated and monitored by dedicated staff, where information is shared freely and patients are partners in their own care.

Positive experiences were clustered in a relatively limited number of 5 primary themes. They included patient stories of high quality care from health care providers and timely access to needed health care services.

3.2.1 Positive Experience 1 – Good Two-Way Physician-Patient Communication

Good communication with family physicians goes a long way to defining positive experiences. A number of research participants were clear that they see their family physicians as their link to the workings of the system, their advocate and their guardian. A number of research participants described the health care system as "only as good as your family doctor", because patients rely on their family doctor for regular assessments of their health care status and for connections to appropriate, needed services. Good two-way communication, including regular exchange of information and knowledge with a family doctor, was described as central to ensuring timely, accurate diagnoses and care.

In general, the average patient comes into contact less frequently with specialists than with their family physician. With specialists, for research participants, good communication was described as extremely important for the patient experience because the patient may be dealing in unfamiliar territory. When a patient first connects with a specialist, they may be anxious and looking for information and answers.

"Good" specialists were described as people who listen to patients and offer whatever information they can, and who remain accessible to the patient and engaged.

For participants, having a positive experience with a physician – in both primary and specialist contexts - usually involved a combination of reliable access, unhurried and high-quality face time, and reliable follow-up.

***Reliable access*:** Since doctors have been described as the 'gatekeepers' of privileged knowledge about treatments and disease management, having a physician that is accessible was central to having a positive experience with the health care system. Participants said they like to feel that they can reach their physicians. Being able to make timely appointments and to have questions answered quickly over the phone or email is important for patients to feel connected to the system.

High-quality face time: For participants, the primary feature of "high quality" face time is not feeling rushed. Patients appreciate feeling like they have a physician's undivided focus. According to participants, the central characteristics of high-quality face time include:

- **Dialogue** – two-way exchange of information and listening. Many patients want to have the opportunity to be active participants in discussions of diagnosis and treatment.
- **Clarity from physicians** – speaking in clear, easy-to-understand language.
- **Physician openness and non-judgment.**
- **Competence** – Patients want to feel that they are safe and in good hands.
- **Honesty** - Patients want physicians to be clear about what they do know, as well as what they don't know.
- **Compassion** – Patients appreciate physicians who empathized and took time to provide reassurance, additional information and reduce patient anxiety.
- **Reliable follow-up** - Patients appreciate a physician who does not forget them when the consult is over, but works hard to arrange hand-offs to other parts of the system and to keep the patient well-informed of his/her test results, next steps, and case progress.

Family Physicians:

"I have had nothing but very positive experiences with my family doctor. I have always been able to get in right away. He is really good, and he is always willing to admit that he doesn't know everything. He admits when he can't diagnose something and acknowledges that we will need to see someone who can."

"[My doctor] is patient, understanding and very caring. He doesn't rush you through your appointment and helps us understand the process in which we are going and will be going. He is very thorough."

"I have an excellent family physician who realizes how difficult it is to live with someone in severe chronic pain."

"My doctor listens, explains and researches answers to any concerns she may not have knowledge of. If unable to arrive at a diagnosis or treatment for a particular problem, she refers me to the appropriate specialist."

Specialists:

"Our son was born with a heart defect. Our doctors were so great at looking after him. They prepared us and him. They spoke to him at his level and us at our level. It made all the difference and made us all more comfortable with what was happening."

"My experience with a specialist was positive. I had had to do a lot of my own education about managing after my incident because it was a month from the incident (which occurred out-of-Province) to my appointment with the specialist. When I did see him, I was able to discuss my concerns about a number of aspects of managing my condition, discuss my goals, and receive the kind of specific guidelines I needed to return to normal. He listened and respected what I had to say. He gave me his undivided attention and the time to learn enough about me to provide useful advice. Another positive was working with a nurse practitioner. Again, she listened and agreed to work with me to implement the plan I had discussed with the specialist. The other positive encounter has been with pharmacists. Thanks to them, I was alerted to potential dangers with my medications, side-effects which need to be reported, and lab work which is very important to do as long as I take a certain one. Their information was invaluable, as I did need to get medications changed."

"I love the doctor who delivered our last baby. He takes time for our concerns and never dismisses us as not knowing what we are talking about. He addresses every area of concern that he or we have."

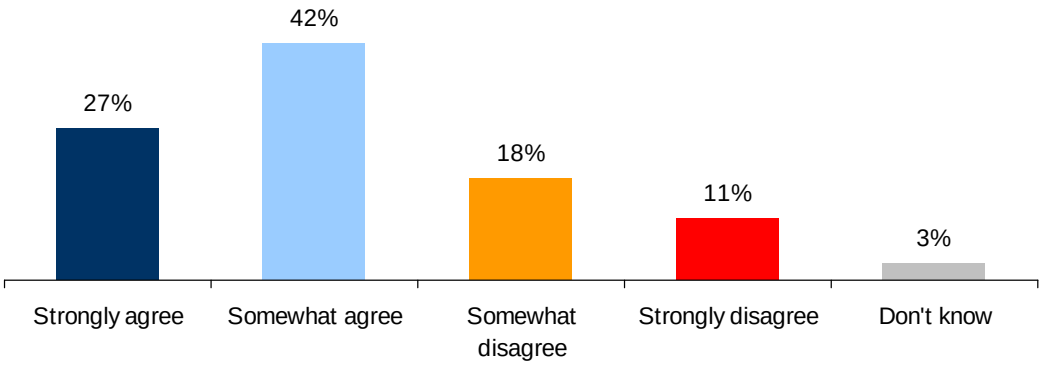
"The psychiatrist was wonderful. She took the time to listen, not judge and did not automatically dole out prescriptions."

"Specialist care (ortho+team) was very good to excellent. I was in a cast for a year. I always got good feedback on progress and prognosis. The casting tech always went the extra mile for comfort and information."

Feeling heard and that your voice counts in dialogue with health care providers is key to a positive experience. Results from the Province-wide survey of Saskatchewan residents show that about two-thirds of residents (69%) agree with the statement that "I feel that I have a say in decision-making about my health care". However, only 27% strongly agree. The 42% that somewhat agree feel that while the system is on the right track, there is room to improve. Almost one in three disagree they have a say with

just over one in ten (11%) strongly disagreeing. For them, the system needs to do an about face before they accept the Saskatchewan health system is committed to working WITH patients rather than working ON patients.

Q I feel that I have a say in decision-making about my health care? (n=1,076)



Patient Story

Carson is a 41 year old male, living in the city with his wife and 2 kids. One day, Carson started experiencing insomnia that was leaving him so tired during the day that it was disrupting his daily routine. Carson went to his family physician who worked together with him to figure out what was causing the insomnia.

Carson's Story – from a patient's point of view

I have always been really healthy and in tune with my body, so when I started experiencing bad insomnia I knew that something wasn't quite right. My family doctor is great, even though it is not always a snap to get in to see him. When I called to make an appointment he was all booked up for the next few weeks but I told his receptionist that I really felt like I needed to see him. She said she would personally talk to him for me. The next day, he actually came down to the store where I worked to talk to me. He said to me, "If you really need me, I will put some time aside. How about you come in tomorrow night after we are closed and we will talk about this?" He was just so empathetic. He sat down with me to talk about all aspects of my symptoms: how much I was sleeping, what I was doing about it, what else was going on in my life. He prescribed a very mild sleeping pill to consider, but encouraged me to keep a 'sleep diary' which eventually helped us both to understand the real cause of my sleeplessness before deciding how to treat it. I had felt so distressed about the insomnia, but that visit made me feel like a million bucks.

3.2.2 Positive Experience 2 – Feeling Connected to the System during a Health Episode

A health crisis can be a very confusing and challenging time for people. The experience of managing a health crisis is more likely to be positive if a patient feels familiar with, and well connected to, their needs within the health care system. Patients rely on physicians and other health care providers to establish connections for them in the system and to support important transitions.

Many participants described positive experiences during the following "transition phases" of their care.

Primary care to specialist: Participants who described positive experiences with the care they received from diagnosis to treatment of a serious illness, such as cancer, often credited their family physicians for the positive experience. Many participants lauded their family physician's skill in coordinating smooth, timely referrals to specialists and specialized treatments. They stressed the importance of having a family doctor with a good network of contacts and strong advocacy and negotiation skills.

Some participants said that they felt well-connected to the system when their family physicians stayed involved in their case, even after a hand-off to a specialist, making sure that the patient did not get "lost" in the system. Participants appreciated physicians who stayed on top of their files so that tests and procedures did not have to be repeated, and new avenues were continually explored when something was not working.

"I read about a procedure that might help me with problems I was having. I asked my family physician if I might be a candidate for this procedure. He referred me to a specialist and I was able to receive this procedure, which greatly improved my quality of life. I received good care and attention throughout the whole process."

"I would credit my cancer care to my family doctor. She had a good chain of communication and contacts. After finding the lump we moved very quickly through the health care system. I felt that everything was under control."

"My Doctor, he is the best at diagnosis and referring on to a specialist if he has exhausted all avenues. This needs to be the practice all take on. Ensuring quick and accurate diagnosis is the key to patient centered care."

"Again the system has worked for me, I have a wonderful doctor and when I was needing to seek help from a psychiatrist, I was able to see an excellent practitioner and I have benefited immensely from this. The response was timely and I have since recovered."

"I think there is good communication between doctors in this community (remote northern area) and the hospital in the city. My doctors in the city provide updates to the doctors here so that I don't have to explain things over and everyone knows what to do."

Primary care to care to specialized services: Many participants had positive experiences using their family physician as a resource to connect them with long-term care services, home care services and other community-based care treatment and prevention programs.

"Navigating access for long term care was difficult but with the assistance of our local family practice physician it was made easier."

"I have some problems with my knees and my doctor was able to get me into a trial at the Kinesiology centre that worked with people to evaluate conditions prior to having to see a specialist. This saved the time of the specialist as well as was able to resolve my problem quicker."

Specialist care to surgery or specialized treatments: Some participants described positive experiences in transitioning from specialist consultations to surgeries or specialized treatments, particularly where specialists remained accessible to the patient and engaged in follow-up and recovery.

"I was diagnosed with prostate cancer in June of 2008. I was referred to an excellent urologist who consulted with both myself and my wife and gave us very straight talk on my options - he also provided several books which confirmed what he told us. I opted for surgery and was put on a waiting list - I was called for surgery on Oct 1/08. The surgery went well, I received excellent nursing care and daily visits from my urologist. I was home after 5 - 6 days and am expecting full recovery."

Post acute follow-up services: Several participants described positive experiences transitioning into more community-based care after discharge from hospital, largely due to good communication from health care providers on how to remain connected to care.

"The care was immediate and consistent throughout my husband's emergency. After his surgery, the follow-up was excellent. The information provided by the emergency room nurses and clerks was thorough and the compassion was genuine."

"After having surgery in Saskatoon we knew that we could go to the clinic in town for advice, checkups, etc."

Inter-regional: Likewise, positive experiences for some participants came from a sense of feeling supported by the system and its staff as the patient moved from one part of the Province to another during a health episode. When the system comes together to bring patients and their family proper information, education and support as they navigate from one hospital to another, patients feel well cared for and confident in the care they are receiving.

"I think there is good communication between doctors in this community (remote northern area) and the hospital in the city. My doctors in the city provide updates to the doctors here so that I don't have to explain things over and everyone knows what to do."

"In general, most of the health care workers were genuinely concerned about my well-being and helpful. My wife found that, although I was unconscious, specialists were available quickly even though we were

at our cottage near Elbow at the time of the medical crisis. I was taken to town by ambulance. The doctor there was in communication with a cardiologist in the city. I was then transported to the nearest city by ambulance with a number of medical staff in attendance. The city sent an ambulance to meet us en route so that qualified ambulance attendants could administer treatment on the way. My wife was given the choice of having me admitted to hospital in the city or transported closer to home. As we live in another city, she asked to have me transferred as long as this would not impact on my situation. In our own city, several specialists conferred in order to arrive at a diagnosis."

Patient Story

Renata is 56 years old and lives in a small city. She has always been very healthy, but six months ago a lump was found during a routine mammogram. Renata has since undergone surgery to remove the lump and continues a regular program of chemotherapy

Renata's Story – from a patient's point of view

Since I turned 50, my doctor has been sending me to have a mammogram every two years. I'm glad about this because otherwise I wouldn't have known about the lump. I have always been very healthy. When the lump was found, my doctor sprung into action so fast. She has a great chain of communication and is well established in the community. That is so important. My downtime was really just a matter of days. A biopsy was done right away, I had an MRI two weeks later, and within a few days I had a surgery already scheduled. My doctor was very straightforward with me about what she couldn't explain, and set me up to meet with my oncologist to have a kind of Q&A before my surgery. The surgeon was also terrific. I met with him before the surgery and he explained everything really thoroughly. The chemo is going pretty well and is on schedule. I can call my doctor anytime to discuss how I am feeling.

3.2.3 Positive Experience 3 – Encountering Genuine and Caring Attitudes from Staff (Non-Physician)

Many stories of positive experiences with the health care system revolved around memories of courteous, kind and respectful interactions with nurses, administrators, aides and other health care workers. In these situations, what made the experience positive was that some participants were feeling that they were treated as people, not just as a case or a number. Many patients described being impressed by staff knowledge, touched by their compassion, and grateful for their patience, understanding and attention to patient comfort.

Hospital: Many participants told stories of compassionate and attentive staff in hospitals. It was not uncommon for participants to talk about staff who had "gone above and beyond the call of duty" to ensure a patient and his/her family were comfortable, and that information was properly conveyed to all parties.

"There were some individual nurses who took the time to listen, answer questions, and treat not just the patient, but the family with respect. They made a difficult situation more tolerable."

"I encountered many nurses, ambulance attendants, security personnel who were very compassionate in their care for me. I was paralyzed and unable to speak because of a brain tumor and my wife was beside me 24/7. She often received care and comfort from the staff in the form of warm blankets, bedside chair beds, and emotional support."

"The health care I received at emergency was amazing. The staff were respectful, listened and showed a genuine care for me as a patient. My stay in the hospital was positive for me and my family."

"A couple of nurses went out of their way to help, and REALLY LISTEN to our concerns, and answer our questions. I actually made a list of my questions at one point, and was able to persuade the nurse to bring the chart into the room and take all the time needed to answer each question. After she left, the other patient in the room even remarked about how good that nurse was, to spend the time to actually answer all those questions and explain things!"

"There were a lot of caring and attentive staff in the obstetrics ward; they even gave me a hug and were so happy for us... even with 12 other babies being born that same night!"

Long-term care: Having parents or family members living in long-term care facilities or nursing homes could be a difficult and unfamiliar situation for many, so the experience of encountering kind, patient and genuine staff in Long Term Care facilities was often another reason for participants to praise the health care system. Knowing that loved ones were well looked after was very important for participants.

"In general, the positive is the most marvelous tenderness and affection of the employees of the system toward the elderly, and the impact that has on the level and quality of care they provide."

"The staff in personal contact with patients at the facility are very caring, professional and provide an excellent environment. They preserve the dignity and health of these individuals."

"What was positive was the fact that the staff in the home where my mother was were understanding, updated daily on the patient's medical condition and are dedicated to making life comfortable for those in long term care."

***In specialized treatment*:** Other participants who had experienced caring and genuine staff while undergoing treatment for serious health conditions found that the attitude of health care providers went a long way to ensuring a good patient experience.

"My father's oncology nurse was always on hand to answer questions, give advice, and help with his cancer treatments"

"The care and love the nurses at the cancer clinic give their patients is positive, even though you appear to be just a number in the waiting room."

*"I received immediate and compassionate care during several very difficult situations involving my reproductive health. The women who cared for me, the Dr, RN, unit clerks, even the women who worked at the information booth were very sincere, patient and calm**."***

Home care: There was a great deal of praise for home care workers among participants who had used home care services, either personally or in their family.

"We have been involved with home are and the geriatric assessment unit at the hospital for the last six months. There has not been a single negative situation during that time. My mother gets two baths per week. I have been present a couple of times when the home are Aides were working with my mother and they were fantastic. One lady was incredible, she helped us at every step and she was a wealth of information. Another home care Nurse was the same. With the general condition of the health care system in Saskatchewan, our experience with home care was very good. Thank You!"

"The nursing staff was supportive. Also the home care nurse, who saw the crisis develop, was very supportive to me and reassured me throughout the process that I was doing the right thing. She also provided clear instructions, which helped."

"My mother has Alzheimer's and the health care workers are generally kind and patient. I had an amazing Home care co-coordinator - I think it's SWADD - who advocated so well on behalf of me and my mother - and father when he was alive."

Care in the community: Some patients shared positive stories about the services that they had accessed and the providers that they had encountered through community-based health programs.

"The programs at Four Directions Community Health Centre are good. It's good that you can walk in to most things like the Hepatitis C program with the nurse at the clinic. It's not judgmental and they remember you. You can also do cooking classes and things, which help if you're feeding kids and trying to stay healthy yourself."

"The nurse helpline has been wonderful - I use it for the nurse to tell me if what I am feeling is serious enough to go to the doctor straight away. They are wonderful, and they always walk you through things and ask you tons of questions. It is so nice to have that qualified person on the line telling you that things are ok – it is very reassuring."

"The planned parenthood clinic got me in immediately and supported me through my procedure. The Doctor really cared."

"I went through the family planning clinic. I would never have known who to turn to if the doctor there didn't recognize the importance of referring me on. They were fantastic at the clinic in Saskatoon, very understanding and caring."

The staff (local Women's Health Centre) have been wonderful. They take lots of time with clients, explain procedures, and remember me and my situation."

***Palliative care*:** Many participants who had been through a palliative care experience with a family member discussed compassionate care and special attention from staff to ensure dignity and quality of life.

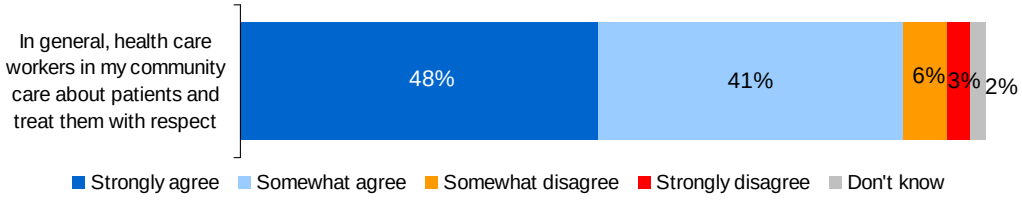
"My mother was in palliative care in three hospitals. The care, concern, and support of all three were extraordinary. Not just for her but also the family. Family members were engaged in the care process with all of the care providers."

"With my dad -- the palliative care was superb. They were attentive to his wishes -- they discussed the situation with him and the family and allowed him to make his own choices about his care. They were flexible in their treatment. They gave excellent advice and support to the family to enable us to care for him at home."

"The palliative home care was amazing. It's different with them – they do everything."

Results from the Province-wide survey of Saskatchewan residents show that close to 9-in-10 Saskatchewan residents (89%) agree with the statement "In general, health care workers in my community care about patients and treat them with respect."

Q For each of the following statements about health care please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree? (n=1,076)



Patient Story

Rochelle is 27 years old and lives in a small city with her husband and her six-month old son. After having her baby, Rochelle had a lot of difficulty with breastfeeding. Rochelle was very upset and anxious as she struggled with feeding. A lactation consultant helped coach Rochelle through her difficulties, helping Rochelle to feel competent and reassured.

Rochelle's Story – from a patient's point of view

I had a lot of difficulties with breastfeeding when I came home from the hospital. I got a call from a lactation consultant to see how we were doing and I explained that I wasn't doing well. The lactation consultant offered to come in and help out. Things worked out really well when the consultant was in the room, but it seemed like everything fell apart again the moment she left. My son was not gaining weight, and I was told that I wasn't producing enough milk. That was very hard for me. I had so much guilt. The lactation consultant came back and sat on my couch with me and reassured me that I was a good mom. She sat with me while I cried and shared personal stories with me about her life, which helped me know that I wasn't alone. She really took the time to make sure that my baby and I were both doing OK. I can phone her at home and she will give me little tips if I have questions. The fact that she cares so much really makes a difference.

3.2.4 Positive Experience 4 – "Speed" in Accessing Needed Services and Providers

Waiting can be anxiety provoking and draining for patients – whether it's waiting for an ambulance, for tests, surgeries or specialist appointments. Long waits and the uncertainty – along with being stressful – often prove to be disruptive to a patient's lifestyle. Speed, however, was a very important component of many participants' descriptions of positive experiences with the health care system.

Rapid emergency response: In general, a positive experience with emergency services is a "fast" experience with few hold-ups to high quality care. For individuals living in rural or remote areas, "speed" and efficient access to care were particularly important in defining a positive experience.

"When I had my heart attack, I received a quick response to my medical distress. I had my heart attack in a rural area thus there was a hospital that I could go to to be stabilized and then transported to Saskatoon to receive the more intense treatment required.

"The rural referral was prompt, the wait in emergency in Saskatoon was less than 4 hours and admission was efficient."

"I went to emergency on a Friday with severe pain, saw a surgeon very quickly, had a CT scan, was diagnosed with ovarian cancer, was admitted by midnight, saw a specialist on Monday, surgery on Wednesday - very speedy service."

"I had bypass surgery. My family doctor got me into the cardiologist and I was operated on and back at home within 2 weeks. Everything felt very well organized. "

Timely surgeries: What is considered "timely" is variable; however, it is a descriptor that was used by participants who believed that the length of their wait was consistent with the level of attention and urgency due to their case.

"I was fortunate to have my gallbladder attack immediately followed up by investigation and surgery."

"I knew the doctor and he was able to get me in for my knee operation. The nurses were excellent, the operation was not an overnight stay and it was able to be done within an hour of my home. I was able to get in for the operation in a reasonable length of time - about six months - and best of all the operations greatly reduced my pain"

"My surgery date was within reason. I was given a reasonable amount of time to make arrangements for work."

"I received referrals to a specialist in a very timely manner. After the specialist visit, I had my surgery scheduled within 3 months, which I thought was very timely. The surgeon as well as all the nurses and other workers were very good, and treatment went well."

Rapid access to diagnostics and testing: For others, positive stories centered on a quick turn around from seeing a physician to getting an appointment for diagnostic testing. It was often articulated that speedy access to specialized tests contributed to a positive encounter with the system.

"My positive experience was prompt assistance and helpful acceleration of schedules for imaging services by a hospital Emergency physician. I was lucky -- he was helpful beyond what might have been strictly expected."

"Here we can get blood, urine and other tests done at labs that are convenient and open long hours."

"I was booked immediately for tests by my physician for a possible heart problem. I found all hospital staff were very helpful and gave me good explanations of what to expect during diagnostic tests."

"There is a diabetes collaborative in place in my community. Access to lab services for A1C testing is quick. We have nurse educators to assist in care if needed."

***Rapid specialist connections*:** Rapid referrals and appointments for specialist services were the cornerstone of positive experiences for a number of patients. Often, participants appreciated having family physicians who were 'well connected' to the system and were able to advocate on their behalf to get them into necessary appointments in a reasonable timeframe.

"I was able to see a grief counselor when I asked in a relatively short time."

"I am a diabetic so I get to see my doctor pretty often and my experiences have all been positive. I have gotten in to see a specialist when I have needed to, they always make sure that everything is going ok, they make sure everything is under control and always put me in touch with who can help me."

"The first appointment with the specialist happened very fast (within about 2 or 3 months of being referred by my family doctor.)"

"The fact that my family physician personally phoned a specialist regarding my condition was really positive. I was seen the following day and the day after that I had surgery in Saskatoon."

Timely access to rehab or therapy: After a serious injury or medical incident, a primary consideration for patients is being able to regain quality of life. Access to quick rehabilitation and therapy services was a positive experience articulated by some participants.

"I got good care in a private home after my injury. I received therapy on my hand so I could use it again. I was able to get therapy right away. This was arranged through home care."

Cancer care: Some participants with cancer described a positive experience characterized by quick access to specialized services or treatments.

"My positive experience was a caring medical community. Perhaps that is because my health issue (cancer) was not an elective procedure. From diagnosis, to surgery, chemo and radiation, and now follow-up, I was moved through the system smoothly and with compassion."

"Radiation appointments were consistently on time. Like clockwork! Staff was very professional. They displayed an interested and caring style."

"I received prompt attention where there was a concern that I may have cancer. The system responded quickly once I was diagnosed. CAT scans, x-rays, bone scans were done quickly and the results were available to the oncologists almost right away. The doctors at the Allan Blair work as a team and put thought into planning treatment that is tailor made for my condition. All of the staff, whether it is the receptionist or nurse at the Clinic are pleasant, respectful and caring people."

Patient Story

Samantha lives in the city with her five young children. Samantha does not have a family doctor, but uses a medi-centre downtown. Last year Samantha went in to complain of persistent pain from urinating. After running a test, the doctor explained that she had a urinary tract infection and prescribed a course of antibiotics. One month later, Samantha returned to the medi-centre with the same symptoms. When she had to return a third time, Samantha was in a great deal of pain and was feeling very anxious and upset. The doctor referred Samantha to a urologist.

Samantha's Story – from a patient's point of view

I was so tired of finishing a course of antibiotics only to develop another infection in the next couple of weeks. I was pleased when I got a referral to a urologist, but I was also skeptical. I'd heard of people waiting ages to see specialists and I just didn't think I could go through that! At first they made my appointment a month away, but the receptionist kindly encouraged me to call back regularly for cancellations. I followed her advice and was able to see the doctor in just a few days. I was worried that all I would get was another prescription for antibiotics, but the doctor surprised me by suggesting a non-pharmaceutical approach for my problem – mixing water with baking soda – to ease the pain and urgency. He even booked me a follow-up appointment for a month later, just in case I needed it.

3.2.5 Positive Experience 5 - Access to Culturally Oriented Health Services

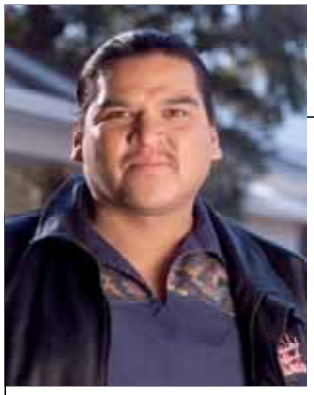
Many participants who had used services designed to respect cultural beliefs and practices, social context, and family circumstances, spoke of positive experiences with the services provided.

"*The Hospital has a spiritual room where I was allowed to participate in my cultural practices. I was pleased with my experience because the hospital asked which tribe I belonged to in an effort to identify the right Elder Tribal leader.*"

"*The Hospital respects me and I was able to participate in smudging with my son.*"

"My mother-in-law had knee replacement surgery. Coming from a small northern community (she rarely leaves the community), she is not as comfortable speaking English, but everyone at the hospital was great."

"The Counselor was very understanding and could speak my own language which is Cree"



Patient Story

Lee is 30 years old and lives about 40 minutes outside of a major city on a medium-sized reserve. Lee recently began seeing a physical therapist at a local hospital to help him recover from minor injuries resulting from a car accident. Lee and his family appreciated that his cultural beliefs and practices were respected in the hospital

Lee's Story – from a patient's point of view

I have never liked hospitals very much and my family has never felt comfortable going there. I remember going when I was a little kid and feeling very intimidated by the staff and the hospital. This time I have felt really at home. Many employees are from First Nations and appreciate the cultural diversity in the medical facility. I was pleased with my experience because the hospital asked which tribe I belonged to in an effort to identify the right Elder Tribal leader. I saw families performing smudging ceremonies. It was very reassuring for me to see this kind of thing.

3.3 Negative Patient Experiences

Negative experiences were common and varied. There were 14 common negative experiences described below. They included patient stories of poor communication from health care providers to challenges in accessing needed health care services. Taken together, these negative experiences help us define a made-in-Saskatchewan agenda for improvement to the health care system. Not change from one system to another, but change in how we run the system we have so that more people can enjoy the care described in the previous section. Below are quotations from real patient stories, clearly describing each experience.

3.3.1 Negative Experience 1 - Feeling Lost in the System

Many participants told us about feeling lost within the health care system. Patient explanations for feeling lost typically fell into two categories:

- **Perceived System Disorganization** – Several participants described the system as "disorganized". Many said they felt literally lost in the system because they saw the system as a poor custodian of patient health information. Patient transfers and movement from one part of the system to another were frequently described with such words as "choppy", conveying the perception and experience of a lack of clear order.
- **Navigational Challenges and Abandonment** – Participants described feeling unqualified to navigate the system. The system is seen to be insufficiently attentive to, or supportive of, patients grappling

for a place and a priority in the continuum of care. This was especially true of participants who are considered vulnerable for reasons of age or illness, and participants who have a low level of confidence in advocating their own needs in the system.

3.3.1.1 System Disorganization Experience

Experience of Poor Health Records Management: A "health record" was perceived to give patients a place in the system. However, a number of participants were concerned about the state of their health records in the system. Many had never seen their "health record" and were not sure that one even existed for them in any durable form. Some said that their record had been lost or destroyed.

"My doctor moved and I hadn't been in a while, so they destroyed my record."

Participants used terms such as "scattered bits of paper" to describe their health records. Many participants did not believe their health records to be useful, or really even "used" in the system. Many felt that their health records were not reviewed by front line providers for background on the patient, not always updated or changed to better represent a patient context, not permanent, not shared with patients, and certainly not comprehensive, integrated documents that could act as a summary of a patient's multiple contacts with the health care system.

A major concern was about the poor sharing of records or patient health information between providers in the continuum of care. The following negative experiences were believed to result from ineptitude in information sharing:

- Duplication of tests and medical interviews due to lack of or ineffective transfer of personal health information;
- Receiving conflicting medical treatment information, advice, or discharge information; and,
- Receiving treatment advice or medication that was in conflict with medical history.

"Our files are all on paper only, so when people are asked to go to the city to be treated, their files don't follow them there"

"It's frustrating because the system is not automated. Doctors can't easily get into my medical information. I always have to make requests for the medical facility here to transfer my files to the city when I go there for treatment. Everything is always shuttling back and forth. Things can get lost or take a long time."

"Files should be transferred so that a history can be maintained through to new doctors. At least that way the new doctor will know what was going on at the time, and can move forward from there. Why wouldn't your new doctor want to know what you have been through so far, because how are you supposed to remember everything yourself? I just want to get everyone on the same page and that shouldn't be a crime, especially when you put your trust in your doctors and the healthcare system."

"Test results don't seem to be shared among physicians. The results aren't held in a central repository for specialists to review new and historical information. This results in specialized tests being repeated causing delays, adding exposure to potentially harmful radiation."

Many participants saw electronic health records as a relatively simple solution, and were perplexed about why an inconsistent, relatively arcane approach to health information continued to persist.

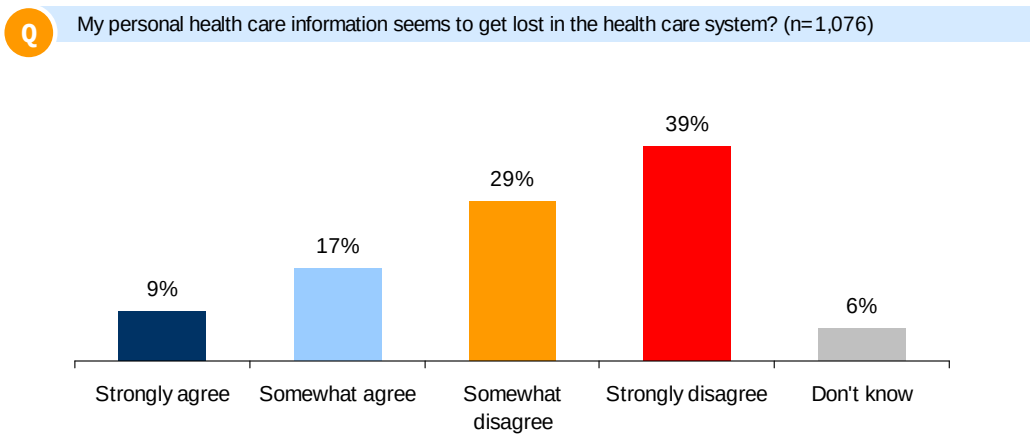
"I think health care should move to electronic charting from the doctor's office and on through the health care system. That way the client's chart would be available for pre surgery, in case of injury, if the individual moves to a new town or whatever. All health care professionals should be given restricted access to the charts so that the dietitian, for example, could add her notes to the chart if she counseled someone for diabetes and then this would be available for other professionals. She would also have access to lab test results, meds, etc. This would be extremely beneficial for all health care professionals and would make for the best coordination in services with fewer errors and lost information or important information that is never shared between professionals because of the "closed" system we have."

If the system could not be relied on for transfer of patient records, then some participants wanted the opportunity to take charge of managing their own health records. Participants said that they would use their own files to provide their own health narrative. There was a lot of confusion evident over a patient's right to retain copies of his/her own files.

"It's about me. It's my body. I should be allowed to see it – I don't need it held in trust for me only. Besides, they'll destroy them if you haven't come in for a while. That's not right – it's not theirs, it's yours."

"File sharing – and knowing your own file – can make a big difference. Who knows our bodies better than ourselves? We need to learn to be more involved in our health care. The more we know, we're helping the doctors so that they don't need to see us so often."

Results from the Province-wide survey of Saskatchewan residents show that about 1-in-4 (26%) agree with the statement that "My personal health information seems to get lost in the health care system".



Who is in charge? Concerns about accountability: Many participants found health care institutions to be confusing and disorienting. Some participants seemed to see the system as a vague constellation of "parts" and "providers" – labs, clinics, hospitals – but were unsure of how everything linked together. Some participants were concerned about falling through "cracks".

A major concern was about who in the system is "in charge" of care. In hospitals or other care facilities, many did not understand how things were organized in the ward. There was a lot of confusion evident about who was ultimately responsible and accountable to the patient:

"Our major complaint is that we lost a family member. To us this is the major concern. Now we might have an avenue of presenting our case in an attempt to remedy the cause of his demise so it doesn't happen to someone else. A person enters a hospital to get well, not to die! As far as we could see, our family member saw many doctors. He saw a lung specialist, a kidney specialist, a heart specialist, and on and on! BUT who was really in charge? Upon one of our visits which coincided with the doctor's visit I asked the doctor who was actually in charge of my brother-in-law because as far as I could see there was no continuity in his care. He told me that he was in charge of his case now and he would continue to monitor him for the next three days. After that another doctor would be in charge. I noticed that he was carrying a binder about an inch and a half thick which constituted most of this patient's records. So I asked if he had read the reports he was carrying. Well, he had read the last few pages which were 'current'! Here was a patient, at death's door, and the last few pages were the only thing important in his life!!!!! There was, it seems, no one responsible for this patient because each doctor treated him for whatever was his field of expertise and pumped him full of pills for whatever he thought was his ailment. He eventually died of septicemia --- explain that one please!!!! The hospital assumed no responsibility for his infections ---- all of those were 'brought in' by the patient, so they claimed!"

"I was diagnosed with a rare form of cancer. Passed around to several doctors, surgeons and oncologists. Then referred out of Province. I felt like no one was responsible for my care. Follow up would be recommended but no one knew who was in charge of my care so it was never done. I found this out by getting a copy of my chart to ensure that I receive the appropriate follow up. I feel like the only one looking out for my care is me; however the health system is not "user friendly" for patients. For example, obtaining copies of my notes or radiology films usually involved several visits, signatures and sometimes requires me to get other health care people to request on my behalf. One department's release of information policies would be different than the rest. In my situation, I was going through the system on an urgent basis and did not have the time, energy or knowledge to be looking after my own care. There was also a lack of communication between facilities, departments, specialist, hospitals that made my care not very consistent."

"Before I was diagnosed with hemochromatosis, I was really falling through the cracks. I was being shifted around from specialist to specialist – health care is so compartmentalized with no one putting the whole picture together."

"My mom has so many health issues- she can go to one specialist about her lungs, or another specialist for something else, but they don't take into consideration that she has asthma problems, and the she is prescribed something that she can't take because it reacts. Doctors should be more in tune with the whole history of the patient, not just focused on dealing with one area."

Another issue contributing to feeling "lost" was the difficulty that some participants felt in trying to distinguish between members of staff in the hospital. Participants complained of not being able to tell the difference, and could not always account for who was who.

"People in charge have to be identified. I think that would be a really significant change that would make me feel a lot better. That kind of accountability. Identification is key when dealing with professionals."

"When everyone wears the same thing, I can't tell who the nurse is, who is the doctor, and who is the cleaner. I can't tell who is actually there to help me. It's bewildering."

"When doctors and nurses are running around, who are you going to ask for things?"

"In each hospital, there are numerous health care workers on the floor. They all wear similar clothing and seldom wear name tags. When I wanted to inquire as to my Aunt's condition, I had no idea who to talk to as you cannot tell the difference between a doctor, R.N. or housekeeper. It is also very confusing for an elderly patient to see a multitude of workers every day without name tags and try to figure out who is your Dr. or nurse. Is there no dress code in hospitals? Half the young women are wearing wind pants and bunny hugs which certainly does not look very professional. Just because all the people who work there are familiar with who does what does not mean that the rest of us (patients or visitors) know who to talk to."

Patient Story

Sandra is a 50 year old retired teacher who lives in the city with her husband and teenaged daughter. Sandra has always been extremely healthy and aware of changes in her body. Sandra is very diligent about making and keeping doctor's appointments because she is concerned about the various types of cancer that have turned up in her family. Sandra is currently living with a diagnosis of cancer.

Sandra's Story – from a patient's point of view

Earlier this year I went to the doctor to complain of pain in my abdomen. The doctor asked me a few questions but a hurried examination indicated nothing wrong. I began to experience more pain and went back about six weeks later. I was then referred to a gynecologist who sent me for an ultrasound ten weeks later. I never got the results of the ultrasound from my family doctor or my gynecologist. The ultrasound technician kept telling me that the gynecologist would go over the results with me, so I just waited. A few weeks later the pain became so bad that I called an ambulance to take me to emergency. They gave me some morphine and asked me to come back the next day for another ultrasound. I was also referred for some other tests. It was shortly after that when I learned that I had cancer. Within a few weeks, the Cancer Clinic informed me that an appointment had been made for me to have an ultrasound. I questioned why the ultrasounds done at the hospital could not be used. I arranged to have the ultrasound report sent to the Cancer Clinic with its agreement instead of following through with diagnostic duplication. Now what? I am concerned that I could be dying and the system seems to keep losing everything. "No news is good news" just doesn't alleviate the wondering.

3.3.1.2 Navigation Challenges

Experience of feeling unqualified to advocate: Some patients feel lost in the system because they are unfamiliar with, and intimidated by, the health care system.

Caregivers of frail elderly patients or very ill family members expressed concern that their loved ones were not qualified to cope with the expectations and responsibilities placed on patients in the system to:

- Ask questions and familiarize themselves with their journey of care;
- Coordinate appointments; and,
- Advocate for priority.

A number of caregivers expressed this by clearly saying that if they had not been available as a resource to a family member through their health crisis, they would have felt "lost".

"If I hadn't been in the room with my mother to ask questions, my mother wouldn't have. My mother is very trusting and without me in the room, between all of her providers she might end up on over 50 pills. You need an advocate."

"More and more of my friends are saying you need an advocate. When you are sick, let's face it - you aren't thinking straight and you need someone there who will clearly hear the messages."

"There is no follow up, there are so many people who are alone and have nobody, and there are so many people who need support, they just need somebody to check on them."

Experience of feeling unqualified to find one's way: Several participants articulated a lack of support available to assist patients who need to access multiple or foreign health care resources. Frustration, and even fear, was evident among participants who had suffered serious illnesses or interventions in a context of poor communication or little understanding with how the system works.

"It can be very difficult when you are sick to take control of all of your appointments and what you need to do, especially if you are not used to it. You need someone to help you. You basically have to be a doctor to navigate your way through the healthcare system here in Saskatchewan!"

"Years ago I wasn't afraid to go to the hospital on my own. Now if I were told I had to be in a hospital and drugged by myself I would be very concerned because I would not be able to monitor my own safety. The trust I used to have is gone; I just wouldn't go through it alone or let that happen to my family."

"There is so much lack of communication between the system and the regular Joe blow out there, it is incredible. To try and find the appropriate person in whatever department, at whichever hospital at whatever level is an absolute nightmare."

Those participants who, as patients, received neither an indication of their next steps nor any ongoing support in the wake of a serious intervention felt particularly abandoned and confused by the system.

"After the surgery on my brain I left the hospital after three days. I think it was too early. Maybe they needed the room. I left the hospital and thought someone would call to see if I was OK in a day or two. No one called. No homecare or nothing. I don't know why. I just lay there and hoped it would be OK. I had to come back a week later to get the staples out of my head. I wasn't well when I came home. I wasn't offered any help. I just went back."

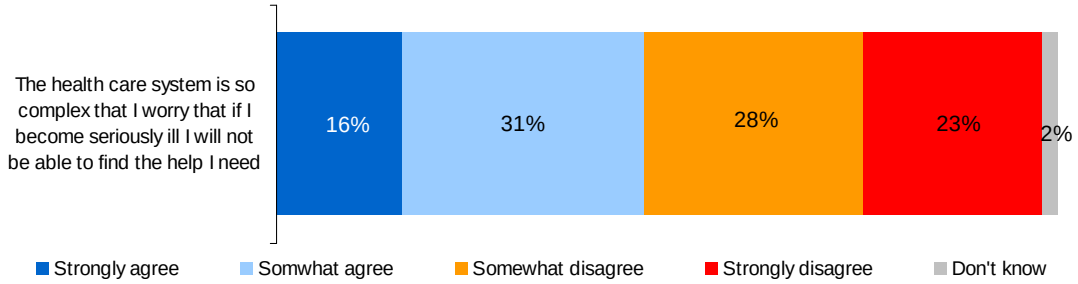
"The hospital care of 19 days was good, after I got a bed. I lay in the corridor for 27 hours, or in a corner of the emergency ward. I was to be sent home with no home care whatsoever. I don't know who was to inject blood thinner into my belly for the next 4 weeks. I asked to be sent to a nursing home because I was so weak. I went to a nursing home, and I paid for that for about 5 weeks."

"I was sent home that night [following a bladder]. I live one hundred miles from Regina so I had to find someplace to stay. I was still draining and had to report to a day clinic. This happened just before the Remembrance Day holiday. The clinic closed. I was left for 3 days before the tube was removed. This was painful and prolonged and very upsetting for me. I have to drive myself to and from city hospitals. Why couldn't I have stayed in over night?"

Results from the Province-wide survey of Saskatchewan residents show that almost half of residents - 47% - agree with the statement that "The health care system is so complex that I worry that if I become ill I will not be able to find the help I need." The analysis of the survey data shows that patients who

agree with this statement are much more likely to provide negative ratings of the health care system than those who disagree. In some cases, people concerned about their ability to navigate the system gave negative ratings that were twice as high as those who were confident.

Q For each of the following statements about health care please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree? (n=1,076)



Transition challenges are clearly identified as a major issue in the province-wide survey patient journey mini-surveys. On average, 20% of the latest patient journeys we explored received a poor or very poor rating for transitions. Communication of next steps by staff received a poor or very poor rating in 12% of those journeys.

Problem transitions overwhelmingly begin in primary care (53%). Two categories [specialist physicians (32%) and diagnostic testing (18%)] account for the majority of the destinations.

Patient Story

Lloyd is 53 years old and lives alone in a small town about 3 hours from the city. He has been unable to work for several years due to a neurological condition. Earlier this year, Lloyd underwent brain surgery involving a deep brain implant. Lloyd was very nervous about the surgery but it went well. Three days after the surgery, Lloyd was sent home. Lloyd did not feel ready to go home and was unsure of how to care for himself.

Lloyd's Story – from a patient's point of view

The whole surgery experience was pretty overwhelming. It was like all of a sudden I had it and then I was home again. I was probably sent home because they needed my room. I just got home and I wasn't sure what to do. I was in a lot of pain and I had a lot of prescriptions to fill and no one to help me. Nobody offered me any homecare. I just thought OK, I have to go back in a week to get my stitches out, and then I'll get someone to help me with all my questions. I waited a long time at the hospital for those stitches and no one who knew me from the surgery came around to say hello and check-in. When I finally got the stitches out, I asked if they could send a nurse around sometimes because I didn't feel well at all - someone to help me function. Nobody ever called on me. I called my family doctor and his assistant said that it hadn't been noted in my file that I'd had the surgery already. That didn't make sense to me, don't doctors talk to each other? She just said I should take it easy and to make sure I wasn't alone. My doctor never called to follow-up. I feel like I'm really lucky something terrible didn't happen. Let's face it, when you are sick you aren't thinking straight and you need someone there who knows and cares that you're out there.

3.3.2 Negative Experience 2 - Uncaring and Dismissive Attitudes from Health Care Workers

Many negative experiences in the health care system revolved around poor interactions with health care staff. The type of poor staff behaviour most likely to be encountered varied from context to context. While poor attitudes can manifest at many levels, most patient stories were focused on interactions with physicians and/or nurses.

3.3.2.1 Uncaring and Dismissive Attitudes from Physicians

When participants complained about the attitude or behaviour of physicians, they were most likely to point to having felt dismissed, judged or irrelevant.

Dismissive behaviour – Some participants complained of physicians who did not acknowledge their role in the interaction and as a result, were concerned that their voice was not properly 'heard'. Some participants felt that their family doctor did not listen to them or try to get to know them either as patients or people. These participants described feeling "shut out" of participation in decision-making about their care and felt as though they weren't taken seriously. They described feeling unwelcome to participate in dialogue and spoke of being frequently rebuffed when asking questions or attempting to offer information.

"He made me feel like I wasn't a person, just a number to push out the door as quickly as he could.."

"My mother said to me after seeing her doctor, "I don't think he hears me when I talk." She doesn't feel looked after."

"My father has been suffering from Alzheimer's for the past 18 months. We have had him into Mental Health several times, the Dr. laughed off our concerns with statements like "the stress can make them do inappropriate things". We were unsuccessful at getting him any help other than basic meds. When my father continued to show up at the hospital looking for his dead wife, the hospital got Social Services involved. Suddenly the head of Mental Health was interested in him, except now he wanted to put him away into Regional Care. It took a lot of frustrating discussion to have the doctor agree to a private care home. Why was there no interest to begin with? Why did the doctor decide to take the extreme measure of Regional Care once Social Services got involved?"

"Doctors never explain to you what is wrong with you. There have been numerous times that I have gone in and left with prescriptions for various things but I don't know what I am being given. They don't communicate but they are quick to medicate, medicate, medicate. I feel like even when I do ask a question, they are brushing me off, and they look at me like 'why are you asking me these questions?"

Judgmental behaviour – Some participants complained that their physicians were judgmental about their lifestyles choices and physical condition, making communication both emotionally distressing and uncomfortable.

"I won't see my doctor anymore because he judges me for being a single mother and being young. Everything is my fault when I tell him what's wrong."

Arrogance – Some participants had experiences where they felt their doctor behaved in a fashion that was self-important and condescending.

"Doctors just don't listen to you. The difference between God and the doctors in this Province is that God doesn't pretend to be a doctor."

"I went to one specialist who kept referring to my two-year-old daughter as 'it'. When my husband corrected him, his response was "when you've been doing this for as long as I have, they are all 'it'." Last time I checked, my daughter was a human being, not an object." (PWE)

"Doctors treat you like you know nothing, and they have all the knowledge. They need to remember that everybody is human."

3.3.2.2 Uncaring and Dismissive Attitudes from Staff

Some participants discussed being treated with a lack of respect, compassion or empathy by staff in hospitals or other treatment facilities. This experience was often very distressing for participants and their family members because of the relative weakness and vulnerability of patients.

Staff Overworked: Many attributed bad behaviour to staff being 'run off their feet' or 'overstretched' rather than being fundamentally unsympathetic. Participants also acknowledged that people presenting with problems in the hospital could often be trying on the patience and compassion of staff. However, participants did not accept these circumstances as an excuse for rudeness.

"When you do go to the ER, it's almost like you are intruding on the nurse's time. They have their tasks they need to do, and they are always so busy doing their tasks that it's almost like a 'don't bug me, you are invading my space' attitude, which is very frustrating."

"Staff need to be more compassionate and more responsive to your needs. You get some that are so rude and ignorant. You see those 'we don't tolerate abuse signs' in the waiting rooms but this needs to be a mutual thing, whenever you start to confront the nurses with anything they victimize themselves."

Some participants identified problems as a morale issue.

"The nursing staff need to as well be held to a higher level of accountability in terms of how they conduct themselves at the bedside. Some of the nurses behave like they hate their jobs and anytime you ask for something you are a huge bother. Their attitude stinks!!"

Emergency room**:** Poor staff behaviour in the ER was very distressing for some participants. It was discussed that patients who present in the ER are often in pain, stressed out, scared, and in need of answers. As such, getting "straight armed" by staff in the ER could be infuriating.

"A friend of mine went into the ER because she was experiencing pains. They took her right away, she had some x-rays done immediately but she hadn't had anything to eat or drink so she was very thirsty. She asked one of the nurses for a glass of water and the response that she got was 'we are not running a McDonalds here'."

"The attitude of the frontline workers in the ER is that they do you a favour. Their attitude is so bad with me I would not go back short of a bullet wound."

"The employees at Triage seem unwilling to deal kindly with patients. They themselves appear to be angry and impatient with the situations that present themselves. There is little or no compassion which worsens the incident for the patient."

***In-patient stays*:** A number of stories were about insensitivity and lack of "caring" during longer hospital stays or in long-term care.

"My daughter is in a long term care facility, once when we went to visit her she had soiled herself. When I alerted the nurses, one of them snapped back at me: "Can't this wait until after dinner?" I was like, no – she's uncomfortable!"

"When I was recovering in long-term care I saw some pretty bad things. They (the staff) were militaristic there. They would come in the morning and whip off the sheets and snap open the curtains and it's just not warm or kind. They need to be gentler with people."

"My friend's son is in long-term care and it really bothers me because the way they dress him is so awful and disrespectful. They wouldn't go out on the street looking the way they dress him to look. I don't know why they don't try harder."

"During my surgery, I shared a room for two weeks with an 85 year old elderly lady. The nurses treated the elderly lady with no respect. I thought it was disturbing and I reported it to the hospital staff. I woke up one night because this lady was screaming for help; anyone could have heard her but nobody came. She asked for sleeping pills and the nurse responded with a negative tone by saying "I'll give you some sleeping pills, I'll put a hammer to your head."

***During treatment*:** Other participants spoke of rude, uncompassionate or disengaged behaviour while in the vulnerable position of receiving treatment or surgery.

"I had surgery in September of 2007. My first OR time was booked as a Day Surgery. It was cancelled at 4:00 p.m., after I spent all day NPO in the Day Surgery unit. The surgeon scheduled me to have the surgery on the upcoming Saturday. I presented myself to the Admitting department on the Saturday morning. No one was aware of my surgeon's plans to do my surgery. The Admitting staffs were extremely rude and ill mannered. It seemed like I was a major inconvenience for them. I felt unwell, in pain and was NPO for the second time. There was very little compassion for how I felt. When I told the Admitting staff I needed to lie down, I was put in a small waiting room off the ER, which had only a

leather loveseat in it. I had to ask for a pillow and a blanket. Finally I was moved into the ER to be prepared for surgery. The nurses were by and large very good. I waited in the ER most of the afternoon, only to have my surgery cancelled at 6:00 p.m. that evening. The surgeon relayed a message to me, via the nurses, that I would have my surgery the following day, Sunday. He did not talk to me himself. I made it very clear to the ER staff that I would not be spending the night in the ER--they would need to find me a room for the night on one of the wards. That didn't go over well but I did get a room on a ward and the nurses there were super. Finally the next day I had surgery in the morning, recovered in the Recovery Room and went back to my room on the ward. My surgeon did not see me at all post op. I was discharged home later that evening. I am sure an intern or resident must have ordered my discharge but I saw no doctor following surgery. I was never so happy to see my family and go home with them. We live two hours from Saskatoon. Even the trip home, post op with incisions, in a vehicle for two hours, was not as bad as staying in the hospital and being treated poorly."

"I was in the hospital having a pelvic exam when the obstetrician took a personal phone call while he was examining me. Here I am sitting with my legs in stirrups and his phone starts making a moo-ing sound or a rooster sound. The nurse was holding the phone up to his ear so he could chat while I was lying on the table in a compromised position."

"I'm not sure if the nurse knew that I used to be a junkie but when she went to do the blood draw she said: 'I don't know why you need me. You know how to stick a needled in your arm.' Maybe it was supposed to be lighthearted, but nurses aren't supposed to talk like that to anyone. The sign that bothers me the most in the hospital is the one that says 'we will not tolerate any abuse – 0 tolerance'…but often when you leave, you are the ones who feels like you've been abused."

"It all comes down to communication, starting with the words that they chose to use. When you are in the middle of a crisis you don't want to be spoken to disrespectfully; you need to be treated with more compassion. We need to figure out what the next step is to bring the respect back."

For several participants, a distressing aspect of poor staff behaviour was their belief that they were powerless to do anything about it. Few were aware of formal mechanisms for dealing with a complaint or requesting a change to how care is provided.

"I don't know where I report things, who deals with complaints?"

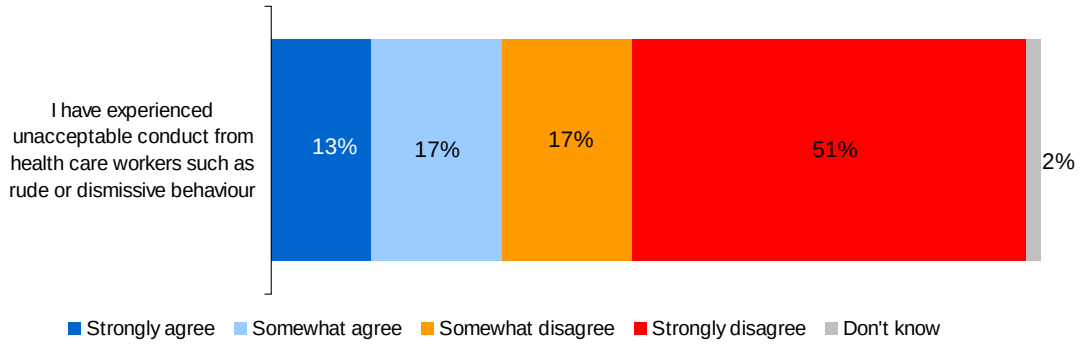
"There needs to be some place where people can raise specific concerns or specific problems about their doctors. That is not very well communicated at all, there needs to be some kind of ombudsperson"

"There is no formal mechanism to complain, writing to an MLA is just a drop in a bucket. Sometimes you just want a plain apology for being rude. It almost seems hopeless, because they are the doctors and they are up here, and we are down here, so it's not going to matter and why even bother."

"Even though I work in the health system, I was afraid if I made a complaint my loved one would suffer because of it. I have spoken to many residents and family members who are fearful to bring forward concerns in long term care because of fear of retaliation against the resident receiving care."

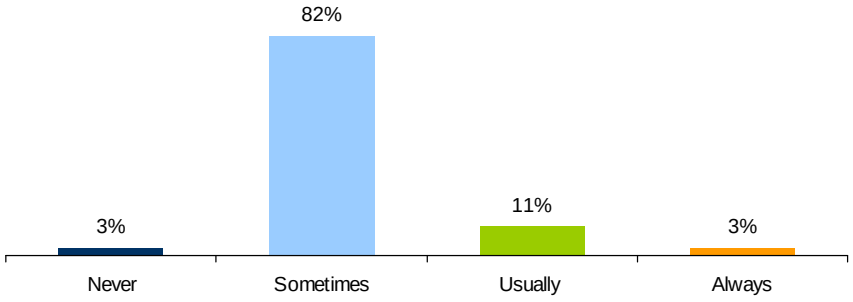
Results from the Province-wide survey of Saskatchewan residents show that 3-in-10 residents (30%) agree that they have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour. This is a particular concern for First Nations and Métis respondents. With 45% agreement among both First Nations and Métis, it is clear that people within the health care system are much more likely to offend these groups than the public as a whole.

Q For each of the following statements about health care please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree? (n=1,076)



Of those patients who agree that they have experienced unacceptable conduct from health care workers, the majority say that they experience rude or dismissive behaviour "sometimes" (79%), while 12% say "usually".

Q How often do you experience rude or dismissive behaviour from health care workers? Is it never, sometimes, usually or always? (n=318)



Patient Story

John is 33 years old and a recovering IV drug user. Recently, John has started to participate in a methadone clinic in his city. John is HIV positive but in stable health. John is currently living in a city shelter but is hoping to find a more permanent place to live as soon as he is clean again.

John's Story – from a patient's point of view

I guess you could say I try to avoid doctors and nurses as much as I can. I don't get treated very well when I'm at the hospital. The last time I went to emergency I was coughing pretty bad. I thought I might have pneumonia because I was coughing up blood and in a lot of pain. I waited for a long time to see anyone. They just put me on a gurney out in the hallway for a few hours. Every time I started up with a coughing fit the nurse at the desk would tell me to quiet down. When I finally got in to see a nurse she said, "So you're the one making all of the racket!" I don't know if she had my file or not, maybe she just took one look at me and pigeon-holed me as a junkie, but when she went to draw my blood she said, "I don't know why you need me. You know how to stick a needle in your arm!" Maybe it was supposed to be lighthearted, but nurses aren't supposed to talk like that to anyone. The sign that bothers me the most in the hospital is the one that says 'we will not tolerate any abuse – 0 tolerance' but often when you leave, you are the one who feels like you have been abused.

3.3.3 Negative Experience 3 - Feeling Inadequately Served in Hospital Emergency Rooms

The most commonly heard negative participant experiences were about hospital emergency rooms and excessively long wait times (three hours or more).

"I am concerned about the long wait times in the ER room. Sometimes I have walked out of there without seeing anyone because the wait times are just too long, and I have kids at home so I just can't wait around there forever."

"The very worst part is the long waits in Emergency & ERC, while a bed is made available. Then the actual bed in Emergency - 40 hours in an ER bed/stretcher is totally unacceptable! When a person is seriously ill and suffering, there should not be such long waits. The first time I was brought into ER it was 1:30 pm Sunday. and I was moved to the ERC at 6:00 pm that day. I did not move to a ward until 4:00 am Tues. The second time I was put into ER at 10:30 am Saturday and moved to ERC at 11:00 pm Saturday. I finally received a ward bed in ERC at 7:30 pm Sunday and was moved to a ward at 6:00 am on Monday. The care in ER, although it is acceptable, is nothing compared to the care received from the nursing staff that is specialized in a ward. The fact of the long waits is the reason I am hesitant to return to ER, which is not helping my situation when I need medical attention."

***Poor communication*:** While it was understood that long wait times are somewhat 'par for the course', the lack of communication over delays or the complete absence of status updates was thought to be an inexcusable oversight. Many expressed confusion about how admitting procedures work and how priority is established.

"I don't understand why they can't tell you how long the wait is going to be when you're in the ER, it would make it more bearable."

"Some of the waiting times are unbelievable in the ER area. Why is it taking so long? I don't understand it. No one tells you why it is taking so long. They just tell you to sit there and wait. That part I find very frustrating."

"It's like when Air Canada doesn't explain the delays to passengers – people get irate because they've paid for something and no one is telling them why they aren't getting it. If you just try your best to explain to people what's going on and how much longer, they'll be more sympathetic. At least they'll be able to make sense of it. So you wonder if there's really an acceptable explanation."

***Stressful, uncomfortable waiting environment*:** There was widespread agreement among participants that the way ER rooms are operating now is inadequately addressing the 'empathetic' side of care and that certain inefficiencies are resulting in very trying experiences for the patient, poor impressions of both the staff and the hospital, and a sense of mistreatment.

"If you feel like you can't breathe it's the scariest thing in the world. When I arrived at the hospital there wasn't a seat to be had. I asked the lady there - I'm not sure if she was a nurse or what she was - if I could go to another hospital. She said it wouldn't be long but she didn't tell me how long it would be. She gave me some forms to fill out but I told her I couldn't do them right away because I thought I was having a heart attack. I had to sit on the floor because I didn't have strength. I just curled up on the floor. They finally took me in after about forty minutes of so of me just sitting there, slumped on the floor, feeling like I couldn't breathe. It was so frightening. "

Lack of cleanliness in ER rooms and lack of safety were also problems that worried some participants. Many described having felt uncomfortable and ill-at-ease in ER.

"It is so stupid to expose very sick and untreated people to lots of other very sick people for such a long time."

"I am not a prejudice person, but it's not comfortable how they let all kinds of people into emergency to use the washroom to wash up and you can't stop them wandering around the patients. It's not very comfortable for people waiting."

Lack of alternatives to ER: Many participants suggested that emergency rooms become overcrowded because too many non-emergencies wind up there. This made some participants very bitter towards other patients and angry at the system for allowing the ER to act as a safety net or 'catch all' for the health care system.

"Everyone goes to the ER for everything in this town. There are just so many unnecessary visits. This is happening because the system has changed. When we used to have more family physicians, you would

just go to your family physician for everything – today you need to go to ER because your family doctor can't deal with it or you don't have one."

"I believe our ER is used for a lot of things that aren't emergencies, and I think that is where we should have that help line."

Those who agreed that they had visited emergency rooms for reasons that could be termed "non-emergency" complained of a dearth of alternative options – either they did not have a primary care physician or they could not get a timely appointment to see one.

"Where are you supposed to go? There's no walk-in here. Doctor's book up every day before your call even gets through. It's emergency, that's where you can go."

One participant pointed out that positive bedside manner is extremely important not only for making the patient feel cared for and comfortable, but also for making the patient feel empowered to look after themselves:

"Positive bedside manner spills over into the attitude of the patient and gives him/her confidence to look after themselves. A negative manner will spill over to the patient."

The Province-wide survey shows that ER's are, on average, part of 40% of the patient journeys we explored. ER care figures particularly highly in serious medical incidents (58%), care for aging friends or family members (57%), care for a seriously ill child (55%) and addictions (45%).

In terms of wait list concerns, ER tops the list of problem areas for dependent child and elderly care and comes second for serious illness and third for mental health.

Patient Story

Lenore is 48 years old and lives in the city. She has always been healthy. Earlier this year, Lenore was raking leaves in her backyard on a Saturday afternoon when she started to feel short of breath followed by chest pains. Lenore's neighbour drove her the ten blocks to the hospital. When Lenore arrived, it was so crowded she had to sit on the floor. Lenore was extremely anxious.

Lenore's Story – from a patient's point of view

When I arrived at the hospital there wasn't a seat to be had. I needed to sit down. The people already sitting down looked like they had ear infections or sore knees, the kind of stuff that they should have gone to a clinic for. Isn't the emergency room for emergencies? Shouldn't there be someone there at the hospital evaluating these people and sending them to a clinic if the case is not urgent? I asked the lady there - I'm not sure if she was a nurse or what she was - if I should go to another hospital. She said it would be better to wait but she didn't tell me how long it would be. She gave me some forms to fill out but I told her I couldn't do them right then and that I thought I was having a heart attack. I had to sit on the floor because I didn't have any strength. I just curled up on the floor. They finally took me in after about forty minutes or so of me just sitting there, slumped on the floor, feeling like I couldn't breathe. It was so scary.

3.3.4 Negative Experience 4 - Long Waits for Diagnostics and Surgeries

Long wait times for access to specialist physicians, surgeries, diagnostic procedures and medical equipment were a negative experience for a number of participants. While many appreciated the high demand for surgeries and diagnostics alongside the limited supply of physicians and technicians, the waiting was described as unduly anxiety-provoking and uncomfortable for those who were in pain, or living without an understanding of what was wrong with them.

***Diagnostic services*:** While only a small number of participants we spoke with had direct experience with medical need of major diagnostic equipment, those who had been made to wait shared their experience of the intense anxiety that they felt while waiting.

"If there might be something wrong with you, you want to know as soon as you can. Machines cost a lot, but does it cost less to let a whole lot of people's symptoms get worse before finding out there's something major that's the matter."

"My mother went to Calgary and paid to get an MRI in a private clinic because she had the option there, which she didn't have here. She was waiting so long here; she just felt it was really the safest thing to do."

Some participants expressed frustration at the lack of follow-up on wait times for tests.

"In the fall of 2005 during my annual physical, I asked my GP for a screening colonoscopy because of my family history and age. She agreed and said I would be called with a date. In the fall of 2006 at my next

annual physical my GP asked if I had had the colonoscopy. I said no, that I had not been called. Before I left she called the surgeon's office, to whom she had made the referral, to see why I had not been called. The explanation was that the surgeon had a 12-month+ colonoscopy waiting list. Why did this surgeon not let my GP know this a year ago and perhaps suggest referring me to another surgeon? Instead of letting me sit on a waiting list while my GP assumed this was looked after. Now to the positive piece – My GP immediately asked for another surgeon in the same office. I had the screening colonoscopy within two months in Jan 2007. Results were positive and I had surgery within one month in Feb 2007. The surgery and associated care all went smoothly, in a timely manner and kindly delivered."

***Elective and non-emergency surgeries*:** Wait times for elective and non-emergency surgeries were a frustration for participants who had experienced them personally, or within their families. Particularly disconcerting to them was their sense of powerlessness over scheduling and a feeling of helplessness while they waited for a concrete surgical date. Many struggled with the experience of poor communication of specific information.

"I've been waiting on a surgery list for hip replacement for too long. I am replying for my mother, but she is in constant pain and because of compensating for her hip, now her knees are showing signs of stress. I am worried she will fall and break something before she gets the surgery."

"I am responding to this on behalf of my 78 year old mother who is waiting on the list for hip replacement. She is in severe pain and hoping every day to get "the call". It took a long time to get on the list and when she called this Monday to find out where on the list she was, the Surgery Care Coordinator told her she had only been put on the list in October and it was a 2 year waiting list. She is so discouraged."(PWE)

"I am trying to get in to see a vascular surgeon and I can't! He is backed up for 4 to 5 months!"

While most participants did expect some wait, there was clear confusion evident about how priority is established. Many were putting their lives on hold while awaiting clear direction on when to expect surgery.

"I'm not able to make any long term plans as a family because I will have to take the first surgery time that becomes available no matter what we have planned."

"I am currently waiting for surgery to correct a hiatus hernia and esophogitis (I believe it is called a fundoapplication). I have been waiting for over two years. I suffer daily with extreme heartburn and I am worried the damage from the acid may increase my chances of developing a cancer related to damage in the esophagus in the future. Because I am not seen as a priority for surgery, I don't seem to be moving forward on the waiting list. I find this extremely frustrating as it seems like I have to wait for more damage to occur before I am seen as a priority. Preventative treatment should be important as well. My heartburn affects my daily life. It wakes me at night, and all the medications I take to try to control it affect my stomach in negative ways - bloating, cramping, constipation. I hope that I will be seen as a

priority for surgery soon. I know there are higher priority cases, such as those with cancer, but I also feel like I deserve the care. I take care of myself, I eat well, exercise and rarely visit the doctor, so I don't cost the health care system much, so I would appreciate the care when I need it."

Poor communication surrounding surgeries was particularly frustrating in cases where the patient had a date set, only for it to be later cancelled.

"I've had a couple of my surgeries cancelled due to NO beds available after my surgery. I would have had to stay for 10 days and there were no beds. So I had to wait for 6 more months. Not pleasant with my illness. I was in constant pain and lost over 70 pounds. Then 2 times I sat in my hospital gown, fasting since the night before and it wasn't until 5:30 pm that I was told it was cancelled because an emergency surgery was being preformed and the other time the emergency room was busy, so there was no bed for me. That made me mad!"

Some participants expressed a sense that the system is disorganized when it comes to setting up surgeries. There was a sense that wait lists were not being properly managed, and that an element of organizational oversight was missing.

"I am on a waiting list for a knee replacement, and have phoned the Health Region, and talked with my local doctors, but cannot get a consistent date of when my surgery will be. I live alone on a farm, and it is limiting my ability to get around. I tell my doctor this, but it doesn't help as he blames the Health Region. When I phone the Health Region, the lady answering the phone blames the doctors and nurses. It is confusing, and they just shift the blame rather than getting to the root of the problem and letting people know what is actually going on. I have said my complaint to the Patient Advocate, but this also has not helped. I am frustrated, and would have had new knees by now if I had just gone to Alberta and paid for it."

"I received notice on Dec. 4, 2008, that I am to have cataract surgery – at the end of March – a wait of 4 months. Then I received 2 letters from the Health Region OR Scheduling Office to call. I did call, and was informed the wait time would be 6-9 months. The letters state "If you have already been scheduled or have had your surgery, please disregard this letter." So here we have a scheduling office which doesn't know who is having surgery and who is not. And they tell me I have to wait 6-9 months. The doctor's office says "Disregard this nonsense. We do our own booking and scheduling, and we'll see you Mar. 31. Now, I want to know what this OR Scheduling Office is and why are we, as taxpayers, having to pay for it. Clearly, it serves no useful purpose, and seems to be working at odds with the surgeon's office. There is a difference between a 4 month wait and a 6-9 month wait. I tried to speak to the manager of this office, but he/she has never returned my call."

Others expressed frustration over access channels for surgery and the centralization of surgical services. Frustration was evident over the relative neglect of facilities in smaller communities to get through the backlog more effectively.

"To only have one OR operating over Christmas for all of the City of Saskatoon as well as North and Northeast Saskatchewan is not best practice and access to medical care. I cannot believe that living in a so called industrial country that anyone would have to wait 6 days for surgery to repair a badly fractured leg. My animal would have received surgery quicker. We are spending millions of dollars now in healthcare and still not receiving best practice and prompt access to care.....we cannot afford what we have and it is only going to get worse. Why are we not expanding services like orthopedics back to communities like Humboldt and Melfort? When you look at the OR slate on a given day at RUH there are 10-12 ortho cases waiting to go, some of these could easily be done in an outlying area and take the stress off the city because it is clear that Saskatoon cannot handle it."

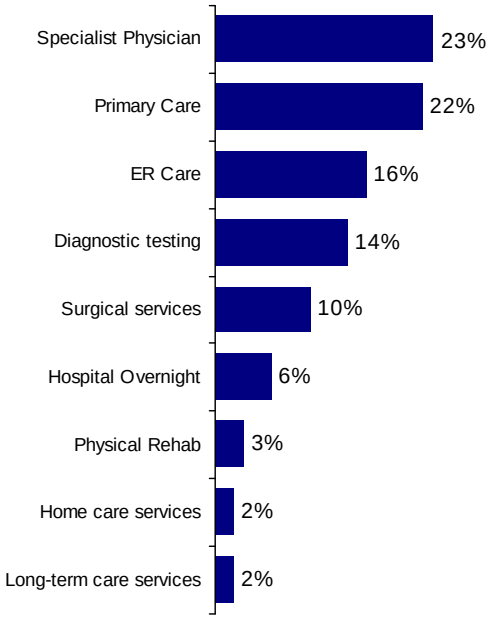
In many cases, participants had experienced pain, extended dependence on painkillers or life interruptions while they waited for surgeries. This worried participants from both a physical and emotional perspective.

"I have lower back problems so I asked my doctor what my options are beyond pain killers. My Doctor wasn't very helpful and just said there is nothing she can really do to stop the deterioration before surgery. And we don't know if I'll need that. I just wanted a second opinion but she was so eager to just prescribe pain medications – and she refused to listen. I'm reluctant to take the pain medication because they don't agree with me and they are very addictive. I just want to know if there are specific back doctors that I can go to."

"Once the surgery has been completed I will have to wean off of the six different medications I am on."

The Province-wide mini-survey probed people who identified a waiting time concern to see which area of service provided the greatest concern. Diagnostic services were the area of greatest concern for 14% and surgical waits was the greatest concern for 10%. However, for the serious illness patient journey wait times for surgical care was the number one concern. Diagnostic testing was the top concern of at least 1-in-5 respondents for the chronic illness and long-tern condition patient journeys.

Q In which part of the system did you have the greatest problem with ***length of wait times?***



Patient Story

Andrew is 22 years old and lives in a small town. Andrew has had tonsillitis a number of times and has had to miss several days of work in the last two years because of it. Two years ago, Andrew's family doctor told him that his tonsils would have to come out if he had another infection. He's had two infections since then but has been on a waiting list for surgery in the nearest city for over a year now.

Andrew's Story – from a patient's point of view

I am waiting to hear if I can get my tonsils out this year. I really hope so because I don't want to have to go through another infection. The last time I was sick I had to miss over a week of work and I couldn't talk at all. The time before that I got a bad ear infection too. I'm on the waiting list at the hospital two hours away, but I don't know when they'll get me in. I just don't understand why I can't get this done at the hospital here in town? I mean, it's not a complicated surgery and every time I go there the place is pretty much empty. Or why can't they just send me to the first hospital where a spot opens up? I've been waiting so long that I'd say I deserve to be next anywhere! It's just so frustrating, I feel like I've had this problem my entire life.

3.3.5 Negative Experience 5 – Difficulties Accessing Specialized Services

A number of participants discussed difficulties in accessing specialized services, including consultations with specialist physicians and access to specialized therapies such as physiotherapy or occupational therapy. A number of participants described long waits as exhausting, often requiring them to "put their quality of life on hold" while they waited.

***Specialist appointments*:** A number of participants discussed long wait times for accessing specialist services.

"I have now been waiting for over 1 year to see an endocrinologist."

"Waiting 6-8 weeks to see the hematologist in my opinion was too long."

"I was supposed to see a specialist for a stomach condition I've had since I've been pregnant. The pain got worse the further along I got, and I kept calling, kept getting put off, wasn't sure when I'd get in. No one tells me. My baby's due tomorrow now, so I guess it just never worked out. I guess it's not happening."

Sometimes this difficulty was attributed to slowness or ineptitude on the part of family physicians in facilitating a hand-off to an appropriate specialist.

"Slow communication time between doctors and specialists means long wait times for procedures and tests for patients."

Other times participants just assumed that relative to demand, there were just too few specialists. On the patient end, this meant frustration, pain and confusion.

"A key factor in my negative experience was the difficulty in getting in to see specialists to get my condition accurately diagnosed. Even when I finally got an appointment most of the specialists were too overworked to be able to take the time to conduct anything more than a cursory examination."

Many participants believed that the waiting times to see specialists or to receive specialized services were resulting in ongoing treatment delays, worsening conditions and prolonged pain.

"Lack of specialists is causing doctors to prescribe medicine without the proper evaluation."

"I waited a long time to see an orthopedic specialist - it took 3 doctors and over 2 years to get me on a waiting list for surgery. Now I have to suffer in pain with my disability for 18 months to 2 years for surgery to try and fix my problem."

"There was a long wait time to see a specialist for my condition. The longer I waited, the worse the condition became. The less the wait, the better the chance of at least slowing its progression with medication and treatment. There is a need for more specialists--in this case--rheumatology.... Once I saw

the specialist, she and I spent two and a half years trying to find a med. or combination of meds that would help."

Treatments: Some participants awaiting specialized treatment, such as chemotherapy, were frustrated by not having a better sense of when they would be in a position to access treatment, particularly under frightening and life changing or life-altering circumstances, such as cancer.

"Since my operation, I have waited 8 weeks for chemo… I had a new patient orientation session at the Cancer Centre on Mar.1. My tumor was very aggressive and I know that I need chemo sooner rather than later. The Canadian Breast Cancer Initiative (2nd ed., 2001) says, "Chemotherapy should begin as soon as possible after your operation, usually within 4 to 6 weeks". (p. 23) I have called the social worker at the Cancer Centre; the regional quality of care person, and the Sask government quality of care person. NO-ONE can find out how much longer I still need to wait, or whether my treatment will begin within 12 weeks of surgery (which is the cut-off time for clinical trials). I need to know NOW whether I will receive timely treatment. If I won't then I'll apply to the Sask Cancer Agency for out-of-Province treatment; but I'm in a catch-22 situation because I can't find out this information. It's a ridiculous thing; if I broke a leg, no-one would dream of telling me that they don't know when I'll get treated. Here I am, in the worst case scenario with a potentially lethal disease, and no-one will tell me when I can get treatment?????"

***Medical equipment*:** Some individuals were voicing concern over the limited access to medical equipment (often in their homes) when they needed it. This was posing problems for individuals who had medical conditions that needed to be managed, but who wanted to maintain a level of independence by living in their own homes.

"I was diagnosed with a tumor in my whole abdomen and I had to have an IV line put into my heart. I had to fight for medical equipment so that I could go home and spend time with my family but the doctors weren't going to let me since there were too many other people who needed that equipment. I fought and fought for it. They told us it was delayed at the courier company, but we later found out it was sitting in the basement of the hospital the whole time."

"Why does anyone in this Province have to worry about whether or not there is going to be a piece of equipment that they need?"

Rehabilitation, physiotherapies and other therapies: Access to rehabilitative therapies was another issue. There was a concern about long waits and enough staffing to allow for adequate participants access to therapies and enough time for patients to use these therapies to promote recovery. Therapy was viewed as fundamental for reducing pain, helping with re-integration, and potentially reducing the need for surgeries down the road.

"I don't know that the doctors use physical therapy as much as they should. In my case, that meant not getting surgery."

"Physio is so overbooked and understaffed – it's a wonder if you get in. Then you go there, they give you a couple of exercises, and they send you on your way. I barely learned anything. They trained me on some special lifting equipment for like 15 minutes and then just told me to repeat it at home with some heavy tins of beans. That's not really going to work."

"The physio in hospital is a joke. You need time and patience from therapists after a hip replacement. Not two minutes of rushed exercises."

***Rural/Urban inequities*:** For participants in rural and remote parts of Saskatchewan, experiences accessing specialized services were perceived to be longer – connected to the lack of specialists available and the long wait times to see specialists.

"There are no specialized services in rural Saskatchewan - you need travel to larger centres. It's expensive with long waiting lists. I found a good specialist, but I had to travel 350KM to get there."

"We don't have enough specialized doctors in rural Saskatchewan as our children are not getting the expertise they need. We live in a small community and 90% of the time we have to drive to Swift Current emergency to get any answers for our kid's illnesses."

Concerns about inequities in delivery of care between rural and urban areas were not limited to major medical interventions. Concerns were also evident with care in the community, including ongoing treatments for common chronic illnesses, home care services, pharma services, and rehabilitation programs.

"If I lived in a large urban center the quality of care would be much higher than in the small town I live in and I am not even allowed to attend any of the rehabs for my illness because I do not live in Saskatoon!"

"Being older and living in a small town, made it difficult for me to travel to see the specialist or for any type of therapy. It is difficult for anyone to keep up exercises on their own but especially so if there is pain present and no support."

"When there is a need for physiotherapy, we have to travel at least 160 km. return for an appointment. We used to have a PT come to our town but that was all centralized about two years ago. So it is difficult for rural citizens to access this service easily. It is an all day excursion".

"It is so disappointing that we don't have dialysis treatment centres in communities with hospitals large enough to accommodate patients to minimize commute - travel & treatment time - and restore quality of life for patients. This district is too large a district to be without a dialysis treatment centre."

"Prescriptions take too long to be delivered to the clinic. Taxis do not have a regular schedule for picking up prescriptions in this small community. Taxis should be picking up prescriptions once per week, but indicated that the schedule is not being followed. I currently wait four days to have my prescriptions filled."

3.3.6 Negative Experience 6 – Poor Case Management/Communication with Physicians

Participants shared experiences of lack of thoroughness in examinations, leading to slow diagnosis of problems, misdiagnosis, and treatment of symptoms rather than problems. Improved patient-provider interactions is the second most frequent volunteered improvement in the mini-surveys exploring specific patient experiences.

***Missed/Slow diagnosis*:** Some participants shared experiences of misdiagnosis or of lengthy diagnostic experiences. These experiences made it difficult for participants to feel they could continue to trust their health care providers. In some cases, slow progress on diagnosing a health problem had been quite serious, or even fatal.

"For over a year, my husband went back and forth to our family physician who repeatedly prescribed hemorrhoid treatments for his rectal pain and bleeding. At no time was a fecal sample taken. It finally got to the point where he was in so much pain that I went to the doctor with him. I said to the doctor, 'I've been married to this man for 45 years. There is something dreadfully wrong. It has to be more than hemorrhoids!"' Finally this doctor called to get my husband into a hospital nearby. Once we got there, we got x-rays right away and serious blockages were discovered. No one really explained to us what this meant. Eventually we went to Regina by ambulance and after a few hours, we were given a diagnosis of rectal cancer. So all that time my husband had been treated for hemorrhoids, he was really suffering from rectal cancer!"

"My youngest daughter, when she was 3 months old, was very ill. I took her to a pediatrician who said she was fine and probably just had a milk allergy but she didn't get any better. I then took her to a walk-in clinic doctors and they told me that she was fine too. Finally I had to take her to the ER because she was getting worse. They had to hook her up to an IV because she was severely dehydrated. They figured out she had a bladder infection that had gone into her blood stream. They told me that she could have died if it had all been left another day. They had to put a catheter in her. None of the doctors before had even taken a simple urine sample. It was a nightmare – it could have been a really fatal error."

"My mother has been abandoned by our health care system. She had a fractured and dislocated shoulder which was improperly looked after. No follow up x-ray was done at emergency to make sure the shoulder was fixed. One year later three surgeries were required to repair it as a result of negligence by the emergency doctor and poor decision making by the surgeon. She ended up having a severe stroke which has left her mentally incompetent. The system has dumped her in my lap!!"

"My wife has cervical cancer. It was diagnosed in 2005. The family Doctor she had before the cancer was found did not find the problem. The wife went back when she was in a lot of pain. The Doctor put her on pills for pain. He told her to come back when done. Then in that time her menstrual period went on for 4 months. When she went back to this Doctor and told her about this other problem the Doctor told her it was part of going through change of life. The pain in her legs and back were getting worse. Then the Doctor told her it was her back and she needed orthopedic shoes and said she was going to send her to a

Back Specialist, which took 5 months to get in and see. This Doctor, when she did get in said that there was nothing wrong with her back. Back to her family Doctor, more pills. Then one night pain was so bad she went to the Hospital. She got to see an Oncologist. Did some tests and was sent home. Went to the Oncologist office and was told about the cancer. But was told if it was found out a few months earlier it could have been taken care of."

For participants living in rural or remote parts of the Province, the risk of poor case management was perceived to be much greater due to lesser proximity to needed care in urban centres.

"Living in rural Saskatchewan puts a patient in the negative to start with. When a serious illness is in question getting a diagnosis in a timely fashion can be difficult- with both the Doctor and the length of time it takes to get appointments for further testing in the urban centres."

***Treatment of symptoms, not problems*:** Some participants expressed frustration that progress on their case was on "hold" while symptoms got treated as opposed to underlying problems. While it was well understood that this could happen when a physician simply did not have another answer, it was expected that more effort should be made to connect the patient with appropriate resources who could help, rather than allowing a long, anxiety-provoking "guess and check" period to go forward.

"Doctors treat symptoms, they don't treat the individual, and that is my biggest problem with the healthcare system."

"Perhaps we need more doctors so that each could see fewer people and perhaps make the time to diagnose properly. Although I do first check things out with my GP because I do not like to take pharmaceuticals I would prefer to be able to see a holistic doctor if that is my choice. Drug companies are not interested in getting people healthy; they are interested in making money. It seems that regular MDs are more interested in writing prescriptions than in wellness."

"Over prescribing is a problem. There is no 'let's keep searching for the cause'. Pill pushing is like continuing to drive when your oil light comes on, it doesn't solve anything, it just puts a band aid over it"

"Doctors are writing unnecessary prescriptions without properly understanding the problem. The pain is often prolonged since the prescription is incorrect. Doctors don't believe me when I say I'm still in pain."

Insufficient face time: Poor case management experiences were frequently attributed to not having enough face time with physicians. This was seen to be more of a systemic problem rather than an individual-level physician attitude problem. However, participants felt that short appointments left little time for two-way dialogue, questions or meticulousness and that these were contributing to very partial or fragmented care. In particular, many participants were very concerned about a tendency toward a "one problem per appointment" policy in some family doctors' offices.

"I went into see the doctor, I sat down, and I told him I had two or three things I had to discuss and he said 'keep it to one because I have people waiting'. He didn't have time to listen to me because there

were people waiting in the other room. There's such a 'hurry up' mentality and it means things get missed."

"I always feel rushed through when I go see my family doctor. I am only allowed one problem per appointment and it makes me so frustrated because some things might be related. Doctors are too overbooked, they see too many patients. But if the alternative is not seeing me at all, I guess I'll take the partial care."

Poor communication channels with the patient: Particularly distressing for participants was when physicians were incommunicado or vague with them about important information concerning their care. This included information about their test results.

"My doctor says 'no news is good news'. Obviously she has no idea how terrifying that is. When you don't hear, you want to feel relieved but you're still worried that maybe they've lost something or forgot to call."

"I had to wait for 18 months to see a neurologist, who later ordered some tests and those tests took a year and a half for each one. Afterwards, I never heard back from the neurologist to see if we were going to undergo a course of drug treatments. That was a little frustrating"

Another problem was unclear directives and communication to patients about their case and related planning, resulting in delays and issues with health care progress.

"I went in for a hysterectomy and the doctor yelled at me because I was menstruating. No one told me that I couldn't have the surgery if I was on my period. The doctor was so mad, he threw his pad down. Maybe he thought I didn't listen to someone – but no one ever told me."

"I was ill-prepared for my surgery, due to my physician not informing me of the overnight stay and the recuperation period (4-6 weeks off from work and a 2 ½ week back to work program implemented by my employer, to accommodate me, on short notice). Post-surgery I was catheterized without being informed prior to surgery and upon awaking from anesthetic was startled to find the tube that I had tugged almost fully out and had to be put back in. I have been told by many friends, family and co-workers that they were not fully informed on the details of surgery and recouping time."

Patient Story

Peter, aged 68, was very active and had always been in excellent health. One day he started to experience rectal bleeding of unknown cause. After a week of discomfort, he went to see his primary care physician who diagnosed him with hemorrhoids. After a month, the discomfort and bleeding was getting worse, so Peter returned to see his doctor and was encouraged to continue treating his stubborn hemorrhoids**.**

Peter's Story – from a spouse's point of view

For over a year, Peter went back and forth to our family physician who repeatedly prescribed hemorrhoid treatments for his pain and bleeding. At no time was a fecal sample taken and this made us feel a little uncertain about the diagnosis. It finally got to the point where Peter was in so much pain that I went to the doctor with him. I said to the doctor, "I've been married to this man for 45 years. There is something dreadfully wrong. It has to be more than hemorrhoids!" Finally this doctor called to get my husband into a hospital nearby. We got there straight away, but Peter's files didn't. We had to spend half the day having his history taken over again. Once they got to the x-rays "serious blockages" were discovered. No one really explained to us what this meant. Eventually we went to Regina by ambulance and after a few hours we were given a diagnosis of rectal cancer. So all that time my husband had been treated for hemorrhoids, he was really suffering from rectal cancer! If I hadn't been there with Peter in the doctor's office that day, he may have never gotten a proper diagnosis. As it is, Peter may only have a few more months.

3.3.7 Negative Experience 7 - Difficulties Accessing Appropriate Family Health Care

Several patients described their negative experience with the health care system as not having a reliable family doctor or having difficulties accessing appropriate and timely family health care services. It was commonly expressed that the healthcare you receive is only as good as your family doctor. Having access to a good family doctor was often characterized as a right for citizens since the strength of one's relationship with a family doctor was seen to be the key to timely and appropriate access to additional services.

"A family doctor is important. If you have a family doctor then you don't have to explain things over and over again - they know your history, and there aren't the same concerns when it comes to mixing medications."

"It all comes down to the relationship you have with your doctor. You simply need to get a doctor you can call your family doctor and then pretty much, the rest is history."

However, negative experiences with accessing family health care were very common among participants. Many individuals were facing difficulties finding, maintaining, and getting in to see their family doctors, giving rise to concerns about the inconsistency and the quality of their care.

"I moved to this town 6 years ago. We couldn't find a family doctor right away which turned out to be a huge problem because my son sees allergy specialist in Saskatoon and they wouldn't let us back to see him without a new referral from a family doctor. Our only choice was ER."

"I don't have a family doctor so I have difficulty getting referrals when I need them. Also it bothers me that I can't get a second opinion because there's no one around to give it."

"There is a lack of doctors in very small communities. The fact that there are communities where there isn't a doctor at all times scares me."

***Access to timely appointments*:** For some participants, the issue was not about the absence of a family doctor but gaining access to that family doctor. Many found it hard to schedule timely family appointments or to see their family doctors in times of urgency, resulting in increased dependency on emergency rooms.

"My family doctor does same-day appointments because otherwise you'll wait for a month. So you have to get on the phone first thing in the morning and hope for the best, but sometimes it doesn't work out. So you go to emergency."

"It's so hard to get into your doctor's office, so it is good when you can get in and out in the ER. My husband has to go see the doctor quite frequently, but it takes so long for him to get an appointment."

***Frequent turnover*:** Several groups expressed concern over the frequent physician turnover in communities in Saskatchewan. While this was not strictly a small community issue, the topic was frequently discussed in rural and regional centres. Many perceived that local physicians did not take their communities seriously and that the hope of establishing a long-term relationship with a physician was likely unrealistic.

"So many doctors are using these areas as a stepping stone, and since we do need someone, we take anything we can get. There is no permanency."

"They take us on as guinea pigs here. We just get the new doctors in training."

The experience of losing a trusted family doctor was hard on some participants. Many participants had been through the often challenging experience of finding a new family doctor when an established physician had left. Not only was it a difficult task, but while in limbo, participants felt vulnerable and anxious.

"It's like you just get a really good doctor, or counselor, and you are making progress...and then all of a sudden that one is gone. Then you have to start new, from scratch, and that is difficult."

"I'm afraid my community is served now with little continuity. I cannot understand why this is so and why two of the Doctors whom I prefer don't make it clear whether they will be returning to their practice after their sick medical leave. This distresses me. Shall I become a permanent patient of their replacement, who will only be around for a year, or what????"

"It would be helpful if Doctors were here in our rural area for more than just a few months. We don't know them and they never get to know us. Sometimes a patient needs to be listened to and this is a failure sometimes on the Doctor's part. Too many people fall through the cracks"

"I don't have a family doctor and neither of the doctors in town are taking new patients. You have to go through an interview in order for a doctor to agree to see you!"

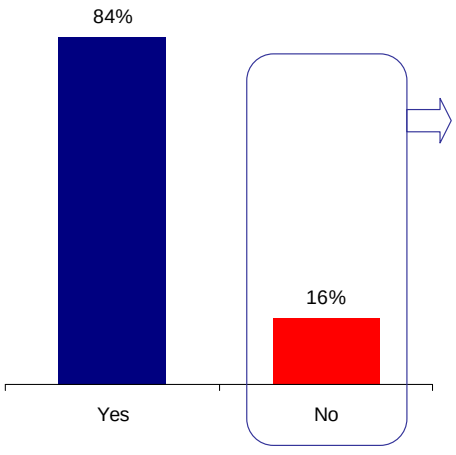
While the transient nature of physicians in some communities was an irritant, many participants suggested that the relative lack of enticements for physicians to come to, or to stay on, in small towns was perpetuating the problem.

"Small towns just can't keep doctors, and to find good doctors, it is difficult. But it's hard to be a professional in this community – it's hard on the spouse, the family. There isn't much action here for them."

"Doctors here in town have been here for years, they don't want to change. And it's so hard to get new doctors to come here and stay in this area."

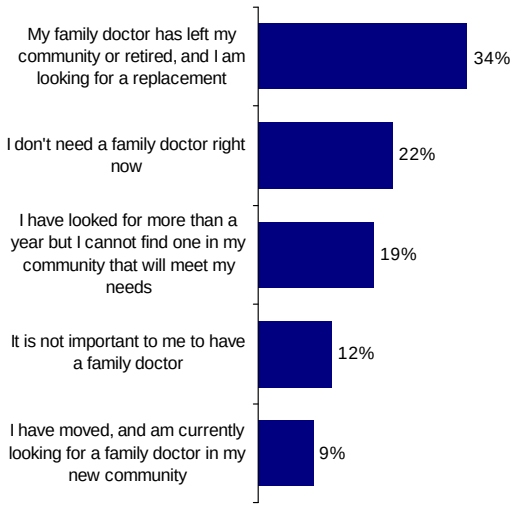
Results from the Province-wide survey of the Saskatchewan health care system show 16% of residents reporting that they do not have a family doctor. Among this group, more than 4-in-10 are still looking for a doctor with over a third (34%) saying that they are looking because their family doctor has left their community or retired, and 9% reporting they are looking because they have moved. Just over one third are not looking because they feel they don't need a family doctor right now (22%) or say it is not important to them to have a family doctor (12%). One number to be concerned about is the 19% who have looked for a year but can't find a doctor that meets their needs in their community.

Q Do you currently have a doctor in Saskatchewan? (n=1,076)



Note: Don't know (<1%) not shown

Q Which of the following statements is most true for you? (n=167)



***Lack of choice*:** In rural communities and regional centres in particular, some participants discussed feeling 'trapped' by a lack of options for family health care in their communities. People did not feel as though they should be expected to settle for 'whatever they can get', but expressed that this was the reality in their communities. Problems reported with physicians typically revolved around language barriers, cultural clashes and attitude or perceived incompetence.

"My doctor seems nice but his English is atrocious. We can't really communicate."

"My family doctor is abrupt and makes me feel like a bad mother every time I'm there. I've just gone back to seeing the doctor I grew up with in Alberta rather than the one 5 minutes away. People in the community say it's a cultural issue that he doesn't deal well with women. Why do we have him here then?"

"Just because a doctor feels that he is good enough to grace our town, doesn't mean he is good enough to be here. They seem to have to answer to no one. There is a doctor here who spent twenty minutes looking up information on his palm pilot about my prescription, which he'd never heard of, and then challenging me about the appropriateness of that prescription for my situation. It was a prescription that I'd been comfortably taking for a long time. I was like, you don't even know what you're talking about? It was so frustrating. I'll never go back to him."

"A newcomer to the Province seven months ago, I have a long-term health condition requiring services at home as well as physician assistance. Before I moved, I contacted the health region regarding services availability, and the medical clinic regarding physician services. On arrival, everything went well with Home Care and has continued to do so – they have been very helpful and pleasant. My experience with physicians, however, has been extremely negative. There is only one doctor accepting new patients here so I had no choice as to care provider but as I had called ahead and received assurances re: care, I was not concerned. However, this physician turned out to be extremely closed-minded and negative to me. I don't know what I will do if I need acute care or emergency care at some time as I have no faith at all in this doctor's skills or knowledge."

For those who accessed rotating doctors in their communities, frequent appointment delays and problems with inconsistency could be cited.

"My community is served by physicians from a larger centre about 25 miles away. The Doctors rotate their visits to my community on a weekly basis, but that is sometimes interrupted by surgeries in the larger centre or medical conferences or illnesses. Sometimes when appointments have been made for 2 p.m. for example, it might well be 6 p.m. before the Doctor is seen. Our community is 'walking on thin ice' - always wary that we will lose our Physician services."

***Access to more natural or holistic family Health Care*:** There were a number of participants who voiced concern over a lack of integration of alternative medicine into mainstream primary health care. Some participants said that they were interested in alternative or natural medicine, but had difficulty affording

care through the traditional pathways. Some had paid significantly out-of-pocket for naturopaths or homeopathic doctors.

"I'd been waiting years to have my son's psychological problems properly assessed, and I was sick of not getting a diagnosis and getting pushed drugs by people who'd only seen him for 5 minutes. I paid for natural advice too. I paid for my son to have a live blood analysis. It was fascinating to learn how that worked."

"When you are really sick you want to try everything. I did some herbal supplements for a while, but as a single mom, it is very expensive. And with that kind of therapy, they recommend you try these things for a minimum of a year before your body starts recognizing the changes...I couldn't afford to stay on them for a long period of time so I don't know what kind of long term effects they would have had. But maybe I would have been better off."

"About 5 years ago, I started to feel really sick all of the time - I was in pain, I was exhausted and I had no energy. I went to see several doctors and specialists, but I was losing the battle. They were not doing the right tests, nobody could figure out what was wrong with me. So finally, in sheer desperation, I went sobbing to a friend who recommended a book to me by Gaber Mathe. The book went over some of the things that are regularly missed by doctors in our mainstream health care system. My friend suggested I see her homeopathic doctor. I went to this doctor and told him, "I am falling through the cracks! Nobody can figure this out!" He was amazing. He diagnosed my genetic condition and essentially saved my life."

A concern among these participants was the apparent closed–mindedness of the mainstream system to the wealth of knowledge found within alternative forms of treatment. Many individuals felt that their family physicians were judgmental about alternatives and wanted to find a family doctor who was knowledgeable and respectful of alternatives as part of an overall lifestyle choice and wellness strategy.

"I think we are so archaic here. You don't always need the high end doctor, you need them for the surgery, but we aren't all in dire straits, maybe there are other support systems that can help people who aren't really severe."

"Doctors don't act like they recognize the value of alternative medicine. Granting access to preventative care programs will reduce the burden placed on the medical system. The medical system has heavy demand because alternative treatments are not included in the medical plan."

"The health system is still driven by 'response', and we need to be more 'preventative', addressing our health before we have a problem, that's where we need to be integrated. I would like to have a 'family' healthcare plan, something that integrates, and is focused on the whole family. Wellness care, rather than sickness response."

"These alternatives aren't recognized by Sask health. It just seems like there aren't enough options, and not everyone thinks the same way. Who's to say that there aren't other options that are available for us? Who's to say we need to put all the chemicals in our bodies unnecessarily if there are other options?"

Patient Story

Melanie is 35 years old and lives in a town about 2 hours outside of a city. Melanie has three young children and her youngest son suffers from numerous allergies and intolerances. Recently Melanie's family doctor moved out of Saskatchewan. Melanie is exhausted from looking for another local physician who can meet her family's needs.

Melanie's Story – from a patient's point of view

Maybe I should have expected it, but when Dr. Lockhart told me she was moving out of Saskatchewan, I was just devastated. She has been so wonderful with me and my family. The other doctor in her old clinic can't take any new patients. There's a new doctor in town, but everyone says he probably won't be here too long. Sometimes I just feel like this community is just a stepping stone for new doctors. I don't want to get my kids used to someone new again and then have to change. Understanding Alexander's allergies has been a real challenge for us, so it's very important for me to have a family doctor who is familiar with his patterns. It is so exhausting trying to find someone. I took the day off work and drove an hour and a half to check out the clinic in another town. Turns out the doctor there would only be able to take me, not my family.

3.3.8 Negative Experience 8 - Limitations in Available Home Care Services

Many participants had very positive stories about home care. A number of participants went out of their way to emphasize the value of home care - particularly when there are waiting lists for long-term care – and especially for patients who have difficulty coping on their own but who do not require as high a level of support as would be mandated by public long-term care facilities.

"We need to have a really good homecare system. It is something we are all going to need to access sooner or later and it will be able to help the aging population. It will take some pressure off the doctors."

Some participants expressed negative experiences in trying to obtain home care services. This was more of an issue noted in rural areas.

"Home care is a joke in rural areas."

"You need to be on a waiting list for home care forever in rural areas."

"Elderly people love this community and want to live at home in the north, however there is a lack of homecare services available to them."

"I don't understand why a hospital stay is no longer an option, especially when there is no home care to assist upon release. Family members do not have the expertise to provide the care, and in many cases,

they have jobs and families that also need attention. Spouses in their 90's shouldn't be asked to care for loved ones around the clock."

Some people reported that their home care experiences fell short of expectations. In particular, some participants and caregivers said they had expected more knowledge from home care staff.

"When mother was in her final stages, home care came in to help with blood pressure checks. I appreciated their coming in, but my expectations were that they would know more than me about what's wrong and when we should go to the hospital and that sort of thing. But this person just did blood pressure, that's it. I didn't get a clue from the person to relieve questions and anxiety."

In other cases, there were stories of individuals who had had positive initial experiences with home care, but had become disappointed with the lack of follow through and repeat care they were receiving.

"Home care locally came to asses my father after he had surgery. The assessment and recommendations were all good, but the follow up in terms of sorting out his medications wasn't that great. An aide did that for him once, but she never followed up to make sure he was taking his pills properly, and that disappointed me."

Limitations in services available, particularly housekeeping and personal services were raised by some home care users. The possibility that expectations were not properly managed by home care providers or assessors may be part of the issue.

"It would be nice if they talked to me a little more and helped me with things but I understand that they've got a lot of rounds to make."

Caregivers also expressed some concern about the limited offerings of home care, hoping for more support and services to alleviate pressures on the patients and their families.

"Home care that will help out with more duties for patients & spouses would be great in rural areas. It would provide relief for caregivers, just to get away for a day. Day care is available in cities & towns, but not always easily accessible for rural residents."

Dementia and Alzheimer's were raised as areas where home care staff was sometimes under qualified to handle patient needs. In the case of dementia and Alzheimer's, however, not only was lack of knowledge identified as a problem but also lack of consistency in care.

"Home care services are very inadequate and are not set up in the patient's best interest. For example, staff providing home care are not trained or educated regarding Alzheimer's and home care sends different people each visit when it is important to have the same person and consistent care."

"Home care is inconsistent. Consistency of visits is essential when dealing with advanced dementia."

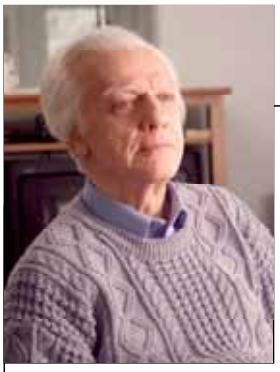
Occasional long waits for assessment services, particularly for the elderly, were flagged as a problem.

"My dad went for 2 months without a bath. Until he was assessed to see what stage he was at, he couldn't even be taken to a facility to be given a bath."

Other problems cited with home care experiences included frequent cancellations and inconsistency in staffing and service delivery, resulting in poor follow-up.

"I don't think homecare is very helpful at all. They don't come when they are supposed to, they set times but don't show up, nobody checks up to make sure that the service is being done."

"Nurses in home care were good, consistent. But the care people – the special aides - were always switching. They came in and made supper but didn't engage much with the patient. I wasn't able to be there all the time so guess it was better than nobody there. Aides are overstretched. Maybe they didn't feel they were really serving a purpose."



Patient Story

Patrick is 81 years old and lives in a house in the city with his wife. Patrick had a stroke about six months ago, shortly after finishing treatment for prostate cancer. The stroke left Patrick paralyzed on his left side, so he spent some time at a local rehabilitation hospital. Since Patrick has returned home, he has been cared for by his wife who is also 81. Homecare comes occasionally for Patrick, but his daughter is concerned that they are not doing enough to take the burden off of her mother.

Patrick's Story – from a daughter's point of view

After my dad's stroke he spent some time in rehab to get his muscles working again. I don't think he was in there long enough, I don't think they did everything they could because he was still pretty weak when he came home. Homecare was supposed to come to do some therapy with him, but there were so many scheduling conflicts and cancellations that I don't think he got any stronger. Mum has had to do everything for him. Someone comes in to take his blood pressure once a week, but they don't have the knowledge to answer any of Mum's other questions. What really gets to me is that Dad had to wait two months for a bath. There are so many hoops you need to go through to get a simple bath! He had to be assessed, he had to wait for the results of that assessment, and then only to find out that all they can offer is for Mum to take him herself to the local retirement facility where they'll bathe him. I think she pays twenty bucks for each bath. I've told her that we should try to get him into long-term care, but she has a real "through sickness and in health" mentality. She won't separate from him, no matter how worn out she is.

3.3.9 Negative Experience 9 – Feeling that the Province Seems Ill-Equipped to Meet the Care Needs of the Aging Population

Some participants described a perception of long waiting lists for long-term care services. A number of participants expressed concerns over whether they or their family members will have the option to live in appropriate full or part-time care facilities when they are no longer able to manage without support at home. Many complained of long term care shortages, with waiting lists being 'books' not 'pages'. Several participants were under the impression that access was limited only to patients who required very high-levels of support, leaving a gap in care for those who require a more medium level.

"We need more housing for people who require 24 hour management, but now 24 hour care is at a premium. It is going to get worse as the baby boom now is at age 63-64 and coming on for years after. I had to go 90 miles away to a private, municipally operated care home to house my elder because she did not need any of the high care available near where we live. And she would have been very uncomfortable in such a care situation, also. There is GREAT need for new and more of these places to be opening, not being threatened with closure. There is going to be a glut of seniors requiring care SOON."

"The problem is the waiting lists for long-term care – you have to be on your last legs in order to get in."

"Our Community does not have any old folk's home or Senior lodge specifically. People are forced to take care of themselves until they are critically ill. The patient only has the option to enroll in a long-term facility once they get to a risky medical phase."

Many were not comfortable with the idea of having to travel far from family in order to access long-term care or appropriate senior's living accommodation for either themselves or their families. Many considered the need to travel for care to be very emotionally taxing. A particularly difficult situation was raised on more than one occasion of some spouses having to live in separate communities in order for both to have access to appropriate levels of care.

"My 89 year old father was placed in a nursing home 40 miles from his home – too far for his wife to visit him. He was put there because there was room – but no consideration was given to the fact that he was not going to have visitors because he was too far away. Initially he was to be put in one 150 miles away, until my sister kicked up a fuss. I know of 5 other people from 4 other health districts who were put in communities where they knew nobody and which were too far away for spouse, friends and family to visit. For instance one French speaking lady was put in a home in which all the elderly residents spoke Ukrainian! Because there was room there. In another case, a Cree speaking woman from Cumberland House was put in a nursing home in Hudson Bay! I could go on and on."

"There was no long term care facility in the community my mother in law lived in, so she had to be put in a nursing home in a neighbouring county. It was really hard for her – she had roots in her town."

"I approached the system regarding residential care for my parents. As they were at different 'levels of care' they would have had to separate to receive care. They had been married for 65 years. This was a completely negative experience. In order to remain together they had to purchase service from the private sector. The cost of this for two people, one level 4, one level 2, was over $ 60,000 per year."

Of particular concern for participants was obtaining care for people living with dementia and the level of care available for these individuals. Participants expressed concerns about the ability of either private care or public care to accommodate the needs of dementia patients.

"There will simply not be enough public long term care beds. The "private care home" network is a zoo of expensive and unqualified care. Most of the few available spaces are not suitable (secure) for patients with dementia."

"My mother has Alzheimer's Disease which is a chronic disease and in my opinion the number is steadily growing. Diagnosis is extremely difficult to obtain especially if the sufferer is not competent. Once a diagnosis of dementia [Alzheimer's] is confirmed, obtaining medical treatment can be hindered - as it was in my experience - by the fact that I had no legal authority to proceed. I had to apply for Adult Guardianship and I believe I was among some of the first to apply. Since this was new to all involved it took over a year to be granted and was financially draining for me. In the meantime, my mother was without proper medical care and unsupervised at times because I could not personally do it and I could not pay for it or in reality instate care for her until I was recognized as her guardian. Home Care only deals with physical limitations. Once assessed, the wait time for placement in a special care home is an issue."

"My 74 year older brother with dementia is being looked after by my 74 year old cousin because the District can't accommodate him. He had bladder cancer and had it removed 2 years ago and now has an ostomy which he can't look after himself because he just doesn't remember how to - and I was told that private care homes were the answer. He only has his old age pension and security so he can't afford private care and it's hard to find one that would look after the ostomy. Luckily our cousin is kindhearted and is willing to look after him. But, she is of the age that soon she won't be able to and then what? We need more senior's facilities."

Some participants were very concerned about the cost of long term care homes and the lack of funding available for private care.

"My 93 year old mother who has been living in her own senior's apartment had a bad fall in late December 2008. . . if my mother needed to be placed in private home care she would have to pay between $1500 to $2500 dollars a month. . . Throughout this process every person I contacted or who contacted me wanted very much to help but unfortunately none of them were able to do anything because of a government policy that ignores people needing a private care home. I can't begin to convey how much stress this has caused. I believe that the government has to start funding private care home residents in the same way it funds nursing home residents. By not doing so it places some people in an impossible situation."

"We need more appropriate spaces in long term care. This issue is going to grow with our aging population unless new spaces are built. Many faith-based and other organizations would be willing to step up to the plate and fund-raise, were it not for the onerous requirement of the 35% local share."

Some participants with family members currently living in long-term care facilities told us about negative experiences with quality of care, including staff carelessness and inattention to patient comfort. Some attributed these negative experiences to over-stretched staff at certain facilities, and the challenges that come with managing the care of an aging population.

"I think that staff needs to have more training in terms of empathy and how the family is struggling with someone in long-term care. I realize that they are often overworked and short staffed but that is not my

problem and we still have to pay the same amount for his care whether a staff member is sick or not, so our loved one's care should still be of the utmost importance. We do not get a reduction if they fail to get some of the care done. They should also be taught not to verbalize to the family how overworked they are to make excuses for the lack of care."

"People working in LTC facilities need to keep a closer watch on elderly clients. Just because they are not "ill" and want to be as independent as possible does not mean they are not frail and need assistance. My mother died because she fell trying to "not bother the staff".

A few concerns were raised about the condition of long-term care facilities. Some were not comfortable with the quality of the physical space for patients living in long-term care.

"My father-in-law was suddenly diagnosed with Dementia in December, 2008. The experience with doctors, nurses, social workers was positive. The big surprise was the deplorable condition of the long-term care. Imagine being a hard working middle class retiree sleeping in the bed you worked to keep for 40 years. Suddenly someone tells you that this dilapidated room with no bathroom door and no maintenance for a decade is your new home. To top it all off, you get to pay $1,000/month extra to stay there. The Director was sympathetic, but has no budget."

***Support and engagement of caregivers*:** For full-time caregivers, a lack of support and engagement services were a concern in two main ways: greater engagement and more support - both financially and otherwise.

Many caregivers felt that they were the best advocates for their family members and should be taken seriously in their treatment.

"In facilities, family members would benefit on having some input if that is possible on the types of activities their elderly family members could participate in and also in the choice of their diets."

"The doctor really didn't have a good knowledge base around geriatric care and, as a result of treating a condition my dad had, really messed up several other of his systems. The doctor of course has a lot of credibility with my dad - I think this is a generational and historical thing - and he doesn't think to question the doctor which is a real problem when he then has to deal with and recover from complications caused by improper treatment in the first place. There is no where to go to discuss these concerns either - the medical associations listen politely, but that doctor is still practicing and messing up the health of old people. I have decided that the only way to keep my dad safe is to be very involved in his health regime, including attending appointments with him if necessary and talking to the doctor(s) with his permission. It is very scary."

Secondly, some felt that access to consistent, high quality respite services had been a problem. Either space was too infrequently available for the caregiver or too hard to get to for the patient.

"The trouble with respite care is you can only get in there once a week. You are only allowed to respite 4 weeks out of the year. For some people, that is not enough."

"The long wait time to get my relative into a senior home necessitated some family members taking leave without pay to help care for her before we finally got her placed. We were required to move her to several different places for respite care, which was very stressful for her. Depending on how far each senior home was, there was also the cost in time and money by family members to visit her so that she would not feel totally abandoned".

Some participants discussed the advantages of more care in the community for caregivers.

"Adult Day Centre spaces are crucial to the well-being of the adult with dementia or other high-care needs and provide much-needed respite to the family caregivers."

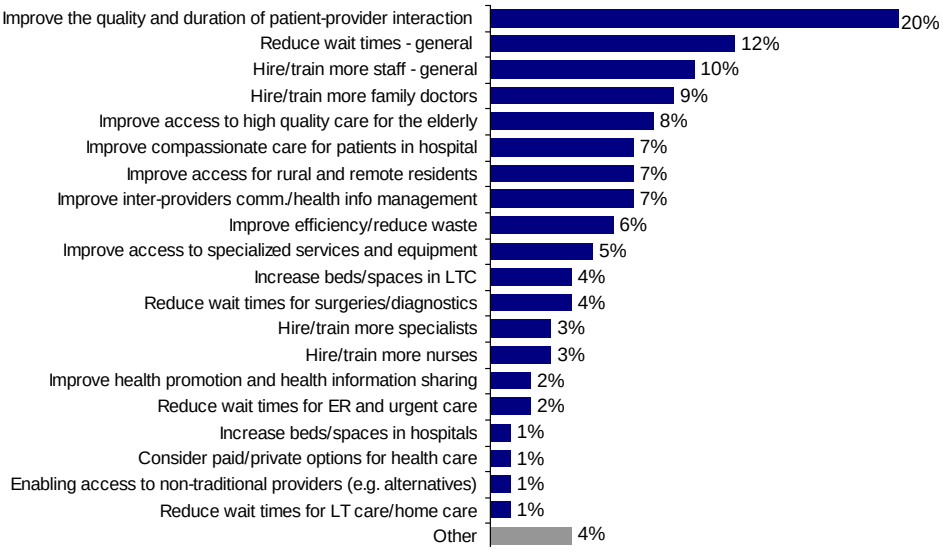
The Province-wide survey showed that seeking care for an elderly friend or family members was one of the three most common health experiences. Almost a quarter of respondents have sought advice or treatment for an aging relative or friend in the past five years. Unfortunately, this particular patient journey generates some of the lowest overall satisfaction scores in the survey with just 21% saying they had an excellent experience and 1-in-5 reporting a poor or very poor experience.

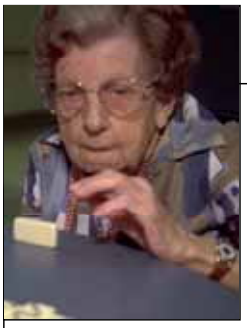
Care for the elderly engages all aspects of the system. While obviously this patient journey has the highest experience with long term care and homecare, it is more frequently a driver of ER visits and overnight hospital care.

Problems experienced in this patient journey are similar to the average with waiting times topping the list followed by transitions. Wait times for ERs (24%) and specialists (23%) top the list of wait time concerns. Transitions from primary care and hospitals to specialists were the big issues in transitions.

While the broad category of better access through either reduced wait times or more resources was the main suggestion for improvements, communications improvements were suggested more frequently than average with improving the patient-provider interaction topping the list of specific suggestions.

Q From your point of view, what one thing could the health care system do differently that would make the biggest improvement for people who use the health care system to …? (n=221)





Patient Story

Ruth is 94 years old and lives in a small city. She is diabetic and suffers from severe arthritis in her hands and feet. Until this year, Ruth lived alone in a small apartment. Her niece, Sarah, visited frequently and was very concerned about Ruth's ability to cope on her own. Ruth was not taking her medication consistently and often seemed sad and lonely. Sarah fought hard for over a year to get her aunt into a local long-term care facility. After three weeks of being there, Sarah really started to wonder if her aunt was better off.

Ruth's Story – from a niece's point of view

I remember going to visit Ruth at her apartment last year and thinking 'this just can't go on'. She needed more help and she needed company. I thought long-term care would make the most sense, but you can't just open up a phone book and find a place to go. It's difficult to get in even for someone her age. We had an assessor come in but I wasn't happy about how the assessment was done. She saw Ruth alone without any family members there – Ruth could have told her anything. After the assessment, the nurse said Ruth wasn't eligible to go the long-term care facility in town. They suggested I consider a private home three hours away. I couldn't see myself driving down there to visit three times a week, and I am the only family that looks after her. There is a good home about 40 minutes away, but that one's in another region. I wrote my MLA, I called the local lodge every week, and after a year of fighting tooth and nail, she got in. But I can't say it's been too much of a comfort to me. I dropped in a month ago to say hello and she didn't know who she was, or where she was, or anything! When I asked the nurse what happened, she said that they saw that Ruth's hands and feet were looking very crippled so they gave her some painkillers. They did this without consulting me. Ruth wasn't in pain, they just thought she was. They stopped the painkillers and Ruth, thankfully, is back to her old self. When I told my friends this story they said that overmedication happens all the time there, especially painkillers.

3.3.10 Negative Experience 10 - Feeling Under-Supported by Maternal and Child Health Services

Some new mothers told us about having felt under attended-to during childbirth. Some felt that communication about what to expect during delivery had been poor. For others, the actual delivery experience fell short of the expectations of some women who had felt hurried, ignored or confused throughout labour and childbirth. After-care was also described as insufficient for some who did not feel they were provided with adequate lactation support or other public health services designed to teach best practices for child health and development.

Childbirth: Childbirth, especially a family's first child, can be a very physically and emotionally exhausting experience. Many mothers described feeling ill-at-ease in hospital during labour and delivery or immediately post-partum. Sometimes rough-handling by staff were concerns.

"The L+D nurse that physically pushed me into the position she wanted me in with no discussion or respect for my body."

"I was told there was no birthing room available for some time so I was not able to receive some of the comforting aspects of those rooms during my pregnancy."

"Labour can be a very anxious time for a pregnant woman and interventions are constantly being thrown at a labouring woman without consent and explanation. The culture must change to allow women a voice in what kind of birth they want, without being told the doctor only likes to birth babies with the mother laying down. The baby is whisked away, despite studies showing that babies should be allowed to breastfeed immediately after birth when they are most alert. My experience with many other mothers is that their labour experience and post-labour experience (not being given pain medication, being brushed off by nurses when they have questions) has led to an unsatisfactory experience that has contributed, in many cases, to post-partum depression."

***Post partum and discharge communication*:** After delivery, a number of women expressed that the level of support, reassurance and communication regarding next steps they had received fell short of their expectations. Many mothers felt rushed and under-supported in learning how to cope with their new baby. A particular concern here was support with breastfeeding.

"After the birth, there was no communication about where my baby was from post-partum staff. I had to find a nurse and ask, only to find out she was still in NICU after being told she would only be there for a few hours. I was also angry because NICU staff bottle fed my baby with formula after I expressed the need to breast feed ONLY. I had to ask to be shown how to breastfeed - no teaching was given."

"I had difficulty breast feeding; the nurses had limited time to help because the ward was full. I was told the breast feeding support group was not happening because there was no employee to run the group, and there was no lactation specialist employed by the region."

"The nursing staff we dealt with were more concerned with their breaks than helping us with our new baby. Our baby was born, after the quick cleanup and measurements were taken, everyone left and didn't ensure our baby got skin time with her mother and breastfed right away. The after care on postpartum was no better, the nurses came around only when asked and didn't seem to have any interest in helping at all. It was very disappointing to say the least."

Some mothers were concerned about being discharged from the hospital too soon, before they were ready. Some women felt that there had been little effort to assess or support their readiness to leave at the time of discharge.

"First-time Moms should be kept in hospital more than 24 hours, so that nurses can give them advice, teach them how to look after a newborn baby, provide instruction and help on breastfeeding, show them how to bathe a baby, etc., etc. My daughter was in for just 24 hours and sent home to fend for herself with a newborn. Home care nurse didn't show up for 6 days because of the holidays - there was no one on call to cover - babies get born every day of the year! Nurses didn't help my daughter - she rang twice during the night for help with breastfeeding - no one came. They gave the baby to my daughter 2 hours after birth, and never came back to check on them."

Concerns about early discharge were of particular concern for participants who lived in rural areas, far from the delivery hospital.

"Being requested to leave the hospital after a 4th child and a tubal when the baby was less than 24 hours old did not sit right. I was going home to three small children in rural Saskatchewan with no support."

"A lot of rural hospitals are not equipped with maternity and delivery. It would be nice to see first time mothers being able to stay in the hospital for more than 24 hours. It just seems to soon to be going home."

***Care in the community*:** Some mothers expressed having felt under-supported in learning how to care for their babies after leaving the hospital. Again, breast feeding was the most common unmet need; however, interest in other public educational programs, currently perceived to be lacking, were also cited.

"Is there a way we can help the new moms by setting up a program to help us learn how to take care of our babies? When you are a young mom, you don't really understand and you need that little extra attention. We don't get taught what to look for when a kid is sick, and how to deal with that. There is no program, that's why there are so many young moms who don't know how to breastfeed properly because they aren't taught how to do it. Public health kind of helps, but not enough."

"There needs to be more time and more supports for the parents before you go, because you can often be flying blind"

***Fertility issues*:** Some women discussed difficult experiences accessing fertility treatments and information. Wait times were described as long and agonizing. Some women mentioned a need for improved emotional and mental health supports in helping family's with mental health needs.

"There has been a real lack of communication from the Genetics Department once our fertility issue was discovered. Keep being told to call back in four weeks, with no news. Just communicate with patients and schedule an appointment, even if the appointment is 4 or 5 months in the future. It at least gives patients peace of mind that their file has not been lost under someone's desk."

"The wait time to see fertility specialist has been long. It takes long even to get response from the specialist as to what length of wait to expect."

"There needs to be more sensitivity to needs and the correlation between mental health and fertility in a female patient"

***Lack of dedicated pediatric health care*:** A shortage of dedicated pediatric health care in the Province was also a frustration for some parents. Some parents were concerned that non-specialized health care workers lacked the knowledge, practice skills and communication required to diagnose and treat children effectively. Others were concerned that pediatric cases simply were understaffed to provide the care that patients required.

"Also, a big thing is finding a knowledgeable doctor who specializes in his disability. I'll ask the doctor "is this common with people who have CP?" and the doctor doesn't know. And to find someone who my son can talk with - counselor or something - to relate with. He always says to me - you don't know what I'm going through."

"The amount of time nurses spent with a patient (particularly on the Peds ward) was very minimal. As a parent, I felt I could not responsibly leave my child unattended on that ward since her needs would not be met. By pure luck or the grace of God, my child's life was saved by someone passing by her room while she was in distress and I had gone to have a shower. By staying in the hospital room with my child, I am saving the nurses time and energy, but was often disrespected by them. Multiple times, I have stopped hospital staff from giving an incorrect med or incorrect dose of the right med."

A frequently cited concern was lack of access, or inadequate services, for autism and other mental health or developmental disorders that commonly appear in childhood. Lack of service coordination was also mentioned.

"There is no coordinated autism service in this Province and that is a huge negative to our health care system. There is also a waiting list for services with over 200 children on it and this is unacceptable. Early intervention is key in this disorder and the early intervention dollars that should be spent now will be minuscule compared to the long term care costs the government will face when these children become adults.

"I have two boys with autism and there is no coordination of autism services in this Province. That is a key factor in making our experience with the health care system negative. Lack of case coordination forces parents to become case managers for their children. It forces us, on top of all the care required for our children, to read and learn as much as we can about autism and the many, many facets of the disorder. We run the risk of being influenced by quacks with unscientific remedies. We need case managers who have an expertise and background in autism to help us understand what kinds of services may help with the behaviours or physical problems. Our children have mobility issues, sensory issues, sleep issues, communication issues, daily living skill issues, nutrition issues and more. We live with our children 24 hours a day and when they are struggling, we need support and education to learn how to possibly prevent the behaviours, we need help to keep our families together, we need to learn how to communicate with our children, we need experts to suggest ways to manage the problems that we face every day."

"It took almost three years for my son to be assessed for Pervasive Development Disorder."

"My son has an auditory processing disorder and speech language problems. As a pre-schooler, we were able to access speech language pathology services through the health system. Once he got into school, this stopped. The SLP services and the psychology services within the school system are terrible...both the amount and the quality. My son was labeled "ADHD" even though this diagnosis had been ruled out on two occasions. We were fortunate to have a great psychologist through Mental Health, but had to hire our own SLP privately at great expense to us."

Many said they would like to see a pediatric hospital in the Province.

"We need to really be serious about building a proper Children's hospital. In the University hospital there are only 36 beds on the pediatric floor and 9 beds in ICU. My question to the government is are our children not as important as children in other Provinces? Alberta has two children's hospital and Saskatchewan has none. I really hope that the Saskatchewan Government gives their head a shake and reprioritize. Healthcare should come first. I want the MLAs and Premier to put themselves in my families and other family's shoes and then maybe they will realize something needs to be changed, the sooner the better."

However, others pointed to the need to re-organize current pediatric wards to ensure that they were set-up for children and their families. The concern was that the current pediatric set-up in hospitals was not always comfortable for families. More disconcerting for some was having their children treated in adult wards without respecting the child or family's sensitivities.

"They put people from the nursing home in with the children in the same ward. I wanted to pump breast milk, but the nurses told me there was no private place to do this, and to be careful because there was an old pervert on the ward who had been wandering around and peeking on women, so I had to go and pump in the bathroom. What the heck are old people, even old men, doing on the pediatric ward when women and children are in there?"

"We are bound within our health district. If your child has a severe physical condition, they will send them to one of the big hospitals for pediatric care. But if your child's problem is more of a mental disorder, you will have to stay within your system because there are general mental health services around. This means that there have been times when my child had had to be hospitalized with adults with mental health problems and this can be scary for him."

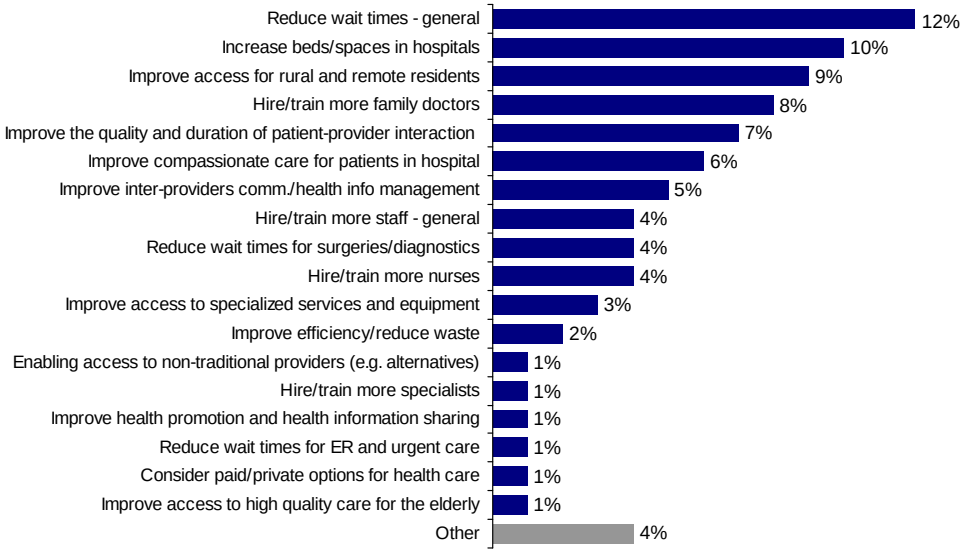
The Province-wide survey results were very positive for maternal and reproductive health but the areas of concern were consistent with the qualitative findings. The number of excellent ratings topped the chart with 43% of those who access this care for themselves reporting an excellent experience.

This particular patient journey focused primarily on primary care, over night hospital stays and, to a somewhat lesser degree, diagnostics.

Problems are infrequent in maternal and reproductive health. Just 11% report a poor experience in waiting times, 10% in transitions and everything else is 7% or less. The number who gave staff knowledge a poor rating is just 2%.

Despite the generally positive reaction to their experience, respondents still had no difficulty in making recommendations for improvement. Overwhelmingly these suggestions for improvement are about access.

Q From your point of view, what one thing could the health care system do differently that would make the biggest improvement for people who use the health care system to …? (n=148)



Patient Story

Cecile is 19 years old and 28 weeks pregnant with her second baby. Cecile and her boyfriend live in the small Métis community where they grew up. Cecile did not finish high school after her first baby. On Cecile's last visit to the doctor, she was told that she had gestational diabetes but was given little information as to what that meant, or how it would affect her and her baby.

Cecile's Story – from a patient's point of view

When I went to see the doctor last month, he said that I have gestational diabetes. At first I was scared because I thought that I would need to get needles, but he said that for now I should just be careful to eat healthier foods and to exercise more. He asked me if I had questions, but I didn't know what to ask because I didn't know all the words he was using: glucose, insulin. I tried to remember them so I could ask someone to look them up for me online, but I forgot a lot of them. I don't know how much of the food we buy needs to be fresh. My mum says not to worry because she ate the same things as me when she was pregnant. Fruits and vegetables are so expensive right now for us. It is too cold to walk outside now and there's nowhere to go to exercise. I have to make another appointment but I'm afraid the doctor will be mad at me because I haven't made enough changes.

3.3.11 Negative Experience 11 - Difficulties Accessing Appropriate Mental Health Care and Addictions Services

***Mental Health Care*:** A number of participants who had sought advice or treatment for mental health care services described difficulties connecting with appropriate mental health resources. A number of participants described long and agonizing waits for assessment services, psychiatrists, psychologists, and social workers. Many participants stressed the importance of feeling connected to services and support when help was sought. Too often, resources could not be accessed right away and barriers to access made participants feel alone and disillusioned. In some cases, they would give up.

"The services, for mental health, once accessed were very good. The wait time is far too long. Generally, people who ASK to receive mental health services are at the brink, an 8-10 week wait time is NOT ACCEPTABLE."

"The waiting lists to see a mental health professional are ridiculous. Someone in need of mental health help generally needs the help now, not in 6 months."

"When I really needed the [mental health] help there was no one available. I had to wait for 6 weeks. Then when we finally got in, the one I was seeing was changing jobs so had to wait again. So I said forget it!"

"I was ill for one year and saw many medical people here but no one diagnosed my condition properly. I traveled to New Brunswick, saw a Mental Health Nurse in the Emergency dept. there and was diagnosed within 1 1/2 hours with anxious depression. I had an appointment with a psychiatrist within 2 weeks. I

immediately contacted my family doctor here and asked for a referral to a psychiatrist as I was returning home soon. It took 6 months to get an appointment".

Some participants were managing their mental health care with advice and treatment from a family doctor, but were not fully confident in their physician's expertise, knowledge and level of skill.

"I have been extremely disappointed with the Mental Health system in Saskatchewan. We moved here from Ontario where we had an excellent family doctor and a wonderful Cognitive Psychologist to provide excellent medical care. When we asked one of our first family doctors here about a cognitive psychologist, he replied "A what?". This does not inspire confidence. The family doctor that we are currently with seems to be willing to at least put a little effort into the process and prescribed an additional anti-depressant and then referred my husband to a psychiatrist. But when we received the phone call to set up an appointment, we were told it was a nine-month wait list."

"I have been on anti-depressants for a long time. I would like to get off of them, but I need to have a good family doctor to supervise that and I don't have one. That scares me. It's a weaning process. I'd like to do it, but I can't do it on my own."

"The doctor handed me a tissue and told me to try to get myself together."

***Care in crisis*:** Many described problems with accessing appropriate care when in crisis. Due to long waits for ongoing support, and a perceived lack of alternative routes for mental health crises, some participants described negative experiences accessing emergency services after having reached a crisis point.

"The only way to get a psychiatrist here is to threaten to commit suicide. That's the only way to get access to a psychiatrist. Or you can go to the ER and the doctor there can sign to get your drugs."

"It is really sad that the mentally ill seem to be deemed by some in Health care as second class citizens. Residents in Emergency need to have a little more understanding for the mentally ill as it is often difficult enough for these patients to deal with everyday living, let alone a crisis. We have a long way to go, before Mental Health is really understood by both the public and the members of the Emergency Health care professionals."

"I have accessed the mental health system for treatment of my son. The response was poor. I have accessed the ER on two occasions. Once because he was suicidal. We were sent home. Within two weeks we had to commit him to access treatment. Again, a year later the experience was no better. He was considered an emergency with an appointment three weeks down the road. Somehow we have kept him alive in spite of the lack of support he received. Mental health services need 24 hour response to crisis."

***Treatment with drugs*:** Among the participants who participated in research, problems with over-prescription of mental health medication, as well as concerns about their physicians' drug knowledge surfaced frequently.

"I took my son to see a psychiatrist and within 15 minutes he wanted to put my son on Paxil and a buffer for the Paxil. I was furious, I don't want to fill him up with drugs I wanted to find out what is wrong with him and learn other strategies to deal with it. I wanted to find out other holistic or counseling options, but you just don't say that around doctors. There are other options in this world, and there are so many advances technologically. I just shook my head and walked away and never went back. Everything was so fast with him, it was almost like a paddle run. If the sessions had been a little bit longer then it might have been better but you can't just rush through everything and then expect me to understand why"

"Doctors should be available for phone calls, questions, and support. Doctors should treat the root causes of these issues and not though very damaging drugs at patients that do no good"

***Care in the community*:** Some participants identified a shortage of community-based resources to support patients and their families in managing mental health concerns.

"I am not a doctor but I do ask myself if more counseling or community services could improve."

"The only access to counseling is through mental health clinics that have heavy stigma attached to them. I had mild depression and needed someone to speak to and unless I wanted to pay for it--it didn't happen. I am not going to go hang out with the severely affected people at the Hospital. Also because I worked in the Hospital at the time, I felt that was not a private or dignified way to obtain mental health services."

"We need more community based mental health services that are more readily accessible. Let's not use up valuable hospital space. Let's solve some of the mental health issues before they become critical."

Some participants appeared very concerned and confused about how to navigate the health care system effectively when trying to obtain treatment or advice for mental health issues.

"I think my husband has a mental health problem. I don't know what to do for him. People say I can't get help for him unless he wants to help himself. I can't do anything?"

"If you are depressed or injured, the system will dismiss you as an attention seeker – they think you are faking. They take you seriously when they find your body."

The province-wide survey looked at mental and emotional health separately from addictions. Both journeys are less common than most of the other categories. Approximately 1-in-7 people have sought out mental and emotional health care in the past five years while just 4% report seeking medical help for addictions.

Mental and emotional health journeys are taken disproportionately by people under 45 without children. Addiction journeys are more evenly spread between lifecycle groups but tend to be focused on the under 25 groups. Both journeys are taken disproportionately by First Nations and Métis people and are more common in urban and Northern settings.

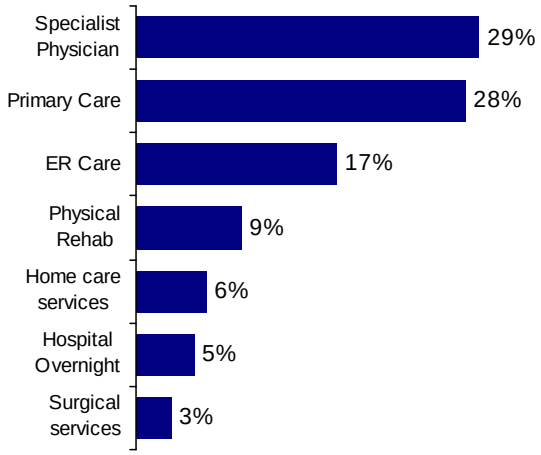
Those seeking addiction care are considerably more satisfied than those seeking mental or emotional health care. Also the addiction sample is small so the margin of error is large; people seeking addiction care are a little above average in rating that care is excellent (34%) while those seeking mental or emotional care are ten points lower at 24%.

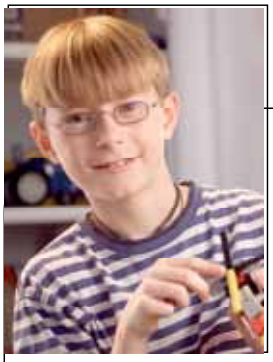
Mental and emotional health patient journeys are centered on primary care with significant engagement from specialists and diagnostics. Addictions journeys are similar but are more likely to also involve ER and overnight hospital visits.

One-in-five mental and emotional health patient journeys experience wait times or transition issues. They also tend to experience more staff issues than what is typical, particularly when it comes to staff knowledge. Addiction care also has roughly similar levels of problems with access and transition but has fewer challenges with staff with the exception of communications of next steps.

Mental and emotional health wait times issues occurred mostly for specialist and primary care. The sample of addiction patients with transition issues was too small to reliably dig into the details. We did not have enough transition issue cases in either journey to provide a detailed analysis.

Q **Mental Health -** *length of wait times? (n=33)*





Patient Story

Colin is 10 years old and lives with his mother and three siblings in rural Saskatchewan. Recently, Colin was diagnosed with Pervasive Development Disorder (PDD). Colin's behavioural problems were first brought to his mother's attention in kindergarten when he became easily frustrated and sometimes violent. While a bright student and fast learner, Colin would frequently beat his head against a brick wall when things did not go his way. Colin was on a waiting list for two and a half years before his assessment was made. Colin's mother found few resources available to help her progress in working with Colin.

Colin's Story – from a mother's point of view

When Colin's kindergarten teacher first had me in to talk about his behaviour, I had no idea what I was supposed to do. I knew he got frustrated easily, was a bit impatient, but I didn't think it was a serious disorder. But things kept getting worse. He was violent and the teachers said he was out of control. I got him on a waiting list to have his mental health assessed. We were on that waiting list for almost three years. Why are there such long waiting lists just to get the assessment? And what are parents like me supposed to do in the meantime? I went to see a doctor around here who recommended that we put Colin on Paxil, which is a drug for major depression and anxiety. I read that it's one of the hardest drugs out there to come off of. I didn't want to pump Colin up full of drugs before we even knew what was wrong with him. It would have been much more helpful if I'd been referred to someone to work with me on Colin's social skills. It's not like our lives were put on pause while we waited for assessment. I'm trying my best with him but most of what I learned was from the internet.

3.3.12 Negative Experience 12 – Medically Required Transportation and Accommodation Issues for Remote/Rural Locations

Medical related travel is trying for patients. While many understand the need for travel as a reality of rural and remote living, there is a sense that very few services are offered to alleviate the stress and that little is done to support these patients. One particular concern was the seeming disregard for the burden placed on patients who were required to make frequent trips. Notably, poor coordination of appointments outside of the city was flagged as a concern.

"When you have to travel 3 hours to Saskatoon for tests and to see specialists it would be better if these appointments could be organized to cut down on travel expenses and to get quicker results. Most appointments need to be booked 6 weeks in advance. If some of these could be booked close together that would help. When you are sick and in pain 6 weeks is a long time. You start feeling like just a file in someone's desk that no one cares about and you are in pain 24/7."

"I am completing this survey for my 84 year old mother who has breast cancer. She lives 2 hours away but has to go to Regina for treatments. Often she has appointments with different specialists and has to make numerous trips. Why can't there be some coordination to reduce trips."

"Dates of specialist appointments are not on the same day so it often means traveling in 2-3 times for a specialist!"

In some cases, participants perceived the travel to be unnecessary and of little value.

"My mother has to take a 4.5 hour bus to Saskatoon and a taxi to her appointment, which sometimes is required but other times it seems her doctor in this community could do just as much and communicate with the Saskatoon doctor. She is on a very limited income."

"The experience of the pre-op clinic at the hospital in the city was very negative. I have had to go through the process twice for joint replacements and found it a waste of my time and very negative overall. It takes a complete day, most of which is spent waiting to see health care people for just a couple of minutes. These are not the same health care people that are involved in my surgery or recovery process afterwards. We live several hours outside of Saskatoon and therefore have to arrange to stay overnight the day before and if weather is bad, another night after the clinic, or travel there and back early in the morning and late at night. I saw different people the day of my surgery and afterwards and they asked me the same questions all over again! My wife and I are very busy and can't afford to take all of that time off. Beverages are supplied for us, but no food which can be a whole issue in itself. Everything that I needed to know about my replacement surgery was contained in the information my specialist gave me. There was absolutely nothing new given to me at the pre-op clinic."

Some participants living in remote and rural areas voiced frustration over a lack of financial and other supports available to those who require medical travel and accommodation. Participants complained that two-way transportation was not always offered or arranged for those who could not manage on their own, and the need for patient accommodation or food vouchers was not always taken into account. Some participants told us that they had not been reimbursed for significant out-of-pocket travel expenses, despite the financial burden of travel on families.

"My community has a large diabetic population and they do not have a dialysis service here so patients have to travel to Saskatoon to receive treatment. Some cannot afford the extra cost of travel and food."

"The government needs to come up with a better plan to reduce the cost and time for the patient to travel down south. Patients that need regular treatment and follow-up consultations with specialists should be relocated down south, at the government's expense, instead of having the patient travel back and forth."

"The participant stated that if you want to stay in a hotel they require that you have a MasterCard. Many people do not have a credit card to secure a room, therefore they have to go to Lodge where there are no diabetic services and you are disrespected. Elderly people have to share a room with 3 other people at the Lodge, many would like their own room."

A number of participants were concerned about the lack of support available for patient escorts – within or outside of the Province. Particularly for First Nations and Métis participants, there was frustration about having to send loved ones who were very ill – and not always able to speak for themselves due to illness or language barriers – alone to urban centers for treatment.

"My baby was born with kidney and heart problems and required an operation in Edmonton. Unfortunately, medical officials informed us parents that only one parent was allowed to travel with the child to the medical facility. Since she needed to be in the hospital for 9 months, it's been an ongoing issue."

"You require my young and elderly family members to travel from a remote location to an unfamiliar environment to receive treatment from strangers without any escort or support."

"My wife had to go to Saskatoon, she was 61 and continuously sick. I talked to the nurse to explain that she needs a helper – an escort - because medical files are not transferred from north to south health care providers and as an escort could help both to provide background information and take care of my wife. I was refused."

"Elders are sent out without English translators. Elders can't usually read English. Doctors become frustrated since they don't understand the patient's condition."

For on-reserve participants, there were reported inconsistencies in what local Bands would pay for in terms of medically-required travel and escort services, and this was causing confusion and frustration for many. Some patients had serious difficulty paying for services.

On a separate note, many participants were frustrated by the premise of travel. These participants said they did not understand why their own communities can't be serving their needs more effectively, particularly on things that had historically been provided. Centralization of services in urban areas was a frustration for patients living at great distance from urban centres.

"Our community has over 10,000 people now, so how come our hospital is nothing more than a glorified doctor's office that can barely handle more than bandage? We used to deliver babies, do surgeries, and actually had wards to look after the sick!"

"I don't understand why we don't do what we used to do here anymore – it used to be you could get your tonsils out right here in town."

"Somehow we must continue to improve and carry on the services we presently have. The people in the rural centres in our Province cannot be forgotten. To simply create a better health facility in a larger centre with even more doctors is not the answer. There are many people in these areas who are older and much older who cannot readily cope with travel distances. Instead of the amalgamation of health services into one large centre in an area, we must keep quality services provided in our local medical centres"

Patient Story

Bill is 58 years old and has spent his entire life living on reserve in northern Saskatchewan. Bill is skeptical of mainstream doctors and in the past has chosen to rely only on traditional healing methods when he is sick. His first language is Dené and his English is very limited. Last night his 30 year-old daughter took him to the local hospital because his vision suddenly became very blurry. The physicians decided it would be best for Bill to go to the city for treatment.

Bill's Story – from a daughter's point of view

The physicians said we have to act fast, but I know my dad is afraid to go. He has never had to cope in the city. I asked the hospital if we can send someone with him, someone who can help translate for him and look after him, but they can't cover that kind of travel. He doesn't have a medical history on file, so an escort could help answer questions about his health that only he knows. I'm not sure he would have understood anything if I wasn't there last night. It scares me that when he's released from the hospital there won't be anyone to help him get back home. I can't afford to go with him. Even if I could pay for the flights, I can't leave my family at home for 2 or 3 days.

3.3.13 Negative Experience 13 – Experience of Cultural Insensitivity Among Health Care Workers

Some participants, particularly First Nations and Métis participants, discussed experiences of cultural insensitivity in health care settings. Some reported racism or intolerance on the part of health care workers. Others complained that facilities in their communities, including the equipment and programs available, were not well-adapted for the needs of First Nations and Métis people. Others suggested that health care workers did not make enough effort to adapt their communication style (explanations, dialogue) to the cultural context of some patients.

***Experiences of racism or intolerance*:** Some First Nations and Métis people reported having felt discriminated against in a health care environment for reasons of race.

"I haven't been able to talk to anyone about the prejudice – I just think that's the way it is. A white woman in the ER had stubbed her toe and she was taken in before me, even though I had been there for 4 hours and was really sick. Nurses have made inappropriate comments that were rude and not called for. I just let it go, because that is just the way that some people are and it's not going to change."

"People can be racist at the hospital. They might just act toward you like you are drunk before asking what is wrong."

"The Reserves in Saskatchewan have Health Centres and it would be excellent to have funding to build our own First Nation Hospitals on Reserve. It would eliminate racism and superior attitudes of white front line worker that I have experienced….I believe racism exists in Saskatchewan toward First Nation

people and other Ethnic groups excluding the white population. It's hard to understand unless you have been subject to racism yourself. I think treating people as valuable and important, no matter who it is is a priority."

***Experiences of culturally inappropriate communication*:** Some participants said that they had experienced situations where doctors did not speak in basic language when discussing diagnoses. This was a particular concern that was flagged for elders and non-educated people everywhere, including those on-reserve. Some participants said that many typically do not understand their condition when leaving the hospital.

"I did not understand my brother's fibromatosis medical condition since the doctor used medical terminology. It was only clear when I saw a commercial on the television."

"Doctors do not speak in basic language when discussing the diagnosis with the elderly and non-educated people in my community. As a result, some do not understand their condition when leaving the hospital."

Some participants talked of language barriers causing communication difficulties for those seeking medical care in their community.

"Elders have a hard time communicating with the medical staff at the facility. Elders can only speak Cree."

"The Doctor is often so busy they don't have time to chat about the overall medication review of the patient. The fact that the elder's first language is Cree may mean they have a hard time speaking up for themselves, so they often not say anything. It would be great to have an Interpreter on call and a First Nation person on staff to help in any way possible."

"We need translators for the hospital. Black Lake is a Dene speaking area and the Elders can't explain to the doctor what is bothering them or what is wrong."

"Cree language is important in Saskatchewan, we have 74 Reserves across Saskatchewan and we need to make sure there are First Nation people in the Health care system."

***Systemic problems – inequities*:** In general, a number of participants commented on a perception of there being problems with the Ministry of Health's overall approach to ensuring culturally appropriate care and delivering care in an equitable fashion.

"Now relating to the Cardiac Rehab program, I notice that it appears to be for white people only. No aboriginal people there except myself. When I asked the staff about this, they said yes, the aboriginal people don't seem to come. And Cardiac Rehab is doing what to address this?? I also noted that in the Diabetes Education program that Aboriginal people do not come, either. This inequity needs to be addressed, especially with the numbers of aboriginal people with diabetes and heart disease."

"The health of Aboriginal peoples in this Province has long been documented as an issue. With rising statistics in all sectors, we all know there is a great need to act quickly. Demographics show that this is Saskatchewan's fastest growing population... yet so much needs to be done. Sask health needs to start working with Aboriginal people - mainly through partnerships. Aboriginal people can help themselves ... Sask health needs to take the time to listen, respect the aboriginal way of doing things and allow for mutual respect when it comes to health initiatives. If Sask health does not know how to do this then maybe they should listen more and talk less."

Some participants raised relative inequities in coverage for Treaty coverage compared with Métis coverage.

"Treaty people are treated before Métis people, because specialists/dentists are guaranteed to be paid. Some people take out their own teeth because they don't have insurance."

The results of the Province-wide survey strongly support these qualitative findings. As noted earlier, First Nations and Métis respondents are almost twice as likely to report having experienced unacceptable behaviour from health care workers at some time in the past.

There is, however, some evidence that the system may be improving in how First Nations and Métis patients perceive their treatment. While the measure above refers to lifetime experience, the mini-surveys explore the most recent experiences. Looking at the three communications measures in the mini-survey, there is no consistent pattern of any significant differences in how First Nations and Métis rate their experiences compared to patients from other backgrounds.

Patient Story

Luke is a 16 year old boy who lives on a reserve about 2 hours away from a small city. Luke suffers from severe headaches and is frequently taken to the medical clinic by his parents or grandparents. They do not have a family doctor. Luke's grandmother, whose first language is Cree, believes that they are not treated with respect at the clinic because they are First Nations.

Luke's Story – from a grandmother's point of view

It really upsets me, but I just can't help but feel my grandson is a victim of racism. I took him into the medical clinic once when he was really having a hard time but the nurses denied him medical treatment. Because of the way Luke was rubbing his head, they said he probably had lice or scabies. They said we had to leave because we posed a danger to the other patients at the facility, but no one ever looked at him. I am not very good at communicating in English sometimes, but all we wanted was to get some help for the pain he was in, we weren't there to disturb anyone. They just think we are not clean.

3.3.14 Negative Experience 14 – Unexpected Out of Pocket Costs for Services

A number of participants told us that they were surprised by having to pay out-of-pocket expenses for certain health care services, particularly ambulance services, care homes, rehabilitation or therapy services, certain medical equipment and dental care. For some participants, medical related costs had become an unanticipated strain on personal finances.

***Emergency travel*:** Emergency travel was the most commonly cited out-of-pocket pressure for participants, particularly ambulance and air travel. People were generally confused about under what circumstances they should expect to pay and when coverage was available.

"Because my son was deemed a critical airway, the Regina doctors wanted a Calgary team to come and get him just in case he needed an emergency tracheotomy in the air. The night before we were supposed to go to Calgary, Bedline in Regina informed my husband and I that for the Calgary team to come it was going to cost $45,000 and they would not pay. If my husband and I wanted to pay the $45,000 then Calgary could come. But who has that kind of money. This added extra stress that we didn't need. Regina put a team together and we hoped and prayed that nothing would go wrong on the plane. We felt that my son was not getting the best care he deserved for the transport."

"The extra expense of the ambulance ride - $2,000 in my case - for people living in rural areas may cause people not to seek treatment at all. This inequality needs to be fixed."

"A rural ambulance would not pick up a First Nations patient for hospital-to-hospital transfer until they received $1,500. The family stressed trying to find resources. First nation clients are not included in health coverage for Sask health."

"In our case we really needed an air ambulance and the service was good. But we weren't properly told of the costs for the air ambulance. ER needs to be aware of the costs of services to properly inform patients. It could make a difference to some."

"The negative part was the "bill" I received for an ambulance journey from a rural hospital to Saskatoon and it is part of same health region. $700.00 was a bit much to take for that service when in medical distress."

"Although I was unable to go back to the hospital closer to home by car, I was charged the full rate for an ambulance. I also had to pay full price for the trip into Saskatoon as these were both considered "transfers". e.g. No refund by Blue Cross."

***Specialized services*:** A second issue of unexpected out-of-pocket costs was surrounding specialized therapies and services. Some participants were paying significantly out-of-pocket for physical rehabilitation, as well as chiropractic and other alternative care services.

"In my case, physical therapy was required. Health region pays for 4 visits. Not much. Should a sick person have to worry about such things? Only 1 visit left and I am not well yet? Now what? Just forget about my problem because I cannot afford to pay out of pocket for further treatments?"

"Chiropractic care - although it is within the more alternative health care, I have had numerous whiplashes and it has definitely benefited. However, I can no longer afford the extra $17 per treatment cost. I had another whiplash a month ago and I cannot afford treatment."

Others cited costs involved in counseling and psychological services.

"My counselor is good and sympathetic. But it's so expensive to see him."

Several parents shared stories of having paid significantly out-of-pocket for assessment and treatment or therapy services for their children with developmental or mental health needs.

"Our son has Autism and we don't find very many services out there for him that don't cost us $90 per hour or more. Things like Occupational Therapy and Speech and Language Therapy should be covered by Sask Health. Required treatment for all other illness are covered, so why not Autism!!!"

"I have an autistic son who needs specialists. It was very hard to find a physician that could diagnose my son. My husband and I eventually paid out of our own pocket to send hair/blood samples to the US for a proper diagnosis. The procedure was recommended by a physician at Saskatoon. She said that SaskHealth does not cover the cost for analysis and that they have to be sent out of Province. She also stated that there is a lack of speech pathologists in the community and expressed the need for one especially for children whom are diagnosed at a young age."

"My six year old son has Fetal Alcohol Syndrome. We have learnt how to advocate on his behalf. The process has been extremely time intense and frustrating. The wait list to see the pediatric specialist at the Children's rehabilitation program is a year long. The wait to access speech therapy is very long. Once your child reaches school age, they have to discontinue services in this program and receive services through the school board. Those services are not sufficient so you need to supplement with private speech therapy. Except that there are essentially no private speech therapists in the city accepting new patients. There are huge wait lists and very high costs for this service."

Some women expressed disappointment at the lack of financial coverage for fertility treatments.

"There needs to be better supports for people who are having fertility problems. It is very expensive and not covered by a lot of health plans. I don't think that a lot of men who make government policy know how some women feel, how some women have a burning desire to be a mother, and that support is just not there."

"I am disappointed, as a woman experiencing secondary infertility, that the wait for IVF in this Province is so long and is in no way covered."

***Medical equipment and supplies*:** Some participants had experienced difficulty making ends meet to pay for required medical equipment or supplies to treat chronic illnesses

"We need better health coverage for supplies for Type 1 diabetics, no matter what the age. Most adults can't afford to keep up with all the costs and will end up needing three times the care."

"I have to pay for the cost of my C-pap humidifier and mask to treat my chronic condition."

***Care for seniors*:** As also outlined in earlier sections on long-term care, several participants were concerned about the costs that go along with living in long-term care or for personal care for seniors.

"My parents not only had to pay the total monthly cost of care but also highly expensive drugs (i.e. aquacel) and were ineligible for special or consultative services (such as blood work, or consultation with the wound specialist employed by the Health District)."

"Twenty dollars to get my father a simple sponge bath every couple of weeks."

Prescription drugs: Other participants had difficult experiences managing their regular prescription drug costs.

"The focus of the system should be to put the right medications in the hands of the people that need them. Doing so would lower the overall costs of the Medicare system."

"I can't manage the price of one of my asthma medications, which was not covered by my insurance. My doctor was to fill out an Exception Drug Status form but never got back to me - I ended up discontinuing the drug due to the cost."

"Cost of medications!!!!! Such a negative experience. I am on long-term disability and have lost all my work benefits e.g. dental, meds, physio. I have 2 young children who also need dental/orthodontic services etc. We are the people who need these services the most, at a time when our income is compromised! Does that make any sense??"

3.4 Validation of Patient Experiences by Health Care Providers

For the most part, providers were not surprised by the experiences patients had shared with the researchers in Phase 1. As illustrated by the quotes below, the patient experience themes presented to health care providers were both what they were expecting to hear, and consistent with what they had experienced themselves within the system.

3.4.1 Negative Experience 1 – Feeling Lost in the System

"Communication – I think all of the healthcare professionals are guilty of not taking the time to communicate with patients properly. I think poor communication is a big problem we have in our system. When my father was in the hospital I had a great deal of difficulty communicating his needs to

the staff because they didn't seem to care, and when they had information, a lot of them were too busy to provide me with that information. I think a lot of the problems are getting lost in improper communication."

"When I was dealing with a health issue that my mother had, it took me three months to get my mother engaged in the care she required. She didn't have a family doctor and I didn't know where to start – and I am in the healthcare system!"

3.4.2 Negative Experience 2 - Uncaring and Dismissive Attitudes from Health Care Workers

"There needs to be more 'caring' in the system, and not just for the elderly. This lack of consideration of other people, I really think that physicians and caregivers should be looking at the patient as they would a relative or a friend, and I haven't seen that happening for a very long time, and the excuse is that 'we are always so rushed.'"

3.4.3 Negative Experience 3 - Feeling Inadequately Served in Hospital Emergency Rooms

"People who access ER have a low tolerance for anything because they are scared and their families are stressed out. And the staffs are a little lippy - they feel the pressure. It tends to crescendo and build and people who work in those high stress areas need to be extra careful about how they relate because they can be insensitive."

3.4.4 Negative Experience 4 - Long Waits for Diagnostics and Surgeries

"I have patients waiting for neurologists and I know they will never make it to the top of the list because their physicians are just referring them to the specialists that they know, even though their wait times are extremely long."

We are supposed be the 'hip and knee replacement pathway', but we can't actually do the procedures because all of our beds are always full. We are supposed to be fixing 2 joints a day, but we can't even do 2 a week, and the waitlists just keep on getting longer."

3.4.5 Negative Experience 5 – Difficulties Accessing Specialized Services

"We need to be cognizant of the therapy and specialized services needed within the rural communities. It is irritating as a healthcare provider when you can't access services for your own family members, and if I am feeling this way, I can't imagine what it's like for other who aren't used to the system."

"Saskatchewan government has to come to some form of agreement where it won't take so long to access specialized seating, modified chairs, walkers, etc...We need to have more access to specialized equipment that isn't going to cost a lot of money, or take a huge amount of time to access."

3.4.6 Negative Experience 6 – Poor Case Management/Communication with Physicians

"I closed my office. couldn't see patients and give diagnoses in a timely fashion and I was making myself sick...I was wasting a lot of time phoning and begging for reports, being an advocate and I began to realize I was becoming very angry at the system and thought I should go out graciously instead of yelling inappropriately... I don't feel like I should have to be aggressive to get routine tests done in a timely fashion. I think the whole system is not functioning very well...If you have an urgent problem, things are dealt with nicely but on a day to day basis I think we are doing a really poor job."

3.4.7 Negative Experience 7 - Difficulties Accessing Appropriate Family Health Care

"I'm surprised anyone can get into see their family physician...I feel like I'm on the front line of a war zone, I am constantly juggling priorities."

"The 10 minute time slot is making it like a little factory, and it stinks. They aren't really treating you as a person but as whatever problem you are coming in for…"

3.4.8 Negative Experience 8 - Limitations in Available Home Care Services

"There is no point in expanding home care services because they can't handle things now with what they have on their plate. They are understaffed, and overstretched. There needs to be a consistent response from home care, if it is not consistently available then it fails. But we have to be careful if we want to expand - expand to do what? We need to be able to deliver on it."

"There is an array of services aides are expected to provide and it's too much. We are asking home care services to provide a different service in 2009 than what we expected them to provide in 2002, we've downloaded a whole lot on them without increasing their numbers, staffing, their budgets or their ability to provide that care."

3.4.9 Negative Experience 9 – Feeling that the Province Seems Ill-Equipped to Meet the Care Needs of the Aging Population

"We have a pathetic level of care for them, both acute and episodic conditions, and we have very little support systems in place for chronic disease management. A geriatric strategy for this Province is non-existent. We haven't started as a Province looking at the juggernaut coming down the pipe, and we are not managing it appropriately."

"Do we have the community supports and programming to make the elderly feel comfortable at home, and manage them? Probably not. There needs to be geriatric assessment clinics. We have not built the system to allow the providers managing these patients to have the tools at their disposal to treat them appropriately. We are trying to pound square pegs into a round hole."

3.4.10 Negative Experience 10 - Feeling Under-Supported by Maternal and Child Health Services

"There are some people who do have good family support and come home to a clean home, and have a good confidence about taking care of their baby in the home. We do have another group of women

however with practically no pre-natal care. Some women need support and a telephone call is just not enough."

"There is a lack of prevention, lack of preparation, lack of education component – both inside and outside of the hospital. We have some huge accessibility issues and we are setting these mothers up for failure."

3.4.11 Negative Experience 11 - Difficulties Accessing Appropriate Mental Health Care and Addictions Services

"We don't have the training to look after them, we don't have the knowledge to look after the addictions patients in ER. The nasty staff are the ones who have never had an alcoholic in the family. So many staff don't understand that addiction is a disease and they don't have enough skills to look after some of these people...they don't see it as a real illness, like the way they see someone coming in with the flu."

"There is a real lack of knowledge in the health care system about addictions – the only medical detox that is available in any area in this Province is the hospital. There is no other facility, that is all we got but there is no training or support for the staff in these facilities to handle these issues."

3.4.12 Negative Experience 12 – Medically Required Transportation and Accommodation Issues for Remote/Rural Locations

"There is inconsistency in medical travel options. For instance the ambulance ride to the city will be paid for, but not the ambulance ride back, and patients don't want to incur that cost. Further more, because some bands will pay for transportation and others won't, many patients do not want to go in to the city for treatment at all."

"If a patient is discharged after hours or on a weekend and has no family member with them, they have no free way to get back home."

3.4.13 Negative Experience 13 – Experience of Cultural Insensitivity Among Health Care Workers

"We have different doctors, from different places, and we don't give them any kind of orientation, we don't offer any kind of overall sensitivity training."

"Staff aren't going to cultural awareness groups/training – managers have to ensure that this happens"

"There is no education for the providers about the different cultures – why not? It's because people don't think there is a problem, no on wants to admit it."

3.4.14 Negative Experience 14 – Unexpected Out of Pocket Costs for Services

"More physicians should travel – big problem for the patient – but it's easier for the health authority for these patients to find their own transport. Back up equipment would save a lot of money if it meant not sending patients to Saskatoon. But there isn't the willingness, because the cost of the ambulance is not on the hospital, it is on the patient."

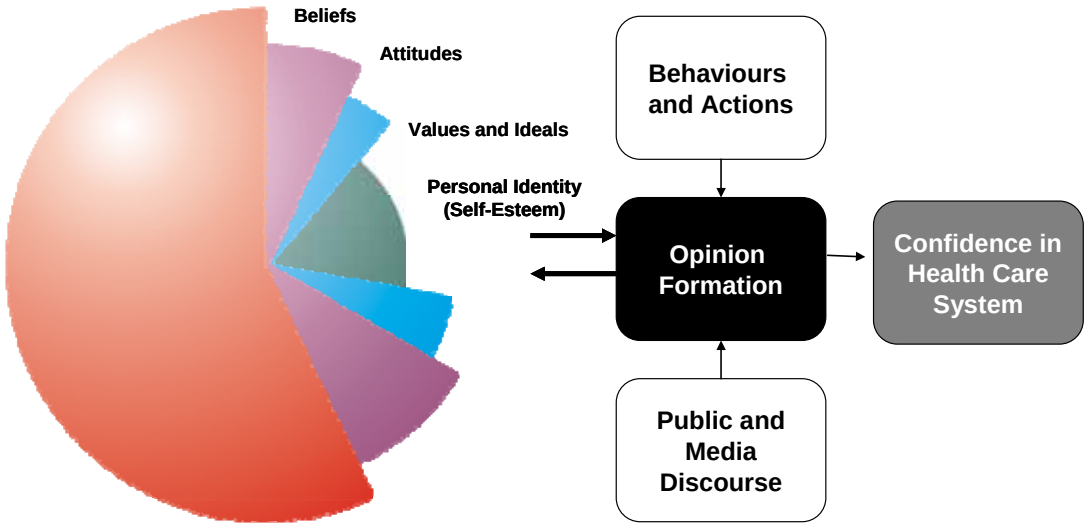
"I have patients with ambulance costs in the $3000-6000 range…costs are huge."

3.5 Measures for Tracking Patient Satisfaction

3.5.1 Establishing and Tracking Benchmarks

How well are we doing in establishing a patient-centred health care system? A key task of the Patient First Experience Review was to identify the key concepts or variables that define a patient-centred system and to develop specific questions to measure progress. Those measures were then included in the Patient First province-wide survey to benchmark performance on those key variables.

Our approach was driven by our understanding of how the public forms and evolves its judgments based on the model below.



To develop the Patient First province-wide survey we needed to answer three questions:

1. What are the key variable(s) we need to understand? (The Dependent variables)
2. What are the key drivers of the Dependent variable(s)? (The Independent Variables)
3. Are there any particular groups of people who are likely to have different points of views? (Segmentation questions)

3.5.2 Dependent Variables

In measuring progress towards a patient-centred health care system, we identified two types of dependent variables we were interested in; performance evaluations of patient experiences and beliefs about the health care system and how it treats patients.

Only people who have directly experienced a specific element of the health care system can form an evaluation of it, leaving many people who cannot provide evaluations of many elements of the health system. They can, however, provide an overall assessment of their care. In the Patient First Review

province-wide survey we measured both satisfaction with the care received over the past year and satisfaction with up to two recent specific health care experiences.

In measuring health experiences, we broke the traditional mold of measuring satisfaction within health delivery silos. Patient experiences are defined by health conditions or incidents, not by the silos that deliver care for that condition or incident. Based on the stories we heard in qualitative discussions and feedback from the Patient Experience Workbook, we developed a list of eight conditions which covered a wide range of health conditions from serious medical incidents such as heart attacks to addictions.

Beliefs (things we think are facts) do not require direct experience and can be more generally held. As well, belief statements work well to measure general orientations of the health care system. In the Patient First province-wide survey we directly measured agreement with the belief statement, "The Saskatchewan health care system puts patients first."

3.5.3 Independent Variables

What elements of the patient experience do we feel drive patient satisfaction with the care they receive and belief that the Saskatchewan health care system puts patient first?

Here we relied on the themes identified in the patient experience and categories of improvement analysis from the first three phases of the Review. In particular, we focused on positive patient experiences as a reflection of the patients' vision of patient-centred care.

For speed and access, we included a performance item rating length of time to access care.

For navigation and coordination, we identified two performance items (transitions and communications of next steps) and two beliefs ('The health care system is so complex I worry that if I become seriously ill I will not be able to find the help I need' and 'My personal health information seems to get lost in the health care system').

For quality of interactions we included two performance ratings (listening and knowledge) and one belief ('I feel that I have a say in decision-making about my health care').

For encountering genuine and caring attitudes we included one performance item (courteousness) and two belief statements ('In general, health care workers in my community care about patients and treat them with respect', and 'I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour').

Many other measures were considered and we would encourage future exploration of alternative measures.

3.5.4 Segmentation Variables

Are there particular groups of people in Saskatchewan who are likely to have different views about the patient experience? Again, based on the qualitative findings of the first three stages of the Patient First Experience Review, we identified three types of variables that may account for different points of views: basic demographics including ethnicity and region; relationship to the health care system as a professional provider, as a voluntary care giver and in relation to health status; and fundamental attitudinal orientations towards the health care system.

Our initial intention with the attitudinal questions was to create an attitudinal cluster analysis which grouped people according to their shared attitudes. However, during our work on the cluster analysis we found that two key attitudes - confidence in system navigation and consumerism - did most of the work and that it was simpler to tell the story by focusing on these two attitudes as opposed to using a cluster that confused the issues.

3.5.5 Critical Tracking Items

From this initial survey several items emerge as critical. First, we strongly recommend that the Ministry and its delivery partners include the system navigation item in future surveys. This item had by far the strongest relationship with patient satisfaction but the causal relationship is unclear. Is system navigation uncertainty a consequent or a cause of poor patient experience? If it is a cause, then patient education, case management and navigation initiatives are critical to improving the patient experience. Related to this belief is a need for performance tracking for transitions and communications of next steps.

Second, it is important to track First Nations and Métis ancestry on an ongoing basis. There is a very worrying finding of high levels of reported historic unacceptable provider behaviour. Although there is an offsetting finding in current experience, there is reason to pay close attention to the First Nation and Métis experience on an ongoing basis.

Third, we would encourage future research to build on the patient journey approach. It is clear from the findings of the Patient First province-wide survey that different experiences draw on multiple but different sets of delivery silos. Not surprisingly, each journey is defined by unique problems and challenges. Solutions that deliver a more patient-centred system need to reflect the unique nature of each journey.

4.0 Exploring Causes for Patient Experiences: Findings From Patient and Provider Research

In focus groups with patients and the general public, participants were encouraged to think about and to suggest "causes" - underlying reasons - for their positive and negative experiences as patients. When the research team met with front line providers, they too were asked to provide input on the "enablers" of common positive experiences and the drivers of negative experiences.

By and large, providers were practical and constructive rather than defensive about the causes of negative patient experiences. Providers were very amenable to discussing improvements to patient experiences; however, there is a clear call for action on solutions to address the challenges.

In all, there were approximately 160 unique "cause" ideas proposed by patients and providers to explain positive and negative patient experiences. These "cause" ideas have been grouped thematically and reduced to a list of 14 "cause themes". The following table lists the 14 cause themes explained later in more detail.

Summary of Cause Themes			
1	Relationship with Family Doctor	8	Optimizing Use of Health Care Workers' Scope of practice
2	Quality of Interaction between Providers and Patients	9	Rural-Urban Inequities
3	Effectiveness of communication channels between the system and patient	10	Staff Performance/Behaviour Accountability
4	Coordination/Organization of care throughout the continuum	11	Geriatric Health Care Support
		12	Child and Maternal Health Care Support
5	Quality of Health Care Work Force	13	Mental Health Care and Addictions Support
6	Cultural Sensitivity of Workforce	14	Health protection and promotion activities throughout the Province
7	Management of Health Information		

In the table on page 103 we illustrate how the various causes link up to negative patient experiences.

4.1 Cause Theme 1: Relationship with Family Doctor

- **Positive Experience Enabler**: A strong connection to a family doctor
- **Negative Experience Drivers:** Absence of or weak relationship with family health care; insufficient access to a family physician.

A patient's relationship – or lack of relationship – to a family health care provider was identified as a significant determinant of positive or negative experiences in the health care system.

"The Experiences you have are directly proportional to the family doctor that you have." (Patient)

"Our system is good for general health, but if you have a problem then the first thing you need is a doctor who is well connected with referral options." (Patient)

"If I had a patient with cancer even slightly suspected, I would keep the file set aside until I had the results of the ultrasound or other tests, and would spend some time on the phone, and then would follow up....but an awful lot of people don't have a family physician, and that is key." (Provider)

A good relationship with a good family doctor is perceived to offer patients the advantages of:

- An advocate;
- More timely, convenient access to care;
- Accelerated access to treatments and specialists; and
- Comfort and familiarity.

Patients without a consistent family doctor often perceived the following disadvantages:

- Delay seeking primary care at the onset of a problem due to inconvenience of accessing care;
- Difficulty connecting to specialized treatments and providers;
- Over-use of emergency services;
- Hurried consultations (ER, walk-in) and superficial, less personal care;
- Lack of advocacy; and
- Delays in access to treatments and specialists.

Absence of a consistent family doctor is suggested as a driver of negative experiences, so is having a "poor" or an "average" family doctor. While "low quality of interaction" with providers is a separate "cause" of negative experiences discussed in the following section, a relationship with a family doctor can also be considered "poor" if he/she is difficult to access (e.g. if patient waits too long for appointments, has difficulty obtaining responses on questions or concerns). A relationship may also be considered "poor" if a patient does not feel that his/her physician has the time to give his/her case a priority, or does not have the resources or professional network to negotiate the forward movement of a case in a timely fashion.

4.2 Cause Theme 2: Quality of Interaction between Providers and Patients

- **Positive Experience Enabler:** High quality face time with physicians
- **Negative Experience Driver:** Low quality face time with physicians (e.g. lack of two-way communication, inattentiveness in examination, over-prescription).

The quality of patient-provider communication was identified as a significant factor in enabling a positive experience or driving a negative patient experience. High-quality face time with physicians was described by both physicians and patients as enabled by:

- Having enough time during appointments for patient questions and dialogue;
- Experiencing friendliness and openness from physicians;
- Thoroughness of examinations, testing, and physician respect of a patient's knowledge and input;
- Encouragement of patients to participate in decision-making about treatments and care options; and
- Following-up with patients on test results and case progress ("no news is good news" is not good enough).

Patients described low quality patient-physician relationships as driven by:

- Rushed appointments;
- Dismissive behaviour;
- Lack of clarity in communication (either due to language barriers or poor communication skills);
- Judgmental attitudes;
- Physician arrogance;
- Over prescription; and
- Lack of follow-up.

Physicians and providers attributed low-quality face time to a variety of factors, including the fee-for-service compensation model for physicians, time crunch, and stress.

"Doctors get paid by the visit, or the booking. To be a doctor these days has become an assembly line operation, trying to fill offices and push through as many patients as possible."(Patient)

"They rush you through like cows through the chute." (Patient)

"The medical care system is an insular world. There is a disconnect between the outsider and the insider, and the insiders are so used to doing things all the time that they forget that this is a unique experience for the outsider. We have to continually remind the insider that it is not all about our world, and that we exist because the outsiders come to us, and that is where a lot of this miscommunication happens. Part of it is language, and the other thing is the time crunch." (Provider)

"Some patients don't really get heard or examined because we are in a fee for service system, and you get the same fee if you do a good job, or a crappy job." (Provider)

Rushed, and thus low-quality, face-time with physicians can not only make patients feel uncomfortable, but patients and providers point out that this can also contribute to poor case management. Rushing can mean that providers do not pay enough attention to patients' knowledge or explanations of symptoms and history, which can lead to misdiagnosis. Rushing can also mean that providers do not explain diagnoses and treatments thoroughly to patients, leading to patient misunderstandings and inadequate follow-up on advice.

4.3 Cause Theme #3: Effectiveness of communication channels between the system and patient

- **Positive Experience Enabler:** "Touch points" in the system keep the patient well-informed of, and connected, to providers involved in his/her case; Patient/and or family member is an effective self-advocate.
- **Negative Experience Driver:** Poor communication with patients from hospitals, facilities, doctors' offices (e.g. no orientation to hospital environment; no updates on waits for service, test results next steps, staff in charge); No one takes responsibility for the patient file.

When communication channels work effectively, patients should feel familiar with the expected steps in their care journey, apprised of regular updates on timing and progress of their care, able to reach their providers if needed, and informed of what to expect at the point of discharge from care. Both patients and providers suggested that effective communication is enabled when patients have an advocate or "touch point" in the system, "quarterbacking" their care. The "quarterback" can be a family member, a family doctor, a volunteer organization, or system navigator.

Ineffective communication channels between the patient and the system, however, can be a driver of negative experiences in a number of care situations. Communication challenges are exacerbated if a patient does not have an effective "touch point" or advocate within the system (such as a family doctor), or outside of the system (family member or self), who is helping to ensure the proper flow of information.

Poor communication was reported to drive negative experiences in the following situations:

In ER – Negative experiences driven by lack of updates on wait times and/or poor communication of triaging procedures.

"They should put something on the wall that says how long the wait time is going to be. In the hospital, you don't always see the emergencies coming in so you don't see what is going on behind the scenes. You don't always realize all this other stuff is going on." (Patient)

"Maybe people don't understand the way our triage works and that we aren't just making people wait for the sake of making them wait, and we are following guidelines to make this all safe." (Provider)

In hospital – Negative experiences driven by a busy environment where staff does not have time to stop and share information. Patients are often confused in the hospital environment, and often perceive that little effort is made to orient patients to hospital facilities.

"I think all of the healthcare professionals are guilty of not taking the time to communicate with patients properly. I think poor communication is a big problem we have in our system. When my father was in the hospital I had a great deal of difficulty communicating his needs to the staff because they didn't seem to care, and when they had information, a lot of them were too busy to provide me with that information. I think a lot of the problems are getting lost in improper communication and hurry." (Provider)

"Patients don't have a clue who is who. Nurses have lost their identity....who is the nurse? Most people want someone to look after them, but when they are asking all sorts of different people, and everyone looks the same, there needs to be some form of identifier. How could families not be frustrated with us?" (Provider)

While waiting for surgeries/diagnostics **-** Negative experiences driven by poor communication of wait times for surgeries and diagnostics. This includes excluding the patient from dialogue about scheduling.

"Most patients honestly and truly expect to have some wait, but what they want to know is 'when', specifically 'when'. What we provide right now is broad estimates, and they are not reliable, and they are based on retrospective data. These people have their life on hold the entire time they are waiting for surgery, and they don't feel that they have the freedom or the ability to do anything because they don't want to miss a call for surgery. Patients tell me all they want to know is 'when' so that they can plan accordingly, and if that isn't going to work for them and they want to try alternatives, they can exercise another option. But since we don't narrow anything down for them, the entire time they are in limbo. The only information given to the patient is the broad estimate, and they are more frustrated after calling because they have hoped for more." (Provider)

"I like to use the example of the wheat farmer. I have patients who are farmers and their calendars are critical. You can't have a knee replacement scheduled between April and the end of September. It just will never work for the patient. But it happens so often that way with scheduling – without regard for the patient's life and needs - and the frustration these patients feel about that is understandably major. Then they need to reschedule and wait longer in pain. They don't understand why it isn't made more simple." (Provider)

After tests**:** Negative experiences driven by lack of consistent standards for patient-provider communication of test results and diagnosis, meaning patients are often left anxious about where they stand.

"I think the 'you will find out if there is a problem' system is very frustrating for patients. This always leaves the patient hanging because if they don't hear anything this could either mean that 'there really isn't something wrong', or 'I've been forgotten about'. We need to allay fears, they need to be able to just call their doctor's office and be able to be told that a test is negative.'" (Provider)

At time of hospital discharge – Negative experiences driven by inadequate sharing of information from providers on what patients should expect.

"So many leave the hospital and they just don't know what to expect next. Often times, they feel too untethered and will just come back to emergency in a couple of days." (Patient)

"This is a huge issue for patients that are cognitively confused. There is the assumption that the patient understands discharge instructions, and sometimes they don't even get instructions. There is a huge disconnect for anyone who is cognitively confused." (Provider)

4.4 Cause Theme 4: Coordination/Organization of care throughout the continuum

- **Positive Experience Enabler:** Timely, low hassle negotiation of patient movement into the system or from one part of the system to another.
- **Negative Experience Driver:** Inefficiencies, inconvenience and delay in negotiating patient movement into the system and from one part of the system to another.

How care is organized and coordinated can drive positive or negative patient experiences in the following contexts:

Referrals to specialists/specialized services**:** Negative experiences, particularly related to access to specialists, can be driven by lack of efficiencies in referral processes and patient transfers through the health care system. Providers blamed inefficiencies on a tendency among providers to rely on their own insular network of colleagues for referrals, without much exploration of faster or potentially more convenient options for the patient.

"I have patients waiting for neurologists and I know they will never make it to the top of the list because their physicians are just referring them to the specialists that they know, even though their wait times are extremely long." (Provider)

"I think there is a lot of turf protection – it's an old boys club – they like what they like, and they like who they like, and they won't refer to certain specialists because they don't like them. Patients even know that." (Provider)

Testing**:** Duplication of tests was also identified as a driver of negative patient experiences, arising from poorly coordinated/organized care (as well as poor management of health information). The main reasons for duplication of tests suggested by patients and providers were loss of test results, test results

becoming stale due to slowness of patient movement through the system, and physician preferences for their own testing even when other results exist.

"Repeats are a waste of money and a waste of time, just because different areas want to do their own testing. Maybe because they like their own radiologists, and their own machines? I think this is a culture that needs to be stopped, these tests don't need to be repeated. Maybe it's a matter of trust?" (Provider)

***Waiting for surgeries and diagnostic tests*:** Many patients and providers connect the negative experience of long waits for surgeries and diagnostics to poor coordination and organization of wait lists. Poor coordination and inadequate allocation of surgical time – and surgical support -for surgeons was also considered to be a cause of inordinately long waits for surgeries and diagnostics.

"Doctors are moving elsewhere because of all of these regulations that are put on them. There are lots of specialists who are ready to leave the Province because of what the board is trying to force on them. I knew of an Opthamologist who is moving to states because she didn't like the bureaucracy. I also heard of a neurosurgeon who was ready to leave because they weren't going to give him what he needed in order to provide the correct services. Sometimes they are just so bound by the restrictions and therefore couldn't provide the services the way they want to."(Patient)

"Doctors are overworked and they are not getting the back-up they need so that they can have a break. I know a doctor who did 12.5 hours of surgery by herself. How is one medical professional supposed to be able to do all that? Many physicians leave this city and this Province since they have not been given the right support. Dollars mean nothing if you don't have the right support and can't live your life properly."(Patient)

"We may have enough surgeons, just not enough surgical time for them." (Provider)

Providers also suggested that "wait lists" are not well "quarter-backed" – contact with patients should be more frequent to confirm efficiency of scheduling and to avoid cancellation. Some patients complained of barriers to switching wait lists, expressing frustration that some equipment (MRIs, CTs) are underused in some communities.

"Wait list management, I just don't think this is being effectively done. There are people who have been waiting more than 2 years for a scope. Could someone not go through all these forms and call them, ask if they still need to be on the wait list? There is a balance between the physician office and our region to manage this wait list, and I don't know if anyone has the go ahead to take the initiative to do this. Or are we afraid what the appearance of that would be if we went around and made these follow up phone calls?" (Provider)

Some providers offered that the main problem with waiting for surgeries and diagnostic tests were flow issues – that there is too great a bottleneck in the system caused by a large backlog.

"If the waiting list is that long for these procedures (cardiac cath) then the equipment needs to run 24 hours a day until the back log is cleared and that means you need more staff. If you clear the back log in essence you are preventing further more costly care because the sooner you have a cardiac cath and insert stints, or identify who needs bypass, then you can avoid a heart attack and then you've saved money." (Patient)

"Problem is the backlog. The only way to fix our health care system is to catch up on the back log of people waiting for surgery. We will never catch up the way things are now. Anyone who has been waiting for surgery for more than a year should be sent to another Province with shorter wait times to have their surgeries. It could be done so that the surgery itself is covered by the Province but that travel and hotels, etc would have to be covered by the patient. Some surgeries only have a 3 week wait time in Ontario and yet are 2 years behind here? That is not reasonable and needs to change." (Patient)

"When you look at flow, you are looking at how do you match your demand and capacity in the system, you have to look at how many patients are coming in, and how many are going out, and if you have a mismatch, you have to have a plan to deal with that." (Provider)

When there are multiple providers – Negative experiences can be driven by poor inter-provider coordination in patient case management. A lack of inter-provider communication can make patients and providers feel out of touch with the progress and needs of a case, leading to service delays, duplication of tests and contradictions.

"Health care has gone to individualized specialties and very little is left there to tie it all together for the patient. These doctors very rarely ever get together and talk about this as 'a person', there is nothing about 'them' in this service to tie it together. There are very few GP doctors any more unless you are in a larger centre, and that it is taking away from the continuity." (Provider)

"In acute care, your attending physician will say 'I need a consult for this', then 'I need another consult for that'....you don't have one person looking at the whole picture, nobody is standing back looking at the big picture. They come in and are so focused on whatever their area of expertise is, there is no 'round the table' consult with all the healthcare professionals." (Provider)

"Are the doctors communicating amongst themselves here? It's like they are working individually and not as a corporate team within the Province. It would be so much better for the patient if they were collaborating as a corporate team." (Patient)

At discharge – Negative experiences can be driven by poor planning of patient after-care needs, resulting in patients not having access to the resources they require for best recovery when they leave the hospital (e.g. specialized equipment, home care, OT/PT appointments). In some cases, patients are unable to leave the hospital after an intervention because they are insufficiently connected to the resources that they will need outside the hospital, resulting in overcrowding of hospitals.

"The need for equipment is overwhelming, but the supply just isn't there...we don't have the equipment, so we can't discharge people from the hospital, their beds are tied up and then we have to bypass people who may need to get into the hospital." (Provider)

ER – Some patients and providers attribute long waits in ER to poor coordination of care because ER is too often used as a catch-all for patients. Having to contend with too many other patient presentations in ER is often cited as a cause of a negative experience, and frustrations were raised about the absence of viable alternatives to the ER (e.g. walk-in clinics, urgent care centres).

"We get a lot of 911 calls for things that could be addressed by home care. Trouble is that home care is not 24-7." (Provider)

"ER will continue to catch all of the overflow – when another service can't be provided, it is the fall back that ER will provide that service. If that person can't get home care, it's going to fall back to ER. That now is compromising the ability to provide the care they are intended to in ER." (Provider)

"We need to open more 24 mediclinics that can handle minor emergencies, such as a cold, fever, broken bone, so that it keeps the emergency room open for major emergencies. I waited in an emergency room for 6 hours before I was even moved out of the waiting room, despite the fact the nurse was told of my history of my liver spasms - and my narrowed bile duct - and that I have already been hospitalized with jaundice. A man sat next to me with a broken nose that was bleeding and he couldn't even get their attention for a new cloth." (Patient)

Providers pointed out that flow through ER is also impeded by hospital overcrowding from poor discharge planning.

"Critical factor in terms of bottle neck is length of stay of the patients in the hospital – diagnostic turn around, consultation time, finding responsible physician – those are the things that drive lack of availability of stretcher space...it's the admitted patient that is sitting as an admitted patient with no bed to go to, those are the patients that cause the long waiting in the waiting room." (Provider)

"There needs to be more cardiologists to perform the cardiac cath. I tied up an acute care bed for a whole week, which is very costly because the andio suite was so busy they couldn't fit me in. So in essence you are spending twice as much money because there isn't enough staff to perform the procedures to get people moving out of the system and back home, and because I was tying up a bed someone in emergency couldn't get a bed, which is what happened to me; I laid 30 hours in emergency before I could even get a bed. Access to care and best practice to me is not to have someone wait a week for a cardiac cath!" (Patient)

Home Care – Patients and providers often linked their negative experiences with home care to issues of poor service organization and staff scheduling, experienced as frequent cancellations, schedule changes, and staffing inconsistencies. Assessment of home care needs was said to take too long or to be incomplete, resulting in long delays for services and mismatches in patient expectations when services

are finally delivered. It was also pointed out that there is rarely any ongoing assessment in home care or a specified end-point for home care, meaning that some home care may be going on unnecessarily. However, the most common reason provided for home care dissatisfaction was that aides and nurses are understaffed and overstretched.

"There is no point in expanding home care services because they can't handle things now with what they have on their plate. They are understaffed, and overstretched. There needs to be a consistent response from home care, if it is not consistently available then it fails. But we have to be careful if we want to expand - expand to do what? We need to be able to deliver on it." (Provider)

Medical Travel - Patients and providers in rural and remote communities, including predominantly First Nations/Métis communities, linked some of their negative patient experiences in accessing urban care to frustrations with poorly coordinated medical travel. Examples of poor coordination include:

- For on-reserve patients, confusion about the role of bands in providing transportation/escorts;
- Inconsistencies in funding of escorts, meaning patients have to advocate and navigate for themselves under difficult circumstances;
- Escorts are not always appropriate (not always helpful to patient);
- One-way travel costs are sometimes all that is provided – and sometimes no travel costs at all;
- Poor communication between urban and rural hospitals when patients are transferred, resulting in delays in access to care;
- Poor coordination of medical needs when travel is required e.g. multiple appointments could be, but are not scheduled on the same day; and
- Inadequate established standards of where to transfer patients from remote/rural locations – where RHA mandated policies exist, they are perceived to not always be efficient or optimal for the patient.

"Each band has a different travel policy – some will send an escort, some will send a medi-cab, some will not, some you can get authorization day of or one day before for medical travel, others require at least a week's notice. That just highlights what makes the north so unique, we have more hoops to go through, the Province doesn't seem to understand." (Provider)

"There is inconsistency on medical travel options – for instance the ambulance ride to the city will be paid for, but not the ambulance ride back – patients do not want to incur those costs. Furthermore, in First Nations cases, some bands will pay for transportation and others won't, so many patients do not want to go in to the city for treatment at all." (Provider)

"My experience was likely more positive since I work in the system. I watch some of our elderly patients and elderly care givers struggle with the simple things like parking and access to buildings, appointments at two sites in the same day or having to travel from rural areas two different days for appointments that could be scheduled together. We are not client centered we are as a system very system centered we do not listen to the person and this is often the trigger of patient frustration. The system does not operate as a team supporting the patient and on occasion the patient suffers as a result."(Provider)

"There needs to be some way to ensure that whatever hospital a patient is sent to is adequately equipped to care for those referrals. Because that's not always they case." (Patient)

4.5 Cause Theme 5: Quality of Health Care Work Force

- **Positive Experience Enabler:** Patients feel confident in the availability and accessibility of Saskatchewan's health care work force; Patients feel cared for.

- **Negative Experience Driver:** Health care work force is perceived to be unstable and care is of unreliable quality.

Patients, and to a lesser extent, Providers, often attribute negative patient experiences to the quality and quantity of Saskatchewan's health care work force. Patients want to feel that health care workers are committed to their communities, committed to caring, and are accessible. However, the following human resource-based reasons were frequently cited by both patients and providers as the cause of negative experiences for patients:

Lack of resources, including staff shortages – "Staff shortages" were often the first reason that patients provided as the root cause of negative patient experiences. Most dire shortages were perceived to be:

- Nursing personnel - especially psychiatric, critical care, emergency, geriatric;

- Nurse practitioners;

- Family doctors (especially in rural and remote locations);

- Specialists – especially neurologists, psychiatrists, pediatricians, surgeons;

- Diagnostic technicians;

- Therapists – OT/PT, speech therapy, geriatrics; and

- Geriatric supports.

"There needs to be something done about the shortage of nursing staff. I think that shortage puts pressure on people that are working on the front line and in turn makes them maybe less caring, because

they haven't got time to be as respectful as they could be. Things would be a lot easier for patients involved if nurses just even had time to say 'Is there something I could do for you?' like they say in a store. If they didn't ask you that in a store you may leave and never return." (Patient)

***Difficulties retaining health care workers in the Province*:** Staff shortages were often attributed to difficulty keeping health care workers in the Province. Reasons for this included:

- Poor orientation/integration of doctors recruited from outside of Saskatchewan, particularly non-Canadians;
- Not enough access to research opportunities and exciting projects for physicians in Saskatchewan;
- Not enough consideration of the needs of the families of health care workers;
- Not enough full-time positions for nurses and other staff;
- Uncompetitive compensation.

"We don't have the wages in Canada that they have in the States so we are losing doctors all the time." (Patient)

"No one has taken the time to survey the doctors to find out what type of needs doctors have when they move here and what the government can do to satisfy those needs. She says doctors are not informed completely about the conditions in the north and this creates and expectation gap between the doctor and the employer." (Patient)

"The foreign staff entering the system need to be oriented to the community so that they can learn from the community, and the community can learn from them. It is a Province wide problem. There is no introduction to the community where they are going to work and then there are clashes."(Provider)

Other reasons given for health care staff attrition, as well as poor attitudes perceived by patients, included:

Health care workers are "burnt out" – Providers and patients believed that physicians, nurses, and other health care workers in the Province were "burnt out". Staff shortages, resulting in heavy case load pressures for health care workers, were the main reason given for burnout. Overly long nursing shifts (12 hours), heavy on-call responsibilities for physicians, and working in a system that values "fast over thorough" were other reasons provided for burnout.

"I think that nurses working 12 hour shifts is a problem. I don't think you can work full tilt for 12 hours. I don't think anyone can work 12 hours and be as fresh in the 12th hour as they are in the first hour. This ends up being hard on the nurses and hard on the patients."(Patient)

"A good nurse is now a multi-tasker, not someone who cares well for any one patient." (Provider)

"Cut down the hours a nurse works in a day. I think if they worked less hours and gave shifts out properly they wouldn't be so bitter. I have overheard countless conversations between the nurses about either being overworked or never getting enough work because their superiors get first crack at all the shifts. I might not be explaining it well, but I am not exactly sure how their union works. I'm just going off what I've overheard." (Patient)

"They are so overworked – anyone under those conditions will at some point snap. When working over and above their shift, we are all human and if we don't rest our body, you aren't doing yourself any good." (Patient)

Low staff morale – Providers and patients alike complained that many health care workers have "poor attitudes", either due to burnout, lack of supportive leadership, or a workplace culture that can be resistant to change. Providers described workplaces that can suffer from conflicts between staff, high levels of absenteeism, and complaining.

"I think the whole system is not functioning very well. If you have an urgent problem, things are dealt with nicely but on a day to day basis I think we are doing a really poor job. I hear from nurses how unhappy they are, the morale of everyone is really appalling because they feel overworked and put upon and unhappy." (Provider)

"I think health care staff at the home are overworked, and there is not enough of them. Part of it may be cultural. They are tired and grouchy. I think some are just putting in time and I think there are some who just lack bedside manner. They are good as far as their knowledge, but they don't have a good manner." (Provider)

Lack of supportive leadership – Providers suggested that lack of support and leadership direction could be wearing away at the morale and strength of the workforce. Some providers felt that management did not pay enough attention to the staff's work satisfaction, ideas, or enthusiasm for ongoing education.

"I think some of the people in the charge positions are probably deserving of those positions, but lots of issues are people/staff oriented, and there needs to be training out there for people in the management positions on how to actually deal with people… I don't want a complacent boss." (Provider)

4.6 Cause Theme 6: Cultural Sensitivity of Workforce

- **Positive Experience Enablers:** Good cross-cultural training; staff hired for values such as respect, tolerance; diversity of workforce
- **Negative Experience Driver:** Poor cross-cultural training; respect and tolerance of workforce not adequately emphasized.

From a patient perspective, enabling positive experiences relies on a combination of:

- Good cross-cultural training;
- Hiring staff for values such as respect, tolerance;
- Presence of translators and system navigation support for those who do not speak English; and
- Diversity among staff, including strong representation of First Nations and/or Métis providers.

On the other hand, negative experiences, including racism, were attributed to:

- Not enough leadership on cultural issues;
- Insufficient encouragement of staff to participate in cross-cultural training;
- Lack of diversity among staff compared with diversity in the population; and
- Lack of understanding of various cultures, including the sick roles of different cultural groups in Saskatchewan – particularly among staff brought in from outside of Saskatchewan;

"Staff aren't going to cultural awareness groups/training. Managers have to ensure that this happens, but they don't. They put these programs on, and they are good programs, but it's the same people who go every time." (Provider)

4.7 Cause Theme 7: Management of Health Information

- **Negative Experience Driver:** Lack of consistency in managing and sharing patient health information among providers.

Poor and inconsistent management of patient health information was often suggested as a driver of negative patient experiences by both patients and providers. Speed, quality and consistency of patient care were all believed by providers to be impeded by underlying problems with the way patient health information is handled, including:

- Lack of accessible, centralized means of locating patient health information;
- Fragmentation of health information throughout various parts of the system – no consolidated patient "record";
- Inadequate physician recording and reviewing of patient information before/during/post consultation; and
- Too much paperwork on patient files, often badly managed.

"Once you leave a doctor's office, the doctor has most likely forgotten about you. The lack of medical records for patients is shocking, and it is scary for me as a doctor." (Provider)

"Files should be transferred so that a history can be maintained through to new doctors, at least that way a doctor will know what was going on at the time, and can move forward from there. Why wouldn't one doctor want to know what you have been through so far, because how are you supposed to remember? I just want to get everyone on the same page and that shouldn't be a crime, especially when you put your trust in your doctors and the healthcare system." (Patient)

"We often get complaints from patients when they get to their appointments in the city. They will have had their diagnostics done in a rural area and we will get a call from the patient afterwards saying 'you were going to fax our results, and you didn't '. This is a very common problem, things get lost. There needs to be a better system for patient results to get to their specialists, and vice versa." (Provider)

"Loss of requisitions is a huge waste of time, I get nowhere when I complain about this. The inefficiency that is there is unbelievable. When requisitions are in place for months on end, and the patient is finally going to get an MRI why wouldn't you call a day or 2 before to make sure they are coming, so that someone can be slotted into the spot if they aren't going to show up." (Provider)

Some patients and providers also identified patients' own lack of familiarity with health information as a driver of negative experiences. Lack of familiarity can stem from poor personal engagement in one's health, discouragement from maintaining a personal copy of health files, or loss of health files in the system.

4.8 Cause Theme 8: Optimizing Use of Health Care Workers' Scope of practice

- **Negative Experience Driver:** Over-reliance on specialists; under-use of nurses in primary care.

Patients and providers saw sub-optimal use of health care workers' scope of practice within the system as a driver of negative experiences in two distinct cases: 1) over-reliance on specialists and surgeons (surgeries) to solve problems; and 2) under-use of nurses in primary care

Some expressed the view that family practitioners were functioning more as gatekeepers to specialized health care as opposed to being actively engaged in treatment, diagnosis and patient counseling. There was a sense among both patients and providers that due to time constraints, family practitioners were working at the lower-end of their training (routine activities such as taking blood, checking blood pressure), while all else was moving on to specialists. One perceived reason for this frequent handover to specialists was that family physicians did not always have time to review patient cases in extensive detail due to busy schedules. Another reason suggested was the restrictions placed on physicians to prescribe certain diagnostic tests (e.g. ultrasound, MRI).

The consequence was a glut of patients requiring specialized services, resulting in long queues for services and delays before a diagnosis could be made, a test could be performed, or a surgery could be booked.

"We've become too compartmentalized. Everything moves off to a specialist." (Patient)

Some even suggested that specialist time was poorly used for their scope of practice. Given limited resources, some specialists were not focusing on the right job:

"I was told that hematologists need to see internal medicine patients to be able to make enough money. Hematology patients are usually a high workload type of patient, not high volume straight forward patients like in internal medicine. This results in hematologists having a greater wait time for hematology patients who ironically then have to be seen by an internal medicine specialist as happened in my case. Perhaps the fee for service needs to change so that every specialist can see their OWN patient type as this is what they were trained for. At a quick glance it may appear that we need more hematologists because the wait time is so long but in reality the wait time is so long because they are seeing non-hematology patients." (Patient)

Patients and providers suggested that another reason family doctors are unable to practice closer to the top-end of their training is the under-use of highly skilled nurses, particularly nurse practitioners, in primary health care. Many providers expressed that if better funding were available for nurse practitioners, there could be a huge impact on patient experience as care responsibilities could be divided between physicians and nurses. In this model, nurses could perform routine tasks (e.g. prescribe medications, complete routine physicals, and provide routine care to chronic patients) to free-up physician time for more complex cases.

"Nurses are so capable, and have so much knowledge, but they don't have the power, the doctors have all the power. They need to be better utilized."(Patient)

"If every doctor's office had a nurse practitioner it would cut down a huge amount of the physicians work load." (Provider)

4.9 Cause Theme 9: Rural-Urban Inequities

- **Negative Experience Drivers:** Patients can't access local family health care, routine specialist consults in rural and remote locations.

Service inequities across the continuum of care were a cause of negative patient experiences for people residing in rural, and to a greater extent, northern and remote locations. The most problematic inequities raised in groups were:

- Perception of under-use of local health centres for primary care, obstetrics, and urgent care;

- Inability to access specialists without significant travel;
- Shortage of family health care services;
- Difficulties accessing long-term care options without significant travel; and
- Shortage of, or lack of, rural non-hospital health services (e.g. therapeutic services, mental health care services, rehabilitation).

"There is inefficient access to specialist care, we need to be cognizant of the therapy needed within the rural communities. It is irritating as a healthcare provider when you can't access services for your own family members, and if I am feeling this way, I can't imagine what it's like for other who aren't used to the system." (Provider)

"Why can't we bring more to the rural? Why build new spaces elsewhere when we have empty wings here in the hospital? Optimize rural hospital space!" (Patient)

4.10 Cause Theme 10: Staff Performance/Behaviour Accountability

- **Negative Experience Driver:** Staff get away with poor behaviour.

Providers and patients both suggested that a sense of powerlessness to do anything about "bad apples" within the work force was a driver of negative patient experiences. Providers discussed how "poor staff" are not easily disciplined or controllable, so their behaviour is allowed to continue to impact patients.

Providers blamed "poor" staff behaviour on the following factors:

Poor Staff Supervision: According to providers in hospitals and facilities, there is rarely a consistent person in charge of keeping up with staff performance. For instance, providers suggested that nurse managers are often too busy in other roles to focus on supervision and management of "caring", and are often not close enough to staff interactions to judge quality of care-giving. Many providers across sectors said that they were not given regular performance reviews, or provided the opportunity to give peer reviews.

"A lot of my bosses don't even know what my job is, they know what it is on paper but my supervisors have no idea about what I actually do on a day to day basis." (Provider)

"The management just isn't seeing what is going on with us. Back in the day, if you had an issue and went to your head nurse, you knew that issue was going to get dealt with, and it would be dealt with." (Provider)

Even when a problem is detected, providers discussed how it is very difficult to discipline staff. The reasons for this included:

- Powerful unions;
- Fear of losing staff when already considered to be shorthanded;
- Bullying/tattletales among staff; and
- Few channels to complain either directly or anonymously about observed problems with staff.

"There is nobody accountable to anyone. Nobody talks to any of the problem makers, the people who are causing the issues are not being dealt with and the frustration is running like a domino, like a wave, and the morale has gone really low." (Provider)

"Very recently someone in a care facility was slapped. We proceeded down the road of discipline, but in the end the staff person is back at work in the same facility, same unit, same patients. It had all to do with the union. How do you explain that to families?" (Provider)

Many patients do not believe that providers are ever made to answer to them either. Many patients complained of not being aware of processes for reporting or following up on complaints about poor staff behaviour experienced or observed in health care centres and facilities.

"Where can you go to take your concerns? Where do you go with your complaints?" (Patient)

4.11 Cause Theme 11: Geriatric Health Care Support

- **Negative Experience Driver:** Under-preparedness for the aging population.

Providers and caregivers to elderly patients identified the heath care system's under-preparedness for the aging population as a significant driver of negative patient experiences. There were five main ways in which the system is perceived to be under-prepared:

Gaps in the system for elderly patients/their families who do not require full-time facility-based support: Elderly patients who fall somewhere between independence and need for full-time care can feel left behind by the system. Patients pointed to a shortage of community day programs as well as a shortage of alternatives to traditional long-term care for people who might require a lower level of support if they could remain closer to their families or with their spouse (e.g. small group homes, assisted living).

"Working in a rural area, you get a lot of patients who aren't able to cope at home, but they also aren't ready to go into a nursing home. It would be nice if there was some place they could go to in between - a facility where they are supervised, but where they can still remain independent. You see a lot of them going into a nursing home and then they just give up on doing anything for themselves." (Provider)

"There should be some kind of transition thing, not full blown level 3 or 4 nursing homes but something in the middle, people may be more receptive to that. Just because you are 80 doesn't mean you are going to fit the mold of needing the whole range of services offered in a nursing home." (Provider)

"I think there are a lot of people who have fallen through the cracks – they don't have enough money for private care, there is no space in LTC – after I've admitted you to the hospital 3 times in the year a red flag should go up." (Provider)

Families plan poorly for their elderly: Another cause of negative experiences was poor family-planning with respect to their elderly. Many families find that they are ill-equipped for the financial, emotional, and time commitments of managing the care of an aging family member.

"Families keep getting taken by surprise by the cost and work involved in elderly care. It used to be that families would take care of their elderly. They should be more accountable." (Provider)

Poor support for Caregivers: Caregivers pointed to lack of respite and financial support (tax breaks, subsidies) as stressful (and driving negative experiences) for those managing the care of their elderly.

"If I have to leave my job to look after my mother, then can you make it worth my while? Give me some kind of tax relief; give me something as a caregiver." (Patient)

Shortage of appropriate long-term care / supportive care options to suit patient lifestyles: Many patients and their families have been through a good deal of stress in managing difficult decisions about long-term care options for their families. In some cases, couples have been split up or family members have had to take up available space in facilities outside of their communities, away from their roots. In some cases, elderly couples were caring for each other – sometimes unsafely – to avoid being split up by long term care administration.

"It feels like sometimes we are expecting the patients' needs to be able to be met by what we are willing to give, not what they need." (Provider)

Shortage of expertise in handling increasingly complex patients: Providers noted an absence of geriatric medical strategy to deal with increasing patient complexity and need for a higher level of support. Fragmented care of the elderly can result in frequent ER admissions, visits to the family doctor, and heavy burden on home care.

"We have a pathetic level of care for geriatric patients, both acute and episodic conditions, and we have very little support systems in place for chronic disease management. A geriatric strategy for this Province is non-existent. We haven't started as a Province to look at the juggernaut coming down the pipe, and we are not managing it appropriately. There needs to be geriatric assessment clinics. We have not built the system to allow the providers managing these more complex patients to have the tools at their disposal to treat them appropriately. We are trying to pound square pegs into a round hole." (Provider)

4.12 Cause Theme 12: Child and Maternal Health Care Support

- **Negative Experience Driver:** Weak support system for new mothers and families with young children.

A driver of negative experiences for new mothers and young families was feeling that the system was insufficiently responsive enough to their needs. Feeling under-supported was explained to be the result of:

- Lack of respect for mothers' comfort and privacy during and post-delivery (maternity ward overcrowding, resulting in a shortage of individual attention);
- Not enough time for some young mothers in-hospital after birth;
- Not enough transitional support for new mothers ("care" visits, lactation support, social networking programs in the community);
- Shortage of access to pediatric care; and
- Long waits for pediatric assessment services for young children.

"24 hour discharge of mothers is very scary to me. The first 48 hours is critical, and even after 48 hours you may not see some normal things manifesting. It's almost like we are setting them up for failure." (Provider)

"There is a lack of prevention, lack of preparation, lack of education component – both inside and outside of the hospital. There are some people who do have good family support and come home to a clean home, and have good confidence about taking care of their baby in the home. We do have another group of women, however, with practically no pre natal preparedness. Some women need support and a telephone call is just not enough." (Provider)

"There are so few pediatricians around. You wait so long and the appointments are so short – which is so hard for you because by the time you get in you are freaking out and have so many questions and you don't know what to prioritize. It's like – here's your 5 minutes, now 'go'. " (Patient)

4.13 Cause Theme 13: Mental Health Care and Addictions Support

- **Negative Experience Drivers:** Lack of mental health and addiction skills/knowledge in the health care system; Gaps in the system for mental health and addictions patients who do not require full-time facility-based support.

Negative experiences for patients with mental health and addictions needs were often attributed to a lack of mental health skills and knowledge in the health care system. Providers and patients saw this to be particularly problematic in the following parts of the health care system:

ER – Many mental health and addiction-related crises cases initially present in hospital emergency rooms. Hospital emergency rooms are often the safety net for these patients. Providers and patients acknowledged that hospital staff are often ill-equipped to interact with these patients, and are often fearful, dismissive or disrespectful.

"We don't have the training to look after them, we don't have the knowledge. The nasty staff are the ones who have never had an alcoholic in the family. So many staff don't understand that addiction is a disease and they don't have enough skills to look after some of these people...they don't see it as a real illness, like the way they see someone coming in with the flu." (Provider)

Family Health Care **-** Some patients, particularly those who had difficulty accessing psychiatric or psychology services, were relying on their family doctor to manage their case and sometimes finding this family doctor to be under-equipped. Some patients believed that over-prescription of medication is a common result of poor knowledge of mental health case management among general practitioners.

"Family physicians are treating over 75% of mental health disorders - and almost every family has been touched by that. Providers need education about seeing this as a 'normal' health problem that can and should be dealt with in a normal way." (Provider)

Community-based Support: Many patients also identified gaps in the system for mental health patients who require ongoing support, but not necessarily at a high professional level. Inability to receive ongoing, convenient, community based support was identified as a significant driver of negative experiences among patients who interact with the mental health care system. Gaps included:

- Shortage of publicly accessible, casual mental health support programs in communities;
- Lack of 24 hour support for mental health crises; and
- Long waits for treatment programs.

"Wait lists for treatment are a real problem. If you are motivated for change today – but if you can't see a counselor for 10 weeks - that is a real problem." (Provider)

"There is nowhere to go. You can go to emergency. Maybe." (Patient)

4.14 Cause Theme 14 – Health protection and promotion activities throughout the Province

- **Negative Experience Drivers:** Insufficient health promotion and health protection activities in the Province (e.g. chronic disease prevention, nutrition, family planning, infection control.)

For some patients and providers, the fundamental cause of negative patient experiences is patient over-reliance on the system in the first place. The reasons provided for this are twofold:

People don't take enough responsibility for their own health – Patients rely too heavily on the health care system to "fix" them. This attitude results in a sicker population that does not take responsibility for their own health, over-uses and overcrowds facilities, and over-stretches health care providers in the process.

"We need to start promoting a patient attitude that you are in charge of your health. There is the idea that the 'system will fix you' and you trust that even if they mess up the first time, the next time it will work out – this attitude would not be the same towards the purchase of any other commodity. There needs to be more emphasis for people to look after themselves." (Provider)

The health care system is insufficiently prevention focused – Many problems could be avoided with expanded effort to teach, support and sustain healthier living.

"We need to do more to promote health in this Province. Part of our job should be making sure less people need us because they are learning to be healthier." (Provider)

Table - Analysis of Causes Driving Experience

	PATIENT EXPERIENCES													
CAUSES	Lost in the System	Uncaring/ Dismissive attitudes	ER Waits	Long waits for diagnostics/ surgeries	Long waits for specialists	Access to Family healthcare	Poor case management	Homecare limitations	Aging Needs	Mom/child care needs	Mental health/ addictions needs	Transportation	Cultural insensitivity	Unexpected costs
Absence of or weak relationship with family health care	x	x	x			x	x		x	x	x			
Low quality face time with Providers	x	x	x			x	x		x	x	x			
Poor communication channels between System and Patient	x	x	x	x	x		x	x	x		x	x	x	x
Poor coordination of care throughout the continuum	x		x	x	x		x	x	x	x	x	x		
Under-supported health care work force	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Low cultural competence of health care work force		x				x	x		x	x	x	x	x	x
Poor/inconsistent health information management	x	x	x	x	x		x	x			x		x	
Sub-optimal use of Health care workers' scope of practice	x		x	x	x		x	x	x	x	x	x		
Rural-Urban Inequities	x	x	x		x	x	x	x	x	x	x	x	x	x
Lack of staff performance/behavioural accountability	x	x		x	x		x			x		x	x	
Insufficient geriatric health care support - preparedness for aging population			x				x	x	x			x		x
Inadequate child and maternal health care support		x	x		x		x			x	x			
Inadequate mental health care support	x		x		x		x		x		x	x		
Inadequate health protection and promotion activities throughout the province	x		x				x		x	x	x			

5.0 Exploring Categories of Improvement for Patient Experiences

In Phases 1, 2 and 3 of the Patient First Review, the general public, patients, and health care providers who participated in the research were encouraged to think about and suggest ways of sustaining and improving the health care system. We asked for solutions that would have a meaningful impact on the experiences identified by the patients in Phase 1. "Solutions" were discussed not only for negative patient experiences, but also for enabling the continuation of positive patient experiences. The efforts made to define patient experiences and their "causes" in Phases 1 and 2 guided the research toward the goal of arriving at viable solutions to protect the best and fix the rest.

In Phase 1, patients were encouraged to discuss "solution" ideas in the context of defining the problems (see Section 2.0). In Phase 2, providers were asked to think about "solutions" for some of the "causes" and "enablers" that they identified for common patient experiences. Over 150 solution ideas were generated in phases 1 and 2. In Phase 3, stakeholders were presented with "categories of improvement to build on with their solution ideas. From the stakeholders, another 350 solution ideas were added in Phase 3 in response to the categories of improvement that were presented. A full listing of solution ideas is available in **Appendix L**.

5.1 Generating and Analyzing Solution Ideas – Phase 1 and 2

Over 150 unique solution ideas were provided by patients, the public and health care providers in Phase and 2 of the review. Some ideas were general in nature while others were very specific. All ideas were grounded in system experience, not necessarily in system knowledge.

Solution ideas provided by patients and health care providers were analyzed using thematic analysis. Ideas were grouped into 19 thematic clusters. These clusters describe goals for bringing about meaningful change to address many of the "causes" of positive and negative experiences in Phases 1 and 2 of the research. The researchers termed this first set of clusters "categories of improvement". These categories of improvement can be thought of as 19 separate buckets of solution ideas for improving patient experiences in terms of access to care, quality of care and efficiency of care delivery.

The first cut of 19 categories of improvement is outlined below in the table on page 149 (found at the end of this section) illustrates how these categories of improvement link to causes. As we discuss, in the next section, this set of categories was later distilled to six.

5.2 Generating and Analysis of Solution Ideas – Phase 3

Prior to stakeholder sessions, categories of improvement were further merged into a set of six broad and distinct categories (listed in the summary table above). This second round of distilling was done to better organize the themes for group discussion - the goal was to make a rather large set of themes more practical to build upon. The table on page 154 illustrates which of the original 19 categories fit within each of the revised six. So, while provider and patient input on solutions was used to define the

categories of improvement, stakeholder consultations were used to build upon the categories of improvement and flesh out solution ideas that would have a meaningful impact on patient experiences.

Stakeholders were tasked with sharing ideas on how to improve the patient experience by focusing on these categories of improvement. Stakeholders worked in facilitated breakout groups of 8 to 10 participants to generate ideas for making headway in various categories of their choosing. In tabling ideas for making improvements in each of the categories, stakeholders were encouraged to think about the barriers to implementing their ideas.

Following stakeholder sessions, a database of solution ideas from Phases 1 – 3 was merged together and organized by the six categories of improvement.

5.3 The First 19 Categories of Improvement – Phases 1 and 2

The first 19 categories of improvement to emerge from provider and patient consultations are detailed below. These are categories for housing solution ideas to the causes of patients' most common negative experiences with the health care system.

5.3.1 Strengthening the patient relationship with family health care

Both providers and patients felt that weak or absent relationships between patients and a single primary care "touch-point" or team were leading to fragmented and disconnected care for patients. Through Phase 1 and Phase 2, participants were very interested in ideas to facilitate better linkages between patients and "the doctor's office". Providers and patients agreed on the need for solutions to promote open, more satisfying dialogue between patients and health care providers. Solution ideas within this category were seen to address causes of negative patient experiences such as poor or inconsistent health information management, absence of or weak family health care, low quality face time with providers, poor communication channels between the system and the patient, poor coordination of care throughout the continuum, and rural-urban inequities**.**

Solution ideas within this category include:

- Mandatory call-backs/emails for test results and other diagnostics;
- Encourage patients to bring discussion lists with them to the doctors' office;
- More team based practices in family health care settings;
- Better communications training in medical school;
- Longer appointment times – consider changing FFS remuneration; and
- Have educational tools/equipment available in doctors' offices to help doctors "teach patients" - e.g. online tools, 3D models on the computer screen.

5.3.2 Improving communication between the system and patients

Weak communication channels between patients and providers - and between patients and "silos" within the system - were believed to be at the root of feeling "lost" in the health care system. Providers and patients discussed solutions for improving communication with patients and their families while in hospital, and for clarifying patient "next steps" and requirements throughout the continuum of care. Solution ideas within this category were focused on addressing causes of negative patient experiences such as poor or inconsistent health information management, sub-optimal use of health care workers' scope of practice, low quality face time with providers, poor communication channels between the system and the patient, poor coordination of care throughout the continuum, rural-urban inequities, and inadequate health protection and promotion activities throughout the Provinces.

Solution ideas within this category include:

- A case manager should be assigned to harness patient care together, either virtually or literally;
- Improving "Patient advocacy" /case management (to address the issue that no one "owns" the patient);
- Informed discharge strategy at all levels of the system so that patients know what the follow-up plan is, and what they need to do in terms of follow-up when they move from one part of the system to another;
- Develop discharge "standards" so that patient discharge plan is communicated in the same way by all providers and follow-up is streamlined; and
- Improving communication with patients surrounding out-of-pocket costs involved in care plan.

5.3.3 Improving Health Information Management

Patients and providers were in agreement that mismanagement of patient health information was contributing to a number of negative patient experiences within the health care system, including duplication of testing, inadequate follow-up on lab results and case management delays. Solution ideas within this category were those suggested to help address such causes of negative experiences as absence or weak relationship with a family health care professional, low quality face time with physicians, poor communication channels between system and patient, poor coordination of care throughout the continuum, rural-urban inequities, and care in the community. On the staff side, solutions for improving health information management were seen to be important for supporting the health care workforce to better perform their roles.

Solution ideas within this category include:

- Introduce Electronic Medical Records – one platform for the system, easily accessible at all system levels (PIP is a good starting point);

- Encourage “round tables” among all players in a patient’s care (e.g. specialist, family doctor, physiotherapists); and
- Team-based practices - support role of physiotherapists/OTs/nutritionists as integral parts of healthcare team.

5.3.4 Improving coordination of care

This category of improvement encompassed solutions that were suggested to tackle barriers to smooth patient “flow” through the continuum of care. These solutions are rooted in improving communication and planning as patients move across a particular stream, such as between the acute system and home care. Solutions within this category are designed to address such causes of negative patient experiences as low quality face time with providers, poor communication channels between the system and the patient, poor coordination of care throughout the continuum, sub-optimal use of health care workers’ scope of practice, under-supported health care work force, rural urban inequities, and transitions to and between care in the community.

Solution ideas proposed here included themes such as:

- More effective planning and procurement of necessary equipment to enable discharge of people who require said equipment to be mobile or to function on their own without full-time support;
- Discharge planning to include local home care planning and to begin immediately upon entry to the health care system;
- Temporary LTC facilities for those in transition from hospital to more independent care and/or waiting for full time care - can use old health facility infrastructures;
- Single queue referrals or central booking for specialists;
- Bring back head nurses for improved ward management and patient tracking; and
- Consolidate patient tests/examinations within the same time frame (in wait list management) to expedite movement through the system.

5.3.5 Enabling all health care workers to work their full scope of practice

This category of improvement addressed solutions centered on expanding the roles of various provider groups to allow them to collaborate more closely with patients, and to enable them to work at the top level of their education, experience and specific competency. A major facet of this category was increasing the use of nurse practitioners in primary care to help accelerate patient access to timely care and support. However, the suggestion to expand the scope of practice of health care workers extended to a number of provider types, such as chiropractors, pharmacists and alternative care providers. Ideas within this category of improvement sought to address such causes of negative patient experiences as

absence or weak relationship with family health care, low quality face time with providers, poor communication channels between the system and the patient, poor coordination of care throughout the continuum, under-supported health care work force, sub-optimal use of health care workers' scope of practice, rural urban inequities, and transitions to and between care in the community.

Solution ideas proposed here included themes such as:

- Involve pharmacists in communicating/re-iterating discharge information/patient care management along with dispensing drugs;
- Expanding the role of family health care workers in ordering specialized tests (has historically been restricted to specialists); and
- Expanding the role of Nurse Practitioners in family health care management e.g. Pre-screening appointments for patients with nurse practitioners or similar before seeing physicians so that patient has time to discuss their issues and get the ball rolling on diagnosis and next steps to treatment without using more physician time.

5.3.6 Improving access to hospital care in emergencies and urgent cases

Solution ideas within this category of improvement are aimed at improving ER flow and wait times, as well as providing people with alternatives to the emergency room for less critical care. An important aspect of this category was also improving patient discharge planning to avoid overcrowding and re-admission (e.g. planned discharge at time of admission, improved / standardized communication with patients and their families at time of discharge). Causes of negative patient experiences believed to be addressed by solutions within this category of improvement include poor coordination of care throughout the continuum, rural/urban inequities, insufficient geriatric health care support, and other care in the community (such as mental health care support).

Solution ideas proposed here included themes such as:

- More "care" in emergency waiting areas - aides, greeters for patient comfort and first aid;
- 24-hour urgent care centres in close proximity to hospital;
- Provide ER and ward patients with more regular updates of time for waits, test results, etc;
- Extended hour walk-in clinics - particularly in small communities;
- Review the value of the health helpline;
- Expand "Fastracking" to urgent care in hospitals;

- Improved discharge planning to ensure proper supports and recourse for patients when they leave the hospital in the community (e.g. ensure physiotherapy/OT is available quickly and facilitated by home care); and
- Have patient information available on how triage works.

5.3.7 Improving wait time for surgeries and diagnostic tests

Solutions within this category include strategies to deal with improving the flow/throughput of surgeries and diagnostic tests and reducing the patient backlog. Ideas within this category were varied and generally seen as helpful in addressing the causes of negative patient experiences including poor communication channels between the system and the patient, poor coordination of care throughout the continuum, and rural-urban inequities for patients seeking elective surgery.

Solution ideas proposed here included themes such as:

- Allow more operating time for surgeons - review outdated bureaucracy that limits surgical time;
- 24-hour use of diagnostic equipment (MRIs, CTs) (or even just run more, e.g. on daily schedule rather than every 3rd Friday, in some cases);
- Assess all wait lists to determine if fundamental problem with waits relate to a backlog or to insufficient capacity;
- Hire more staff to operate specialized equipment (e.g. MRI, ultrasound);
- Improve contact with patients on surgery list so to update more frequently on changes to patient needs/to provide new estimates for patients/review list position and practicality of timing for patient;
- Allow family physicians to prescribe specialized tests/diagnostics;
- Check in with patients one week before major diagnostics/surgeries appointment to avoid cancellation;
- Surgical "blitz" to reduce the backlog;
- Surgical care centres to handle more day to day throughput;
- Develop central booking or "clearing house" of surgeons/specialists listed with wait time information for more efficient physician referrals; and
- Increase awareness of wait list options in other jurisdictions.

5.3.8 Improving Home Care Effectiveness

This category of improvement was bound together by solutions designed to improve accessibility to home care, home care scheduling and coordination of services (e.g. who provides the care and when, level of service available to maintain independence in the community). Solutions to improve home care were seen to have potential positive effects on drivers of negative experience, such as rural-urban inequities, sub-optimal use of health care workers' scope of practice, insufficient geriatric health care support/preparedness for aging population, and care in the community (particularly for child and maternal health care support).

Solution ideas proposed here included themes such as:

- Include family members in initial home care assessment;
- Home care phone calls to check-in with patients;
- Consistent staff scheduling on patient cases;
- Have more highly-qualified nurses in the community to treat patients at home - to take the burden off ER and to identify struggling patients who will require additional support (e.g. mothers and cognitively impaired);
- Subsidies for use of private home care services (e.g. housekeeping, snow shoveling, etc.);
- Improve communication between system and patients/families about what home care can and cannot deliver and the alternatives (private care);
- 24-hour model of "on-call" emergency home care contact point for questions and support; and
- Establish a way to signal when home care support should be finished so that time is not wasted on patients whose needs have been met.

5.3.9 Improving geriatric and long-term care support

This category of improvement includes solution ideas aimed at developing a geriatric care strategy from a medical perspective (e.g. improved access to specialist providers such as geriatricians, longer appointment times), and from a community care perspective (e.g. improving access to long-term care facilities and alternative living environments that respond to a variety of patient needs and lifestyles). Solutions within this category are seen to have a hand in addressing additional causes of negative patient experiences, such as low-quality face time with providers and poor communication between the system and patients.

Solution ideas proposed here included themes such as:

- Develop geriatric assessment clinics;

- Longer appointment times for elderly with their family doctor;
- Joint-replacements and other quality of life enhancing surgeries targeted towards the aging population should be a top priority so that elderly can regain quality of life before they are too far gone and require long-term support;
- More encouragement of family involvement/advocacy in assessment/medical appointments for elderly family members;
- Fund a dedicated geriatric care/research hospital/centre;
- Improve caregiver support - tax relief, financial subsidies;
- Improve community-based respite care/continue to fund palliative care;
- Public campaign to encourage "family planning" surrounding plans for elderly family members' financial needs;
- Subsidies for private care homes if public LTC not available in the community;
- More supportive living alternatives to new LTC structures, especially for couples (e.g. small group homes served by home care/assisted living);
- More day programs for seniors in the community - can use underused hospitals; and
- Government funding for community-run, community-fundraised long-term care homes.

5.3.10 Improving access to care for patients living in rural and remote parts of the Province

This category of improvement encompasses solutions aimed at reducing the need for medically-required travel and - where travel is necessary - improving the effectiveness of medically-required patient travel (e.g. avoiding overnight stays when possible, allowing overnight stays when travel would be difficult, providing escorts, coordination of appointments to avoid multiple trips). Solutions suggested within this category begin to address a number of causes of negative patient experiences for patients in rural and remote areas, including low quality face-time with providers, poor coordination of care throughout the continuum and suboptimal use of health care workers' scope of practice.

Solution ideas proposed here included themes such as:

- Create standardized guidelines of what travel expenses are covered;
- "Greeters"/escorts in the city for patients arriving from the north;
- Universal coverage for medical travel (First Nations);

- Control ambulance costs (not private/not privately owned);
- Additional coverage for travel to urban centres for treatment (e.g. motel, gas);
- Assistance for travel out of Province/out of country;
- Expansion of the telemedicine program; and
- Provider incentives for itinerant or roving specialist clinics.

5.3.11 Improving child and maternal health care support

This category of improvement comprises solutions that focus on developing more supportive maternal care in hospitals, improving access to transitional support in the broader community, and improving access to specialized child health care services. Ideas within this category look to deal with other causes of negative patient experiences for new mothers and young families, including absent or weak relationships with family health care providers, and poor coordination of care throughout the continuum.

Solution ideas proposed here included themes such as:

- DVDs and other free learning tools for new mothers on baby basics;
- Incentives for attending pre / post natal classes;
- Have birthing rooms in hospitals with maternity wards;
- Pre-natal assessment of mother to determine competency/appropriate length of hospital stay;
- Dedicated Healthline for pre / post natal care;
- Provide mother-to-be with appointment / test schedule for duration of pregnancy;
- Have more home care/health visits for new moms, especially re. breastfeeding;
- More social networking classes in the community, e.g., Lamaze classes / post-natal classes can be led by seasoned mothers. These should be recommended to all by family physicians;
- Provide support for families of sick children to travel out of Province;
- Provide services for people with ASD/develop an autism strategy; and
- Provide additional supports for families/caregivers (respite, information, etc.).

5.3.12 Improving mental health care support

Within this category of improvement, solution ideas include strategies for improving system-wide awareness and skills in mental health care among health providers, and improving access to mental health services and support in the community. Solutions within this category can have positive impacts for mental health care patients encountering an absent or weak relationship with a family doctor, low quality face-time with primary care providers, and poor coordination of care throughout the continuum.

Solution ideas proposed here included themes such as:

- General psychiatry should be part of nursing training;
- Psychiatric nurses should be part of general hospital rotation;
- Regular mental health training mandatory for ER staff;
- Improve public education on mental health and available services;
- Connect educational system more effectively to trained professionals;
- Allow room for self and community-based referrals to mental health programs;
- Waiting lists for addiction treatment should be prioritized based on making connections with people when they are motivated for change (e.g. if cancer patient can get fast-tracked once the cancer is identified, mental health patients should be fast-tracked once the patient identifies his/her own need for treatment);
- Target resources for community-based supports outside of ER and family doctors for mental health patients, including adults with brain injuries (housing, respite, mentoring); and
- Target resources for assessment and treatment of developmental illness/condition (e.g. autism).

5.3.13 Enhancing staff supervision and performance review

This category of improvement is made up of solution ideas designed to keep better tabs on the quality of care provided in the system. Ideas within this category were believed to have potential impacts on drivers of negative experiences including low quality face time with providers, deficiencies of support for health care workers and accountability issues. Developing solutions to enable better staff performance were seen to be paramount to bringing about a more patient-centered health care system.

Solution ideas proposed here included themes such as:

- Anonymous reporting avenues for employees who observe poor staff behaviour from other staff;
- Bring back head nurses for improved ward supervision;

- Unannounced inspections of LTC homes;
- Regular training sessions with staff that focus on bringing the patient stories in front of the HCWs - multi-professional training for patient-facing HCW's;
- Find ways to get unions on side with respect to discipline - promotion of "caring" first; and
- 360 degree peer evaluations on a regular schedule – every six months.

5.3.14 Create processes for ensuring accountability to patients

Similar to the category above, ideas within this solution bucket were aimed at developing a more patient-centered system by instituting processes to make health care providers more accountable to patients. Solutions within this category were seen to address the problematic issue of low quality face time with providers across the continuum of care, as well as patient perceptions that the health care system did not always effectively deliver value for money.

Solution ideas proposed here included themes such as:

- Patient comment cards for discharged patients;
- Bring back head nurses or a patient "point person" for hospital wards;
- Have contact person in-hospital to deal with quality assurance/complaints;
- Have a health ombudsman - create a safe, culturally sensitive place for patients or their advocates to report racism, mistreatment;
- Have "secret shopper" patients to keep HCWs on their toes;
- Unannounced inspections of LTC homes;
- Government appointed person or other mechanism for family advocate to turn to with feedback/complaints;
- Continuity of care - keep staff consistent rather than rotating every day; and
- LEAN review of the health care system.

5.3.15 Improving health care leadership system-wide

Patients and providers identified leadership improvement at the very top of the system, and within each silo, as a key goal for the health care system. There was a drive toward solution ideas that enabled clearer, more informed health care planning and decision making at the system and organizational level. At the system-level, leadership change was seen as a possible driver of improvement in the realm of

communication channels between system and patient, coordination of care throughout the continuum, sub-optimal use of health care workers' scope of practice, rural-urban inequities and lack of staff performance/behavioural accountability.

Solution ideas proposed here included themes such as:

- Enable stronger/more supportive management - promotion based on talent, not seniority;
- Clarify decision-making roles within the system;
- Involve health care workers in reform;
- "Do we need so many executives?" (includes ideas such as high salaries of executive/health board members, elimination of executive positions, "less administration");
- Consider a return to volunteer boards with minimal remuneration;
- Fewer health regions; and
- Eliminate health district boards.

5.3.16 Implementing effective strategies to grow and retain the workforce

Patients and providers all emphasized the goal of continuing to recruit and build a strong health care work force. An inadequate supply of health care workers was seen to fundamentally contribute to nearly all key causes of negative patient experiences. While recruitment was believed to be essential, finding retention solutions for the current and upcoming workforce in Saskatchewan through improvements in rewards, quality of life, and satisfaction with scope of practice were seen also to be paramount.

Solution ideas proposed here included themes such as:

- Create more full-time positions for health care workers, particularly in home care;
- Develop First Nations health care recruitment strategy;
- Create orientation programs that help new/foreign doctors develop stronger ties to the community - not just a central orientation program in urban settings;
- Exit interviews for health care workers when they leave the Province;
- Surveying on 'attractiveness' of Saskatchewan for health care workers and the potential motivators for relocating;
- More support for physician research/ special projects in Saskatchewan;

- More staff family focus in recruitment;
- More retention incentives for home grown health care staff - university grants, bursaries with contract, debt forgiveness; and
- Standardize health care worker certifications across Canada for easier mobility.

Most frequently mentioned training and recruitment needs (includes "more doctors and nurses"):

- Need more geriatric supports – i.e. nutritionists, therapists;
- Recruit more nurses - especially psychiatric, critical care, emergency, geriatric;
- Recruit more family doctors;
- Recruit more specialists - i.e. neurologists, psychiatrists, pediatric specialists;
- Incent development of more nurse Practitioners; and
- Recruit more therapists - i.e. OT, speech, podiatry.

5.3.17 Boosting staff morale

Both patients and providers focused on strategies for boosting staff morale, with the main goal of enabling more positive interactions with both each other and with patients. Continually maintaining a high quality workforce was believed to rest on healthy morale. Better role-modeling at the management and senior levels of care were seen to be fundamental. Providers also focused strongly on implementing initiatives to continue to educate and strengthen the workforce. Solving staff morale problems was believed to be closely linked to tackling major problems with patient experiences, including low quality face time with providers.

Solution ideas proposed here included themes such as:

- Bring back head nurses for improved ward management - people need to feel managed;
- Bottom up reviews of the health care system in hospitals, long-term care;
- Shorten nursing shifts;
- Serious and ongoing mentorship programs;
- Professional development credits for health care workers; and
- Financial and non-financial service rewards.

5.3.18 Improving cultural sensitivity/competency

Patients and providers alike identified the importance of improving cultural competence and sensitivity of health care workers in the Province, particularly in relation to First Nation and Métis residents. Improvements in cultural competence and sensitivity were seen to be key to reducing the impact of some of the key drivers of negative experiences for First Nations and Métis residents, such as low quality face time with providers, poor communication channels between the system and the patient, poor coordination of care throughout the continuum and inadequate health protection and promotion efforts within the Province.

Solution ideas proposed here included themes such as:

- More incentives and “encouragement programs” for First Nations and Métis residents to enter health care professions and management;
- Regular, mandatory cross-cultural training of health care workers or necessary e-learning credit;
- Have readily available information for health care workers about the "sick roles" of other cultures – information can be online and interactive; and
- Accessible translation services in all hospitals.

5.3.19 Improving health protection and promotion activity

“An ounce of prevention is a pound of cure” – Ideas for improving patient experiences were often linked to initiatives to keep people healthy and empowered to maintain good health. Solutions within this category were connected with improving patient experiences across the board, in addition to being recognized as a longer-term strategy.

Most needed public health interventions cited:

- Chronic disease prevention and management;
- Mental health stigma reduction and treatment options available;
- Obesity reduction programs;
- Junk food taxation;
- Health food subsidies, particularly in the north;
- Preparation for motherhood;
- How to take better ownership of your own health - improving face time with physicians;
- Dental and other early childhood intervention programs;

- Accident prevention and social integration of seniors; and
- Education/promotion regarding the system itself - e.g. annual statement with actual cost of individual to system for given year, guidelines on when to use ER, instructions on how to report a complaint.

5.4 The Six Categories of Improvement

The solution ideas that formed the original set of 19 categories of improvement were generated in Phase 1 and Phase 2 by health care providers and patients in focus group discussions and workbooks. These solutions responded to the key "causes" of negative patient experiences.

Leading up to Stakeholder sessions in Phase 3, the original set of 19 categories of improvement was distilled into a smaller set of six new categories of improvement. Stakeholders were then invited to generate their ideas for making meaningful headway in each of the six revised categories of improvement in stakeholder sessions and workbooks.

Below we list each of the six revised categories of improvement. For each, we show which of the original set of nineteen categories have been banded together to form the new family.

1. ***Improving the quality of patient interaction*:** This category includes solution areas focused on strengthening patient relationships and communications.
   - Strengthening patient relationship (1)
   - Improving Communication between the System and the Patient (2)
2. ***Improving system integration***: This category includes solutions aimed at improving coordination of care and health information management.
   - Improving Health Information Management (3)
   - Improving Coordination of Care (4)
3. **Improving access to quality, safer health care**: This category includes issues of improving flow through emergency care, improving throughput of surgeries & diagnostics and reducing the backlog, accelerating and expanding access to mental health care and support, child and maternal care and support, and access for residents in remote and rural locations.
   - Enabling all health care providers to work to their full scope of practice (5)
   - Improving access to hospital care in emergencies and urgent cases (6)
   - Improving Wait times for Surgeries and Diagnostic Tests (7)

- Improving Home Care Effectiveness (8)
- Improving Geriatric and Long-term Care Support (9)
- Improved access for people living in rural and remote parts of the Province (10)
- Improving Child and Maternal Health Care Support (11)
- Improving Mental Health Care Support (12)

4. ***Improving system accountability:*** Improving performance management
    - Improving Performance Management (13)
5. ***Building a stronger health care work force****:* Improving retention and recruitment, staff morale and sensitivity-training
    - Improving health care leadership system-wide (14)
    - Implementing effective strategies to build and develop the workforce (15)
    - Boosting staff morale (16)
    - Improving cultural sensitivity/competency of health care workers (17)
6. **Improving health protection and promotion activity in the Province***:* Implementing system-level, community-level and individual-level strategies to promote wellness and prevent illness
    - Improving communication on the role that patients must play in improving and maintaining their health (18)
    - Increase quality of, and access to, health promotion activities and interventions (19)

Below we provide a description of each of the categories of improvement, accompanied by quotes from Phases 1, 2 and 3 of the review that support solutions to advancing the category. By the end of the stakeholder session, there were approximately 450 solution ideas heard in total. *The full listing of solution ideas is available in the table found at the end of this section, organized by category of improvement with details about the phases at which the response was heard.*

Using online workbooks, Saskatchewan stakeholders were provided the opportunity to share their ideas for making meaningful headway in each of the six categories of improvement. In each category below, solution ideas that stem from the patient voice, provider voice and stakeholder voice are presented to illustrate both the breadth and mutuality of ideas heard in Phases 1-3 of the review. For each category of improvement, examples of stakeholder ideas from workbook submissions are provided to show current thought leadership on how to accelerate needed improvements. For each idea, barriers

perceived to stand in the way of implementation are presented in the voice of the stakeholder who forwarded the idea.

5.4.1 Category One: Improving the quality of patient interaction

Solutions suggested within this category of improvement focused primarily on: Strengthening patient relationships with primary health care; and improving communication between the system and the patient. Patients, providers and stakeholders all explored the need to find ways to facilitate better communication and information exchange between patients and their primary caregivers and to promote more effective face-time with physicians and other health care providers in the primary care sector.

Some central ideas in this category included:

1. **Providing more support at the primary care level to help patients navigate the health care system during an illness episode. This was especially emphasized for patients who are vulnerable because they are elderly, very sick, do not speak English well, have physical or mental limitations or are generally uncomfortable speaking with health care professionals.**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders pointed out the role that nurses could play in strengthening patients' connectedness to the health care system and providing advocacy.

Idea: *Nurses should have more freedom or feel more freedom to communicate with patients on the plan of action as physicians either do not take the time or do it so quickly that patients are often left with questions after or misunderstand what physicians said to them. This would include test results, providing that the physician has had an opportunity to approach patient with the results first.*
Barrier: *Tradition. Nurses have only given out information that physicians have instructed them to. Also, time. There is not a lot of time left to talk to the patient and really hear the specific concerns unique to that person.*

Idea: *Registered Nurses (RNs) are to be advocates for their patients. This role needs to be encouraged, respected and supported.*
Barrier: *Management has not respected or supported the role of the Registered Nurse. RNs do not have time to take a strong stand in advocacy. This is discouraged by management and physicians.*

Other ideas from patients, providers and stakeholders:

Patient Voices: *"Could there be a type of "Case Manager" for Cancer patients. First for support but mostly to coordinate visits so more than one specialist can be seen on the same day. This is a hardship for most elderly with travel from any distance from treatment centers."*

"One person should be designated to oversee each persons care. I understand that this would be a great expense, however I feel it is necessary in order to ensure a moderate quality of care. So many things were

forgotten or overlooked in my case that it makes me fearful to have to deal with the health care system in the future. Need to ensure patients are followed up in a timely and accurate fashion."

"A lot of the time, the patient may not really understand what the doctor is doing, and an advocate could ask questions like "what is this for" or "why are you doing this", just to calm the patient. Sometimes things can move so fast that the patient doesn't know what is going on. And sometimes the emergency people looking after the patient can forget that they are a person and they could be scared. Sometimes just a kind gesture is needed."

Provider Voices: *"The 'squeaky wheel gets the grease'…if you aren't a high advocator for yourself and your needs, or you can't do that or don't have a family member to advocate for you, you can wait a very long time before you get to the top of that list. Some of this is about having that nurse, someone doing that pre-screening, triaging, helping the patient understand how to communicate, and where they stand in terms of priority."*

"There needs to be some middle person that can spend time with patients and educate them about their condition and what treatment will be happening. We need to give people education so that they can assume ownership of their condition. Many times people want to help themselves but do not know how. There also needs to be some standards and guidelines provided to receptionists as to how to treat patients and how to more effectively communicate. As a health care professional who worked in small communities for many years I saw many people return from the city following treatment (especially orthopedic) with very little guidelines as far as return to activity and exercises. Some of these people did not know where to turn and subsequently ended up with some life long disabilities that could have been prevented with better education and follow up. There needs to be more patient advocates and educators."

Stakeholder Voices: *"The family physician is supposed to follow the patient through the system; however this doesn't happen now because of turnover of doctors, especially in rural SK. The solution is a patient advocate who would be able to track a patient through their cycle of care and assist them. Currently we only have a patient safety department that deals with concerns of patients after the fact. This is a late response and does nothing to further patient care up front."*

"For aboriginal people there is high anxiety if they don't understand the language. The handholding will navigate the person through the health care system to ensure there is no anxiety within the health care system."

2. Redefining the mode of physician remuneration to allow for longer appointment times.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders explored the idea of considering alternative remuneration plans to better meet patients' needs, particularly in terms of length of appointment times.

Idea: *Since the majority of health care expenditures are consumed by fees, salaries and benefits, it is also essential that the method of remuneration meet the needs of society. Therefore, alternatives to the*

highly inefficient fee for service system of payment need to be identified and implemented, where practicable, if the system is to be patient and not practitioner focused.
Barrier: *Lack of political courage by successive governments to address the issue, poor management and a lack of desire on the part of those benefiting from the current system to "kill the golden goose who keeps on giving, regardless of the quality of care delivered.*

Idea*: Create "margin" in the daily activities of caregivers, particularly MDs, to permit/facilitate more "face time" - by offloading tasks that don't require MDs; by providing alternate remuneration mechanisms that value "face time" over "throughput"; by educating and inviting patients to request additional time (i.e.; when booking) if the need for extended conversation can be anticipated; etc (207015)*
Barrier*: Not enough providers. Inappropriate allocation of responsibilities within care team. Lack of team/turf protection. Lack of role models for different approaches to practice. Greed. Lack of understanding of "system" by patients. Lack of orientation of support staff to need for appropriate booking.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Put all doctors on a contract basis, not fee for service. This would encourage them to take time with patients."*

Provider Voice: *"I think it's less competitive if you are on a wage and you don't worry so much about the number of people you see. I think it can get a little competitive between physicians and I think the primary care centre approach where there's a wage could take that aspect away."*

Stakeholder Voice: *"Redefine the mode of physician remuneration so that patients get quality time not directly linked to a billing code, the premium of which is really time driven."*

3. **Encourage initiatives to implement a team approach to primary care so that patients can access a range of health care services from their family health practice including chronic disease management and disease prevention services. This would include using nurse practitioners more fully.**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders discussed the value of incorporating more team-based approaches to patient case management, particularly in primary care settings.

Idea: *Team based practices. Essentially this is each practitioner "triaging" for the others. Members of the team figure out who the best practitioner is for that patient to see. This cuts down workload for some and better utilizes others.*
Barrier: *Traditional practice views ... unwillingness to change. Lack of other health care providers (e.g. clinic based nurses and pharmacists). Funding for practitioners in this new model (who pays: SK health,*

the clinic, fee-for-service?). Patients uncomfortable with the possibility of not seeing a physician at their visit.

Idea: *Resolve long standing physician issues that prevent meaningful participation of primary care physicians in primary health care teams.*
Barrier*: SMA and Ministry of Health need to bargain more effectively. Investment in physician remuneration that compares with remuneration that can be earned as fee for service*

Other ideas from patients, providers and stakeholders:

Patient Voices: *"We need to be creating real primary care. We need a different model like one in which nurse practitioners work with the patient to set up an individual plan of care. Nurse Practitioners could then refer to physicians or other health care providers - labs, dieticians, physio. There needs to be a better "big picture" in patient care."*

Provider Voice: *"A nurse practitioner in a doctor's office could do a lot – they could do all the blood pressures, all the shots, minor sore throats, ear aches. They could act as an assistant who questions the patient beforehand. The patient will feel heard if they get to spend that time with the nurse practitioner and then the doctor is working at the top end of their practice, as opposed to the bottom end."*

Stakeholder Voices: *"The solution is to not turn patients away, but instead to schedule appropriate time with possibly a nurse practitioner to discuss problems. The practitioner would then present the case to the doctor. We need to have the patient see the "right" care provider at the "right" time – we need to set up primary care teams made up of a variety of health care professionals."*

4. Easier appointment booking and sharing of health information, such as testing needs and results.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders identified the need to find greater efficiencies in how health information is gathered and shared by way of easier, better-coordinated appointment booking and appointment follow-up.

Idea*: Eliminate booking "silos" for tests and appointments to make it easier to accommodate patients to have physician visits and diagnostic testing done on a single visit rather than multiple visits.*
Barrier*: Separate departments, and booking systems/computers.*

Idea: *Patients are required to come to the hospital to have certain tests done (i.e. MRI, pain clinic tests, etc.) that are always set in a hospital. We need to have these types of tests be performed off-site and reduce the backlog of patients having to come to the hospital for these types of test. This would be the same setup for x-rays, etc.*
Barrier: *Cost of building the facility.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Make call-backs mandatory after tests so you know where you stand."*

Provider Voice: *"Reminder calls for diagnostic testing. We get these in our lives all the time, it is a very simple thing when you really look at it."*

Stakeholder Voice: *"Patient access and bookings – looking into alternative booking schedules to improve access to the physicians, such as the principles of the advanced access system. It's a system that has been developed were the most recent appointment is available (less bookings into the future and more immediate bookings)."*

5. Improved patient communication at time of admitting to hospital, especially for emergency patients.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders considered methods of encouraging and incenting better communication from overwrought staff in high pressure situations for patients**.**

Idea: *Office staff for physicians and appointments in hospital tend to lose their compassion when they hear the same questions over and over. Perhaps special recognition or a 5 star rating (like those in hotels!) could be nominated by patients and awarded to offices to motivate them to remember that each patient call is important to that individual and often patient communication and satisfaction overall increases when patients feel they have been treated with respect and kindness. Physicians could take a cue from that as well.*
Barrier: *Someone would have to organize it and make sure it was done on a regular basis.*

Other ideas from patients, providers and stakeholders:

Patient Voices: *"They should put something on the wall that says how long the wait time is going to be. In the hospital, you don't always see the emergencies coming in so you don't see what is going on behind the scenes. You don't always realize all this other stuff is going on."*

Provider Voice: *"Need a list, saying where you are in line and how long you will be. This would give you reassurance that you won't actually be waiting forever."*

Stakeholder Voices: *"We need to update patients so that they can understand the cause of delay."*

6. Improved patient communication at time of hospital discharge.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders suggested ways to improve communication and enhance patient connectedness to the health care system at the time of discharge.

Idea: *Discharges from hospital should go through a checklist so proper communication is done to ensure optimal patient outcome once discharged. Items on the checklist should include family notification if*

appropriate, level of support available to patient and what support may be required. Prescription requirements/availability, cost to patient (informed patient and ability to administer on own), follow-up treatments, i.e. drugs require written orders by physician if another facility/organization required to do. Can the patient access these follow-up services? Clear instructions for follow-up appointments or contact information for patient questions. A short summary of what treatment client received, any infections picked up, unusual lab results, allergies, drug interactions, list of physicians who treated client, and any other necessary info.
Barrier: *This kind of discharging does happen on some units but is not consistent across the board. Time is a factor. Perhaps a spread sheet with tick boxes that staff could tick of at the end of the day would help with the transfers between departments and the overall communication to the next facility. Need something standardized that can be individualized. The standard discharge form is generally non functional for all of the communications now required as patients are often sent home quickly after complicated surgeries and often don't even remember what the discharge nurse told them as they are still recovering from drugs or dealing with pain.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Hire discharge coordinators, enhance communication between jurisdictions so that everyone knows what is happening with the patients care. This is especially important to Aboriginal and other populations in remote areas."*

Provider Voice: *"There needs to be an informed discharge strategy at all levels of system – the patient needs to know what the follow up plan is, and what they need to do in terms of follow-up."*

Stakeholder Voice: *"Each patient requires an assigned person to assist them in discharge planning, or help to facilitate their flow through the health system such as to home care."*

5.4.2 Category Two: Improving System Integration

Solutions suggested within this category included ideas to improve coordination of care and health information management to avoid patients getting lost in the system or receiving duplicated, ill-timed or poorly planned care. This included suggestions to introduce mechanisms to support efficiencies in patient and information management into the system.

Some central ideas within this category included:

1. **Electronic Health Records (one patient, one record) – including a plan, full continuum of care access (including patient) and incentives for use.**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders suggested the need for more integrated, system-wide EHR planning.

Idea: *Adopt a provincial and local Information Management Plan. It will be difficult to move ahead on the eHR work without a solid plan on how to manage information. IM is not just about computers and*

infrastructure; we are doing a poor job in managing the information we have and assessing the gaps of what we don't have.
***Barrier:** Many people think that IM is about computers and technology; that is only one component of it. There is a large misunderstanding (or lack of understanding) on what IM is and how desperately we need to have an IM plan in this Province and in our RHA. If we don't have a coordinated approach to managing the creation, use, and disposal of information, we will always have knowledge and data gaps. We have many gaps in our information needs and data gathering processes however we can't fix them until we know what we don't know. And to fix these gaps will take money.*

***Idea**: Coordination. Transfer of and access to pieces of a person's health care history are not readily accessible to health care providers. A Province-wide electronic chart would help but only if all providers have appropriate means to access it and are comfortable in doing so. (For example, very few physicians utilize the PIP system to view current prescriptions or e-prescribe.)*
***Barrier:** Paper-based health records. Lack of administrative supports (e.g. dictation clerks). Lack of comfort or familiarity with IT solutions.*

Other ideas from patients, providers and stakeholders:

***Patient Voices:** "There is lots of uncoordinated, inconsistent care. We are seeing multiple, different providers and absence of an electronic health record is a problem. We now bring a care plan, created by our son's GP and specialist every time we go to the ER so to ensure more speedy, consistent, waste-free care. A cradle to grave electronic health record for all Saskatchewan residents that can be accessed by any health provider providing care to that patient."*

"We need an electronic health record with patient access."

***Provider Voices:** "Electronic medical records...these need to come together, and we need to be able to insure that these offices can interface within a networking system so that when a test/referral is ordered then there is no need for duplicates...it is partnerships and interdisciplinary approaches. The health regions need to communicate, and we need to focus on certain things to be able to make progress, we need to focus and recognize the fact that this is not 20 or 30 years ago. We need to be able to communicate electronically..."*

"Electronic records would make things simpler. We don't have a 'one' patient chart for you as a person."

***Stakeholder Voices:** "In the USA patients can access their electronic health records on line and can track exactly what is happening with them, as opposed to here where you have to make an appointment to come in and talk to a doctor."*

"Duplication and triplication of tests are occurring because information is not known to other doctors, and in some cases there is even access to electronic records but some doctors won't look at it. A fundamental change in doctors' habits and practices is needed. Doctors are going to make the economic

choice, so all doctors may not want to do this, and incentive for doctors to use this type of system may be needed."

"Connected with e-records, we need to develop a logistics system – an IT system – to track patients through the system like UPS, developed by the private sector."

2. Initiatives to improve ward management, such as bringing back Head Nurses, to keep better track of patients in the hospital.

***STAKEHOLDER WORKBOOK SUBMISSION**:* Improved ward management and clinical supervision were seen to be important steps in achieving a better coordinated, patient-centred system.

***Idea:** Ensure every health professional has access to a clinical supervisor. A clinical supervisor is someone who is a professional, and has specialized training in providing clinical supervision to staff-this is not a manager.*
***Barrier:** Health regions ignoring this need or trying to use OOS managers in this role.*

Other ideas from patients, providers and stakeholders:

***Patient Voices:** "We need to have the head nurses back on the wards like they used to…have the head nurses talking to the patients. As it is now they don't have a clue what is actually going on in their own wards."*

"We need better communication between doctors and patients – also between doctors and nurses. The nurses could make the doctor aware of something that they didn't know, because sometimes doctors come in the room saying 'what can I do for you' like there has been no talk with the nurse who has been seeing the patient in between."

***Provider Voices:** "There is a world of difference in the perceived care from when I started working until now. Part of this is the lack of head nurses, there used to be managers that were 'battle axes' and we need to bring these people back."*

"You can't run the kitchen from the basement. We need the head nurses back on the ward."

***Stakeholder Voice:** "All wards need ambassadors. Patients need to know who the manager is on the ward and that there is one if they have concerns or questions - once discharged they can direct calls there."*

3. Single queues or 'central booking' for more efficient specialist referrals.

STAKEHOLDER WORKBOOK SUBMISSION: Improved use of technology to achieve more streamlined patient "transfers" was seen to be fundamental for reducing delays and patients' sense of feeling lost in the system.

Idea: *A central database needs to be created that houses the referrals. Instead a paper trail of letter writing is done back and forth between physicians. Then a letter is written to the patient and they must ensure that they meet this appointment several months down the road. In turn, family physicians only refer to certain specialists that they know. This type of preferential treatment must stop. All referrals should be housed in a central database and distributed accordingly.*
Barrier: *Shifting from a paper referral system to an electronic one.*

Other ideas from patients, providers and stakeholders:

Provider Voice: *"We need a central booking or "clearing house" of surgeons/specialists listed with wait time information for more efficient physician referrals."*

Stakeholder Voice: *"We can post online wait times and areas of specialization for all specialists. We should have a provincial information network - started with surgical care network – so we can see specialists area of expertise, wait lists, what they have available. A system in place that can navigate and see where the patient will fit in and can book in. A portal to pick and choose for availability."*

4. Improved coordination of patient admission and discharge needs.

STAKEHOLDER WORKBOOK SUBMISSION: One stakeholder pointed to an effective pilot study that improved assessment of patients' admission and discharge needs.

Idea: *We have recently started a pilot study in the region which is called the Acute Care Access Plan. The purpose of this plan is to determine before admission if the client is indeed in need of admission to acute care or if their needs could be better met somewhere else. This is determined by a multi-disciplinary team who looks at the client's needs holistically. The team is made up of a specialist who is most appropriate to the client's treatment needs, nursing supervisor, social worker, home care discharge planner. If it is determined that a client does need admission, the second part to the plan is an acute care access flow sheet which captures the clients treatment plan, referrals needed, predicts the clients length of stay and a planned discharge. The time it takes for the treatment and referrals to be completed is documented. The best part is that the client is involved through the whole process. We are working out the "kinks", but the most important thing we have learned so far, is that the patients who have been involved are extremely impressed with the work the team does in making sure the client is informed of their treatment plan, their expected length of stay, and their discharge plan. They have expressed that they feel "heard" and efficiently looked after making their hospital stay a more positive experience.*
Barrier: *Over-burdened staff trying to take on yet more tasks. However, they are all dedicated and really hope the plan works because they can see it benefits the patient immensely.*

Other ideas from patients, providers and stakeholders:

Provider Voice: *"We need to have a system that accommodates for, and thinks about multiple needs. We need to make sure that services are in place for 'him' - start discharge planning on the day of, or*

before, the patient gets into the hospital. Or make sure the family knows what the journey is going to be for the patient."

Stakeholder Voice: *"System needs to put more focus on specialized admission assessment and discharge planning. Standardized, assessment and discharge protocols and delivery of those plans need to be better coordinated."*

5.4.3 Category Three: Improving Access to Safer Quality Health Care

Solutions within this category of improvement were centered on expanding and accelerating access to care in Saskatchewan for a variety of target audiences, including emergency patients, those waiting for surgeries or procedures, elderly patients aging at home or in long-term care, patients in rural and remote areas, young families, and those seeking treatment or advice for mental health or addictions.

Some central ideas within this category included:

1. **Ensure all professionals in the system are able to work to their full scope of practice to make more effective use of health care resources and to foster a more "big picture" approach to patient care.**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders pointed to the greater role that nurses should be playing in regular primary care case management as well as chronic disease management. Stakeholders also emphasized the need to find effective ways to plug patients into the right care at the right time from the right provider, without having all the burden of care placed on a family doctor.

Idea: *More nurses could be utilized in the area of chronic disease management. Tertiary prevention strategies could be expanded for patients with diabetes, cardiovascular disease, COPD, arthritis etc. and may result in better outcomes.*
Barrier: *Funding is the barrier. For example, the Paul Schwann Cardiac Rehabilitation Program is an excellent tertiary prevention program that deals with clients who have diabetes, cardiovascular disease etc. They work on a very limited budget. If they had more funds they could hire nurses to do teaching with the clients that utilize the program's fitness facilities. Currently the nurse's role is quite limited.*

Idea: *Before we assume there is a shortage of certain health care practitioners that requires immediate remedial action, let's make sure that all regulated health care providers are being utilized in an evidence-based manner to the extent that their respective scopes of practice will permit. For example, can lower cost care by Chiropractors substitute for Physician care for most musculoskeletal disorders? The research overwhelmingly illustrates that it not only can but should be utilized in this fashion because of the improved health outcomes and financial saving that would result. In this regard, please refer to the compendium of research studies that will be provided to you by mail.*
Barrier: *Physician as unquestioned gatekeeper for all health care, lack of respect for and understanding of research, lack of understanding and respect for the education and training of other health care*

practitioners, blind adherence to doing the same things, by the same practitioners in the same way, lack of leadership by successive governments to mandate necessary systemic changes, poor management.

Other ideas from patients, providers and stakeholders:

***Patient Voices**: "Doctors have too much power and not all of the skills needed to provide holistic care. Health care provision should be done by a collaborative team based on what a person needs. Sometimes the best health care provider to lead the team is not the doctor. Leaving the plan of care up to the doctor means that only the biomedical things are focused on, not the other important things that also keep us healthy and out of the hospital."*

***Provider Voice:** "A more multidisciplinary approach would be better – yes, the doctor has 10 min to spend with you, but why not have the pre-screening with another professional to begin with? Like many of our nursing practitioners, they have certain things that they are adept at and they know where things may need further investigation."*

***Stakeholder Voices:** "Better education to professionals about what exactly the other professionals do or can do. So make sure doctors know exactly what kind of training LPNs are now getting and what RNs can do. With the level of training increasing our knowledge of the new training also needs to be increased. So this will stop the push up of jobs."*

"We need an examination of "Client Needs-Based" and provider competencies in all sectors to ensure utilization of full scope of practice and creation of permanent opportunities on that basis. This applies to nurse practitioners, pharmacists, allied health, and physiotherapists."

2. **Providing new urgent care options for patients who require immediate medical attention, but who do not require critical care from emergency physicians (particularly outside normal doctors' offices hours).**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders pointed to the need to expand availability and access to non-critical emergency services.

***Idea**: I know this is probably prohibitively expensive, but I believe that each base acute care facility in Regina and Saskatoon, and perhaps even at the regional hospitals such as Yorkton, Swift Current, PA, Moose Jaw, should have attached to the emergency department, a clinic to which all non-life threatening, non-emergent cases that present at the emergency department should be sent for treatment. Emergency departments should be for true emergencies only.*
***Barrier**: Money to build the facilities and nurses and other professionals to staff them. In Regina, we might have to expropriate property to have a place to do this, and probably would have to in other places as well.*

***Idea**: Urgent Care Clinics could be established in Urban Centers staffed by nurse practitioners, social workers, phlebotomists (blood samples could be sent out) etc. This would take stress off hospital emergency departments. People could be seen quickly by a health care professional who can do a thorough assessment and cases that require further diagnostic testing could be sent over to hospital.*
***Barrier**: Our system is still based on a medical model of care. Nurse practitioners are not utilized to their potential. Funding is also a barrier.*

Other ideas from patients, providers and stakeholders:

***Patient Voice:** "There needs to be a back up 24 hour on site walk in clinic to alleviate the clogs in actual ER."*

***Provider Voice:** "We need a walk-in clinic to take in the renewal of prescriptions, the not so difficult cases...this would relieve ER so much."*

***Stakeholder Voice:** "We need to triage emergency patients into two streams - serious and urgent. We need to create a flow line for "minor emergency" services so real emergencies can be processed within best practice time promises and minor emergencies don't have to wait behind all of them."*

3. Ensuring proper medical supports and disease management to move people out of ER.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders pointed to the need to better manage geriatric cases in particular to avoid bed-blocking in ER.

***Idea:** Geriatric specialized caregiver on med-surg wards or have geriatric clients placed on specified wards while receiving acute treatment with staff trained in dealing with geriatric clients and clients with dementia. Often these clients' basic needs are overlooked such as need for mobilizing, repositioning, feeding, using the bathroom, hygiene, etc. because the acute care nurse relies on patients to do these things themselves. I have often received discharged clients back with new pressure ulcers, heavily sedated and confused or with post-op catheters still in place because it was easier for the acute staff to "look after" the client.*
***Barrier:** Changing how things are done. Staff attitudes. Having management and physicians on board so these clients are not overlooked.*

***Idea**: Geriatric care, LTC homes need to be enhanced to decrease bed=block and shorten surgical wait times.*

***Barrier**: People stay in acute care settings, hospitals, too long, and block beds for others waiting for OR times. Our SK population is aging and if we want to get a handle on what will happen, let's plan now as opposed to being surprised in 5-10 years when geriatric care is the number one concern for SK people, and especially Boomers and Gen X-ers, as our parents are the Boomers.*

Other ideas from patients, providers and stakeholders:

Provider Voice: *"The people who stay long in the ER are the frail elderly and neurology, gastroenterology and cardiology because they are using it as a diagnostic fast track. This is a functional, versus disease management model. It gets back to needing a geriatric model of care for this Province. We are missing the boat, and we don't have the support structures in the community to take care of these people out of the ER."*

Stakeholder Voice: *"There is a need to free up acute care beds from patients needing alternative levels of care - entrance home care, providing funding for private care home spaces, train families and offer supports to facilitate them providing care."*

4. **Ensure that waiting lists for surgeries and diagnostic tests are assessed to understand where backlogs exist and where capacity needs to be increased in order to meet ongoing and long-term demands.**

STAKEHOLDER WORKBOOK SUBMISSION: One stakeholder mentioned the value of BPR to assess wait times.

Idea*: The principle behind Business Process Reengineering (BPR) is to eliminate waste & redundancy and improve processes thereby increasing service levels to the customer, in this case, the patient. A broad health care BPR effort would result in improved processes and lessened wait times for treatment, diagnosis and surgery. BPR should be researched as it is definitely one possible solution to health care process challenges. As a matter of interest, there are a few organizations in the Province who have undertaken a BPR project with great success. (e.g. Saskatchewan WCB, SGI).*
Barrier*: The scope of this undertaking is the main barrier as it is provincial in nature. A response could be to undertake BPR pilots in one or two health regions and then use successes/challenges to roll out to other health regions.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"There needs to be more transparency. What is the expected waiting time for a hip replacement and how is each health distinct doing towards achieving that."*

Provider Voice: *"We need to focus on flow, as opposed to focusing on access. We are currently looking at flow as a strategic issue. When you look at flow, you are looking at how do you match your demand and capacity in the system, you have to look at how many patients are coming in, and how many are going out, and if you have a mismatch, you have to have a plan to deal with that...there is no point in trying to put these initiatives in place unless you have a strategy."*

Stakeholder Voice: *"The Province should establish a "wait times branch" that monitors wait times for various procedures and targets funding accordingly."*

5. **Where additional need is required, consider increasing capacity for specialized tests and surgeries by creating stand-alone centres of excellence that specialize in those tests and surgeries.**

STAKEHOLDER WORKBOOK SUBMISSION: Some stakeholders focused on greater centralization of services throughout the Province as important to controlling wait times.

Idea: *Surgical wait times could be reduced if the rural operating rooms could be better utilized. People travel from rural to the tertiary centers all the time, it would be very beneficial to the system for there to be pockets of excellence in the rural areas that could handle eyes, general surgery. Supports for the clients must be there as well, such as reduced hotel costs or hostels for post recover.*
Barrier: *Promoting this as an exceptional way to address our situation. Physicians in the tertiary centers do not want to lose their income. The cost of providing a place for post surgery recovery if required. Even if it is short term.*

Idea*: Three MRI's in the region - why not have two and staff them both 16 hours a day, less maintenance, and less hours a day when the MRI's are sitting idle. Redirect funding from the purchase of MRI, renovations and operations to reduce # of MRI's and put resources into operating two more effectively.*
Barrier*: Politics - get away from politics and get more into direct patient care and what's best for the patients*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Why can't we bring more to the rural? Why build new spaces when we have empty wings here in the hospital. Optimize rural hospital space."*

Provider Voice: *"We can use rural centres for different specialty needs and tests – we have a lot of rural space that is not optimized and everything does not need to be in one place."*

Stakeholder Voice: *"Centres of Excellence for surgeries in Regional Hospitals - use rural centres of excellence for surgery to reduce wait times. We also need to better define "centres" for other procedures. Right now we it's like each hospital goes out to catch fish every day. And one day you'll catch a red fish, a blue fish and a yellow fish. So today you'll offer red, blue and yellow services. It would make more sense if there was a specialized centre for the red to go to, and for the blue and so on."*

6. **Where there is enough capacity to meet ongoing surgery and diagnostic testing needs but a backlog exists, create initiatives to eliminate the backlog, such as an immediate Province-wide initiative - a "blitz" - to create a short-term boost in surgeries.**

Provider Voice: *"Waits are too long. We are going to have to blitz to begin to reduce these numbers and get these patients through in a reasonable time...have to use the surgical resources we have at hand more effectively. We have too few specialists, if we don't begin to do more surgeries, we are going to have even fewer specialists and we need to be mindful of that. Our process suits us in the system, it*

doesn't suit the patient...and that is where it has to shift, and we have to give patients input on when it's the best time for them to come for that surgery. It's about looking at it from what serves that patient."

Stakeholder Voice: *"Develop more clinical pathways of multidisciplinary health professionals e.g. Hip and knee pathway. This will reduce backlogs of surgeries and diagnostic tests."*

7. Reduce the need for medically-required travel through increased use of techniques such as telehealth and mobile clinics.

STAKEHOLDER WORKBOOK SUBMISSION: Several stakeholders pointed to the value of telehealth in responding to the needs of Saskatchewan's rural and remote population.

Idea: *In rural/remote communities, information technology such as telehealth needs to be expanded and used more.*
Barrier: *I worked in several First Nations communities where they had funded telehealth such as being able to connect a person on reserve with a specialist in mental health via video conferencing, specialized cameras that could show an EEnt specialist on one end the inner ear of a two year old on reserve. The travel time and money saved was huge. Our government needs to put more investment into alternate ways of accessing services like video conferencing and telehealth. Even in each Region, if video conferencing was used instead of many staff on the road traveling from community to community, time and travel expenses would be reduced considerably. Meetings, training sessions, even interviews should be held by video conference.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Stop centralizing everything to the big cities. This community is a big place, we have a lot of people in the surrounding areas. Stop shutting things down and sending everything to Regina and Saskatoon, utilize the resources here. Send the doctors here to use them."*

Provider Voice: *"In the NHS, there are incentives for physicians to set up mobile travel clinics. Here, the onus is on you to set up mobile, specialized travel clinics. It would make much more sense to the patient to go to them on a routine basis."*

Stakeholder Voices: *"We need to expand telehealth in communities and we'll need standards. There is a perception that it is a second class service, so need to get people to try it, get rid of this perceptual challenge."*

"We need to have a provincial review of health care in rural and northern Saskatchewan and look at how to make better use of itinerant consultant clinics."

8. Implementing a strategy to better care for patients aging at home and in long-term care.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders focused on improving staff competency in geriatric care and ensuring availability of affordable care in the community to assess and care for the aging population.

Idea*: I would like to see the development of a geriatric nurse practitioner program as specialists in geriatric nursing care, especially in the community. These people could deal with a great number of the issues around geriatric care including emergency placements in non-acute care facilities.*
Barrier*: Having qualified faculty to teach this program at SIAST and finding the money to begin the program. Having complete lists of all public and private care services available to geriatric NPs and other health care professionals in the community would also help, especially where there may be vacancies in private care homes.*

Idea: *Have a "Senior's check up day" check blood pressure, eating habits, weight, heart rate etc. Could be through home care and could be held in the foyer of the building, or the rec building. Hand out information. This could even be a practicum for LPN program. If they suspect a problem they can help them make an appointment with their doctor. Preventative and informative.*
Barrier: *If used as a practicum, it would be a win-win situation. Otherwise it would be costs for the homecare to participate. There are those who do night turn down service for home care, maybe they would be willing to come earlier in the day for such a check up.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"We need seniors' condo complexes that have full time nurses on staff. I think this would be a wise investment for the government to subsidize, someplace where someone who does need care and someone who doesn't, could still live together."*

Provider Voice: *"We need a functional geriatric program on the acute care side, and the long term care side. And we need geriatric nurses, as well as other specialties, such as nutritionists, that can do that teaching/counseling to support them and maintain there health and independence."*

Stakeholder Voice: *"The scope of care that is needed in home care is not being met by the scope of care that is being given. Sometimes in home care the training needed for these people is not sufficient. If you can give more home care, then the system and hospitals won't be as busy."*

9. Boosting supports for new mothers and young families in the community.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders saw a need to expand opportunities for face-time with new mothers, particularly immediately post-partum in order to better take care of the needs of mother and baby.

Idea: *Designated follow-up clinic times for new moms to come back and see a nurse for questions after discharge for the first 2 weeks of a newborn's life. Public health nurses don't have time to do all the follow-up and moms are discharged too quickly to allow for all the questions that come up or to allow staff to ensure newborn's needs are being met.*
Barrier: *Need a program set up with this specific goal and someone to staff and organize it.*

Idea: *Improved child and maternal health. I provide both these services. We are SEVERELY under resourced. The right people are available - we just need more time.*
Barrier: *Lack of resources. My role in both of these services has been carved out of previous clinical commitments and is inadequate to meet the need of the patients I see. Although research clearly demonstrates the negative impact on children when mothers are anxious and/or depressed antepartum, postpartum or later, this need has been overlooked in Saskatchewan.*

Other ideas from patients, providers and stakeholders:

Patient Voice: *"Is there a way we can help the young moms, set up a program to let them know how to take care of a baby? There is no program, that's why there are so many young moms who don't know how to breast feed properly because they aren't taught how to do it. Public health kind of helps, but not really. When you are a young mom, you don't really understand and you need that little extra attention, but they don't get it here. They don't get taught the understanding of what to look for when a kid is sick, and how to deal with things."*

Provider Voice: *"What we need is a place where women gather, where they do that traditional female learning and exchange…we need more places where people can learn to be parents, staffed by public health nurses, educated parents, nutritionists, people who can do a whole lot of the basic stuff. Going down to the lowest level where the needs are met, as opposed to the highest medical level."*

Stakeholder Voice: *"Develop a system of lay support workers for vulnerable pregnant women and their families."*

10. Initiatives to improve access to high quality mental health and addiction services in primary and acute care, and an expansion of community-based supports.

STAKEHOLDER WORKBOOK SUBMISSION: Some stakeholders suggested a need to explore long-term care and alternative housing options for people with mental health and addiction issues who require more regular health care support.

Idea*: Affordable, semi independent housing options for people with behavioral, ABI, poor mental health, and/or substance abuse issues, seems to be a need in Regina. They often cannot be housed in the same facilities as the frail, elderly population.*

***Barrier**: Limited resources to fill this need. Too much power by i.e., Salvation Army to not consider certain clientele. Because of the affordable housing shortage in Regina, it seems that Salvation Army are now housing an 'easier' clientele (I don't blame).*

***Idea**: There are many bed blockers in mental health such as complex cases and long-term care clients. We need specialized units within long-term care developed and provincial resources to meet the needs of long-term care clients.*
***Barrier**: Dollars for SHNB redevelopment and for difficult to manage units in Long term Care*

Other Ideas from patients, providers and stakeholders:

***Patient Voices:** "We need on call psychiatrists - or a least a mental health nurse that could come to ER and assess patients that present. We need to educate staff that psych patient's are ill-that they need care, not just put off. Staff need to be encouraged to listen to family members - as they are the ones that live with the disease and most likely know what they are talking about."*

"Talk therapy is undervalued in this Province. We need more highly qualified staff to do it."

***Provider Voices:** "We need to put a rotation of general psychiatry back into nursing. There needs to be a specific training for psychiatry, you want to promote awareness so that staff are better equipped to face these cases."*

"Increase public awareness of mental health outside of the mental health community. General thought is to always look at mental health issues in a negative light. If there is some way of educating people that these people are victims and need everyone's help, and need the support of the community, then it would bring it all into a brighter light"

***Stakeholder Voices:** "We need to help shift the culture, design and implement family support systems and "expert peers". Mental Health patients are the most susceptible to falling through the cracks and getting lost."*

"We need assessment tools for addiction and mental health in acute care. Provide pathways for health care providers in acute care to assess and refer patients with problem alcohol or drug use."

5.4.4 Category Four: Improving System Accountability

Solution ideas that fell within this category of improvement largely dealt with methods of internal and external initiatives of improving performance management and ensuring both health care worker and system accountability to patients.

Some central ideas within this category include:

1. **Improving Performance management and establish initiatives to eliminate unprofessional conduct such as rude and dismissive behaviour from health care staff.**

STAKEHOLDER WORKBOOK SUBMISSION: Better arm's length staff supervision and disciplinary processes were seen as key to controlling rude and dismissive staff behaviour.

Idea*: Have internal accountability through quality of care workers, but enable them to have more independence and powers of investigation. They are currently in a conflict situation by investigating their own employer, essentially.*
Barrier*: This appears to be an internal issue, where the barrier to independence currently exists. The Boards, in consultation with government, would have the ability, I think, to consider options to grant broader powers to QCCs.*

Other Ideas from patients, providers and stakeholders:

Patient Voices: *"I think quarterly, doctors should be given their patients' complaints and concerns. If a hotel is concerned about your well being and experience, why isn't your doctor?"*

Provider Voices: *"A reinforcement of what is acceptable is what is missing in our workplace. We need to have some managers that are really strong who walk the floor, and are present in the workplace, and are paying attention."*

"There are no staff evaluations anymore, there haven't been for about 15 years now. Who is going to sit and tell you that you did something wrong? Someone needs to be in charge of the shift, and take the bull by the horns."

Stakeholder Voices: *"We must be able to file a complaint against a colleague and be anonymous or whistle blower protection to ensure that the complaint is heard."*

2. **Creating processes for accountability to patient needs.**

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholder emphasized ideas to use patient feedback and consultation as a measure to ensure, incent and encourage better communication with patients at the front line.

Idea*: Implement more "round table discussions" with family members and staff to try to boost moral and get people working together to make the atmosphere more pleasant for residents.*
Barrier*: Cooperation and willingness to work with families. Staff treat families like "opponents" rather than "team members".*
Idea: *We need the ability to record satisfaction level with the provider at the time of contact. It could be an interactive tool, i.e., "please rate the service you just received" or give one idea to meet your needs better. This would be collated and tabulated.*

Barrier: *For the consumer it is the fear of retribution (consciously and unconsciously).*

Other Ideas from patients, providers and stakeholders:

Patient Voice: *"People in charge have to be identified. I think that would be a really significant change that would make me feel a lot better. That kind of accountability - identification is key when dealing with professionals."*

Provider Voice: *"Grocery stores and department stores have secret shoppers, why don't we have secret patients?"*

Stakeholder Voice: *"Establish patient satisfaction measures."*

3. **Creating processes and implementing initiatives to ensure "value for money" in health care spending (e.g. LEAN).**

STAKEHOLDER WORKBOOK SUBMISSION: LEAN methodology was cited frequently by stakeholders as a way to reduce any waste in the system that does not contribute to the patient experience.

Idea*: Incorporate LEAN methodology into orientation as a means to solve problems. This is a participatory approach and sends the message we are all responsible to make improvements or fix things when it does not work.*
Barrier*: Getting staff education and providing an environment so staff feel empowered to use the tools within LEAN*

Other Ideas from patients, providers and stakeholders:

Patient Voice: *"Money shouldn't just be given; they should also say what it is being given for. There needs to be transparency on what the goals are and how well you are meeting them. There needs to be a performance management plan on "what I will do this year". I want to see reporting on where progress is made, and what is left to accomplish."*

Provider Voice: *"I am a big supporter of LEAN. You have to eliminate efficiencies and waste – everything needs to bring value for the patient."*

Stakeholder Voice: *"We need to apply the LEAN methodology in all areas."*

5.4.5 Category Five: Building a Stronger Health Care Workforce

Solutions that fell within this category of improvement included solutions designed to strengthen the workforce in Saskatchewan, both in terms of quantity, quality and worker satisfaction.

Some central ideas within this category include:

1. Improving health care leadership.

STAKEHOLDER WORKBOOK SUBMISSION: Several stakeholders discussed needing to find ways to improve the visibility of leadership in the system.

Idea: *Leadership is invisible to front line workers. There is disconnection between leaders and staff. Require leaders to walk the hallways and get to know people by name. The lack of connection has led to lack of morale and disillusionment. Staff needs to see honesty, integrity, vision and involvement from their leaders.*

Barrier*: Union/management relations is one barrier. There is distrust from both sides and a lack of willingness to bridge the gap.*

Other Ideas from patients, providers and stakeholders:

Patient Voice: *"Health care policies should be made at a higher level, not departmental level. I don't understand why the same RHA had different policies for the same departments at different hospitals. Saskatchewan Health care is in desperate need of good leadership to oversee a change in how things are run now, towards a more integrated system."*

Provider Voice: *"Managers failure to manage is a big problem ....Morale will be higher if we train and encourage better leadership. They've backed me into a corner for so long - the next time I will come out fighting. They need to look at what they can do for their staff."*

Stakeholder Voice: *"We hear from staff that there are too many managers in the system, yet inside people think there is a shortage of mid-managers. Only a small portion of budget is spent on administration and running the business. If we are to be service oriented, this needs to be much higher, just as it would be in another business/organization. Leadership can't be skimped on."*

2. Boosting staff morale.

STAKEHOLDER WORKBOOK SUBMISSION: Improving exposure to positive mentorship and undertaking to deal with "sick days" and other signifiers of poor morale were seen to be important for strengthening the workforce.

Idea*: Dealing with sick days and inefficiencies are critical for staff morale. This must be done proactively. The worse that morale is, the more sick time a person will take.*
Barrier*: Whoever heads this process of dealing with sick days must have thick skin, get participation from the union, and be willing to stick it out until the improvements to the overall work atmosphere and individual staff workers become apparent to all.*

Idea*: Retaining experienced staff will allow patients to receive a high-level of care and will provide students/trainees with a rich educational experience and mentors in the field.*

***Barrier**: Lack of creative problem-solving and reliance on specific (rigid) models of service delivery. Innovative ideas utilizing the strengths of existing staff could assist in dealing with some service-delivery issues, as well as provide a setting in which staff believes strengths are being utilized and students would want to be a part of their training (hence leading to increased recruitment and retention - if there were positions available - which frequently there are not.) One of my colleagues with 15 years experience has only .5 FTE and has to repeatedly reapply for .2 and .3 positions. She has training as a pediatric neuropsychologist but has never had the opportunity to use this training due to budget constraints in spite of these skills being needed and valued by the cancer centre and pediatric neurology.*

Other Ideas from patients, providers and stakeholders:

***Patient Voice:** "Experience is a big thing. Mentoring is so important. If you are a new nurse coming out of school, you may have the textbook savvy but you don't necessarily have the real world experience, and they only have so many 'buddy' days before they are thrown to the wolves. There should be good, ongoing mentorship."*

***Provider Voice:** "Part of the problem is that the management just isn't seeing what is going on with us, we don't have the same resources and we don't have the same support or back-up, sometimes you need to go to bat for your staff. Back in the day, if you had an issue and went to your head nurse, you knew that issue was going to get dealt with, and it would be dealt with."*

***Stakeholder Voice:** "We need to get better about defining the expectation of what needs to be done, then provide the training to enable the employees to meet this, and then include this in the hiring and recruitment, and complete this by monitoring the process through performance review, and then reward good behaviour. It is an entire cycle that needs to be created. Staff will do better working to that expectation."*

3. Ensure a renewed emphasis on listening and 'customer service' skills in health care.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders emphasized the need to empower all health care staff to understand the importance of their role and their attitude in the big picture of the patient experience.

***Idea**: We need to educate our staff that everyone is an important part of the health care system. In order for this system to work, every set of eyes and ears need to be actively involved while on duty. If the person that is doing housekeeping doesn't feel important then they keep their head down while doing the job and their ears are closed. But if you empower the support staff they become proud, energized and an asset to the health care system. If housekeeping notices a catheter bag that is full, why shouldn't they feel comfortable enough to tell somebody without feeling like they will be told to mind their own business? I have worked as an aide in LTC facilities that have utilized and empowered the entire team*

working in the center and it works great, everyone knows to never step out of their scope of practice, yet they also know that every voice will be heard when spoken.
***Barrier**: The Ego's of Health Care Staff.*

Other Ideas from patients, providers and stakeholders:

***Patient Voice:** "Provide more training to healthcare workers about the role that they play in the entire patient experience, not just health-outcomes. Provide health care workers with more responsibility and leadership roles so that there is an incentive for them to be actively engaged in patient care . . . not "here's another one coming on the conveyor belt."*

***Provider Voice:** "We need to do it in-training programs, and part of that is doing training in multi professional groups - nurses, paramedics, pharmacists doing all of their training together. Physicians don't always do well working in teams but we need to have a quality assurance team where problems can be reported and tracked."*

***Stakeholder Voice:** "We need to introduce the "kindness" concept into academic system – we need to start from when doctors begin their training. We need to educate providers early on, at all levels, that "service" to the "customer" is what they are there for. There seems to be a bit of resistance to this notion sometimes and we need to think about that and understand that better."*

4. Developing the cultural sensitivity of the workforce.

STAKEHOLDER WORKBOOK SUBMISSION: Building cultural competence through continued training and opportunities for stakeholders to develop greater familiarity with difference were emphasized by stakeholders.

***Idea**: Require cultural competence training for all staff. Ensure that staff knows about basic differences between cultures, particularly since we are seeing increasing numbers of staff from collectivistic cultures. Many people are not aware of the basic differences between individualistic and collectivistic societies and this leads to tension.*
***Barrier**: Lack of cultural competence and inflexibility.*

Other Ideas from patients, providers and stakeholders:

***Patient Voice:** "Cree language is important in Saskatchewan. We have 74 reserves across Saskatchewan and we need to make sure there are First Nation people in the Health care system."*

***Provider Voice:** "We need to find out 'sick roles' of other cultures. We need to promote that, and educate the staff. A lunch hour here and there with different, more cultural groups, to really educate people so that they are reminded of differences would be helpful. Even though we get the orientations*

we will never get enough orientations for all the diversity but if we just get comfortable to stop and ask how to make patient groups more comfortable, we will usually get the answer."

Stakeholder Voice: *"We need a more visible aboriginal health unit – translation services, discharge services, start funding what works and stop doing what doesn't work. We need incentives to attract more aboriginals to our workplace - could stabilize workforce in many northern communities."*

5. Implementing effective strategies to build and develop the health care workforce.

STAKEHOLDER WORKBOOK SUBMISSION: Several stakeholders focused on improving retention through better efforts to sustain high quality of life for health care workers in the Province.

Idea: *My idea to improve retention: A Regional Health Authority "welcome wagon", consisting of: (1) a set of real estate agents who will be available on short notice to tour around prospective hires (2) an information package, put together jointly by the Regional Health Authority and Tourism (Saskatoon, Regina, Saskatchewan, etc.) touting the benefits of life here. This would include things to do, places to go, hours of sunshine, quality of life stats, etc. (3) a set of volunteer "welcome families", one member of whom is a Regional Health Worker, who can meet and host (e.g., for supper, for an outing) new hires and their families. The volunteers would be matched to the hires (i.e., a childless couple would welcome same, a family with young children would welcome same, a family with a nurse would welcome same, a family with a doc would welcome same). The volunteer/host family could answer questions, and give the new arrivals something of a toehold socially.*
Barrier: *time, money, and a willingness to organize it.*

Other Ideas from patients, providers and stakeholders:

Patient Voice: *"How about a 'small community' living allowance for doctors to help them stay. For example if you want to go for a nice dinner, or go to something cultural, you have to drive a number of hours. If you can't offer things like that here, allow them to go other places to enjoy things - they aren't just doctors, they are people too who want a social life."*

Provider Voice: *"This Health region is doing nothing to keep workers. There needs to be more proactive measures, the discussions go nowhere and there is little movement (i.e. Staff don't feel cared for by management...'we already got you here, our job is done') We want further education - there is no thinking outside of the box, people in upper management need to listen to front line workers rather than ruling with an iron fist."*

Stakeholder Voice: *"There is too much focus on recruitment and not enough on retention. Why pay new doctors or nurses these big signing bonuses, and not do something for the people who have been there for a long time? It is de-motivational to current staff. Ideas to promote retention do not need to revolve*

around cash, things such as peer recognition, or awards are great and already in place in certain regions. Unions will even like this."

5.4.6 Category Six: Improving health protection and promotion activity in the Province

Solution ideas that could be connected to this category of improvement tended to centre on two main ideas. First, developing initiatives to teach patients that they have a key role to play in maintaining and improving their health – and empowering them with the tools to take that on. Second, implementing system-level strategies to promote health and prevent illness.

Some central ideas within this category include:

1. Patient Empowerment Strategies – Encouraging patients to be part of their own health care team.

STAKEHOLDER WORKBOOK SUBMISSION: Stakeholders suggested ways to encourage meaningful patient engagement in individual level health care dialogue and in planning for public or target group interventions.

Idea*: involve target groups in their health care, i.e. involve youth and allow them to make decisions and choices about their health. Involve the poor in decisions that affect them, look at social determinants of health as opposed to end points in health that are downstream, if people jump in the river, ask them why and what can be done to make them stay safe and dry, at least for a while.*

Idea: *Patients should be encouraged to respectfully challenge, disagree or ask questions, while still being treated respectfully by provider. Patients need to take more responsibility for their own care in regard of symptoms being misdiagnosed due to poor communication between provider and patient. Patients should be encouraged to bring a second person with them who is familiar with their history and situation, so that they are less likely to 'miss something' during a diagnostic interview.*
Barrier: *Traditionally, people are reluctant to challenge a caregiver at any level, because of 'trust'. I have also been treated VERY disrespectfully by a physician when I have politely challenged their assessment of my symptoms or suggested alternatives. I have been asked if I work in healthcare, which to me makes no difference. I choose to be informed and have been treated very disrespectfully for it.*

Other Ideas from patients, providers and stakeholders:

Patient Voices: *"Empower patients - Recognize the expertise of the individual especially in chronic illness Make patient portals to access computerized medical records and information."*

"Somehow, we need to break out the singular program of the education/training of medical practitioners and putting half of that money into the health and education needs of the community. There is no reason why we can't have kids in grade 5/6 who know as much about medicine as people in their 20 and 30s. The better you educate, the more patients can self-advocate."

Provider Voice: *"Coach patients on how they should approach their physician, encourage patients to take someone with them who can fill in the blanks, or who can give some history or who can be more candid and open with the physician about what is really happening. Encourage patients to take the time before their appointment to list out what the things are that they really want their physician to hear from them. Patients expect physicians to look at them and automatically know. It's a two-way street. People need to feel empowered themselves and taking responsibility for their own healthcare is the first step."*

Stakeholder Voice: *"Get the patients involved, initiatives such as a "family panel" made up of family members of people in the hospital work. They go around and tell their story to the healthcare professionals and open up the flow to questions."*

2. Health promotion and prevention activities and interventions.

STAKEHOLDER WORKBOOK SUBMISSION: Regular exposure to health protection messaging was seen still to be important for behaviour change. Some stakeholders suggested that educational interventions, including early-life interventions in school, were critical for bringing about a shift in patient attitudes about their own role in the management of their health.

Idea*: A one-year media campaign (the specific medium could vary) of "52 (one per week) ways to improve your health". Each way would be a quick hit idea on a health improvement strategy, such as: (1) Reduce your salt intake; (2) wear sunscreen; (3) take your meds exactly as prescribed. Each strategy, if presented in print, could be outlined in large bold type. Below would be smaller typeface with information on why this strategy is sound (e.g., basic info., all empirically supported, on salt and hypertension and the dangers of same), and links to websites for still more info. The University of California Berkeley Wellness Letter is full of these kinds of things.*
Barrier: *Money. But the cost of prevention, which can be enhanced via public education, is far cheaper than the cost of treating someone with skin cancer or someone with whose had a stroke or MI secondary to poorly managed hypertension.*

Idea: *Partner with the education system to start healthy initiatives within our schools and reach the children when they are young to emphasize healthy eating and active lifestyles. Grade 10-12 students in Sask currently do not need to take phys ed if they choose not to. I think everyone needs to have some activity in their day especially students.*
Barrier: *Decreased communication and connections with Sask Education and Sask Health.*

Other Ideas from patients, providers and stakeholders:

Patient Voice: *"If you are trying to help yourself there is not enough access to resources to help with prevention and health promotion. It seems so wrong that I can go to the doctor and get pills for high*

blood pressure but that I can't make my own appointment to see a nutritionist to help with my diet or see a personal trainer to help me with my weight. It would be much cheaper to help people with things like stress management, diet, and exercise, but instead we will only help them with depression, obesity, and injuries."

Provider Voice: *"Dental and other public health initiatives should be available without barrier – it shouldn't depend on parental agreement. It's responsible."*

Stakeholder Voice: *"It's about helping people to make healthy choices. We know that in the north there are smaller incomes and food is more expensive. A bag of chips and a coke is a significantly more affordable meal than homemade vegetable soup or salad. We need to attack junk food the way we've attacked smoking. We need to subsidize healthier foods in the north –that's one thing that we can really, actually do."*

5.5 Stakeholder feedback

A full listing of Stakeholder "ideas" and "barriers to ideas" is available in two supplementary documents to this report – 1) The Patient Experience Component Quote Bank; and 2) Patient Experience Component Workbook Results.

Table – Categories of Improvement Aligned with Causes

		CAUSES													
CATEGORY OF IMPROVEMENT (6)	CATEGORY OF IMPROVEMENT (19)	Absence of or weak relationship with family health care	Low quality face time with Providers	Poor communication channels between System and Patient	Poor coordination of care throughout the continuum	Under-supported health care work force	Low cultural competence of workers	Poor/inconsistent health information management	Sub-optimal use of Health care workers' scope of practice	Rural-Urban Inequities	Lack of staff performance/ behavioural accountability	Insufficient geriatric health care support - preparedness for aging population	Inadequate child and maternal health care support	Inadequate mental health care support	Inadequate health protection and promotion activities throughout the province
Improving the Quality of Patient Interaction	Strengthening Patient relationship with family health care	x	x	x	x			x				x	x	x	x
	Improving Communication between the System and the Patient		x	x	x			x	x	x					x
Improving System Integration	Improving Health Information Management	x	x	x	x	x		x		x		x	x	x	
	Improving Coordination of Care		x	x	x	x			x	x		x	x	x	
Improving Access to Safer Health Care	Enabling all health care workers to work their full scope of practice	x	x	x	x	x			x					x	
	Improving access to hospital care in emergencies and urgent cases				x					x		x		x	
	Improving wait times for surgeries and diagnostic tests			x	x							x			
	Improving home care effectiveness								x	x		x	x		
	Improving geriatric and long-term care support		x	x								x			
	Improving access for people living in rural and remote parts of the province	x			x				x	x					
	Improving child and maternal health care support	x			x								x		
	Improving mental health care support	x	x											x	
Improving System Accountability	Improving Performance Management	x	x	x	x	x					x				
Building a Stronger Health Care Work Force	Improving health care leadership system-wide	x	x	x	x	x			x	x	x				
	Implementing effective strategies to build, develop, and retain the workforce	x	x	x	x	x						x			x
	Boosting staff morale	x	x			x									
	Improving cultural sensitivity of the work force		x	x	x		x								x
Improving Health Protection and Promotion Activity in the Province	the role that patients must play in improving and maintaining their health														
	Improving health protection and promotion activity		x							x			x	x	x

6.0 Recommendations to the Commissioner

6.1 Introduction

Sections 2 – 5 of this report provided a summary of the research gathered during the conduct of the PFR – a landmark study in Canada that reviewed system issues from the perspective of those that matter most, the patients. We engaged patients in an open dialogue of their experiences (positive or negative) with the health care system as they navigated their way through the continuum of care. We also listened to what the patients thought were the causes of their experiences, as well as what solutions might be implemented in order to make improvements to the system. We then spoke with the health care providers and system stakeholders to validate what we heard from the patients, and to expand upon the discussion of causes and solutions. This research demonstrated what is widely acknowledged in systems across the world that health care is not patient-centred, and is too provider-centred.

Many health care systems and organizations already believe that they are patient-centred, and that their clinical processes and attitudes/behaviours are solely focused on the patient. Saskatchewan health care providers are no exception to this belief. However upon reflection of what it means to be truly patient-centred, organizations are realizing that *thinking* you are patient-centred does not actually mean you *are* patient-centred.

"We thought we were patient-centred, we really did. We thought we provided very good care, we thought we provided very good service to our patients. But we discovered by actually talking with patients and families in a dialogue that we really were not. And what we have learned is that most of health care is not either."[1]

Systems and organizations who are acknowledging this disconnect are slowly making this shift from being provider focused to being more patient or consumer centered. This shift is happening because of the growing body of evidence and health system stakeholder acceptance that the inclusion of the patient perspective and increasing his/her involvement and their families' in their care, results in better health outcomes and satisfaction.

"Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety is what patient-and-family-centred care is all about. Studies increasingly show that when health care administrators, providers, and patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increase."[2]

Saskatchewan, through the initiation of this review, has acknowledged this need to shift away from the provider-centric model to one that is patient-centred. The Province is now embarking on a journey

[1] Pat Sodomka, Senior Vice President, MCG Health System

[2] Institute for Family-Centered Care, "Advancing the Practice of Patient-and Family-Centered Care"

which seeks to forge those important partnerships between patients, their families, and health care providers in order to improve the patient experience, improve health outcomes, and ultimately increase patient satisfaction. With this Patient First Review, an expectation has been set within the Province that efforts will be made to shift the system to become more patient focused.

In addition to the regular strategic and health system planning completed each year by the Province, the Ministry now must plan and strategize on how to respond to what was heard in the Patient First Review. Patients, Providers, and system stakeholders will hope and expect that meaningful changes will be made to the health care system as a result of this review. The Government of Saskatchewan's role is to take this review, and engrain in the system the patient-centered values which will create a greater sense of system accountability to the patient, and will result in future health system reform and health service delivery being viewed from one primary lens – the patient.

This shift to become patient-centred represents a significant undertaking for the Province; one that requires an unwavering and long term commitment by politicians, bureaucrats, health care providers, and patients alike to implement and sustain meaningful changes to the way health care is delivered. Section 6.0 of the Patient First Review final report builds upon the learnings from the research to provide:

- In Section 6.2, an analysis of what was heard in the research and leading practices from other jurisdictions which serve to validate the hypothesis that the Saskatchewan health care system should become more patient centred;
- In Section 6.3, KPMG's recommendations to the Commissioner on how the Province of Saskatchewan can action the findings from the research by developing of a *"Patient First Transformation Strategy"*. The strategy will outline the Province's plan on how to shift the system to become patient-centred; and,
- In Section 6.4, KPMG's recommendations to the Commissioner on solutions that could enable the transition to a patient-centred model while addressing some of the more pressing system issues (e.g. wait times, ER).

6.2 Validating the Hypothesis

The working hypothesis upon which this project was founded is that the Saskatchewan health care system needs to become more patient centred. In advance of providing specific recommendations to the Commissioner on how the Province could approach the implementation of a patient-centred health care system, it is helpful to revisit some of the results of the research from Sections 2 – 5 in order to validate and support this hypothesis. This validation is supported by an analysis of how the negative patient experiences might have been different had the system been more patient-centred, and through a jurisdictional scan which provides evidence that patient-centred care is considered leading practice in many health systems across the world.

6.2.1 Negative patient experiences revisited from a patient-centred perspective

The analysis undertaken within this section focuses on 8 out of the total 14 negative patient experiences that were heard in the research, and shows how those experiences might have been different if the system were more patient-centred. The 8 themes selected were considered to be representative themes that captured most of the issues heard within the research, and were also reflective of the larger, more systemic issues within Saskatchewan's health care system. As we analyzed each theme from a patient-centred perspective, the results were very consistent in terms of what the delivery of patient-centred care would look like. As such, the 6 themes that were not part of this analysis are not lost in the overall conclusions drawn within this section because they are inherently captured within the outcomes of our analysis. The 8 negative patient experience themes analyzed include:

- Feeling lost in the system;
- Uncaring and dismissive attitudes amongst health care workers;
- Poor case management and communications with physicians;
- Feeling inadequately served in hospital emergency rooms;
- Long waits for services;
- Home care services are inadequately accommodating;
- Sense that the Province is ill-equipped to meet the long term care needs of the aging population; and,
- Cultural incompetence among health care workers.

This analysis provides validation of the hypothesis – that the Saskatchewan health care system needs to become more patient centred – and also provides a platform for the recommendations that are made later in this chapter on how the Province can shift this system to one that is patient-focused.

When analyzing each of the negative patient experience themes, we have rooted our conclusions in the core concepts of what being patient-centred means, which was developed by the Institute for Family-Centred Care. This organization provides leadership to the health care system for advancing the practice of patient- and family-centred care. The Institute serves as a central resource for increasing the understanding of and skills necessary to build partnerships with patients and families, and how to delivery patient- and family-centred care. As a point of reference and validation for the suggestions made in this section on how to become patient-centred and to improve the patient experience, we have

provided the Institute's core concepts, or guiding principles that define what it means for a health care organization to be patient- and family-centred. [3]

- **Dignity and respect** – Health practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information sharing** – Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision making.

- **Participation** – Patients and families are encouraged and supported in participating in care and decision making at the level they choose.

- **Collaboration** – Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education, as well as the delivery of care.

6.2.1.1 Feeling lost in the system

Feeling lost in the system was a common patient experience heard within the research. Patients for the most part were satisfied with the actual delivery of health care services (e.g. a surgery), but were frustrated by their journey through the system. Patients are not expert system navigators, and when patients are not sure about what to expect in terms of next steps, timing, and outcomes, they are left to feel lost and intimidated by the system.

[3] Institute for Family-Centered Care, "Advancing the Practice of Patient-and Family-Centered Care"

Feeling lost in the system		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Disorientation within the system • Feeling unqualified to advocate • Feeling unqualified to find one's way	• Poor inter-provider coordination in case management • Absence of or weak relationship with family health care • Poor health information management • Low quality face time with physicians • Lack of two-way communication between patient and provider • Inadequate or lack of clarity in communications • Lack of advocacy • Lack of follow-up • Poor communication with patients from hospitals, facilities, doctors offices • Inefficiencies, inconvenience and delay in negotiating patient movement into the system and from one part to another	• Providers are better integrated and communicate more effectively with one another about a patients care • Patients are communicated with clearly about next steps, results, and are followed up with on a regular and timely basis • There is clear "ownership" of the patients care • Patient advocates/navigators are made available if needed • Patients have an EHR that follows them through the continuum
• Absence of a health record • Lost/destroyed health records • Scattered and disjointed health records • Repeating health history	• Lack of consistency in managing and sharing patient health information • No consolidated health record • Inadequate recording and viewing of patient information • Too much paperwork	• Every patient has an electronic health record (EHR) that provides a comprehensive summary of medical history • Health history is not repeated at each step, duplicate tests are avoided • Health record is viewed by each provider at each patient touch-point • Health record is updated with each visit • Treatment and advice that does not conflict with medical history

The implementation of the electronic health record (EHR) will provide an effective and integrated information system to better manage the flow of patient records throughout the continuum of care. Patients who are able to access and view their patient records feel empowered with their care, and are less likely to feel lost in the system because they are kept apprised of the details of their care.

While EHR and other information systems are important enablers for achieving patient-centred care, they alone are not sufficient. Health care providers must act as advocates to the patient by truly "knowing" their patients, by acting in their best interests, and assisting with/facilitating their navigation through the system. Communications – with the patient and amongst providers – must also be

improved, and integration of services amongst providers, regional health authorities, and other community organizations must be improved and made more seamless.

If a patient is confident that his/her health record will follow them wherever they go in the system, that they know exactly who is looking after them, what steps are being taken and when, know results as they come in, and providers are acting as an integrated team in the delivery of care, a patient can be made to feel well oriented and confident in the system. A patient-focused perspective is one of partnership between patients, families, and providers. Patients feeling like they are partners in their own care can be involved in decision making about their care, and who are kept informed of their progress and next steps are likely to be more satisfied with their care.

The Institute for Family-Centred Care's core concepts provided earlier – ***information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made to reduce the number of patients feeling lost in the system. Specific improvement opportunities could include: Implementation of EHR; engraining the customer service approach through HR policies and training; providing incentives for providers to work together (e.g. interprofessional, team-based care); providing incentives to providers to conduct patient-focused care; establishing, tracking, and measuring performance indicators related to, for example, effective communications, effective management of health records, and service integration amongst provider groups; .

6.2.1.2 Uncaring and dismissive attitudes from health care workers

Health care, much like the hospitality industry, is a people-focused business. For patients, each touch point in the system represents an opportunity for either good or bad impressions to be made based on their interaction with health care providers. The realities of being a people and services business, is that even if the service (e.g., the surgery, or the diagnostic test) was performed successfully, the overall patient experience can be ruined by a negative interaction with a health care provider. Another perspective can be taken here with some larger-scale system improvement projects underway. Take for example wait times, a patient may be satisfied with the fact that they did not have to wait as long as they expected. However if in the process of checking into the hospital for the surgery they were treated poorly by a nurse or doctor, that lower wait time is no longer as important to them because of how they were treated during their care journey.

Uncaring and dismissive attitudes from health care workers		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Patient role not acknowledged • Not listened to • Not involved in decision-making • Rebuffed from asking questions • Being judged by physicians • Treated with a lack of respect, compassion, empathy • Not feeling "cared" for	• Low quality interactions with physicians and other health care staff • Hurried consultations and superficial, less personal care • Lack of clarity in communications • Judgmental attitudes of health care staff • Physician arrogance • Staff shortages • Staff retention (contributing to shortages) • Health care workers being "burnt out" from heavy case load, shortages, long shifts, etc. • Lack of supportive leadership leading to poor staff morale • Poor staff behaviour is not easily disciplined or controllable • Poor staff supervision	• High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients perspectives are valued and considered • Good two-way communication between patients and providers • Patients feel "cared for" • Patients are aware of avenues / mechanisms to file complaints about staff members • Staff members are accountable to patients and organizations for their behavior

Regardless of how good the delivery of care is, a patient will always expect to be treated appropriately by health care workers. Based on the causes highlighted by the research it is certainly understandable how health care staff can feel overworked and stressed, which can lead to behaviors that are less then ideal in a service-oriented business. But regardless of the environmental factors within a health care organization, the reality is that each heath care worker represents the system as a whole. For each touch point a patient has with a health care worker, a patient's experience can either be made to be positive or negative. Health care workers receive training on how to treat patients "nicely" however this is not followed up on by performance monitoring, role modeling, and leaderships. A patient-centred culture needs to start both from the top – via organizational strategies from executive – and the bottom – via patient-centred training and performance measurement.

The patient-centred approach to address this negative patient experience is also one of fostering partnerships between patients, families, and providers. Patients feeling like they are partners in their own care can be involved in decision making about their care, and who are kept informed of their progress and next steps are likely to be more satisfied with their care. If patients are viewed as equal partners by health care staff, the behaviors begin to shift naturally as everyone is on a level playing field, each contributing to the overall delivery of care. What can't be lost in this discussion is the need for improved support of the health care staff who generally feel overworked and under supported to manage their workload. Staff required the time, tools, supports and leadership to do their core jobs effectively.

The Institute for Family-Centred Care's core concepts – ***dignity and respect, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made to reduce the number of patients encountering uncaring and dismissive attitudes amongst health care workers. Specific improvement opportunities could include: engraining the customer service approach through HR policies and training; developing organizational tools and supports for staff to live the patient-centred values and to feel good about their jobs and roles as service providers; providing incentives for providers to conduct patient centred care; conducting regular customer service surveys; revising accountability/collective bargaining agreements to include patient-centred care criteria and accountabilities; and including patients in health care planning and on advisory boards.

6.2.1.3 Poor case management or communication

Case management can be defined as "The creation of a coordinated, ongoing and personalized strategy for patients with a variety of health care needs (e.g., the elderly and those with long-term illnesses). Primary care physicians act as case managers, planning specialist referrals and provide continuity within the separate services delivered."[4] Effective case management requires a more holistic view of a patient, and effective communication and coordination of care activities with other parts of the system. All providers must feel an obligation for working as part of a care team to move the patient through the system. It is also important that one provider – whether it be a primary care physician or otherwise – must take responsibility and accountability for the patient's journey through the system and the provision of care that meets all of their needs.

We heard from the patients that they were not satisfied with their primary care providers in terms of their ability to own and manage their patient cases, and their ability to communicate effectively with the patients during their journeys.

[4] The McGraw-Hill Companies, Inc., "McGraw-Hill Concise Dictionary of Modern Medicine", 2002.

Poor case management or communication		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Poor interactions with physicians • Not enough time with physicians • Slow diagnosis • Misdiagnosis • Treatment of symptoms rather then problems • Not involved in decision-making • Not enough time to ask questions • Not having/ getting answers	• Weak relationship with family health care • Poor inter-provider coordination in case management • Low quality interactions with physicians and other health care staff • Lack of two-way communication between patient and provider • Hurried consultations and superficial, less personal care • Lack of clarity in communications • Judgmental attitudes of health care staff • Physician arrogance • Staff shortages • Staff retention (contributing to shortages) • Health care workers being "burnt out" from heavy case load, shortages, long shifts, etc. • Lack of supportive leadership leading to poor staff morale • Lack of follow-up • Poor communication with patients from hospitals, facilities, doctors offices • Inefficiencies, inconvenience and delay in negotiating patient movement into the system and from one part to another	• Patients receive personalized care plans • High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients perspectives are valued and considered • Good two-way communication between patients and providers • Patients feel "cared for" • Providers are better integrated and communicate more effectively with one another • Patients are connected to other community organizations by their physician to provide alternate levels of care • Patients are communicated with clearly about next steps, results, and are followed up with on a regular and timely basis

The patient-centred approach to improving case management and communications is similar to that suggested by the "Feeling Lost" theme – the creation of partnerships between patients, families, and providers. As the definition provided above stated, effective case management involves creating a coordinated, ongoing and personalized strategy for patients with a variety of health care needs. In order to be patient-focused with case management, the keys are to effectively communicate with the patient at each step of the care journey, coordinate with other providers for the patients' total care needs, and to involve the patient in an open dialogue, encouraging them to make decisions and to be an active member of their care plans.

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made to address the case management and communications negative experiences of patients. Specific improvement opportunities could include: engraining the customer

service approach through HR policies and training; providing incentives for providers to conduct patient centred care; involving the patient and their family in decision making; creating service level expectations with patients on time to next step, when they will be followed-up with, etc.; and acting on those service levels and conducting regular customer service surveys to gage levels of satisfaction.

6.2.1.4 Feeling inadequately served in hospital emergency rooms

The hospital emergency room (ER) is considered to be the central artery for the health care system. Aside from handling patients with real emergency care needs, the ER has also become the default for patients seeking non-emergency care needs after hours (when offices and clinics are closed), when the medical offices or clinics are not close by, or when they cannot get a timely appointment from their physician. Hospital ER congestion is a highly publicized problem in most health care systems, and its congestion and backlog is symptomatic of many other systemic issues – lack of ALC and long term care beds, lack of general internal medicine beds within the hospital, etc. Patients from the research had many negative experiences as a result of these backlog issues and their overall treatment while in the ER.

Feeling inadequately service in hospital emergency rooms		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Long wait times • Lack of communication over delays and status • Confusion over admitting procedures and prioritization • Uncomfortable waiting environment and a lack of cleanliness in ER • Frustration over perception that non-emergent patients are causing congestion • Frustration over lack of care options	• Insufficient access to family physician • Hurried consultations • Poor communications from hospitals to patients on wait times, triaging procedures, status, etc. • Poor coordination of care because ER is a "catch-all" for care • Lack of alternatives (e.g., walk-in clinics, urgent care centres) • Hospital overcrowding • Poor discharge planning	• High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients perspectives are valued and considered • Communications are transparent and patients are kept apprised of status on wait time • Patients are given their care plan and understand the steps that are to be taken • Patients are treated with respect and dignity while in the ER • Patients in the ER are waiting in a clean, comfortable, and safe environment

The patient-centred approach to improving negative experiences in the ER is centred on improving communications. Patients know and understand that when they enter a hospital ER that there will be a wait time. Patients generally also understand that there is some triaging and prioritization that needs to happen in order to address critical cases (e.g., heart attack), before less urgent cases (e.g., broken leg). What is most frustrating for patients is the "not knowing" aspect of their ER experience. People would rather hear that they will be waiting for 4 hours, rather then not knowing at all. To be patient-centred in the ER means that all staff should be providing open, honest, communications to patients, while being as sympathetic and empathetic as possible. The ER is a highly intimidating and stressful experience to begin with, so making the experience more patient-centred also involves staff focusing on making each touch point or staff interaction as pleasant as possible.

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made address the hospital ER negative experiences of patients. Specific improvement opportunities could include: engraining the customer service approach through HR policies and training; providing incentives for providers to conduct patient centred care; involving the patient and their family in decision making; leveraging devices such as an electronic white board in the ER that indicates who is responsible for patients and when they were last seen by a physician or nurse; providing care plans to ER patients so they know the steps that are to be taken; and other ER patient flow initiatives (e.g., providing alternative settings for less urgent patients, improving access to primary care, lean process improvements, etc.) that will assist to ease congestion in the ER.

6.2.1.5 Long waits for services

Whether it is for specialist physicians, surgeries, diagnostics procedures, medical equipment, specialist services, or family health care, the issue of wait times was prevalent in our discussions with patients. The issue of patients "not knowing" when they will receive their surgery or diagnostic test puts a lot of stress and anxiety on the patient when dealing with a health episode. Even if a health care system can successfully reduce wait times for hip replacement surgeries for example, a patient experience can still be negative if they are not communicated with about when to expect the surgery, or are not made aware of what measures can be taken to manage pain while they wait for their procedure. Tackling the wait times issue is about more then just reducing the actual time from referral to procedure; it is also about how the patient experience is managed while waiting. The research indicated that wait times and the lack of communication in the process of waiting was a significant factor in deciding the patient's level of satisfaction with their experience.

Long waits for services – specialists, surgeries, diagnostic procedures, medical equipment, specialized services		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Long waits for specialist physicians, surgeries, diagnostic procedures, medical equipment, and specialized services • Anxiety about not knowing what was wrong • Being left in pain while waiting • Powerless and helpless over scheduling • Difficulties accessing specialty services • Duplication of tests	• Weak or insufficient access to family physician • Difficulty connecting to specialized treatments and providers • Delays in access to treatments and specialists • Poor quality interactions with physicians • Poor communications with patients from hospitals, facilities, doctors' offices for updates on wait times and test result next steps • Lack of efficiencies in the referrals processes and patient transfers through the system • Providers rely too heavily on their own networks • Poorly coordinated/organized care and wait list management • Loss of tests, tests becoming stale due to slowness of patient movement through the system • Poor coordination and inadequate allocation of surgical time for surgeons • Wait lists not well "quarter-backed" • System backlog issues • Poor inter-provider coordination in patient case management • Shortage of, or lack of, rural non-hospital health services • Inadequate/poorly coordinated medical travel	• High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients perspectives are valued and considered • Communications are transparent and patients are kept apprised of status on wait time and test results • Wait lists are viewable online in order to see place in queue • Patients are provided with options for places of surgeries/diagnostics tests • Every patient has an electronic health record (EHR) that provides a comprehensive summary of medical history including tests completed and the results • Providers are better integrated and communicate more effectively with one another about a patients care • Better scheduling practices of surgeries and diagnostic tests making them more accessible to patients – time or location • Accessible and coordinated travel options for patients in all regions of the Province

Long waits for services – family health care		
Current Patient Experience	**Potential causes**	**Patient-centred Experience**
• Difficulties accessing appropriate family health care • Difficulties maintaining family doctor • Lack choice for family doctors • Increased dependency on ER • Poor quality interactions • Difficultly obtaining responses on questions or concerns • Difficulty accessing other specialized services	• Weak or insufficient access to family physician • Poor quality interactions with family physician • Family physician shortage • Frequent physician turnover • Lack of choice of family doctor • Rushed appointments • Lack of clarity of communication (either due to language barriers or poor communication skills) • Fee-for-service compensation model • Health care workers are "burnt out" • Poor morale • Poor cross-cultural training; respect and tolerance not adequately emphasized • Language barriers and cultural clashes • Lack of diversity of staff • Lack of understanding of various cultures and their traditions • Reliance on family physician to coordinate access to other services (e.g., mental health)	• Patients are provided with options on who their family care provider is • Patients are provided with timely access to their family physician • Providers are paid based on performance including patient-centred care • High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients perspectives are valued and considered • Communications are transparent and patients are kept apprised of next steps and timing of their care plan • Care plans are personalized for every patient • Providers are better integrated and communicate more effectively with one another about a patients care

In order to be more patient-centred as it relates to wait times for services, the system and its providers must focus on providing more timely and transparent communications with patients. The issue of not knowing – whether it be the scheduling of a surgery or diagnostic test, or what the results and next steps are – is a source of much anxiety and stress for patients. Being more patient-centred also means providers, including family physicians, need to improve the quality of their interactions with their patients at every touch point. For many the family physician is the connection to the rest of the system, and their sole voice or advocate who assist the patients with navigation. This reliance on family physicians makes their relationship with patients critical to the patient's experience, and therefore must be fostered in a positive and productive manner. A patient-focused perspective is also one of partnership between patients, families, and providers. Patients feeling like they are partners in their own care can be involved in decision making about their care, and who are kept informed of their progress and next steps, are likely to be more satisfied with their care.

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made to address the negative experiences of patients waiting for services. Specific improvement opportunities could include: engraining the customer service approach through HR policies and training; providing incentives for providers to conduct patient centred care; involving the patient and their family in decision making; launching regular patient feedback surveys; applying queuing theory to the scheduling of surgeries and diagnostic tests – making them more accessible and convenient to patients; implementing advanced/open access scheduling practices – which facilitate say day appointments – to improve access to primary care; and leveraging capacity within the system to avoid backlogs in certain areas.

6.2.1.6 Home care services are inadequately accommodating

Home care services are provided to many patients such as those who are frail or elderly, children at risk, people with disabilities or palliative patients. The aim of home care is to provide patients with the level of care they require within their own homes so that they may continue to live as independently as possible. With shorter hospital stays becoming the norm within most hospitals, and the aging population, the demand for home care services will likely continue to increase. Home care represents a critical service to the health care system because it can enhance people's dignity and well-being while allowing them to be somewhat independent; however the patient experience in accessing these services within the Province was not always positive.

Home care services are inadequately accommodating		
Current Patient Experience	**Potential causes**	**Patient-focused Experience**
• Long waits for assessments • Frequent cancellations • Inflexibility in scheduling • Limitations on services that are available • Feeling under-supported • Lack of follow-up after initial visit	• Inefficiencies, inconvenience in negotiating • Poor service organization and staff scheduling • Assessment of home care needs takes too long or is incomplete • Long delays for services • Mismatches in patient expectations when services are delivered • No specific end-point for home care • Aides and nurses are understaffed and overstretched	• Patients are provided with timely access to home care services • High quality interactions with health care providers • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients have the option to be partners in decision making with health care providers • Patients can choose from a list of options on what home care services they'd like, and are provided with other community-based alternatives (e.g. volunteer associations, YMCA, etc.) to home care • Patients perspectives are valued and considered • Communications are transparent and patients are kept apprised of next steps, timing of their care plan, and expectations for home care (what they will get) • Care plans are personalized and communicated on timely basis (e.g. well before discharge) • Providers are better integrated and communicate more effectively with one another about a patients care

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made to address negative experiences of patients associated with home care services. Specific improvement opportunities could include: engraining the customer service approach through HR policies and training; providing incentives for providers to conduct patient centred care; involving the patient and their family in decision making; improving case management practices; leveraging capacity within the system to avoid backlogs in certain areas; integrating home care providers with primary care; use of alternative providers; empowering personal support workers (PSWs) to provide a larger scope of services; and implementing self management solutions (e.g. diabetes registry) for chronic disease management.

6.2.1.7 Sense that the Province is ill-equipped to meet the long term care needs of the aging population

The issues associated with the aging population are ones that put a great deal of stress on health care systems that are already constrained by limited capacity and funds to delivery services to the broader population. The aging population presents some specific challenges to the delivery of health care services including: the need for the system to provide support to the increasing number of informal caregivers in the communities; the increased demand for long-term care service and facilities; the increased demand for supportive housing; the change in skills of the providers that is need to service this demographic; and the increase in diseases and disabilities associated with aging that require levels of care. With the current population demographic – 20% of population over the age of 60 (2007)[5] – we heard many negative experiences from patients and their families related to challenges in accessing long term care for the aging population. As Saskatchewan's population continues to age, the demands of this demographic on the health care system will continue to put a larger strain on resources and capacity and access issues are likely to worsen.

Sense that the Province is ill-equipped to meet the long term care needs of the aging population		
Current Patient Experience	**Potential causes**	**Patient-focused Experience**
• Long wait lists • Not knowing if family members can live in full or part time care facilities • Having to travel far distances to visit loved ones • Staff carelessness and inattention to patient comfort • Shortage of facilities • Lack of knowledge of care options	• Lack of patient advocate • Poor communication from facilities and doctors offices for updates on wait times • Inefficiencies/inconvenience and delay in negotiating patient movement from one part of the system to the other • Staff shortages • Health care workers are "burnt out" • Lack of long term care options without significant travel • Lack of alternatives to traditional long term care • Poor family-planning • Shortage of appropriate long-term care / supportive care options to suit patient lifestyles • Shortage of expertise in handling increasingly complex patients	• Patients are provided with timely access to long term care services and facilities • High quality interactions with health care providers, where patient and caregiver perspectives are valued and considered • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients and caregivers have the option to be partners in decision making with health care providers • Patients and caregivers are provided with options on where to receive care based on proximity to family and friends • Communications are transparent and patients/caregivers are kept apprised of next steps, timing of their care plan, and expectations for long term care • Care plans are personalized and communicated on timely basis • Providers are better integrated and communicate more effectively with one another about a patients care • Patients have supports in their communities which provide them with long term care options

[5] Statistics Canada - 2007 estimates of population (Census and administrative data), CANSIM (database).

There is no doubt that the aging population presents challenges to the system which would be difficult to address solely through the implementation of patient-centred practices. Understanding this reality, the system can do more to improve the patient experience for those that are in need of health care services for the elderly. The patient-centred themes are similar to others already listed in terms of improving communications throughout the care journey with the patient, treating the patient and their family as partners in their care, and providing them with timely information and regular updates on things such as wait times and test results. These practices can help to improve the overall patient experience by taking out the element of not knowing what lies ahead for a patients care plan. To be patient-centred also requires that the system properly acknowledge the vital and extensive role that informal caregivers play in supporting older clients at home and with their medical interactions. The system must improve their interactions with these caregivers by providing them with timely information the supports required (e.g., information on community organizations, home care options, etc.) to provide the proper care at home to patients.

There is also a need for increased community care as a result of the elderly wanting to stay within their community and not wanting to enter into long term care facilities. To be patient-centred the system must acknowledge this strong preference and work to provide more supports in communities where people live so that there are options for long term care.

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred improvements that can be made address the hospital ER negative experiences of patients. Specific improvement opportunities could include: engraining the customer service approach through HR policies and training; providing incentives for providers to conduct patient centred care; involving the patient, their family and caregivers in decision making; providing community support options and wellness programs to address long term care needs; providing senior friendly hospitals to lower lengths of stay and increase effective recovery; and fostering relationships with, communicating with, and providing tools and supports to caregivers to assist with the provision of care to the elderly.

6.2.1.8 Experience of cultural incompetence amongst health care workers

Research shows that health and social outcomes experienced by First Nations and Métis peoples are lower than the health and social outcomes for the rest of the population. First Nation and Métis people are faced with many health crises including diabetes rates that are three to five times higher than non-Aboriginal Canadians, TB rates that are eight to ten times higher than overall Canadian rates, and many other crisis's that place high demands on the health care system. The First Nation and Métis population are also faced with other life challenges such as high poverty rates, drug and alcohol addictions, increased suicide risks and low education levels.[6] In Saskatchewan, Aboriginal people make up 14.9% of

[6] Regina Qu'Appelle Health Region: http://rqhealth.ca/programs/aboriginal/aboriginal_health.shtml

the population compared to the national average of 3.8%. This includes 9.6% North American Indian and 5.0% Métis. The only province (not territory) with a higher percentage is Manitoba at 15.5%. Saskatchewan also has the greatest percentage of First Nations people (10% of total population) out of all of the provinces (not including territories). Approximately 12% of the total Aboriginal population in Canada lives in Saskatchewan. Since 1996, the First Nation population in Saskatchewan has increased by 25%, while the Métis population in Saskatchewan has increased by 34%.[7] With such a large and important group within the Province presenting many unique challenges to the broader health care system, the Province is currently working on several initiatives aimed specifically at addressing the health needs of this population group, and to improve the patient experience and health outcomes.

Throughout the research we heard the voices of many First Nation and Métis citizens, and while some expressed positive experiences, most expressed dissatisfaction with the delivery of health care in the Province.

Experience of cultural incompetence amongst health care workers		
Current Patient Experience	**Potential causes**	**Patient-focused Experience**
• Treated insensitively • Racism • Intolerance • Facilities / equipment not well adapted to meet FN/Métis needs • Inappropriate communications from health care workers • Not understanding condition when leaving health care worker • Difficulty accessing health care	• No sensitivity training • Lack of cultural awareness groups/training • Insufficient encouragement to participate in cross-cultural training • Lack of diversity of staff compared with diversity in the population • Lack of understanding of various cultures	• High quality interactions with health care providers, where patient and caregiver perspectives are valued and considered • Patients are being treated with respect and dignity – this includes sensitivity to cultural beliefs and traditions • Patients and caregivers have the option to be partners in decision making with health care providers • Patients and caregivers are provided with options on where to receive care based on proximity to family and friends • Communications are culturally appropriate and transparent • Patients/caregivers are kept apprised of next steps, timing of their care plan • Care plans are personalized and communicated on timely basis • Providers are better integrated and communicate more effectively with one another about a patients care

The Institute for Family-Centred Care's core concepts – ***dignity and respect, information sharing, participation, and collaboration*** – serve as useful guiding principles for the types of patient-centred

[7] Government of Saskatchewan: 2006 census data.

improvements that can be made address the experience of cultural incompetence amongst health care workers. Specific improvement opportunities could include: Implementation of patient advocates that have a deep understanding of the culture of these populations and can assist them in their care journey; develop a recruitment strategy that looks to increase the number of First Nation/Métis health care staff; develop a cultural safety perspective for diagnosing, treating and supporting First Nations and Métis people's well-being; develop a First Nation/Métis training program and educational curriculum to provide health care staff with the necessary knowledge, understanding, and sensitivity to the issues of the community; and involving the patient, their family and caregivers in decision making..

6.2.2 Conclusions from the research

The analysis completed for the 8 negative patient experiences themes demonstrate how the patient experience could have been improved with the implementation of patient-focused values and processes. While there are some more technical improvements that can be made to become a patient-focused system (e.g., EHR, electronic whiteboards in ERs, other communications-facilitating devices or processes, etc.), most of the improvements are focused on the following 4 things:

- **Improved leadership at all levels of health care** – leadership must set the vision, establish the targets, and be vigilant in monitoring the performance of their organizations. To become patient-centred, health care organizations must make an unwavering commitment that this will be the new "way of life", and instill those patient-centred values into the staff through the provision of support (training, education) and incentives. Without leadership commitment, the patient-centred approach will fail and things will revert back to the way they were.

- **Attitudinal/cultural shifts** – changing the attitudes and cultures of health care organizations and staff to think of patients as partners in their own care, and as equal members of the care team.

- **Open communications** – patients want to know who, where, what, when, why, and how for the care that is being provided. Typically communications between the system and patients is poor, resulting in negative patient experiences from the "not knowing" factor. As partners in care, providers should be communicating openly, honestly, with patients on some regular basis. The more patients know (within reason of course), the better they are able to manage their own stress and anxiety levels within the system. Communications must also be appropriate based on the targeted audience. Patients regardless of background or beliefs must be communicated with in a manner that is understandable so that they understand their health, next steps, etc.

- **Behavioral shifts** – With the change in attitude/mindset, and more open and culturally appropriate communications, the behaviors of health care staff should shift to be more inclusive with the patient in the provision of care, including them in decision making, listening to and considering their thoughts and opinions, and treating them as equals.

The analysis of negative patient experiences from a patient-centred perspective provide evidence that patient-centred care can lead to more positive experiences, which have been proven to result in better health outcomes.

We will now provide a jurisdictional scan of leading practices in the area of patient-centred care which serve to provide further evidence that patient-centeredness is a logical and rational direction for the Province of Saskatchewan to strive for with their health care system.

6.2.3 Patient First Jurisdictional Review

This section of the report provides examples from a jurisdictional scan of health care systems and/or organizations that have taken a patient-centred approach. The analysis provided in the previous section outlined the benefits of having a patient-centred system to the overall patient experience. The jurisdictional review provides concrete examples of actual patient-centred implementations and organizations who have "led the charge" in guiding health care providers in defining what patient-centred means, what its benefits are, and how to implement within their organizations. Some of the examples in US hospitals also show some of the quantifiable benefits from a patient satisfaction and health care delivery perspective.

6.2.3.1 Canada

Trillium Health Centre, Mississauga ON: Four years ago the Trillium Health Centre included in its yearly strategic plan, strategic directions and goals related to being patient-centred. In 2007, the hospital's strategic plan included as one of five strategic directions – "Create the Ideal Patient Experience (IPE)" – which consists of: Daily goal setting with patients; Design of the IPE at the micro system and macro system; Implementation of new care delivery models; Rollout of service culture standards; and Spreading and sustaining their "Safer Healthcare Now Program".

A key initiative that was part of their patient-centred program was the construction of a patient-centred clinical wing. In the construction of this wing, the following patient-centred philosophies/approaches were taken:

- Trillium involved patients in the design of the wing and its layout concepts.
- All beds face the windows.
- Rooms with two beds have a dividing wall between the beds so as to appear like two rooms. These two-bed rooms share a bathroom, but have their own separate entrances.
- Corridors are wider and there is more storage space to reduce clutter in the hallways.
- They have decentralized nursing stations so that nurses are closer to their patients.

Trillium has also implemented some patient-centred clinical processes within the wing:

- Patient hand-offs between nursing shifts happen at the patents bed.
- Whiteboards are installed at the end of each patient's bed where daily goals are posted.
- All nurses have cell phones which are connected to the call buttons of the patients they are assigned.

According to Janet Davidson, Trillium Health Centre CEO, the key lessons learned in implementing patient-centred care are: The direction must be established from the top; the organization must live the patient-centred values and be quite deliberate in its execution of them; a hospital must redesign the models of care around being patient-centred; you should if at all possible redesign the building and its layout; you must change the way care plans are developed; and most importantly, you must change the motivations and behaviours of staff. Janet cited the largest obstacle in implementing patient-centred values is the time commitment, but when the organization is committed, the staff become committed, and the implementation of changes happen. [8]

Barrie Community Health Centre, Barrie ON: - The Barrie Community Health Centre implemented a program called "Breathe Easy" for chronic disease management. Breath Easy is a structured, evidence-based, patient-centered program taught by trained volunteer lay leaders to teach their participants, and their caregivers or partners, the skills they need to manage the day-to-day challenges of living with a chronic health condition. The program is modeled after the Stanford-based program, which teaches about goal-setting, appropriate medication for symptom management, effective communication techniques to develop healthier relationships with spouses, partners and health care providers and managing fear, frustration and difficult emotions.

This is an example of a patient-centred program where an organization is making a commitment to educate and provide tools to its patient in order to encourage self-management of chronic conditions. This approach empowers the patient with decision making autonomy, and really puts the patient at the centre of care. According to the hospital, the program teaches patients to "think outside the box, to be inventive in dealing with their disabilities, and to learn skills to help manage physical and mental challenges." Patients are also taught to be self-aware, and to work with the doctors and not against them as partners in their care plans. [9]

University Health Network (UHN), Toronto ON: As Canada's largest hospital, UHN is often on the leading edge of clinical process redesign and quality/safety initiatives. UHN has spent the last three years implementing Lean/Six Sigma as their continuous improvement methodology. Lean is an approach to process improvement that is patient-centred because it approaches redesign from the patients' perspective. It looks at clinical processes and asks the question – does each step of a process

[8] Interview with Janet Davidson, CEO Trillium Health Centre – June 4, 2009

[9] http://www.health.gov.on.ca/english/providers/program/cdpm/pdf/barrie.pdf

add value to the patient? Where the answer is no, that component/step in is "leaned out" to make the process more efficient, and also more "valued" by the patient.

UHN has also established a core value within its nursing department for Patient Centred Care (PCC). The vision statement for PCC is: "At University Health Network, each of us has a role to play – and the power to make a difference in the experience that patients and families have at UHN. Sometimes, it might be as simple as stopping to provide directions to family members. While at the bedside, it will mean taking the time to ask patients if they have any questions, concerns, fears or anxieties about their care." [10]

Health Canada[11]: Health Canada has developed a strategy which describes how they would like to change the way health care providers would be educated in order to achieve system change through patient-centred practice. This strategy, known as "Interprofessional Education for Collaborative Patient-Centred Practice", is seeking to provide health care workers with the knowledge and training to work effectively on interprofessional teams, and to provide patient-centred care.

According to Health Canada, there is growing consensus that interprofessional collaborative patient-centered practice - across all health sectors and along the continuum of care - will contribute to the following:

- improved population health / patient care;
- improved access to health care;
- improved recruitment and retention of health care providers;
- improved patient safety and communication among health care providers;
- more efficient and effective employment of health human resources; and
- improved satisfaction among patients and health care providers.

This example demonstrates the importance of revising educational and training programs for health care providers in order to achieve the delivery of patient-centred care. It also highlights what many experts in the literature feel, that interprofessional care is essential to achieving patient-centred care. The notion of a group of health care professionals teaming with patients, families, and caregivers in the delivery of care exemplifies the Institute for Family-Centred Care's values discussed earlier of *dignity and respect, information sharing, participation, and collaboration*.

[10] http://www.uhn.ca/About_UHN/nursing/site/professional_practice/pcc/index.asp
[11] http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/interprof/index-eng.php

Canada Health Infoway (CHI)[12]: CHI is a not for profit organization tasked with the mandate of providing assistance to Provinces and Territories with the implementation of electronic health records (EHR). EHR is considered to be an important enabler of patient-centred care due to the issues currently faced by patients with the poor management of their personal health records. CHI is currently sponsoring and funding many EHR implementations across Canada, all of which are patient-centred, aimed at improving communications with patients, encouraging self-care, and improving the overall patient experience:

- **At Group Health Centre in Sault St Marie**, electronic health records are being used to facilitate sharing of information between doctors and pharmacists. The result of this sharing is that patients with multiple health issues are provided with better and safer care. The pharmacists' access to patient records expands scope of the overall care that is provided by bringing the pharmacists expertise into the care group. Providing this interprofessional team with electronic health records for patients' results in the avoidance of potentially dangerous drug interactions and the enhancement of the quality and coordination of care.

- **Health regions in Edmonton and Calgary** have developed diabetes management strategies that leverage the provincial Netcare electronic health record network. This provides physicians and other health care providers with the information needed to track and treat people with diabetes. Through this system, health professionals have access to their patients' latest blood work, blood pressure and cholesterol results, as well as up-to-date files on medications and treatments – all essential data to reduce the risk of complications and the need for hospitalization. Patient portal implementations are also planned in the future. These portals will provide patients with a place to view and access their personal health records. The portal will also provide them with functionality such as confirming appointments, checking test results, and monitoring vital signs and blood work. The portal will also provide patients with information on preventative care, as well as self-management techniques that they can follow to manage their own care more effectively.

- **"My CARE Source" at the Grand River Hospital in Kitchener, Ontario**, provides cancer patients with safe access to reliable information about their care and what they can do to optimize their health and well being. The confidential, personalized website enables patients to access information about their care team, medications, surgery, treatments and side effects. More than just a means to allow patients to actively participate in their care, consumer health solutions signal a new way to start thinking about the future of health care delivery.

[12] http://www2.infoway-inforoute.ca/Documents/Infoway_Business_Plan_2008-2009_Eng.pdf

6.2.3.2 United States

Institute of Medicine (IOM)[13]: Organizations such as the IOM are providing leadership and guidance to health care providers on how to improve safety, quality, and performance within the system. Patient-centred care has been around for a long time, but it is organizations like IOM that are formalizing the strategies and approaches to making improvements in the delivery of health care by taking a patient-centred approach.

A commonly sited reference to patient-centred care is based on the work completed by IOM in 2001 where they developed and proposed six aims for a healthcare system. Those aims are provided below:

- **Safe** – avoiding injuries to patients from the care that is intended to help them;
- **Effective** – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse);
- **Patient-centered** – providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions;
- **Timely** – reducing waits and sometimes harmful delays for those who receive care and those who give care; and, Efficient – avoiding waste, in particular waste of equipment, supplies, ideas and energy; and
- **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Additionally, IOM also created 10 rules for redesigning clinical processes:

- **Care is based on continuous healing relationships.** Patients should receive care whenever they need it and in many forms, not just face-to-face visits. This implies that the health care system must be responsive at all times, and access to care should be provided over the Internet, by telephone, and by other means in addition to in-person visits.
- **Care is customized according to patient needs and values.** The system should be designed to meet the most common types of needs, but should have the capability to respond to individual patient choices and preferences.
- **The patient is the source of control.** Patients should be given the necessary information and opportunity to exercise the degree of control they choose over health care decisions that affect

[13] Institute of Medicine. "Crossing the Quality Chasm: A New Health System for the 21st Century", 2001.

them. The system should be able to accommodate differences in patient preferences and encourage shared decision making.

- **Knowledge is shared and information flows freely.** Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.

- **Decision making is evidence-based.** Patients should receive care based on the best available scientific knowledge. Care should not vary illogically from clinician to clinician or from place to place.

- **Safety is a system property.** Patients should be safe from injury caused by the care system. Reducing risk and ensuring safety require greater attention to systems that help prevent and mitigate errors.

- **Transparency is necessary.** The system should make available to patients and their families information that enables them to make informed decisions when selecting a health plan, hospital, or clinical practice, or when choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.

- **Needs are anticipated.** The system should anticipate patient needs, rather than simply react to events.

- **Waste is continuously decreased.** The system should not waste resources or patient time.

- **Cooperation among clinicians is a priority.** Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care.

By listing "patient centred" as one of its six values of health care, IOM is communicating a clear message to the system that this is a critical perspective for health care organizations to take in order to deliver care more effectively. If you look at each of their redesign principles, each one relates back to the patient and the core values of what a patient-centred system is. Health care organizations look to IOM for leading practice thinking on issues within the health care system, and these values and principles are certainly prevalent in reviewing leading practice jurisdictional research as being foundational for organizations making improvements and/or system transformations.

Institute for Healthcare Improvement (IHI): Like IOM, IHI is another organization looked to by the broader health care system for leading practice guidance and strategies on how to shape and improve the health care system. IHI has also developed a body of knowledge on what it means to be a patient-centred system, and has a section on its website dedicated to patient centeredness where providers can look for examples of leading practice tools, strategies, approaches, and success stories related to

patient-centred organizations. In a recent article, Don Berwick, President and CEO of IHI, shared his definition of what patient-centred care is:[14]

"The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care."

Berwick also shared in this article his perspective on how a system under this definition might be different:

- Hospitals would have no restrictions on visiting -- no restrictions of place or time or person, except restrictions chosen by and under the control of each individual patient.
- Patients would determine what food they eat and what clothes they wear in hospitals (to the extent that health status allows).
- Patients and family members would participate in rounds.
- Patients and families would participate in the design of health care processes and services.
- Medical records would belong to patients. Clinicians, rather than patients, would need to have permission to gain access to them.
- Shared decision-making technologies would be used universally.
- Operating room schedules would conform to ideal queuing theory designs aimed at minimizing waiting time, rather than to the convenience of clinicians.
- Patients physically capable of self-care would, in all situations, have the option to do it.

MCG Health System, Augusta GA: The MCG Health System began its transformation to becoming patient-centre in 1990 when they were designing a new children's hospital. They invited patients and family members to serve as committee members to assist with planning and designing the new hospital. The results of the inclusion of patients and family in the design process are still evident in the physical plant, as well as the policies, programs, and services offered by the hospital. The patient satisfaction ratings within this hospital are still among the highest as measured by Press Ganey.

MCG Health System has made a real commitment to delivering patient-centred care by continuing to include patients and family on advisory groups, and by engraining the values within staff that patient-centre care means developing partnerships with patients and their families.

[14] Don Berwick. "What 'Patient-Centered' Should Mean: Confessions of an Extremist", Health Affairs, May 2009.

Most recently MCG involved patients in the planning and redesigning of a new adult neuroscience unit, and even involved the patients in interviewing prospective physicians and nurses who were to be hired into the unit. After converting this unit to a patient-centred care model, patient satisfaction improved significantly, staff vacancy rate dropped from 7.5% to zero, and there were RNs who were waiting for openings to become available within the unit. MCG also enjoyed some positive performance improvement outcomes – length of stay for neurosurgery patients are cut in half, discharges increased by clinical outcomes by 15.5%, and medication errors decreased by 62%.[15]

Dana Farber Cancer Institute, Boston MA: Dana Farber has adopted the Institute for Family-Centre Care's cover values – *dignity and respect, information sharing, participation, and collaboration* – into its organizational values and strategies. Dana Farber firmly believes in the value that patients and their families bring to the delivery of health care services, and that they should be treated as equal partners in their care. At this leading cancer institute, patients are actively participating in how they approach care through their participation in Patient and Family Advisory Councils (PFACs), which are made up of patients, families, and staff members. Through this forum, patients are speaking with and collaborating with clinical staff, and are sharing their ideas and experiences with the hospital with the aim of improving the care is delivered. Patients have the opportunity through these committees to participate and provide input for a myriad of topics/issues including: organizational policies, continuous improvement, educational programming, recruitment, quality improvement and risk management. Patients are also provided with the opportunity to participate in the evaluation of quality improvement initiatives – making them a critical voice in the design, implementation, and evaluation of improvements, all from the patient's perspective.

Alaska Native Medical Center, Anchorage, AK[16]: The Alaska Native Medical Center is a tribally-owned health care system that serves Alaska Natives and American Indians. The Southcentral Foundation (SCF) at the Alaska Native Medical Center in Anchorage was designed from the ground up by its customer-owners. The hospital has very deliberately called their 'patients', 'customer-owners' because it sets the tone for patient-centred care by establishing that patients are not at their institution to be cared for, but to partners in their care and are receiving a service (health care) not as a visitor, but as an owner in the hospital. This customer service oriented philosophy is at the heart of their organizational values, where their customer-owners drive everything from the design of the physical space to the integration of traditional healing and tribal doctors into their processes. The values identified by the customer-owner that are important to them – such as being culturally sensitive to their traditions and beliefs – are considered and integrated into care planning and are used to help people and their families set health-related goals. An example, Douglas Eby, Vice President of Medical Services, statues that; "In Native cultures, grandparents are responsible for passing on important traditions to their grandchildren. So

[15] Hospitals and Health Networks Quality Update – "Engaging Patients & Families: A High Leverage Tool for Health Care Leaders", August 2006.

[16] http://www.ihi.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/ImprovementStories

with an individual who is diabetic, for example, we would try not to say, 'You need to lose weight and stop smoking.' We might say, 'If you are going to teach your grandchild to fish, you will need to feel the bottom of the river with your feet, and controlling your diabetes will keep your feet healthy.'"

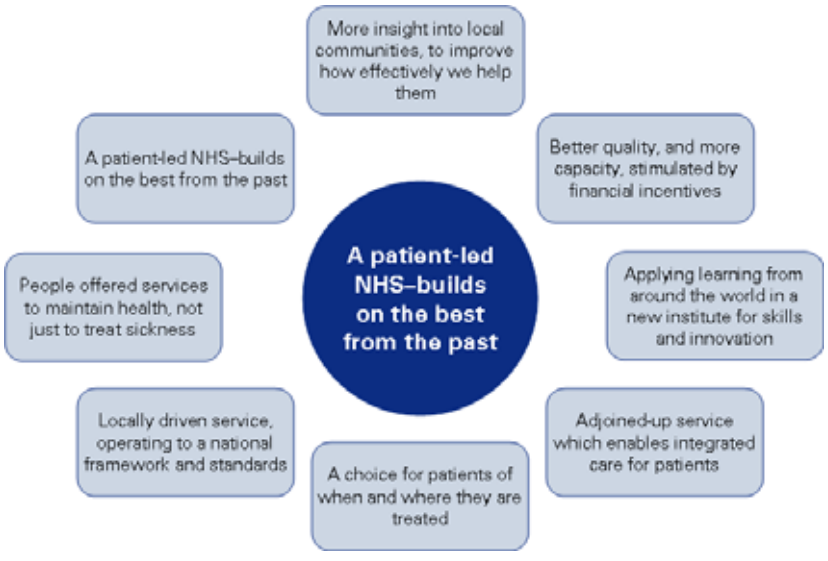
Since implementing the patient-centred approach, the hospital has reported that patient satisfaction is not the only benefactor from this approach. Their hospital has seen the number of days stayed in their facility go down 40 percent over the past seven years, and have seen a reduction in their per capita costs year over year.

6.2.3.3 International

United Kingdom: Always on the leading edge of health care reform, the NHS completed in 2005 as part of its overall Improvement Plan a strategy on how to create a patient-led NHS. The strategy starts out by acknowledging the systems' efforts to make improvements to the quality of health care services through improving access, increasing capacity, reducing wait times, decreasing mortality rates, and increasing patient safety. Having enjoyed many accomplishments through these and other improvements, the NHS recognized the importance of shifting their thinking to patient-centred, patient-led care.

"… the ambition for the next few years is to deliver a change which is even more profound – to change the whole system so that there is more choice, more personalized care, real empowerment of people to improve their health – a fundamental change in our relationships with patients and the public. In other words, to move from a service that does things to and for its patients to one which is patient-led, where the service works with patients to support them with their health needs."

The model laid out in the strategy is illustrated in the diagram below[17]:



[17] NHS. "Creating a Patient-led NHS. Delivering the NHS Improvement Plan". March 2005.

NHS is also tackling large-scale system transformation through the design of a constitution. This constitution establishes principles and values that are to be carried out by the health care system. It establishes the commitments to patients, public, and staff in the form or rights/entitlements, and how the NHS will deliver on those commitments. Lastly, the constitution outlines the roles and responsibilities of the patients and the health care providers and their obligations to each other to ensure that the NHS operations fairly.

The NHS outlined seven key principles as organizational guidelines[18]:

- The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, religion or sexual orientation.
- Access to NHS services is based on clinical need, not an individual's ability to pay.
- The NHS aspires to high standards of excellence and professionalism
- NHS services must reflect the needs and preferences of patients, their families and their caregivers.
- The NHS works across organizational boundaries and in partnership with other organizations in the interest of patients, local communities and the wider population.
- The NHS is committed to providing best value for taxpayers' money and the most effective and fair use of finite resources.
- The NHS is accountable to the public, communities and patients that it serves.

The principles outlined in the constitution serve to reinforce the NHS's patient-led strategy, and are consistent with leading practice views of what a patient-centred system looks like.

6.2.3.4 Jurisdictional review conclusion and lessons learned

Based on a high level scan of Canadian, US, and UK jurisdictions, there is sufficient evidence of health care organizations and systems taking who are taking patient-centred approach. Based on the results of this research, the US and UK appear to be taking more of a leading role with organizations such as IOM, IHI, Centre for Family-Centred Care, and NHS spending considerable time and resources in developing strategies and approaches for becoming patient-centred. This system-wide perspective provides health care organizations with a body of knowledge and tools to assess the merits of being patient-centred, and to begin planning the implementation of patient-centred initiatives.

Within Canada there appears to be only isolated pockets of explicit patient-centeredness within health care organizations. With the exception of the reference to Health Canada and their views on interprofessional care as being a patient-centred approach, there does not seem to be any organizations

[18] NHS. "Constitution. A draft for consultation, July 2008"

– government or otherwise – who are taking a holistic and system wide view of patient-centred care. Our recommendations provided later in this chapter on how Saskatchewan could implement patient-centred care takes this system wide perspective. If the Province commits to tackling this issue Provincially, Saskatchewan will position itself as thought leaders in Canada.

The lessons learned from the research that can be applied to the planning, design, and implementation of a patient-centred system are as follow:

- **Leadership must be fully committed** – in order to shift organizational attitudes and behaviours from current practices to a patient-centred model, the direction must be established from the top, and must permeate through the entire organization. Leadership must be willing to make a long term commitment, and must define what being patient-centred means to their organization. The strategic directions must be reflected in all aspects of the organization including clinical processes, human resource management, education and training programs, corporate communications, as well as performance management.

- **A paradigm shift is required on how patients are viewed** – *"It's a change in thinking from serving patients and families to partnering with patients and families." (Pat Sodomka, Senior VP, MCG Health System)* This quote from an executive that is currently running and patient-centred hospital is consistent with what was read in the research, that a shift in thinking needed to happen with organizations and their staff. That shift is going away from the traditional view of the patient as being someone who is visiting a health care professional to be cared for, to a patient-centred view of the patient as an equal partner in the care team. Patients want to feel like they are able to provide input into their own care, that they have options and choices to make, and that they are treated as equal partner ***working with*** a health care team rather then being ***worked on*** by health professionals.

- **The core concepts provided by the Institute for Family-Centred Care encapsulate what it means to be patient-centred** – Organizations such as IHI and IOM have done an extensive amount of work on defining what it means to be patient-centred. The Institute's core concepts really resonated with the collective thinking across Canada, US, and the UK on what patient-centred care means. Their four concepts of dignity and respect, information sharing, participation, and collaboration could be easily applied and overlaid onto system thinking, and will serve as a set of simple and useful guidelines for any organization looking to become patient-centred.

- **Patient and family participation on committees** – this was one of the primary methods used to shift the culture of organizations to become patient-centred. Involving patients and their families is a powerful mechanism for them to provide input into the design of how health care is delivered. Organizations had patients involved in providing input to many facets of health care delivery including the design of physical plants, policy, training, and safety/quality initiatives. In addition to the day-to-day behaviours needed to be patient-centred, this seemed to be an effective and meaningful way to instill the values of a patient-centred culture into the organization but allowing by

showing staff that patient and family input into how health care is delivered are important, and even critical perspectives.

- **No system is the same** – while general guidelines for patient-centre models are helpful, each organization should engage in a process of engagement with their patients and families to understand what they value in the delivery of health care. No "one size fits all" when it comes to health care delivery models, so an organization should be diligent, and start the process of inclusion early in defining the strategy, by taking the time to understand what patients want and expect from them.

- **Clinical performance benefits can result from being patient-centred –** being patient-centred sounds on the surface to be "touchy feely" and not easily translatable to clinical outcomes. The body of evidence is showing that not only are patients' satisfaction ratings going up in patient-centred systems, but organizations are enjoying actual performance benefits (e.g. reduced length of stay, increased discharges, etc.). Being patient-centred should be thought of not only as a means to make patients feel better about their experience, but also to achieve improvements in safety, quality and performance.

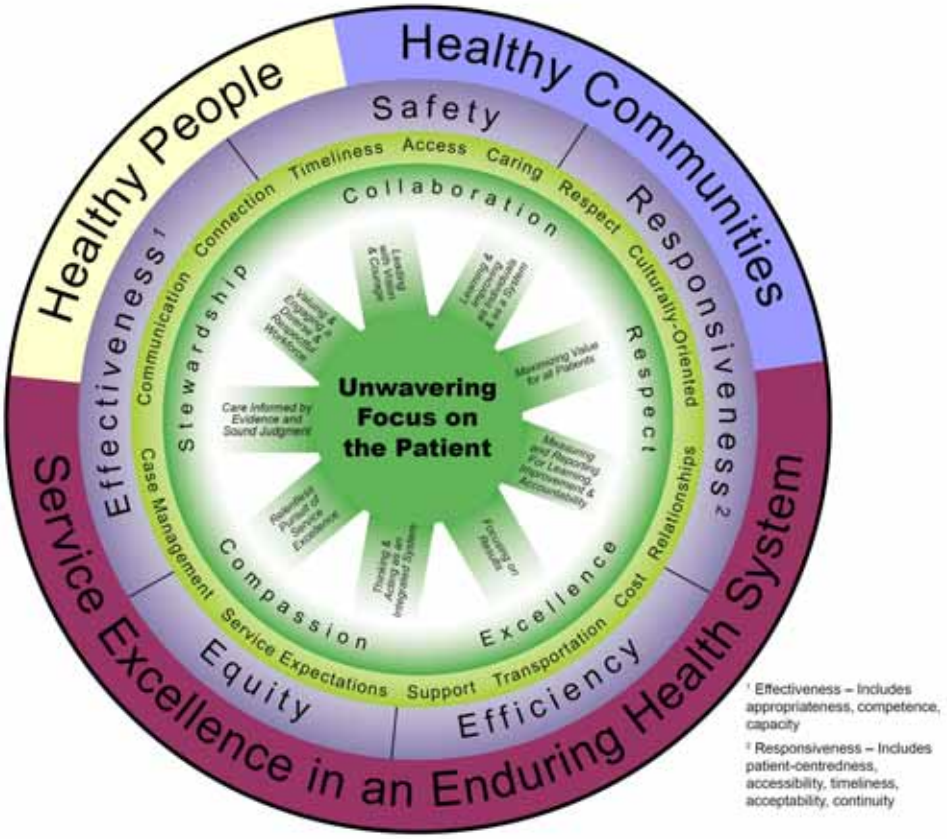
- **Improvement opportunities are broad and organization-wide –** in order to transform the organization to become patient-centred, changes and improvements are needed in areas that span the entire health care organization. Care delivery models must be reviewed and redesigned, building/space improvements can be made, new building constructions should be influenced by patient-centred principles, HR policies should be reviewed and updated, and performance management systems should reflect patient-centred care criteria. Becoming patient-centred is a journey that will take each organization many years to make all the necessary changes. This reinforces the point make earlier around leadership making a long term and deliberate commitment to this transformation.

6.2.4 Saskatchewan – Making the shift

As demonstrated by the analysis completed in Section 6.1 which demonstrates the benefits to the patient of having a patient-centred system, and the leading practice research supporting and providing evidence of other jurisdictions/organizations undertaking this transformation, there is strong merit to the Province's desire to become more patient-centred. In fact, the Province has already taken the first and most important step for transforming their health care system to become patient-centred – it has acknowledged that the system in its current state is not patient-centred. Through the conduct of the Patient First Review, the Province is sending a message to providers, stakeholders, the public, and the patients of the health care system that they are prepared to embark on a system wide change that will see the delivery of health care services become more patient-centred. The Patient First Review has also started the process of gathering the input necessary for the development of the Patient First Strategy by seeking input from the patients on what they like and don't like about this system. The research in

Sections 3 – 5 provides the Province with a solid foundation from which to build upon as it moves forward with defining what patient-centred means to Saskatchewan's system.

The Province has also taken an important second step in its transformation by undertaking a strategic planning cycle that is centred on their unwavering commitment to patients. An illustration of the strategic directions for the healthcare system from 2009/2010 – 2011/2012 is shown below:



As demonstrated by the Province's draft strategic plan diagram, the MOH is taking a patient-centred view of how it plans the improvements that are to be made within the system. Having "Unwavering Focus on the Patient" at the centre of the strategic plan provides focus within the Ministry on why system improvements are needed – to improve the patient experience.

The three bars that make up the outer layer of the diagram above are the MOH's vision for health system planning – healthy people, health communities, service excellence in an enduring health system. Within each of these pillars, the Ministry is planning and designing specific health system improvement initiatives with the overarching goal of improving the delivery of care while improving the patient experience. In the design of these initiatives the Province is integrating patient-centred concepts and approaches into their strategies and plans.

With the conduct of the Patient First Review, the strategic planning the MOH has completed that is centered around the patient, and the initiatives that are being planned with specific focus on patient-centred practices, the Province has taken some meaningful steps towards building a foundation for change.

With these stepping stones in place, the Province has a basis and a meaningful starting point for their overarching goal to shift the health care system to one that is patient-centred. The next section of this chapter provides KPMG's recommendations on how the Province can approach the system to ask its health care organizations and providers to adopt the values and practices of patient-centred care.

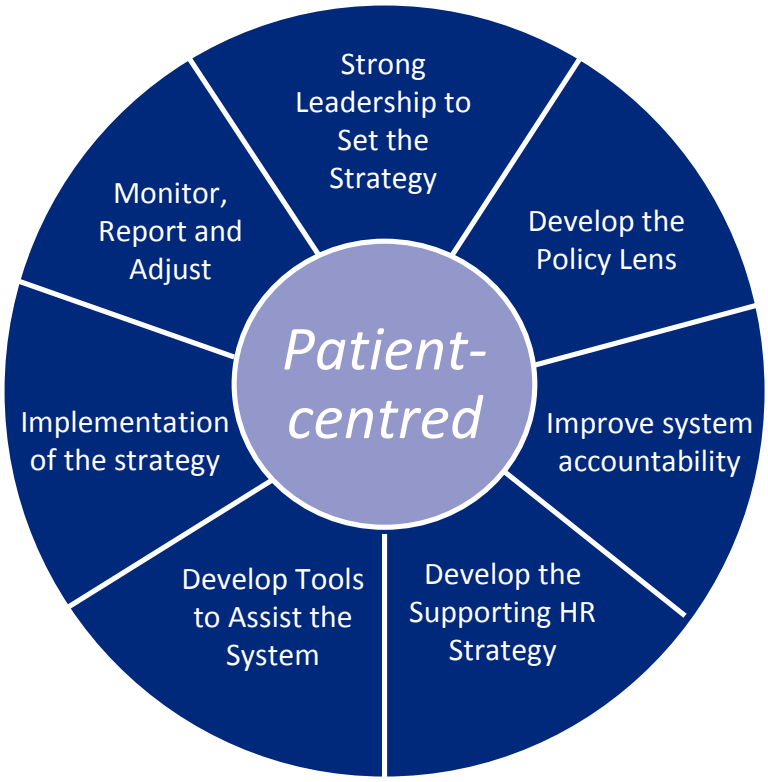
6.3 Saskatchewan Patient First Strategy

In this chapter we have provided a summary of the negative patient experiences and how those experiences might have been different if the system was patient-centered. We then provided a high level jurisdictional scan which provided a sample of actual patient-centred implementations within health care organizations, as well as some leading practice thinking from organizations such as IHI, IOM, and the Institute for Family-Centred Care. A summary of the Ministry of Health's strategic planning process and its alignment with patient-centred care was also described, further demonstrating the Province's commitment to becoming patient-centred.

With all of the research from Sections 3 – 5 on patient experiences, causes, and possible solutions, and Sections 6.2 providing validation that being patient-centred is the right approach for the health care system, the question that needs to be addressed is – How should the Province of Saskatchewan approach the transformation of the entire health care system to become patient-centred?

In Section 6.3 we provide our recommendations to the Commissioner for how the Province could approach the implementation of such a large, significant, and long term transformation. Our recommendations are based upon our experience in working with clients to implement large scale health care system transformations, the insights gained from the research conducted by the Patient First Review, and upon key lessons learned from the jurisdictional scan. Our recommendations are focused specifically on how the Province could approach the implementation of a system-wide patient-centred model. Our recommendations do not provide specific direction on how health care organizations themselves can become patient-centred, though some tools and guidelines will be presented that can be used in this capacity.

The conceptual model that will be used to guide our discussion is illustrated below and later described in detail:



6.3.1 Strong leadership that sets the strategy

"Patient- and family-centred care is a journey, it's not a project. This is a person-by-person change; it's a change in your culture. It's a change in the mindset of the leaders of the organization as well as the staff. It's something that over time will amaze you on what it will do for your hospital."[19]

The quote from Pat Sodomka, Senior Vice President of a large US hospital that has gone through the transformation of becoming patient-centred, provides an appreciation for the scope and magnitude of what is involved in shifting an organization's culture from one state to another. In order to transform an organization to become patient-centred, changes and improvements are needed in areas that span the entire health care organization. Care delivery models must be reviewed and redesigned, building/space improvements can be made, new building constructions should be influenced by patient-centred principles, HR policies should be reviewed and updated, and performance management systems should reflect patient-centred care criteria. Becoming patient-centred is a journey that will take each organization many years to make all the necessary changes.

The challenge that lies ahead for Saskatchewan is how to effectively guide an entire system of health care providers to make the necessary changes to their organizations in order to achieve this shift to a

[19] Pat Sodomka, Senior Vice President, MCG Health System

model of patient-centeredness. While there has been a lot of great work already completed within the MOH on shaping their strategic planning and initiatives based on becoming patient-centred, we recommend that the Province establish clear leadership and accountability for shifting the system to a patient-centred model.

We have learned from other large scale system transformations in the health care sector that establishing senior executive leadership is a critical to the success. In Ontario for example, the mandate to role out the Local Health Integration Networks (LHINs) was a daunting exercise requiring an entire system to shift the way they thought and operated away from the centralized control of the Ministry of Health, to the decentralized model where LHINs are making planning and funding decisions at the local level. KPMG recently conducted the "LHIN Effectiveness Review" which was a legislated assessment of how effectively the Ministry has devolved their authority to the LHINs, and how effectively the LHINs are operating in their roles. Through this extensive study we learned that a critical success factor for implementing the LHINs was the strong leadership provided by the Health Results Team (HRT). This team of senior healthcare executives was at arms length from government, and was given the authority to push this mandate forward.

Another example of a successful large-scale transformation was in Alberta in 1993 when the health care system transitioned to a regional model. Regardless of the fact that they have since reversed this regional model to a centralized body of control and decision making, the initial regional transformation was a success due in large part to senior sponsorship by Cabinet. It was Cabinet who defined what the regional model would look like, and pushed it down to the system after carefully planning how it would be implemented. With direction coming from the level of Cabinet, and with the strategy being well defined, the system had a consistent understanding of what the regional model looked like, and how it would be implemented.

In order to provide adequate leadership for this system transformation, we recommend that the Province undertake the following steps:

- **Establish/Formalize Senior Executive Sponsorship** – There is already support within the Ministry at the Minister and Deputy level for the Patient First Review. There is also support from the Regional Health Authorities, the Health Quality Council, and other health care stakeholders and providers. We recommend that the Province formalize this support through the establishment of a *Patient First Transformation Team*. This team will be tasked with establishing the Patient First Strategy on how to transform the system to a patient-centred model, and will also be accountable for the results. This shift will be a long term transformation, which will require this team to lead this system with vision and courage over a long period of time. Given the long term horizon for this transformation, the Province should consider having some or all positions within the team refresh with some regularity (e.g. every 3 years).

- **Define the top-down strategy for patient-centred care in Saskatchewan** – Leveraging the wealth of literature on patient-centred care created by organizations such as IHI, IOM, and the Institute for Family-Centred Care, the Patient First Transformation Team should engage in a formal planning process in order to define patient-centre care in the Province, and to establish what the vision, mission, and goals are for the transformation. The goal of this strategizing is to provide a platform for change that everyone in the system and the public can understand, and have everyone "on the same page" in terms of what is being asked of the system, what the goals and timelines are for the transformation, and what the benefits to the system will be.

- **Involve patients and their families in the development of the strategy** – While a top-down approach to developing the strategy is needed in order to provide the means of implementing the strategy, the system would not begin on a good note if the strategy did not have the "bottom-up" perspectives of the patients and their families/caregivers. In the spirit of being patient-centred, we recommend that the Province formally include patients and their families in the development of the Patient First Strategy. The Province could also consider having patient/family representation on the Patient First Transformation Team as a way to include this bottom-up perspective in the development of the strategy.

- **Recognize that one size does not fit all –** when developing the Patient First Strategy, it should be acknowledged that each region, hospital, long term care facility, and health care organization is unique in many ways. The strategy that is developed should provide the necessary guidelines, tools and direction on the overall strategy and expectations of health care providers to become patient-centred, however the ultimate implementation responsibility should lie with the health care organizations themselves. Each region and organization will have some uniqueness to them which will require customization of a generic approach, and this should be acknowledged in both the design and execution of the strategy. What would be reasonable to expect is to mandate that the providers involve patients and their families in defining their organizations' individual transformation goals and approaches.

With the appropriate leadership team in place – the Patient First Transformation Team – and a well defined vision and delivery strategy, which includes input from patients and their families, the Province will be in a position to begin with some more detailed planned on how to enable/facilitate the system shift.

6.3.2 Develop the patient-centred policy lens

With a defined strategy, vision, and mission in place, we recommend that the Patient First Transformation Team develop a Patient First Policy Lens. The purpose of the Policy Lens would be to provide an analytical framework to assess policies, programs, practices, and improvement projects (in place or proposed) from the perspective of being patient-centred and improving the patient experience. The Policy Lens would be designed to:

- Strengthen the capacity of government, providers, and other health care stakeholder organizations to identify the strength of their patient-centred practices.

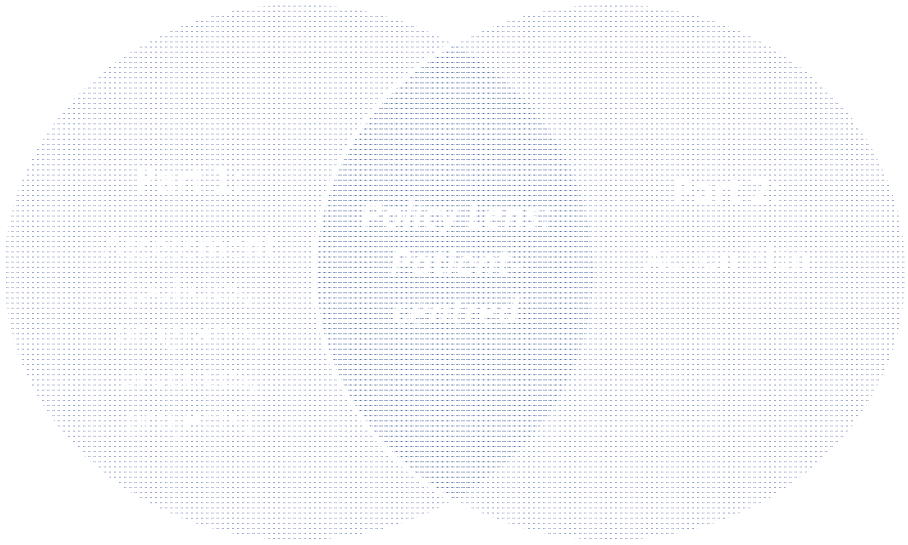
- Provide a method for reviewing current or planned improvement projects (e.g. wait times) to determine if they are designed with a patient-centred perspective in mind.

- Provide a method for identifying ways to improve policies, programs, practices, and improvement projects to be more patient-centred.

There is a tendency in the health care sector to focus on the technical aspects of health care (e.g. hips and knees, wait times, ER congestion), and not on the patient experience. While system goals such as the reduction of wait times are ultimately designed to improve the patient experience by decreasing the time it takes for them to receive their surgery, the patient's experience and journey along the way to get the surgery is not often considered. In a patient-centred system, and with a Policy Lens such as the one suggested here, the system is forced to look at clinical processes from a different perspective. With this lens, wait times will be looked at from many different perspectives in addition to the actual reduction of the wait times: Was the patient provided with an estimate of their wait in a timely manner? Was the patient provided with an explanation of why the wait time was as long as it was? Has the patient been referred to the appropriate care to help them manage their condition while waiting for their surgery? In order for a wait times initiative to be truly patient-centred, these and other questions need to be asked when reviewing policies, processes, current/planned initiatives, and performance management.

When developed, the Policy Lens will ensure that policies, programs, practices and improvement projects are being developed and critiqued based on the correct input and feedback – the degree to which they are patient-centred. The lens stresses the importance of talking to patients about policies, programs and practices that directly affect them. Policy makers, program managers, service delivery organizations, researchers and evaluators, clinicians, and patient advocacy groups are encouraged to use the Policy Lens to evaluate the strengths and weaknesses of their policies, programs and practices, and improvement projects to determine what implications they have upon patients. Moreover, the lens urges them to make patients part of the solution as they seek to address the implications of their policies, programs and practices and make improvements.

The Patient First Policy Lens is illustrated below and later described in detail:



To develop Part 1 of the Policy Lens, the Patient First Transformation Team should be building upon the strategic planning work it did in defining what patient-centred means, and what the goals and objectives are in order to develop a set of questions by which to assess policy/ program / practice/ improvement projects. The questions could be based upon, for example, the Institute for Family-Centred Care's core concepts of:

- **Dignity and respect:**
    - Does our organization and staff actively listen to our patients and their families?
    - Do we provide mechanisms for regular and ongoing feedback from our patients?
    - Have we consciously incorporated the values, beliefs, and cultural backgrounds of our patients into our planning and delivery of care?
    - Will our proposed improvement project (e.g. implementation of electronic whiteboards in the ER) result in our patients and their families feeling like they were treated with respect and dignity?
    - Does our proposed project improve the patient experience at each touch point within our organization?
- **Information sharing:**
    - Do we communicate and share complete and unbiased information with our patients and families in ways that are affirming and useful?

- Do we provide timely, completed, and accurate information to patients and families in order to allow them to effectively participate in care and decision making?
- Do we schedule and complete patient and family follow-ups when we say we will?
- Do we provide our patients with enough information for them to feel comfortable about their care plans?
- Do we view and update the patient record each time we consult with a patient?
- Do we make every effort to ensure that patient information is transferred and received by other physicians/organizations for referrals?
- Does our proposed project consider all touch points in the system for the patient and how information will be exchanged?
- Does our proposed project contribute to the effective flow of patient information?

- **Participation**
  - Do we encourage patients and families to participate in care and decision making at the level they choose?
  - Do we listen to and act upon suggestions from our patients and their families on how to improve our care practices?
  - Do we offer our patients and families options for their care?
  - Are we open to our patients and their families selecting options that we may not feel are best for the patient?
  - Have we included patients in the design of our proposed project?
  - Does our proposed project allow for patient participation in the delivery of care?

- **Collaboration**
  - Do we actively collaborate with patients and their families in the development of policy and program, implementation, and evaluation; in facility design; and in professional education?
  - Do we actively collaborate with patients and their families in the delivery of care?
  - Do we include patients and their families on Advisory Committees?
  - Do we collaborate on the design, implementation and evaluation of process/clinical improvement projects?
  - Does our proposed project encourage collaboration with patients and their families?
  - Is there anything about our project that would prevent collaboration?

Part 2 of the Policy Lens asks organizations to take the information gleaned through the checklists in Part 1, and work towards creating an action plan. Based upon the answers to the questions within the checklist, adjustments can be made to policy/ program / practice/ improvement projects that result in more patient-centred outcomes.

The development of a standardized Patient First Policy Lens will ultimately assist the system with the assessment of their care policies and practices through a patient-centred perspective, and provide direction on where adjustments need to be made. The Lens also allows the system to be able to re-evaluate all current (e.g. wait times) and future/planned initiatives from a patient-centred perspective and allow adjustments to the approach being taken if necessary.

6.3.3 Improve system accountability

In order to truly effect meaningful change in the system to become patient-centred, the Province should redefine and revise the Ministry accountability agreements with the RHA's, and the colleges should do the same between themselves and their health care constituents.

To become patient-centred requires a shift in the attitudes and behaviours of health care workers. To achieve this shift, from current practice to patient-centred practice, the accountability agreements are a critically important lever to motivate the desired behaviours in the system. The need to undertake this exercise underscores the importance of senior leadership who are committed to the transformation, and are willing to push it through the system, which includes the difficult task of changing the way organizations and people are measured.

We recommend the following activities take place to shift system accountability:

- **Revise/update the accountability agreements in the system** – "You get what you measure." This adage certainly applies to the scope of changes required to shift behaviours amongst health care workers. In order to become a patient-centred system, patient-centred criteria and performance measures must appear in health system accountability agreements in order to achieve the desired outcomes. While health care organizations and their staff are well intentioned to provide patient-centred care, there needs to be formal expectations stated within their agreements in order to truly shift behaviours and achieve results. A shift is needed from the current accountability framework which measures primarily dollars and provider performance, to also focus on patient-centred criteria, the patient experience, and overall patient satisfaction. The envisioned strategy will not gain the traction it needs without injecting the patient perspective into these agreements. This will not only shift behaviours, but it will also tie provider accountability more directly to the patients and their level of satisfaction. Example measures that could be included are: communications with patients; helpful and respectful staff; shared decision making; information sharing; self care

management and support; self care efficacy; patient activation; understanding population needs and preferences; and customer service, convenience, and comfort.[20]

- **Provide the necessary incentives to motivate the desired behaviours** – From a provider perspective "you get what you pay for", and to become patient-centred, the system will have to provide the appropriate incentives in order to motivate the desired behaviours. Based upon the changes made to the accountability agreements to reflect patient-centred performance criteria and measures, formal incentives will need to be built into the system that reward providers for conducting patient-centred care. Changes to the funding model will be required in order to pay physicians, for example, not on the basis of patient visits, but rather on a capitation basis. Incentives could be built into the funding model which rewards behaviours for things such as interprofessional practice, case conferencing, improved clinical pathways, patient satisfaction, communication with patients, etc. In Ontario for example, the Family Health Team (FHT) physicians are paid on a capitation basis and not per visit. Physicians that are part of an FHT are also provided with incentive bonuses for patients undergoing certain procedures such as the number of females receiving a pap test (aimed at preventative health).

- **Explore a shared accountability model –** currently providers are responsible and accountable for their specific piece of health care delivery, with no ties to the performance of physicians for whom they might have referred cases, or other professionals they might have consulted. Under a shared accountability model, the health care practitioners will be jointly responsible and accountable for the care a patient receives throughout the continuum. This shared accountability serves multiple purposes including: encouraging interprofessional/team-based care, promotes improved provider/service integration, and motivates behaviours of the providers to take a more holistic view of a patients care across the continuum. To achieve shared accountability, this would require in a shift in the current structures from funder and provider to funder and groups of providers for a specific program or service. For example, instead of having an accountability agreement with a hospital, the accountability agreement would be with a hospital, a long-term care home and a family health team for the provision of diabetes services. Within a shared accountability agreement, the funding could be linked to patient performance targets.

- **Establish reporting mechanisms and processes –** given the scope of this shift, to being a patient-centred model, we recommend that the Province consider monitoring and reporting the results of the patient-centred performance measures in a transparent way. Wait times in Ontario became a political agenda in 2005, and has received a great deal of attention and funding support within the Province. With this public attention comes a desire to see results. You can now visit the Ontario Wait Times site and view ongoing results and achievements in the reduction of wait times across the

[20] Foundation for Accountability. "Patient-centered Care Measures for the National Health Care Quality Report (Defining Patient-centered Care)". May 2000.

Province. Saskatchewan could establish the processes and mechanisms (e.g. a portal) to collect, track, monitor, and communicate the results of patient-centred care performance measures. Efforts must be made to ensure that the data presented is reliable and accurate to have credibility and longevity in the system.

- **Involve the patients and their families in defining the measures –** through the conduct of the Patient First Review, the Province has gained perspective on what issues are important to patients. From this information you could glean from it what measures would be important to track and monitor. We recommend that the Province take this a step further and formally involve the patients and their families/caregivers in the identification and development of performance indicators. A patient advisory group could be created to work with the Province on what measures could be tracked and how they should be communicated/reported. It is important that the measures reflect the cultural diversity of the Province to incorporate, for example, measures specific to how First Nation/Métis patients are cared for in the system.

- **Involve patients in the assessment of provider business cases for funding –** when providers come forward with business cases requesting funding for new programs/buildings, the Province could involve patients in the evaluation of these requests based on patient-centred criteria. If completed, the Patient First Policy Lens could certainly be used as a tool for this type of evaluation.

The redefinition/improvement of the accountability and performance management system will be a critical success factor to achieve patient-centred care. While this system-wide approach is vital to a broader implementation across all health care organizations, individual health care providers can also make meaningful advancements by reviewing its own internal policies and performance management systems.

6.3.4 Develop the supporting HR strategy

The values, principles, and approaches of patient-centred care must be injected into every aspect of the system – this includes the human resources strategy. The Province of Saskatchewan is currently building a 10 year health human resources strategy aimed at addressing, among other things, the following issues: Retention issues – especially physicians in rural, remote areas; Recruitment issues – to address the challenges in attracting talent to Saskatchewan, and especially in rural/remote areas; and Workforce Quality – ensuring that health care organizations are staffed by the highest quality health care professionals. Given the timing of the development of this strategy, we recommend that the Province take a patient-centred approach in its development by:

- **Aligning the strategy to educate health professionals with patient-centre vision, mission, and goals –** either in concert with the development of the overall strategy, or in addition to it, the Province should develop a training and education strategy that is patient-centred. From this strategy the necessary supports to realize the training and education strategy will be developed.

- **Developing provincial patient-centred professional standards –** the standards by which health care professionals are held to in the Province should be revisited and updated to include patient-centred skills, competencies, and behaviours.

- **Developing a patient-centred training and education program –** health care staff working in the field will require significant up front and ongoing training and development on how to approach their jobs with a patient-centred perspective. It is helpful in this context to think of the training needed as a reorientation of providing care to patients to a customer service perspective. Disney for example, provides seminars for health care professionals where they pass along their customer service values and approaches in a health care setting. When you take this course as a health care professional your are taught about how to: Identify how to anticipate the needs, wants, stereotypes, and emotions of your customers/patients in order to exceed their service expectations; bring "personality" to your organization by establishing a service theme and aligning your organizational resources to support it; improve policies, tasks, and procedures within your organization to promote the delivery of quality service to your customers/patients; and create an environment that reflects your organization's commitment to quality and encourages its delivery. Disney's course is but one example of the type of training to take, but does provide a valuable perspective on what being patient-centred means in a health care setting.

- **Integrating patient-centred care practices into the medical school program –** it will be in the Province's interests to influence the course curriculums and clinical work undertaken by medical school systems in order to have students coming into the field that are trained in patient-centred care. For students coming to work from other Provinces or countries, Saskatchewan should build a mandatory patient-centred training course to ensure that all health professionals beginning to work in the Province are ready to provide patient-centred care.

- **Review the scope of practice for health care professionals –** as part of the larger HHR strategy, the Province should also undergo a review of the scope of practice for health care professionals. Through this exercise, scope and roles should be defined within a patient-centred perspective, and opportunities to mandate integrated/interprofessional/team-based models of care should be established. Leading practice suggests that interprofessional care is a key enabler of patient-centred care because of the value patients place on having a team overlooking their care plans.

The transition to becoming a patient-centred system will be a long journey for the Province, and the health care professionals will require supports and training throughout the transition to manage the changes that are being introduced. Developing a supporting HR strategy is another critical success factor to enable this system shift. Similar to accountability, organizations themselves can implement supporting HR strategies and policies to encourage patient-centred care, but we believe strongly that Province should set the direction up front, and let the providers customize to suit their individual organizational needs.

6.3.5 Develop tools to assist the system

In order to facilitate organizations in becoming patient-centred, we recommend that the Province develop a set of tools and templates that will assist health care providers in making changes to their culture, their processes, and their clinical practices. Recognizing that each health care provider within each region has elements of uniqueness, the tools developed should be directional only, and be flexible and scalable to allow for local customization. These tools can be viewed as a starting point for many organizations to be used to begin their patient-centred journey.

- **Self assessment tool** – using the Patient First Strategy as a starting point, the Province should develop a self assessment tool that will be used by health care providers to assess their level of patient-centeredness. This diagnostic tool will provide a starting point for organizations to not only understand what patient-centred means, but also how patient-centred their practices are or are not. The Picker Institute – an international not-for-profit organization that supports the research in the field of patient-centred care – recently developed a patient-centred care improvement guide. Within that guide they provide a comprehensive self-assessment tool that could offer the Province with a valuable starting point. The categories of questions asked within the tool include: Setting the Stage, Strengthening the Foundation; Communicating Effectively with Patients and Families; Personalization of Care; Continuity of Care; Access to Information; Family Involvement; Environment of Care; Spirituality; and Integrative Medicine.[21] These categories of questions are in alignment with the patient-centred core concepts discussed earlier. The categories of questions established, and the questions within those categories, should reflect the vision, mission, and values outlined within the broader Provincial Patient First Strategy.

- **Create provincially mandated patient-centred customer satisfaction surveys** – while many survey instruments exist in the system already, we recommend that they become a formally mandated tool within the system. With revisions to the performance measures to include patient-centred criteria, the Province should develop standard customer satisfaction survey for health care organizations to execute as part of their system accountability agreements. Organizations will become measured by the metrics provided by these surveys and given direction on how to improve their patient-centred care.

- **Provide example terms of reference for patient- and family-centred advisory committees –** leading practice patient-centred care organizations actively involve patients and their families on a variety of advisory committees. Examples of committees that hospitals have patient and families participate in, are for clinical process improvements (design, implementation, evaluation), quality improvements (design, implementation, evaluation), recruitment, and building/layout design. The Province should assist the system with their transformation by conducting further research on what

[21] The Picker Institute. "Patient-Centered Care Improvement Guide". October 2008.

types of committees leading practice suggests patients and their families should be involved with, and then developing example terms of reference so that organizations can action these committees with some guidance.

- **Continued investment in electronic health records and other IT solutions** – patient-centred themes of information sharing, timely access to information, and self-management can be enabled by the implementation of an electronic health record and other IT solutions such as patient portals. While the Province is well underway with its EHR implementations, Saskatchewan should consider this a key enabler of patient-centred care and continue to invest time and resources for implementation. These must be designed and implemented with the appropriated security measures to adhere to privacy regulations.

- **Provide guidance to health care providers on process improvement approaches** – the Province should continue to invest in process redesign techniques such as Lean that aim to improve the delivery of care from a patient's perspective.

- **Develop a Provincial "Patient First Resource Centre"** – this centre would provide research, develop tools, and provide assistance (e.g. via call centre) to organizations implementing patient-centred care practices.

The tools mentioned above are examples of what could be developed by the Province to facilitate health care providers on how they can become patient-centred. We believe that investment in these and other tools are important enablers for a system-wide patient-centred transformation.

6.3.6 Implementation of the strategy

KPMG has provided recommendations on what preparatory work the Province should undertake in order to lay the foundation for change in the system. We have identified the need for a Patient First Transformation Team who would lead the development of the Patient First Strategy, and who would own the accountability for the implementation and results. We recognize however that the implementation of a large-system wide transformation should reside within an organization that is permanent in order establish the infrastructure needed for this long term commitment. This section provides options for where the Patient First Strategy might reside and be implemented from. Based on what the Province decides, the supporting governance structure must be established which would outline the roles, responsibilities, and accountabilities between system stakeholders – the Ministry, RHAs, SAHO, Colleges, the Patient First Transformation Team, etc. – who will be partners in implementation.

- **Option 1, a program within the Ministry of Health (MOH)** – the Ministry represents a logical place for the Patient First Strategy to be driven from. The strategy would have the support of the Minister and Deputy Minister of Health, and provide access to the breadth of resources and infrastructure

needed to drive and sustain the patient-centred transformation. A potential drawback from this approach would be some possible negative perceptions in the system about having government leading a large scale transformation. There is also a perception amongst health care providers that when a program is started up, there is a lot of infrastructure and cost required to set it up, and its felt to be the "flavour of the day", resulting in public and providers being skeptical or cynical about the Program.

- **Option 2, an arms length government agency** – the Province could set up a Patients First Agency who would own and drive the implementation of the Patient First Strategy. An agency that is fully committed to implementing, tracking, and monitoring of the patient-centred transformation would provide a great deal of focus and profile for Patient First, and would establish an organization that would be perceived to be a permanent and long term fixture in the system. This would reflect positively in terms of public perception that this is a long term commitment, and the government is committed to its success. The same potential drawbacks of this approach apply as those stated for the Program option – time, money, infrastructure, and potential negative public perceptions.

- **Option 3, a quality initiative within the Health Quality Council (HQC) –** as an independent agency of the government, the Health Quality Council (HQC) measures and reports on quality of care in Saskatchewan, promotes improvement, and engages its partners in building a better health system. Leading practice suggests that being patient-centred is an effective way of improving quality, and is in fact a quality initiative in its own right. The HQC is therefore a logical organization to own and drive the transformation and sustained efforts required to implement, monitor, and report on the system and its progress in becoming patient-centred.

We have not recommended a preferred option of the three implementation approaches, and there are likely others that should be considered in addition to these. Once the Province makes the commitment to transform the system, there needs to be a great deal of thought and analysis as to how to implement and sustain this change. The main points we want to emphasize in regards to implementation are:

- Being patient-centred is not a project, it's a journey. This journey requires a formal body to drive implementation, to ensure sustainability in the system, and to monitor and report on results against patient-centred performance measures.

- Regardless of the choice that is made, a well established supporting governance structure will be required in order to establish clear roles, responsibilities and accountabilities as it relates to transformation, sustainability, and monitoring and reporting.

6.3.7 Monitor, report and adjust

Becoming patient-centred is not a project, it's a journey. The Province will need to make a significant commitment to this transformation if it wishes to affect change system-wide, and to see the entire health care system become patient-centred. It will be a long term commitment, and will require the focus and attention of staff at all levels of health care organizations and government.

Once health care organizations have begun their journeys to become patient-centred care, the Province needs to be prepared to communicate to the public what the targets are, and then monitor and report on the results on what the progress and achievements have been. Earlier we suggested that the Province should establish a Patient First portal (in the spirit of Ontario's wait times system) to communicate in a transparent way how the system is improving based on the established patient-centred measures.

Throughout this journey there will be a need to adjust the approaches being taken to implement patient-centred care, and perhaps even the measures and how they are tracking them. The Province should be prepared for this long term and continuous improvement initiative. This need for adjustments and continuous improvement underscores the importance of strong leadership, and a permanent organization to own the results and make adjustments as necessary throughout the implementation and while in steady state.

6.3.8 Transformation recommendations summary

At the beginning part of this chapter, we established the case for change, or the burning platform by showing how the results from the research might have been different had the system been more patient-centred. We then showed some leading practice patient-centred implementations to show that patient-centeredness is the direction that many major health care systems are taking, and the positive results that are realized when it is implemented. This analysis served to support and validate the hypothesis that the Saskatchewan health care system is not patient-centred enough, and this is the right direction for the Province to take when transforming the health care system. We then provided the Commissioner with our recommendations on how we believe system-wide change to a patient-centred model can be realized. To summarize, our recommendations to the Commissioner for implementing system-wide change are:

- Establish a team of senior leaders who will have the authority to set a Provincial Strategy, the will to push the change down into the system, and be accountable for the results.
- Develop a policy lens that will be used to evaluate all current and future projects, policies, programs, and practices to ensure they are aligned with patient-centred values.
- Improve system accountability by integrating patient-centred criteria, measures, and expectations into funding and accountability agreements. Changes will also be needed to the funding models to

reflect patient-centred incentives. It is through these two mechanisms that the system can most effectively manage adoption resistance amongst health care providers.

- Develop the supporting HR strategy in order to provide the system with the training, education, and skills required to deliver patient-centred care. Through this strategy the system can also tackle the scope of practice issue in order to encourage interprofessional/team-based care.

- Develop a set of tools and templates to provide to health care organizations in order to assist them with their transformations. "One size does not fit all", so the tools need to be flexible and scalable for organizations of all size, scope, and region.

- The Patient First Strategy should be driven by a formalized organization in partnership with the Patient First Transformation Team in order to implement and sustain the changes.

- The Province should be prepared to monitor, measure, and report on the results of the transformation, and be prepared to make adjustments along the way. This, like many other improvement approaches (e.g. Lean), should be considered a continuous improvement effort and not a point in time solution.

6.4 Solution Recommendations to the Commissioner

The research brought forward hundreds of solution ideas from patients, providers, and system stakeholders on how to fix the issues within the system that are causing negative experiences. This section of the report examines those issues and suggested solutions in summary and provides recommendations to the Commissioner for how the Province could address the primary concerns of its patients. This section provides suggestions for solutions/improvements as suggested by patients and providers which have been communicated to the patients' voice. This section also provides KPMG's recommendations to the Commissioner on how to realize the improvements brought forward from the research, and discusses what the Ministry of Health may already be doing or planning to address the primary concerns of patients.

The primary concerns and issues of dissatisfaction arising from the research from the voice of patients were not regarding the quality of the care they received, but rather with their experience of moving through the health care system itself. They discussed feeling disconnected from their providers, were not always involved in the decision making and that providers didn't always have time for them. Patients also described feeling lost in the system, that it was difficult to navigate and that the coordination among providers and organizations was not always as efficient as possible. Finally, patients also described a frustration with accessing the care they needed whether that be for surgeries, care in the emergency department, or services for rural and remote regions or First Nations and Métis.

These primary concerns are discussed within this following section in the voice of the patient, with a discussion on the options available to the Province to address those concerns. Recognition is also

needed for the work that is currently underway within the Province. Many of these initiatives are helping to move the Province forward and to address many of the concerns raised during the research. This work should not stop. Theses initiatives should continue, but should be refocused within the context of the larger system transformational shift needed to reorient the system to become patient centred as described in Section 6.4. This transformation is a cultural shift that will require significant long-term thinking that emanates throughout every part of the healthcare system. This transformational shift has the potential to address many of the concerns raised by patients throughout the research.

While this transformation is important work, it is a long-term project, but there are things that can be done in the short and medium term to address the concerns of patients. These are addressed in this section and speak specifically to the concerns raised by patients throughout this study.

Solutions identified from patients in the research have been highlighted in this section. The suggested solutions are in the patients words and are assessed with options presented to the MOH. There were hundreds of solution ideas put forward, most of them with merit. Not all of these solution ideas could be brought forward here. A summary of the solution ideas is presented with those that have the ability to resolve issues at a system level. If a solution idea does not appear in the lists within this section, it does not mean that they weren't good ideas. Each solution idea from the research has the potential to improve the delivery of care and the overall patient experience in some way. The KPMG Team has provided the Ministry with a full set of solution ideas that will be kept on file and considered in future planning as appropriate. However, in order to provide the Province with a set of actionable recommendations, it was necessary to filter the list of solutions based on the following criteria: feasibility, potential impact and alignment with leading practices.

This section comprises the following analysis within each category of improvement:

- **Solution ideas from the research and options for moving forward** – identification of some of the solutions brought forward from the patient research that could have a material impact in addressing the issues within each category of improvement. These solutions have been articulated in the patient's voice.

- **KPMG's recommendations** – for each of the solution ideas brought forward (in the patient's voice), KPMG has provided our recommendations to the Commissioner for how these solutions could be implemented. Recommendations have been coded and numbered for ease of organization and analysis. Each category of improvement has a corresponding acronym, followed by a recommendation number. For example, recommendations within the "Access to safer care" category would be coded ASC #1, ASC #2, ASC #3, etc.

- **Impact Analysis** – for each solution, we have provided the positive impact it could have on the patient experience if they were implemented.

- **Impact/effort analysis of recommendations** – for each recommendation, we have assessed the level of effort to implement (low, medium, high) versus the impact on the patient experience (low, medium, high) and have plotted them on an implementation assessment matrix. This information provides the Commissioner and the Province with a high level understanding of where to focus efforts and resources. For example, recommendations that are low effort and high impact could be considered "low hanging fruit", and could therefore be considered for immediate or short term implementation.

It is important to note that while recommendations for solutions have been provided due to their potential impact on making improvements to the delivery of care and the patient experience, each solution will require investigation and research prior to implementing. Health care solutions are not "plug and play", and so it is recommended that the Province undertake an investigation into the appropriateness of each solution, how it would be implemented, and the level of effort that would be required before making any decisions to move forward with these recommendations.

Many of the solutions brought forward by patients and providers are excellent ideas that will make real change in the Saskatchewan healthcare system. Many of these solutions will need to work in tandem and should form part of an over-arching strategy to address the needs of patients. To this end, it will be important for the MOH to assess the patient journey from end-to-end from a systematic viewpoint to first assess the feasibility of the solutions, and to consider how they apply from a systems perspective, analyzing the impact they will have on immediate issues and the impact they will have on the broader system.

6.4.1 Category One: Improving the quality of patient interaction

Patients described a frustration with their interactions with providers. They sometimes felt short-changed when going to visit the doctor, that all their concerns weren't raised or addressed. They also felt they weren't involved in the care decisions that were made. There were also those that experienced rude or inappropriate behavior. It is these themes that are explored below.

The following table presents the desired system changes voiced by patients and recommendations for how to achieve them.

Solution Ideas for improving the quality of patient interaction (QPI)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Change the way my physician interacts with me, allowing me more time to explain all my concerns and allowing him/her time to explain my full range of options for care	**QPI #1:** Provide incentives / remove disincentives for providers to have longer visit times and engage patients in a discussion about their care options: • Incentives can be a powerful lever to change/motivate behaviours • Need to integrate patient-centered criteria into payment model to incent physicians to improve their patient interactions at every touch point **QPI #2:** Move towards more inter-disciplinary team-based care that leverages physician resources and increases the time available for patients: • Help build capacity in primary care in the areas of disease prevention, rehabilitation and patient self-management • Integration between primary care and specialist services in the community can be strengthened • Improves the quality of the patient interaction when a "team" of professionals are taking a holistic view of a patient's care plan • Also promotes better system access and integration	• Patients concerns are heard and their time is used efficiently • Patients feel part of a team that is collectively working towards meeting their healthcare goals • Patients access to care is improved by leveraging existing resources
• Provide me with someone I can talk to who is familiar with my care and who can help guide me through the system	**QPI #3:** Increase access to Case Management / Advocates • Effective roles to assist patients to communicate with and navigate through the system • Case managers provide patients with someone who "owns" their case and can take a holistic view of their care and help navigate the system • Patient advocates act as a liaison between patients and the system to help them the details of their care plan – this helps to reduce fears the patient may have, increasing patient compliance, and overall improved delivery of care	• Patients feel they always have someone they can talk to who can provide them guidance and advice • Case managers can also be effective at helping higher-risk individuals maintain their health and reduce complications • Advocates can help patients throughout their care journey at each touch point to increase the value of each interaction
• Provide me with information at every stage of my care journey, especially on how long I have to wait and why I have to wait	**QPI #4:** Communicate estimated wait times in Emergency and for surgery shortly after a surgical decision is made, and support patients through their wait • Improve communications with patients to take out the "not knowing" factor from their care – a source of stress and anxiety for most patients • Wait times are inevitable, but patient care during	• Patients are reassured that their care is scheduled and can mentally prepare themselves for the wait • Patients can more effectively plan their care and their lives while they wait for services

Solution Ideas for improving the quality of patient interaction (QPI)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
	that wait is extremely important and primary care teams can work together to provide patients with the care they need while they wait	
• Improve your communication with me throughout my care journey, especially letting me know who each provider is and their assigned role	**QPI #5:** Provide mandatory staff identification badges that clearly identify who they are and their position in the organization • In addition, train staff to introduce themselves to patients upon arrival in their room or at first greeting	• Patients are greeted warmly and by courteous staff and have an understanding of who is providing their care • An introduction by staff provides a basic understanding of the provider and sets up for more appropriate care conversations

The solutions suggested by patients and providers throughout the research can help to address the needs of patients, to connect them more intimately with care providers. To address their concerns patients are asking for more face-to-face time with providers, and an enriched relationship with providers.

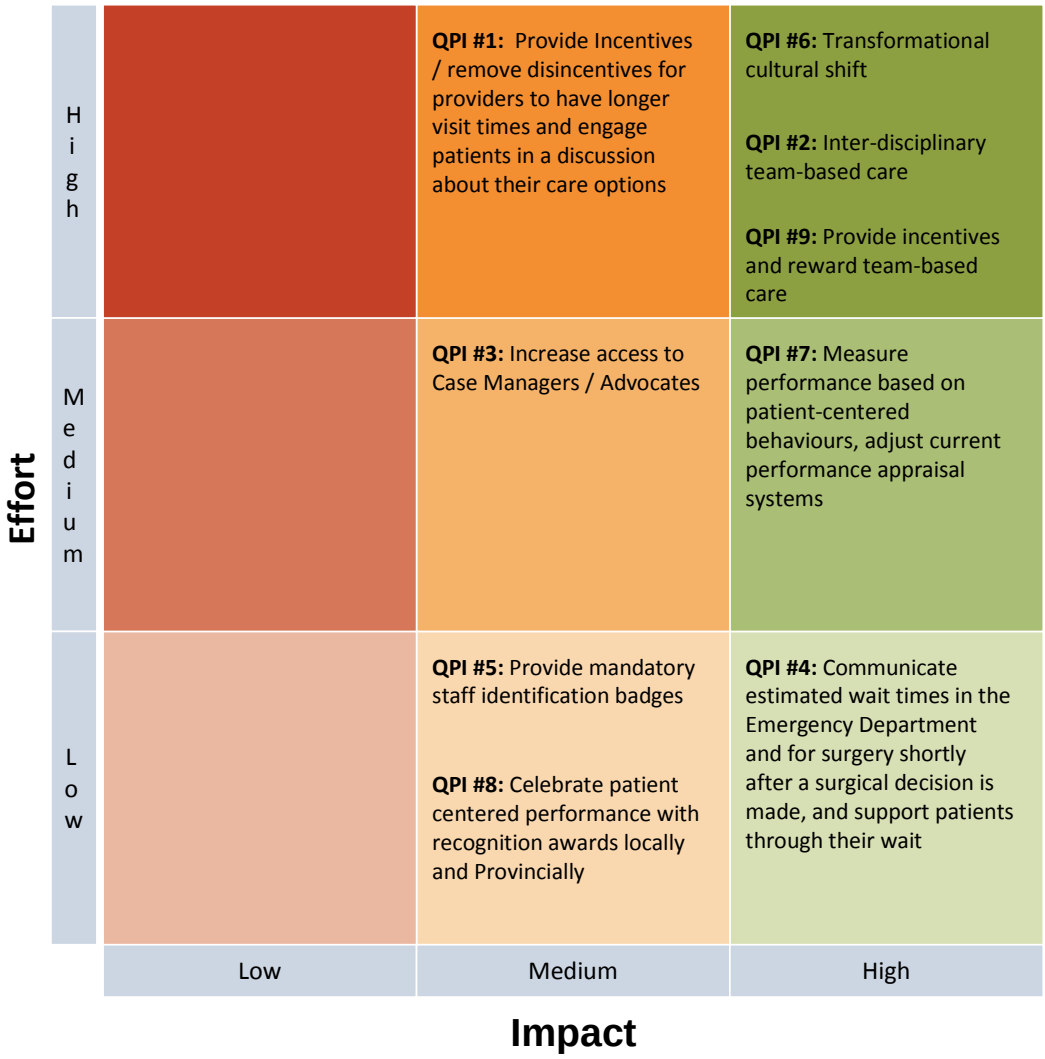
Recommendations to address these concerns as discussed in the table above can include ways to provide incentives to providers or remove current disincentives to providing that type of care. This may include increasing the time a physician visit is expected to take, and working with the college to lay out the expectations for what a visit would entail and what the conversation may look like that includes engaging the patient in a holistic discussion.

Other options that may help to build on those discussed above include the following:

- **QPI #6:** Transformational shift to being patient-centred **–** in order to change the way health care workers interact with patients, a shift in attitude and behaviour is needed. We discussed this shift in detail in Section 6.4, but organizations should shift their delivery models to be based on patient-centred practices, and should begin tracking patient-centred criteria.
- **QPI #7:** Measure performance based on patient-centred behaviors; adjust current performance appraisal systems for providers to include patient-centered behaviors that align with patient-centered values.
- **QPI #8:** Celebrate patient-centered performance with recognition awards locally and provincially.
- **QPI #9:** Provide incentives and reward team-based care, e.g. pay providers for case conferencing and collaborative care, working together to reach shared provider-patient goals.

The recommendations to address the quality of the patient interaction are plotted on the graphic below to compare the level of effort and the impact on improving the quality of the patient interaction. Those

that are high impact and low effort can be implemented immediately in the short term (e.g. communicating estimated wait times). Those that are higher impact with higher levels of effort will require more rigor and will likely be accomplished in the longer term (e.g. inter-professional team-based care).



6.4.1.1 Summary

The recommendations provided above should be considered within the planning work that the Province is currently undertaking to improve the quality of the patient interaction. The Ministry is currently investigating/planning initiatives that are aimed at:

- Building capacity and capability amongst health care providers to undertake quality initiatives with a patient-centred perspective.

- Developing eHealth tools such as websites and portals to improve the flow of information between and amongst the system providers and patients.

- Developing strategies aimed at specific population groups within the Province such as First Nation/Métis and urban/rural residents.

The Province is undergoing a detailed strategic planning exercise that will outline specific projects/initiatives aimed at improving the quality of the patient interaction. When implemented, they will help to address provider-patient interactions by providing training to leadership and staff throughout the system and focusing on what it means to provide care from a patient perspective. In addition to recommendations mentioned above, the Province must also address the larger-scale issues related to the culture of patient care. This will require a broader strategy aimed at shifting the culture of care. A framework for this strategy was provided in Section 6.3, and is concerned with reconciling what was heard most frequently from the patient and provider research: that patients were fairly satisfied with the clinical care they received, they were unsatisfied with the journey and interactions with providers on that journey. Within this framework there are opportunities to leverage physician resources that include an expansion of interdisciplinary team-based primary health care. These care teams have demonstrated improvements in access to primary health care and can make efficient use of limited clinician time.

6.4.2 Category 2: Improving system integration

The following table presents the desired system changes voiced by patients and recommendations for how to achieve them:

Solution Ideas for improving system integration (SI)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Give my doctor tools to communicate more effectively with my specialists and other healthcare providers so I no longer have to repeat my self continuously and my information is not lost between them	**SI #1:** Build on current information technology infrastructure to expand the use of an Electronic Health Record (EHR) • EHR is a key enabler for system integration to link patient's information between primary health, acute care, community care, etc. • Improves patient and provider access to information • Can increase the efficiency and effectiveness of care delivery by having real time access to information • Improve the quality of the patient interaction through improved communications	• Electronic Health records have been shown to improve patient safety and reduce redundant diagnostics and testing • The patient experience is improved because providers from across the system can access the same information providing improved quality of care

Solution Ideas for improving system integration (SI)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• As a patient with chronic diseases, improve the way my providers work together to help me reach my care goals	**SI #2:** Expand access to inter-professional care teams • Improves patient flow from primary care to the areas of disease prevention, rehabilitation and patient self-management • Integration between primary care and specialist services in the community can be strengthened • Also promotes better system access and improved patient interaction **SI #3:** Develop cross-continuum programs focused on specific patient populations (e.g. Diabetes) with shared accountability for patient outcomes • Could be developed for: chronic diseases, mental health and addictions, seniors with complex needs, and other chronic users of the system • Programs include providers from across the continuum of care (team-based care) that come together to plan care processes together with common management and shared performance measures • Reduces potential navigation issues if there is a team of providers taking a holistic approach to a patient's care • Programs are enabled by shared information technology and shared patient records	• Patients feel supported by the care team and are able to more easily maintain their health • Complications are due to chronic disease are reduced and the overall patient experience is improved
• Improve the coordination of care between my hospital stay and home care	**SI #4:** Standardize discharge planning processes • Standardized discharge planning standards would result in consistent processes for discharge planning • Care plans after discharge should be developed and communicated to patients, and connections in the system should be made so patient is not "lost" in the system • Homecare should be involved in the process upfront; notified if a patient is admitted who is already receiving home care and advanced planning and sharing of information for those not already on home care	• Patients are fully informed about the net steps and the requirements for providing care for themselves and through home care for their recovery after hospital care • Patients know who to call if care has not been arranged appropriately

The options discussed in the table above will help to address the concerns raised by patients about feelings of being lost in the system and the poor coordination among providers for their care. These options and others are discussed below:

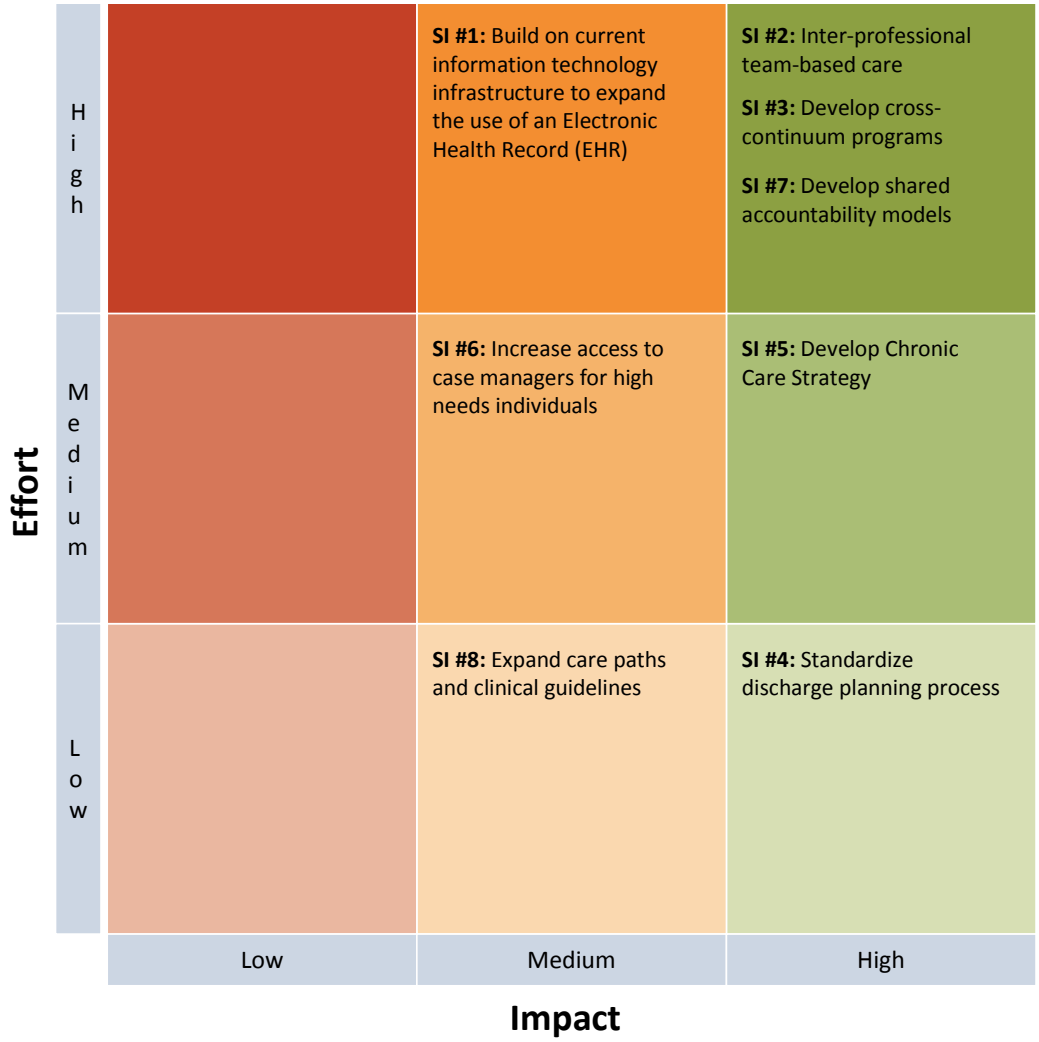
- **SI #5: Develop a Province-wide chronic care strategy.** The strategy would focus on the needs of specific patient populations and find ways to meet their needs. The strategy should also include the identification of individuals at high-risk of developing chronic diseases and effective measures to help them maintain their health and prevent chronic diseases.

- **SI #6: Increase access to case managers for high needs individuals.** Patient needs are not uniform. Those with high care needs for chronic conditions or other reasons may have difficulties maintaining their health. Case management models have been effective at identifying those individuals with high intensity needs and assigning case managers to help them access the care they need and remind them of self-management practices. In the content of improved patient interactions, using a case manager / patient navigators to assist and advocate for patients can greatly assist with navigation through the system. Given the scope of this solution, we suggest initially focusing on those with intensive needs. These should be viewed however as a stop-gap measure when the "system" is not functioning as it should. A well-integrated system will reduce, but may never eliminate the need for system navigators.

- **SI #7: Shared accountability**. Under a shared accountability model, the health care practitioners will be jointly responsible and accountable for the care a patient receives throughout the continuum. This shared accountability serves multiple purposes including: encouraging inter-professional/team-based care, promotes improved provider/service integration, and motivates behaviours of the providers to take a more holistic view of a patients care across the continuum. Shared accountability is a mechanism that can enable integrated cross-continuum programs.

- **SI #8: Expand care paths and clinical guidelines.** Care paths and clinical guidelines designed for both excellence and the patient experience.

The recommendations to address system integration are plotted on the graphic below to compare the level of effort and the impact on improving integration across the healthcare system. Those that are high impact and low effort can be implemented immediately in the short term (e.g., standardizing the discharge planning process to integrate with the community). Those that are higher impact with higher levels of effort will require more rigor and will likely be accomplished in the longer term (e.g., expanded use of Electronic Health Records).



6.4.2.1 Summary

The recommendations provided above should be considered within the planning work that the Province is currently undertaking to improve system integration. The Ministry is currently investigating/planning initiatives that are aimed at:

- Building capacity and capability amongst health care providers to undertake quality initiatives with a patient-centred perspective that are aimed at improving system integration.
- Developing eHealth tools such as websites and portals to improve the accessibility, management and sharing of patient information along the continuum of care.
- Developing strategies aimed at specific population groups within the Province such as seniors and other chronic disease groups.

The Province is undergoing a detailed strategic planning exercise that will outline specific projects/initiatives aimed at improving system integration. Designing projects aimed at improving system integration and therefore integrating care can go a long way towards improving the overall care experience for patients. It is important to focus on particular care paths to assess and find opportunities to integrate along that continuum (e.g. Mental Health and Additions, Chronic Diseases, Seniors with Complex Care Needs and Surgical Care Pathways). The mechanisms that can help providers communicate amongst each other more effectively and with patients can help to alleviate the feelings of being lost in the system. Integration itself should be a core strategy whereby clear goals and targets are established and linkages are developed between providers and organizations that eliminate or reduces the need for system navigators.

6.4.3 Category 3: Improving access to safer health care

Throughout the research, patients indicated they were frustrated with access to care. This reached across the healthcare system to include surgery, emergency care, mental health and addictions, services in rural and remote areas, services for First Nations and Métis, and Geriatric and Long Term Care. The solutions put forward by patients primarily involve increasing the capacity and availability of services in all of these areas. While this may indeed be part of the solution, a more fulsome analysis is required in each of these areas, to assess from a system perspective whether or not access can be improved before additional resources are employed.

The following table presents the desired system changes voiced by patients and recommendations for how to achieve them:

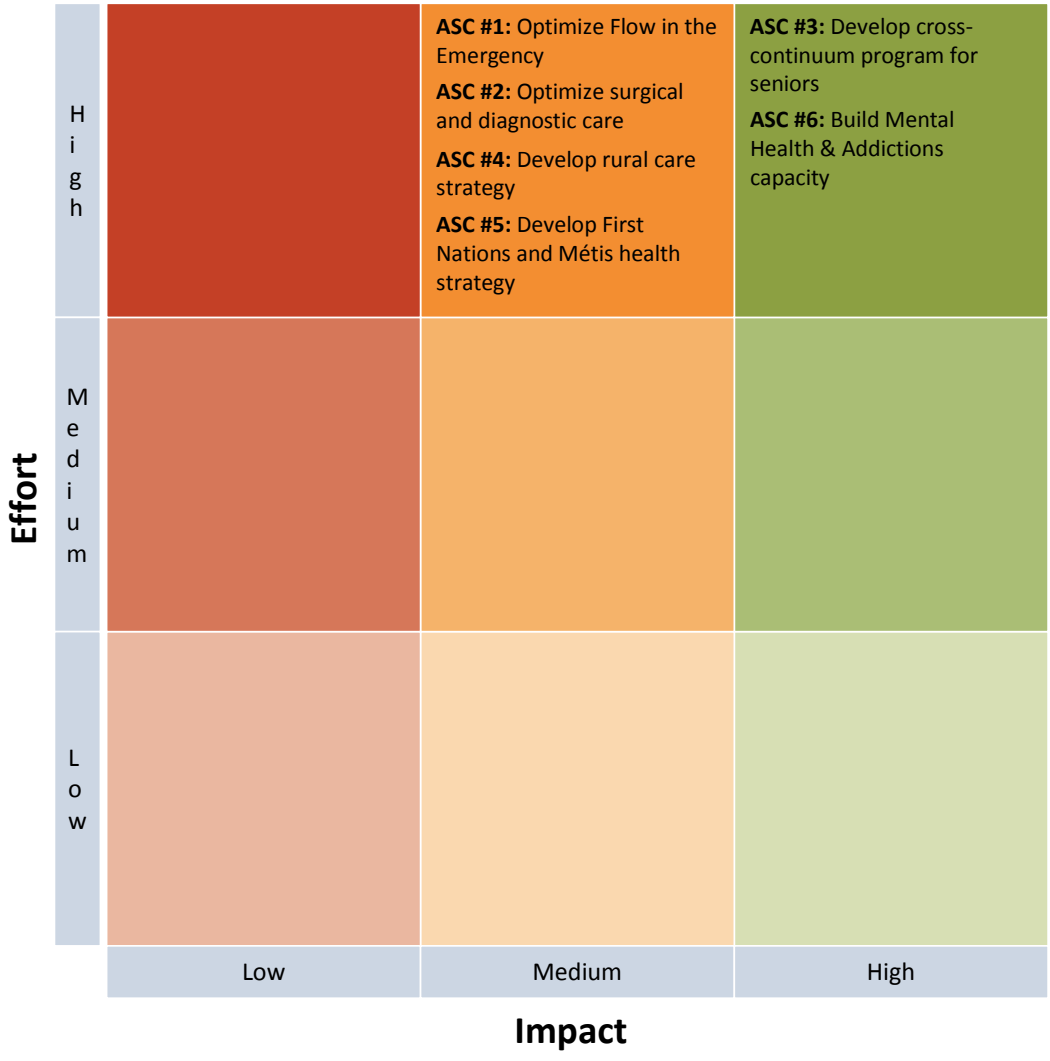
Solution Ideas for improving access to safer care (ASC)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Reduce the amount of time I have to wait for emergency care	**ASC #1:** Optimize flow of emergency care from a systematic perspective, focusing on the bottlenecks in patient flow concerning the emergency from end to end. This includes the following : • Assess demand or the reasons people show up in Emergency and develop treatment options in the community to prevent the use of the Emergency (e.g. physician offices who allocate part of their daily schedule to urgent visits, chronic disease management etc) • Optimize flow in the Emergency and up to inpatient units (Lean is a tool that has demonstrated success in achieving this; implementing FastTrack is an example of a method to improve flow for lower acuity patients) • Optimize flow into the community with standardized discharge processes and integration with community partners that include home care and long term care	• Improvements have been demonstrated along this value chain that do not necessarily require additional human resources or infrastructure – making more effective use of current resources can increase access for patients and improve the quality of care

Solution Ideas for improving access to safer care (ASC)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Reduce the amount of time I have to wait for surgical procedures and diagnostic tests	**ASC #2:** Optimize flow in surgical and diagnostic care from a systematic perspective, focusing on the bottlenecks in patient flow from end to end. Wait times and surgical/diagnostic backlogs are a huge burden to the system. • Assess demand or the reasons people are referred for diagnostics or surgery and develop educational tools for providers to optimize referrals (Some jurisdictions have employed pre-surgical screening to optimize the surgeons time) • Optimize flow in the surgical / diagnostic process that makes efficient use of all resources (Centralized referral and queuing is gaining recognition as a method for improved efficiency; Lean is a tool that has also demonstrated success in achieving this) • Optimize flow into the community with standardized discharge processes and integration with community partners that include rehab, home care etc.	• Wait times have come down in jurisdictions employing resources more effectively for surgical procedures • The result is that patients wait less and resource use in the system is maximized
• Improve/expand the options for care and the ease with which I or my family/caregivers can access geriatric and long term care services in my community	**ASC #3:** Develop cross-continuum programs for seniors with complex needs (this option was discussed earlier in the discussion on Integration) • As part of this strategy, assess the care needs of this population to determine whether there are more cost-effective ways to meet their needs that may include increasing home care supports, increasing funding for activities of daily living and instrumental activities of daily living	• Through additional supports in the community, patients are able to remain in their homes longer and reduce the need for institutionalization
• Make it easier for me to access care when I live in a rural and remote area	**ASC #4:** Develop a rural care strategy that includes the following: • Assessment of the HHR needs of the rural areas (current and expected vacancies and the needs of providers for recruitment and retention) • Centralized locum administration and coordination across the Province to provide cross-fertilization from the urban areas to the rural areas for temporary coverage when needed • Strategies to leverage physician resources that include the use nurse practitioners, physician assistants and an expanded scope of service for emergency medical personnel for care in rural emergency department and in the community • An examination of cost-effective ways to re-deploy rural health care facilities to provide care closer to home where appropriate in partnership with family physicians • Coordination across regional boundaries to provide	• Services are provided closer to home for patients in rural and remote areas, reducing the requirement for travel to urban centres for care

Solution Ideas for improving access to safer care (ASC)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
	diagnostics and laboratory testing closer to home and the coordination of visits scheduling to reduce travel time on patients • Coordination with specialists in urban centers and family physicians in rural areas to allow them to deliver test results to reduce travel • Increased use of telemedicine • The implementation of a rural and remote healthcare travel grant for patients based on the distance traveled for care	
• Make it easier for the First Nations and Métis residents to access care, and make it appropriate and sensitive to the needs of this community	**ASC #5:** Develop a First Nations and Métis healthcare strategy that includes the following: • Assessment of the unique needs of each of these population groups • Strategies to address the social determinants of health across these three population groups • Implementation of patient advocates that have a deep understanding of the culture of these populations and can assist them in their care journey • Development of chronic care strategies that specifically address the needs of First Nations and Métis	• Improved access to care resulting in improved outcomes
• Improve/expand the options for care and the ease with which I or my family/caregivers can access mental health and addictions services	**ASC #6:** Assess demand for services and develop a strategy to create adequate capacity to meet population need that includes the following: • An assessment of the primary care needs of mental health and addictions patients and the development of shared-care models that integrate primary care and community-based mental heath and addictions care • Building community capacity that includes assertive community treatment for people with serious mental illness • Integration of community and hospital providers • Education for emergency service providers on treating patients with mental health and addictions • The development of options for rural and remote patients that include telephone-based cognitive behaviour therapy • Education of primary care providers, especially in rural areas to provide counseling and knowledge of treatment options in the community • Workplace education, prevention, screening and treatment options for depression	• Improved access to mental health and addictions services that provide for a better patient experience and have demonstrated improved outcomes

The options discussed in the table above will help to address the concerns raised by patients about frustrations accessing care. In most of the options discussed above, in order to address the underlying situation, a multi-faceted approach will be required. These strategies require more detailed analysis to support the tactics that should be deployed to resolve them. It is important that the strategies be informed by data to ensure that the underlying issues are resolved. In each it is also important to consider how the systems interact so that unintended consequences do not result by the actions taken to resolve these issues.

The recommendations to address access issues are plotted on the graphic below to compare the level of effort and the impact on improving access to care. All of the recommendations require a high level of effort, but will also have a significant impact on increasing access to care.



6.4.3.1 Summary

The recommendations provided above should be considered within the planning work that the Province is currently undertaking to improve access to safer care. The Ministry is currently investigating/planning initiatives that are aimed at:

- Building capacity and capability amongst health care providers to undertake quality initiatives with a patient-centred perspective aimed at improving access to safer care.
- Developing strategies aimed at specific population groups within the Province such as seniors, First Nation and Métis, and people with mental health looking at ways to improve access to care.
- Increasing surgical capacity in order to reduce wait times for surgeries and therefore improve access to care.

The Province is undergoing a detailed strategic planning exercise that will outline specific projects/initiatives aimed at improving access to safer care. Saskatchewan has been focusing on increasing surgical capacity in order to reduce wait times for surgeries, and will continue to do so as it strives to make improvements to this area within the system that is the source of much concern amongst patients.

The issues associated with accessing care are broad and touch on many points within the system. As such, each of the recommendations mentioned above requires a thoughtful analysis and assessment of the issues in a systematic way. As an example, improving access to Emergency and Urgent care requires a set of initiatives that improves care from end to end. This includes emergency response, the care process and information provided to the patient upon entry to hospital, the use of triage and fast track to better manage the queue, the deployment of efficient care processes that also keep the patient informed throughout their journey, discharge processes that start upon admittance with an estimated date of discharge, and integration with the community to ease the flow of patients out of the hospital and into the community. To support an ER strategy, would also require an assessment of the use of the Emergency Department to look for opportunities to prevent unnecessary use that may include nursing outreach to long term care homes, see and treat protocols for Emergency Medical Services that prevent unnecessary transport to the Emergency, and the scheduling of urgent care clinics in primary health care teams.

Similarly the other initiatives (e.g. geriatrics, mental health and additions etc.) should be approached in the same systematic way to assess capacity and improve service delivery from end to end. Mental Health and Addictions for example should assess the capacity and integration of community mental health and addictions with primary care, developing shared care programs where possible. Assertive Community Treatment programs have also demonstrated effectiveness in treating patient with high needs and severe mental illness. For seniors, an assessment of patient-centered needs may lead to increased finding for both the activities of daily living (ADL) and instrumental activities of daily living

(IADL). Providing these services to seniors have demonstrated cost-effectiveness for keeping seniors in their homes and preventing admission to institutional care.

6.4.4 Category 4: Improving system accountability

Throughout the research patients described frustration with a lack of leadership and the lack of ability to follow-up when care seemed inappropriate or when they had difficulties accessing services.

The following table presents the desired system changes voiced by patients and recommendations for how to achieve them:

Solution Ideas for improving system accountability (SA)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Teach providers how to meet my needs	**SA #1:** Implement a Province wide framework to shift the culture of providers towards providing patient-focused care (see Section 6.3 for a complete description)	• Overall improved care experience from end-to-end
• Improve the supervision of staff in the emergency and inpatient units to prevent rude and inappropriate behavior	**SA #2:** Expand nurse manager capacity for improved clinical management • Enhances a position that provides guidance, direction, and authority on a hospital ward • This would serve to increase the accountability of the staff for their performance	• Improved supervision of staff provides the opportunity for mentoring and staff development, resulting in improved patient experience and patient-centered care
• Pay care providers based on whether my needs are met	**SA #3:** Change performance appraisal systems that reward and recognize patient-centered behaviours, and alignment with patient-centered values • A core value of a patient-centred system is to for health care providers to be accountable to its patients • Patient-centred criteria and performance measures should become part of compensation models and accountability agreements	• Providers perform traits when they are held accountable for them and when there are proper incentives for behaviour • Making desirable behaviours explicit makes the social contract between patients and providers more explicit resulting in a cultural shift towards patient-centered care • A focus on patient-centered providers improves the overall experience for patients
• Let me know how my providers are performing	**SA #4:** Make public reporting on performance mandatory including measures on access, and patient satisfaction in a way that is easily understood by the general public • Provides system and health care staff accountability to patients for their performance and overall delivery of care	• Improves focus on those systems that are reported on and helps to rally providers together to change and improve performance
• Give me someone I can talk to when I have a	**SA #5:** Implement a patient Ombudsman to field and resolve patient complaints, building on the current model of client representatives and quality	• Provides patients with an avenue to resolve issues with their care,

Solution Ideas for improving system accountability (SA)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
complaint	of care coordinators already in place.	especially in situations where they do not feel comfortable approaching care providers or their supervisors

The options presented above will help to address the issues of accountability described by both patients and providers throughout the research. Other options which may also warrant attention include the following:

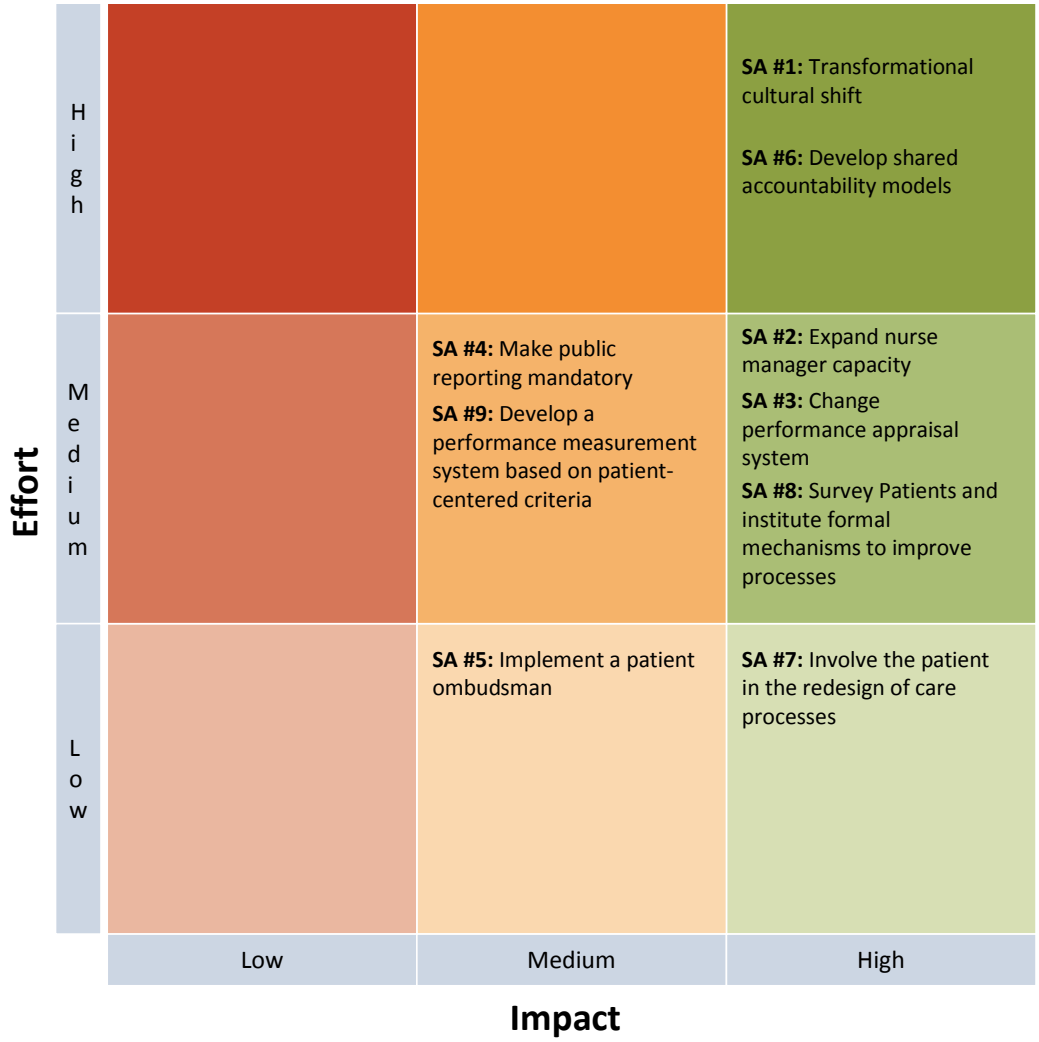
- **SA #6: Shared accountability**. Under a shared accountability model, the health care practitioners will be jointly responsible and accountable for the care a patient receives throughout the continuum. This shared accountability serves multiple purposes including: encouraging interprofessional/team-based care, promotes improved provider/service integration, and motivates behaviours of the providers to take a more holistic view of a patients care across the continuum (also discussed under integration as a mechanism to build integrated program delivery).

- **SA #7: Involve patients in process redesign initiatives.** Involvement of the patient in redesigning patient care processes, either through focus groups, surveys or sitting on continuous improvement teams.

- **SA #8: Patient surveys.** Surveying the patient upon discharge where appropriate and having mechanisms to improve care based on the outcome of the surveys.

- **SA #9: Patient-centred performance measurement.** Performance measurement system based on patient-centred criteria and the patient experience.

The recommendations to improve system accountability are plotted on the graphic below to compare the level of effort and the impact on improving accountability. Those that are high impact and low effort can be implemented immediately in the short term (e.g. Involving the patient in the redesign of care processes). Those that are higher impact with higher levels of effort will require more rigor and will likely be accomplished in the longer term (e.g. the development of shared accountability for patient outcomes across providers).



6.4.4.1 Summary

An accountability framework is a useful tool to help drive behaviour. To enable system change and drive desired behaviours requires a performance management system that reports on the right measures and has in place appropriate incentives and penalties that align with those measures to drive results.

Roles and responsibilities must be clear along each link in the chain from the MOH, down to the provider that is interfacing with the patient. Providers and patients recommended some useful initiatives, however these must be supported by an appropriate accountability framework that measures the right indicators at each interface.

To change the healthcare system to become more patient-centered, the MOH must first define what this means in the context of patient care in Saskatchewan. Second, it would need to build an accountability framework to support this definition, setting achievable measures and targets linked to a

specific goal for the Regions, Primary Care, Public Health and other patient facing bodies with measures and targets that are shared across organizations. Each organization's direct role and responsibility would have to clearly be documented and understood, and the outcome of performance related to the target must clearly be understood (e.g. financial incentives related to achieving or surpassing the target).

To support change on the individual provider level, the same framework must be put in place that includes measures and targets for performance with direct links to the outcomes or consequences of achieving that performance. To help drive some of these behaviours will be the need for increased management support, or supervisory staff on clinical units as recommended by patients and providers. Public reporting is also a useful tool to help drive behavioural change, but it is far more difficult to attach individual behaviours to organizational measures unless there is a clear link between the two.

To enable this accountability the appropriate resources and supports must be in place to support individual providers and organizations to provide the type of care that is desired. How this integrates into a wider patient-centered strategy was discussed in more detail in Section 6.4.

6.4.5 Category 5: Build a stronger health care workforce

In the research, patients and providers identified several challenges they saw with current health human resources. These issues and the solutions they propose are described below. The options are assessed for Ministry action. These options require detailed analysis to assess their feasibility for implementation in the Saskatchewan environment.

The following table presents the desired system changes voiced by patients and recommendations for how to achieve them:

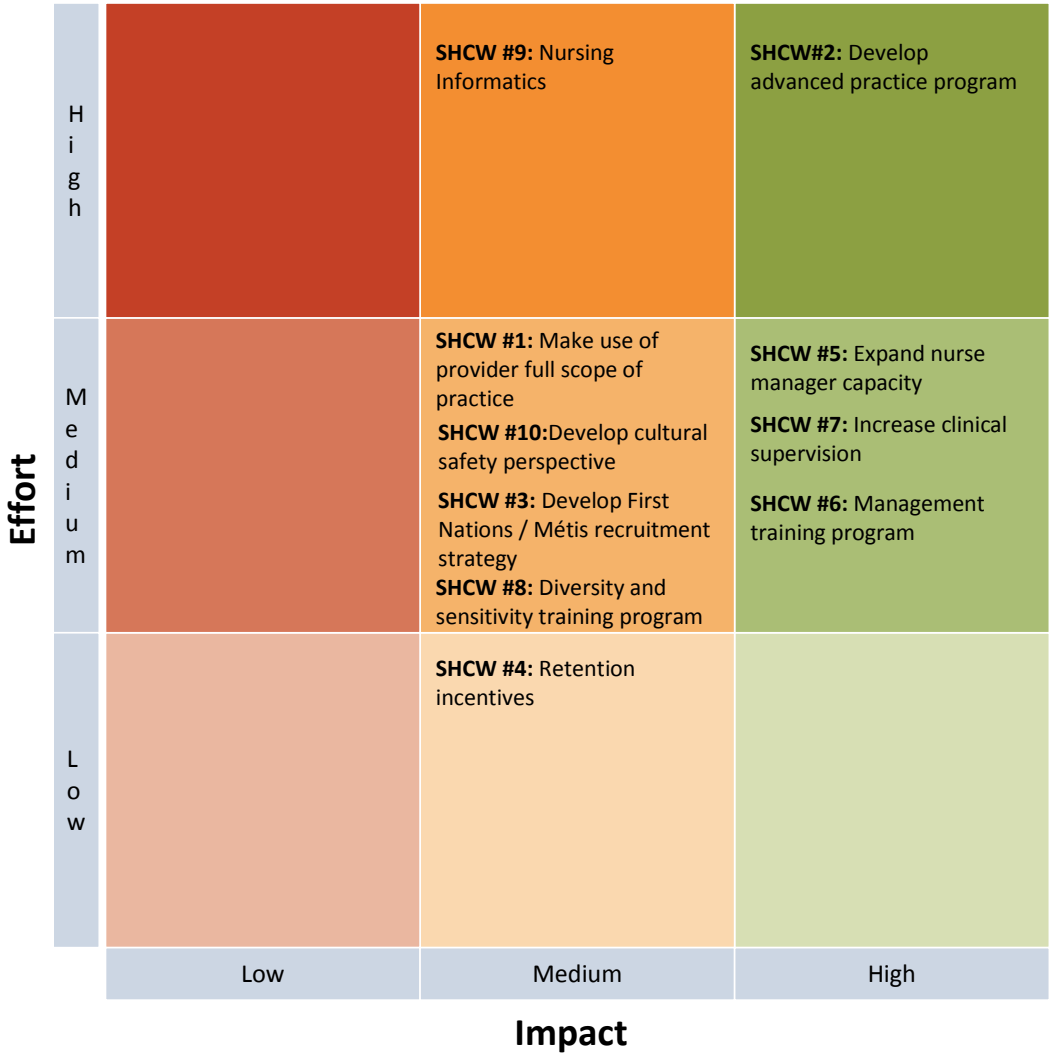
Solution Ideas for building a stronger health care workforce (SHCW)		
Solutions from the Research in the Patients' voice	***KPMG Recommendations***	***Impact on Patients***
• Clarify and make full use every providers abilities so that I know who should be doing what and so that providers effectively utilized	**SHCW #1:** Clearly define and make use of providers full scope of practice • Clarify what health care professionals can and should do when delivering care • Also contributes to improving access and the patient interaction **SHCW #2:** Develop an advanced practice program • Program to improve staff morale by developing and communicating an increased career path trajectory • Provides the ability to leverage current resources in the system	• It is clear to patients who can provide what level of care • Providers time and usage is maximized making better use of resources, increasing access for patients

Solution Ideas for building a stronger health care workforce (SHCW)		
• Improve access to First Nations / Métis heath professionals	**SHCW #3:** Develop a First Nation/Métis recruitment strategy • The Province would benefit from an increase in the First Nation/Métis health care staff • Provides First Nations/Métis patients with a greater level of comfort in their care if someone is fully attuned to their needs , culture and traditions	• Improved ability to communicate with providers who have a deep understanding of the cultural needs of the First Nations / Métis patient
• Provide the circumstances so that providers want to stay in the Province so that my doctor isn't changing every two-years	**SCHW #4:** Provide retention incentives for health care workers to remain in the Province • Retention is a serious issues in the Province, especially in rural and remote areas • Must develop a strategy to retain the health care workers that the Province has so that attrition and staff shortages can be minimized	• Patients experience a continuity of care and develop deeper relationships with care providers who they've known for longer periods of time. • Physician turnover can be a stressful event for patients, especially where there are few doctors available
• Improve the supervision of staff in the emergency and inpatient units to prevent rude and inappropriate behavior	**SHCW #5:** Expand nurse manager capacity for improved ward management • Enhances a position that providers guidance, direction, and authority on a hospital ward • This would serve to increase the accountability of the staff for their performance	• Improved supervision of staff provides the opportunity for mentoring and staff development, resulting in improved patient experience and patient-centered care

The options provided below help to address the health human resource issues identified by both patients and providers in the research. The concept of focusing on health human resources to help transform the healthcare system towards being patient-centered was described in detail in Section 6.4. In addition to this transformational focus, some other options the MOH may want to consider include the following:

- **SHCW #6:** Develop a management training program for developing health care workers to effectively supervise staff.
- **SHCW #7:** Develop policies and staffing strategies to increase the level of clinical supervision.
- **SHCW #8:** Develop a diversity and sensitivity training program for all hospitals and health care organizations.
- **SHCW #9:** Implement nursing informatics to promote bedside patient record updating – addresses the issues of nurses being too busy or getting distracted to updated patient records.
- **SHCW #10:** Develop a cultural safety perspective for diagnosing, treating and supporting First Nations and Métis people's well-being.

The recommendations to build a stronger healthcare workforce are plotted on the graphic below to compare the level of effort and the impact on building a stronger healthcare workforce. Those that are high impact and low effort can be implemented immediately in the short term (e.g. increasing clinical supervision). Those that are higher impact with higher levels of effort will require more rigor and will likely be accomplished in the longer term (e.g. developing advanced practice programs).



6.4.5.1 Summary

The MOH is currently planning to undertake a the development of a workforce action plan and a 10-year health human resource plan that will build on the learning's from recent recruitment and retention initiatives. This is an opportune time for the MOH to build on this plan to include training and development for health care workers across the Province on patient-centered care. This plan should also consider the incentives that will be necessary to change health human behaviour to become more patient-centered. This aspect of changing the culture of healthcare in Saskatchewan is an important

piece of a dramatic change management program to re-orient the system towards meeting the needs of patients that go beyond treating physical symptoms as described in this report. Another key aspect of the Health Human Resource plan should be the development of tools to help the Regions and health human resource departments across the Province make changes to their performance appraisal systems to include appropriate behaviours that align with patient-centered care

6.4.6 Category 6: Improve health protection and promotion activity in the Province

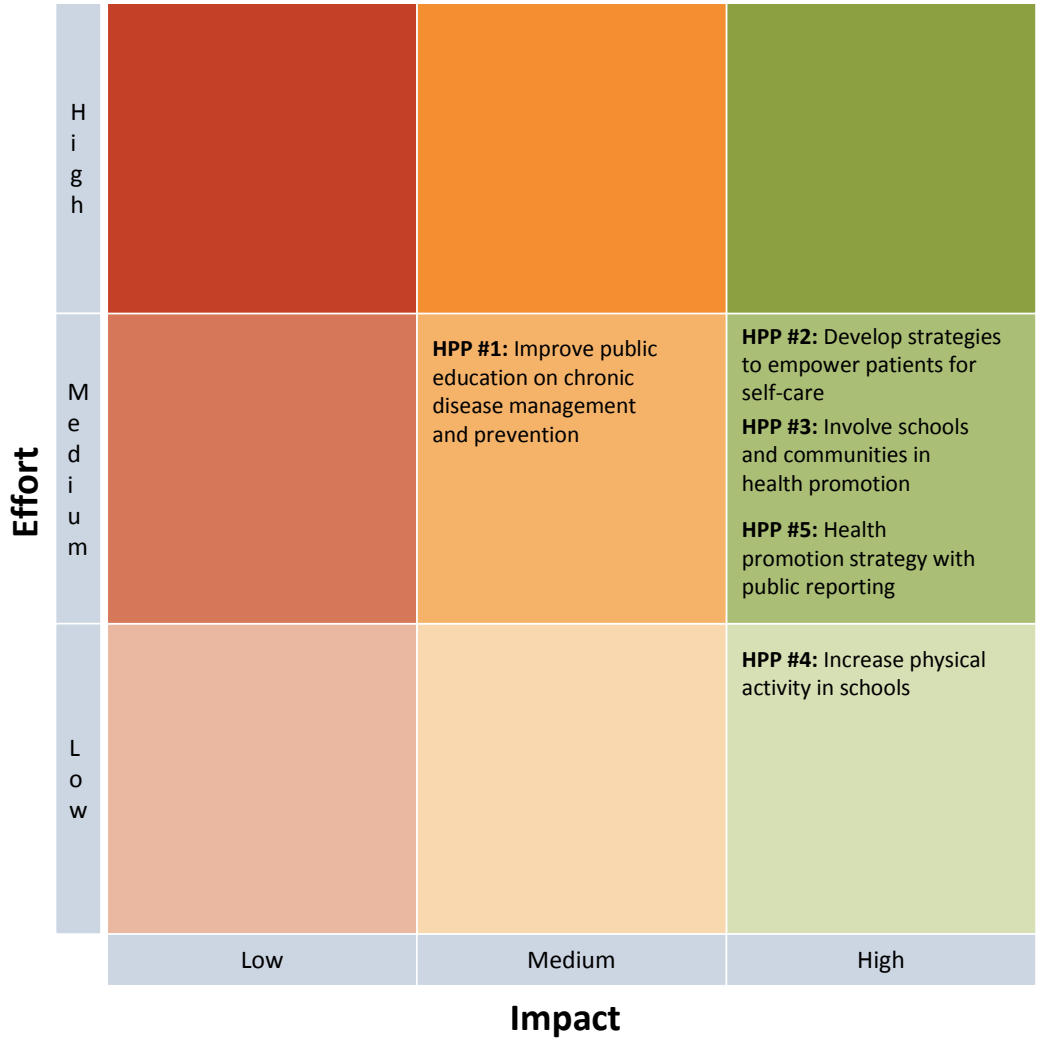
The following table presents the desired system changes voiced by patients and an assessment of these developed into options or recommendations for the MOH. Any recommendations should be investigated for implementation by the Province:

Solution Ideas for improving health protection and promotion in the Province (HPP)		
Solutions from the Research in the Patients' voice	***KPMG's Recommendations***	***Impact on Patients***
• Provide me with the knowledge and tools I need to help me stay healthy	**HPP #1:** Improve public education on chronic disease management and prevention • Demonstrates the impact of lifestyle on diseases and the prevention of diseases • Provides the public and those dealing with chronic disease with tools and information for preventative health and chronic health management **HPP #2:** Develop strategies to empower patients for self-care • Reduces reliance on the healthcare sector for disease management • Involves the patient in their care and makes them directly responsible and accountable for their outcome	• Patients are able to maintain their own health and require less intensive use of the healthcare system • Patients with chronic diseases are empowered to manage their own disease and require less face-time with providers
• Health education is an important part of my community and should be delivered in my community	**HPP #3:** Involve schools and communities in the promotion of health • Integrate "grassroots" health protection and promotion principles with children to manage future onset of health issues • Recognizes that health is broader than the service provided by the healthcare system an includes other stakeholder groups, e.g. schools • Involve communities in the promotion of health (e.g., volunteer organizations such as faith-based groups to support health promotion strategies) **HPP #4:** Increase physical activities in schools • Another strategy to have schools play an important role in active health protection and promotion	• Makes communities more responsible for the health of their residents • Promotes healthy, active living in communities throughout all stages of life

Patients and providers brought forth many great suggested solutions for improving health promotion and protection activities in the Province. The Province should also consider:

- **HPP #5: Developing a health promotion strategy with public reporting:**
    - Develop performance indicators on the health of the population and risk factors for chronic disease and cancer (e.g. rates of smoking, high-risk alcohol consumption, percent of the population that eats five servings of fruits or vegetables a day, individuals without a family physician, proportion of the population that rate their health as good or excellent etc.).
    - Develop specific strategies to address each indicator and make departments and/or organizations accountable for reaching specific targets.
    - Report these indicators publicly.

The recommendations to improve health protection and promotion are plotted on the graphic below to compare the level of effort and the impact on improving health protection and promotion. Those that are high impact and low effort can be implemented immediately in the short term (e.g. increasing physical activity in schools). Those that are higher impact with higher levels of effort will require more rigor and will likely be accomplished in the longer term (e.g. developing strategies to improve self care).



6.4.6.1 Summary

Health protection and promotion plays an important role in helping individuals maintain their health; especially for someone with one or multiple chronic conditions. The initiatives recommended by patients and providers all provide valid tools for helping people remain active and maintain healthy lifestyles. The Province is currently developing a plan to address system improvements across the public health domains. This action should include an assessment of the population's ability to engage in healthy lifestyles and addressing the supports that may be required. Any efforts should be integrated with primary health care and specifically efforts to address chronic disease management in the Province.

6.4.7 Implementation

Having completed an analysis of the solutions brought forward from the research that KPMG felt could make a material impact on improving the patient experience, with specific recommendations for how to implement those solutions, we now shift our focus to implementation timing.

This section focuses on those initiatives that the Province should consider for short term (1 year), medium term (3 years) and long term (5 years). This determination was made in part through the matrices at the end of each recommendation section that compared level of effort to impact on resolving system issues. The diagram below identifies the suggested timing/sequencing for all of the recommendations made in the previous section. These recommendations should form the priority areas of focus over the short, medium and long term. Following this section, the impact on the patient experience is described through a series of vignettes from the patient voice.

6.4.7.1 Short term implementation (1 year)

Those initiatives that can be done in the short term are more easily implemented with the least amount of effort. The Province should be able to quickly show progress in addressing the patient issues identified. Short term recommendations are identified for each theme discussed previously as identified in the table below. Some of these initiatives include finding ways to communicate more effectively with patients that include providing them with information on their wait time and ensuring they have access to the care they need while they wait. Another easily implemented initiative is involving patients in the redesign of care processes. This can be easily achieved and can demonstrate quick results.

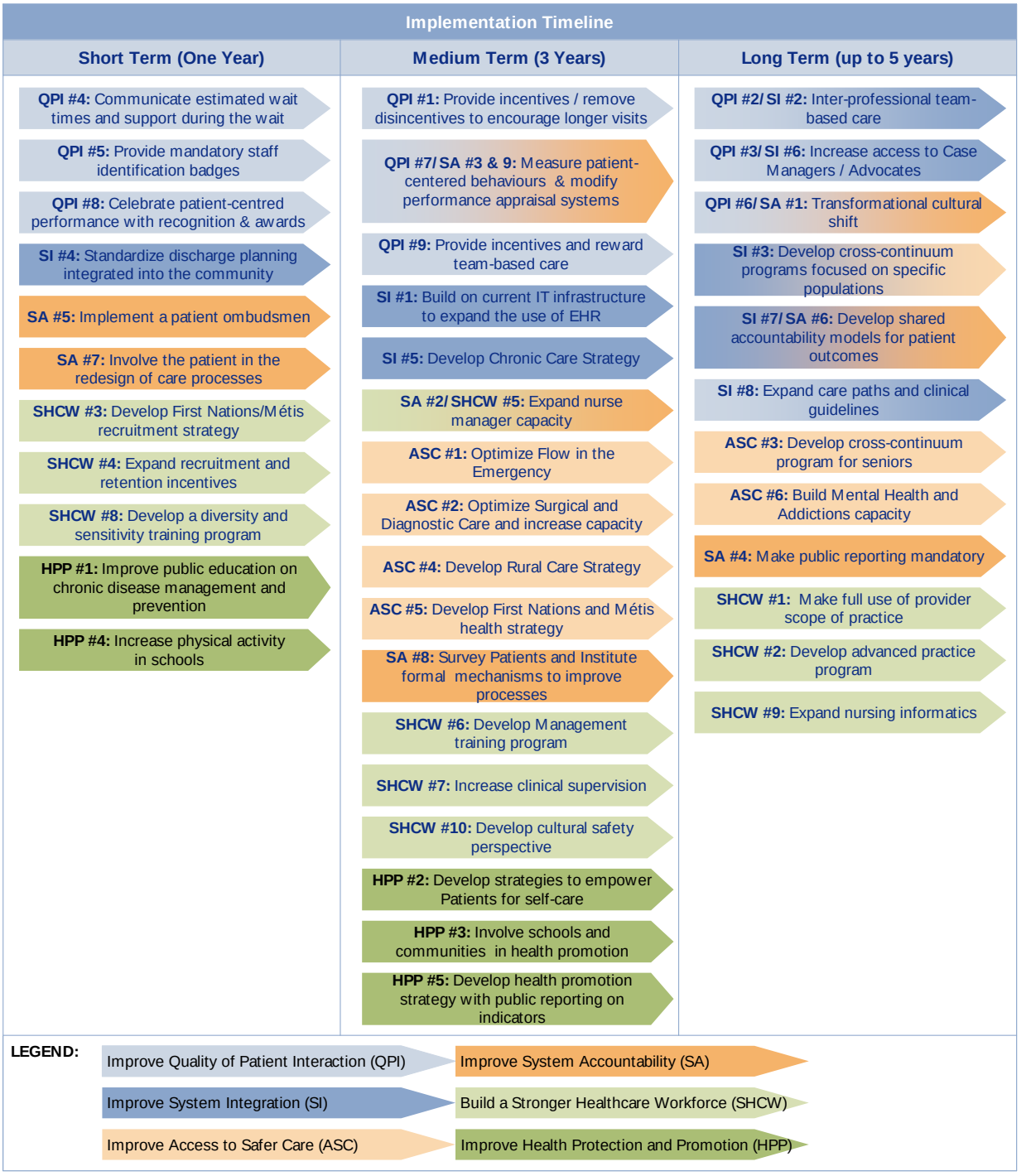
6.4.7.2 Medium term implementation (1-3 years)

The initiatives identified over the medium term are those ones that require more analysis, system change or take more effort to complete. Some of the initiatives identified above that fall into this category include changing performance appraisal systems to reflect and reward for patient centered behaviours. Another important initiative that will have high impact that can be achieved in the short-to-medium term is the placement of more head nurses to provide the important supervisory role and to mentor and provide staff guidance on appropriate patient-centered behaviours.

6.4.7.3 Long term implementation (3-5 years)

The long term initiatives will take a much longer time to implement and will likely require structure and infrastructure to support their ongoing implementation. These initiatives will also take longer to demonstrate value. Some of the initiatives that will have high impact as noted in the table above include the expansion of Electronic Health Records, the cultural transformational shift of the healthcare system and the optimization of Emergency, surgical care and diagnostics.

Combined these initiatives will demonstrate immediate action and results while continuing the ongoing transformation of the Saskatchewan healthcare system. The impact this will have on patients is described in the next section from the point of view of the patient.


Implementation Timeline
Short Term (One Year)
QPI #4: Communicate estimated wait times and support during the wait
QPI #5: Provide mandatory staff identification badges
QPI #8: Celebrate patient-centred performance with recognition & awards
SI #4: Standardize discharge planning integrated into the community
SA #5: Implement a patient ombudsmen
SA #7: Involve the patient in the redesign of care processes
SHCW #3: Develop First Nations/Métis recruitment strategy
SHCW #4: Expand recruitment and retention incentives
SHCW #8: Develop a diversity and sensitivity training program
HPP #1: Improve public education on chronic disease management and prevention
HPP #4: Increase physical activity in schools
Medium Term (3 Years)
QPI #1: Provide incentives / remove disincentives to encourage longer visits
QPI #7/ SA #3 & 9: Measure patient-centered behaviours & modify performance appraisal systems
QPI #9: Provide incentives and reward team-based care
SI #1: Build on current IT infrastructure to expand the use of EHR
SI #5: Develop Chronic Care Strategy
SA #2/ SHCW #5: Expand nurse manager capacity
ASC #1: Optimize Flow in the Emergency
ASC #2: Optimize Surgical and Diagnostic Care and increase capacity
ASC #4: Develop Rural Care Strategy
ASC #5: Develop First Nations and Métis health strategy
SA #8: Survey Patients and Institute formal mechanisms to improve processes
SHCW #6: Develop Management training program
SHCW #7: Increase clinical supervision
SHCW #10: Develop cultural safety perspective
HPP #2: Develop strategies to empower Patients for self-care
HPP #3: Involve schools and communities in health promotion
HPP #5: Develop health promotion strategy with public reporting on indicators
Long Term (up to 5 years)
QPI #2/ SI #2: Inter-professional team-based care
QPI #3/ SI #6: Increase access to Case Managers / Advocates
QPI #6/ SA #1: Transformational cultural shift
SI #3: Develop cross-continuum programs focused on specific populations
SI #7/ SA #6: Develop shared accountability models for patient outcomes
SI #8: Expand care paths and clinical guidelines
ASC #3: Develop cross-continuum program for seniors
ASC #6: Build Mental Health and Addictions capacity
SA #4: Make public reporting mandatory
SHCW #1: Make full use of provider scope of practice
SHCW #2: Develop advanced practice program
SHCW #9: Expand nursing informatics
LEGEND:
Improve Quality of Patient Interaction (QPI)
Improve System Accountability (SA)
Improve System Integration (SI)
Build a Stronger Healthcare Workforce (SHCW)
Improve Access to Safer Care (ASC)
Improve Health Protection and Promotion (HPP)

6.4.8 Impact on Patient Experience

Patients provided a wealth of information throughout this study. They expressed their concerns for the system and suggested solutions for addressing those core issues. The MOH has the opportunity to radically change patient care in the Province through the recommendations presented in this report. The following is a look at the potential impact these changes could have on the patient experience in the words of the patient.

6.4.8.1 Improvements to the Quality of the Patient Interaction

Based on the research from the review we heard that patients were generally satisfied with the actual delivery of care when it was provided within the healthcare system, however it was the interaction with providers they felt dissatisfied with. Patients were left with a feeling of disengagement from the decision making processes related to their care, and sometimes experienced rude or inappropriate behaviour. The recommendations to address these issues deal primarily with transforming the system to create a more caring environment, communicating more effectively with patients in a way that suits their needs. In a more patient-centered system a patient might experience the following:

Joseph is a 73 year old man who was just told he will need his hip replaced:

"*My surgeon was very thorough. He explained what was wrong with my hip and walked me through the alternatives. Together we made the decision that surgery was the right route for me. I was called shortly after my visit with the surgeon and was provided with my surgery date. I was assigned a coordinator, who made sure that I had the supports I needed to get me through the wait. She set me up with a physiotherapist who came to my house. I was surprised to find out that my physiotherapist and surgeon actually discussed my case before my next visit. I certainly feel well cared for.*"

6.4.8.2 Improvements to Integrate the System

Based on the research from the review we heard that patients were generally satisfied with the actual delivery of care when it was provided within the healthcare system, however it was the feeling of being lost in the system that left them feeling dissatisfied. When patients felt lost, they described having no one to help guide them in their journey as they attempted to navigate through the continuum of care. These feelings were attributed to a lack of system integration, or poor connections and communication among providers and organizations throughout the system. Through the recommendations to address these issues a patient may have the following experience:

Ben is a 52-year old with multiple chronic conditions:

"Ever since signing up with my new doctor's office my health has been really good. There's a whole team of people that take care of me and help me with whatever problem I have. They even have a pharmacist to help me figure out my medications. I don't always see the doctor, but it's much easier to get an appointment now and the team members there don't rush me out the door. They also see my patient

record from the hospital and from my home care nurse which makes it easier for me, since I don't have to repeat myself or carry around my medical chart. We're all working together to help me achieve my health goals."

6.4.8.3 Improving access

While patients described some difficulties accessing care, the primary concerns they had were with wait times in the Emergency Department and with surgical and diagnostic procedures. They also described difficulties accessing Geriatric and Long Term Care, rural and remote areas, Mental Health and Addictions and health services for First Nations and Métis. The recommendations suggest taking a systematic view of each problem area and optimizing care processes before assessing whether new resources or infrastructure are required. Once addressed, a patient may one day say the following:

Beth is a single 32-year-old mother of 3:

"It used to be such a horror having to come to the Emergency Department whenever one of my children got sick. The wait was way too long, especially having to wait with three kids if I couldn't find someone to watch them. It used to prevent us from coming unless we thought it was a critical emergency. Now we're assessed and seen within a few hours. Even when Jonny was admitted for his bad asthma attack, we thought we'd be waiting forever in the Emergency, but they assessed and admitted him to the inpatient unit within a couple of hours. I no longer have to think twice about going. I know it's there for us when we need it."

Robert is a 32 year old living in rural Saskatchewan

"*When I was going through all the testing last year and was finally diagnosed with cancer, I had to do a lot of travel into the city. It made it difficult to manage while trying to stay at work. The nurses and doctors at the cancer center were great; they tried to coordinate all my tests on the same day and even sent the results to my family doctor in town, so I didn't have to make the drive into the city to get the results."*

6.4.8.4 Improving Accountability

Patients want a system that is more responsive to their needs. In order to accomplish this, there needs to be someone in the system that is responsible and accountable for creating those behaviours. Under an improved system, with improved accountability for the patient experience, a patient may one day say the following:

Emily is a 44 year old who recently had emergency back surgery

"While I was recovering after surgery in hospital, the head nurse came to my room and actually asked me how my stay was, and whether there was anything they could do to improve it. After we talked for a few minutes and I provided her with some advice, she asked if I would be willing to participate in a design forum with another patient and staff from the hospital to look at redesigning some of the care

processes that I experienced. I jumped at the chance and was excited that I would have the opportunity to change things for future patients."

6.4.8.5 Building a Stronger Healthcare Workforce

People are the foundation of the Saskatchewan healthcare system. It is people that deliver the care patients need and it is them who will need to be involved in transforming it into a stronger, more patient-centered system. Through the recommendations to build a stronger healthcare workforce, a patient may one day make the following statement:

Hannah is a 79 year-old woman who recently had knee surgery

"When I was in hospital recuperating from knee surgery, I had to get up every once in a while to go the bathroom. One of the nurses was quite rude to me in the middle of the night and I asked to see her manager. A few minutes later her manager came in and we discussed what had happened. The nurse manager brought the nurse in and asked her to apologize and discussed with her the importance of patient-centered care. She was very professional and didn't do it in a demeaning way to the nurse. Every other interaction following that experience was just wonderful."

Glen is a 39 year-old from First Nation resident

"*When I used to come to town to use the hospital, I never felt like I was respected. I never felt like the doctors and nurses really tried to understand my health and who I was. Now when I come there is someone there who greets me and helps me find my way through the hospital. There are also doctors and nurses who are First Nations and who take the time to understand me as a person. Even in the Emergency, the people there are more sensitive to my needs and I believe it has had an impact on helping me improve my health."*

6.4.8.6 Improving Health Protection and Promotion

There is a lot that patient's feel they can be doing to maintain their own health. They don't however always feel they have adequate education on making healthy choices or how to maintain a healthy lifestyle. Many patients recommended the expansion of health promotion and protection in ways that empower them in maintaining healthy lifestyles. Under this scenario, a patient may one day say the following:

Edna is a 38 year-old mother of 2:

"Ever since the government launched the new health promotion strategy I have noticed an increase in the number of community programs dedicated to health promotion and protection. I have taken advantage of these programs in order to learn how to better manage my health and to be preventative rather then reactive with how I manage my health and wellbeing. Thanks to these programs I feel like I know how to make healthier choices. I quit smoking, I drink less and I try to eat healthy and make healthy meals for the kids. I feel like it's had a big impact on how I feel. It has also helped me lose

weight. I was even able to attend a healthy eating class at my church. All the materials were paid for by the government. Now because of my keen interest and successful self-help story, my pastor has asked me to take the training to teach the class, something I'm really looking forward to."

7.0 Summary of Recommendations

In advance of concluding this final report, a summary of recommendations to the Commissioner is provided in this section in order to collect all of the recommendations throughout Chapter 6. This section will serve as quick reference guide for readers of the report who wish to easily find all of the recommendations from the Patient First Review.

Further detail on each of the recommendations is provided in Section 6.0 of this report.

7.1 Recommendations to transform the system to become patient-centred

The Province has expressed a desire and willingness to undertake a large-scale system transformation through the conduct of this review. The results of this review and an analysis of leading practice and other jurisdictions support the model of patient-centred care. The Province could consider making the shift to patient-centred care through a large-scale system transformation initiative. Should the Province choose to undertake a change of this scale; KPMG has provided recommendations to the Commissioner for how the Province can achieve such a broad and significant transformation on a system-wide basis. We recognize that these recommendations require a long term commitment from the Province; however it will also be up to the individual providers and system stakeholder to transform clinical processes to become patient-centred. Our recommendations for system-wide change suggest that in order to truly achieve system-wide change it will take the dedication and focus of both the government and the health care system broadly.

Our recommendations to the Commissioner for how system-wide change to a patient-centred model can be realized are as follows:

Recommendation #1 – Establish strong senior leadership to set the strategy: The strategy starts with a commitment from the top. The defining aspect of that commitment is courage. While we believe Saskatchewan currently enjoys a very positive environment to implement change for the better, no matter how collaborative the process, not all stakeholders will support every decision and most decisions will be implemented imperfectly. When mistakes are made or circumstances are more difficult, it will take courage for leaders to stick to the strategy instead of reacting to the crisis of the moment.

Recommendation #2 – Develop a patient-centred policy lens: The policy lens is fundamental to a long term transformation. The policy lens is a tool that assesses system initiatives from a patient perspective. It asks questions such as, how does the proposed project improve the patient experience and how has patient input and feedback been solicited and considered?

Recommendation #3 – Improve system accountability: The need to improve system accountability was a core finding of all three elements of the consultation process. The input from participants and

suggestions for implementation are covered in detail in the report. The key point to make in this summary is "You get what you measure". Since we don't measure the human costs and benefits, we don't incent behaviours that enhance caring and compassion within the patient journey and may, in some cases, discourage the behaviour we seek.

Recommendation #4 – Develop the supporting HR strategy: Developing the supporting HR strategy is a fundamental enabler of a patient-centred system. Saskatchewan has already embarked on the development of a 10 year health human resource strategy. It will be critical to ensure the strategy is aligned with a patient-centred system and not in conflict with it. It is also important to remember that while top-level commitment to a patient-centred system is necessary, it is not sufficient. Patient-centred care is delivered at the front line. With that in mind, it is important that early milestones be developed to demonstrate progress to health providers as well as patients.

Recommendation #5 – Develop tools to assist the system: Developing tools is a mechanical but necessary task. Some of these tools – particularly enhancing the province's existing system of electronic health records – are huge tasks that will take time. Other tools, such as developing provincial resources to assist front-line organizations in process improvement, can be implemented much more quickly and will leverage the activities of others.

Recommendation #6 – Establish an implementation body/organization to lead the charge: Implementation comes back to the question of where the institutional responsibility will lie. Health system leaders are busy people with many operational and strategic demands on their time. Based on our understanding of successful and less successful Canadian attempts at fundamental health care change, we have recommended that a specific, dedicated Patient First Transformation Team be established to advocate for change and be accountable for the results. The government could establish the team as a program in the Ministry, a program in the Health Quality Council, as a stand alone agency or through another vehicle, just so long as the Patient First initiative has a champion.

Recommendation #7 – Monitor, report and adjust the transformation strategy: Finally, the key point of the "monitor, report and adjust" recommendation is that moving to a patient-centred system is a journey. While we strongly recommend the system leadership develop a continuous set of milestones to focus efforts and provide demonstrations of success, the reality is that fundamental cultural and institutional change requires long lead times during which circumstances change, lessons are learned and adjustment is required.

7.2 Recommendations to improve the delivery of care

In addition to the recommendations made to shift the system to a patient-centred model, KPMG has also provided a set of recommendations which address specific health care delivery issues communicated by the patients throughout the review. These recommendations have been developed not only in the spirit of improving care, but also in how to deliver patient-centred care. The recommendations have been organized by the 6 categories developed by the research team in Section 5.0 of this report.

7.2.1 Recommendations to improve the quality of the patient interaction:

- Provide incentives / remove disincentives for providers to have longer visit times and engage patients in a discussion about their care options.
- Move towards more inter-disciplinary team-based care that leverages physician resources and increases the time available for patients.
- Increase access to Case Management / Advocates.
- Communicate estimated wait times in Emergency and for surgery shortly after a surgical decision is made, and support patients through their wait.
- Provide mandatory staff identification badges that clearly identify who they are and their position in the organization.
- Implement a system-wide transformation shift to become a patient-centred system.
- Measure performance based on patient-centred behaviors; adjust current performance appraisal systems for providers to include patient-centered behaviors that align with patient-centered values.
- Celebrate patient-centered performance with recognition awards locally and provincially.
- Provide incentives and reward team-based care, e.g. pay providers for case conferencing and collaborative care, working together to reach shared provider-patient goals.

7.2.2 Recommendations to improve system integration:

- Build on current information technology infrastructure to expand the use of an Electronic Health Record (EHR).
- Expand access to inter-professional care teams.

- Develop cross-continuum programs focused on specific patient populations (e.g. Diabetes) with shared accountability for patient outcomes.
- Standardize discharge planning processes.
- Develop a Province-wide chronic care strategy.
- Increase access to case managers for high needs individuals.
- Implement a shared accountability model where health care practitioners are jointly responsible and accountable for the care a patient receives throughout the continuum.
- Expand care paths and clinical guidelines.

7.2.3 Recommendations to improve access to quality, safer health care:

- Optimize flow of emergency care from a systematic perspective, focusing on the bottlenecks in patient flow concerning the emergency from end to end.
- Optimize flow in surgical and diagnostic care from a systematic perspective, focusing on the bottlenecks in patient flow from end to end. Wait times and surgical/diagnostic backlogs are a huge burden to the system.
- Develop cross-continuum programs for seniors with complex needs.
- Develop a rural care strategy.
- Develop a First Nations and Métis healthcare strategy.
- Assess demand for services and develop a strategy to create adequate capacity to meet population need.

7.2.4 Recommendations to improve system accountability:

- Implement a Province wide framework to shift the culture of providers towards providing patient-focused care.
- Expand nurse manager capacity for improved ward management.
- Change performance appraisal systems that reward and recognize patient-centered behaviours, and alignment with patient-centered values.

- Make public reporting on performance mandatory including measures on access, and patient satisfaction in a way that is easily understood by the general public.
- Implement a patient Ombudsman to field and resolve patient complaints, building on the current model of client representatives and quality of care coordinators already in place.
- Implement a shared accountability model where health care practitioners are jointly responsible and accountable for the care a patient receives throughout the continuum.
- Involve patients in process redesign initiatives.
- Survey patients upon discharge where appropriate and have mechanisms to improve care based on the outcome of the surveys.
- Implement a performance measurement system based on patient-centred criteria and the patient experience.

7.2.5 Recommendations to build a stronger health care workforce:

- Clearly define and make use of providers' full scope of practice.
- Develop an advanced practice program.
- Develop a First Nation/Métis recruitment strategy.
- Provide retention incentives for health care workers to remain in the Province.
- Expand nurse manager capacity for improved ward management.
- Develop a management training program for developing health care workers to effectively supervise staff.
- Develop policies and staffing strategies to increase the level of clinical supervision.
- Develop a diversity and sensitivity training program for all hospitals and health care organizations.
- Implement nursing informatics to promote bedside patient record updating – addresses the issues of nurses being too busy or getting distracted to updated patient records.
- Develop a cultural safety perspective for diagnosing, treating and supporting First Nations and Métis people's well-being.

7.2.6 Recommendations to improve health protection and promotion:

- Improve public education on chronic disease management and prevention.
- Develop strategies to empower patients for self-care.
- Involve schools in the promotion of health in communities.
- Increase physical activities in schools.
- Develop a health promotion strategy with public reporting.

8.0 Conclusion

The Patient First Review is a landmark study that will create the foundation for transformational change in the Saskatchewan healthcare system. Patients from across the Province described their experiences, which for many can be a very personal experience. While many had praise for the overall care they received, there were still common themes that emerged. These themes as described in this document and told by patients were primarily concerned with the quality of the interactions they have with care providers and the lack of communication; difficulties they have navigating the healthcare system and the seemingly un-coordination of the system; and, the difficulties they have accessing care.

To address these concerns requires significant transformation of the healthcare system to address primarily the culture of healthcare to re-orient every aspect of care towards meeting the needs of patients. Don Berwick, the pre-eminent champion of patient-centered care describes it as "the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care".

Providing patient-centered care should not add another layer to an already over-burdened healthcare system, rather it should change the way care is provided, so that each and every interaction is provided in a way that meets individual patient needs. This may include the following:

- Exploring the patient's reason for visit, concerns, and need for information, not limiting their visit to one concern;
- Seeking an integrated understanding of the patients' world – life issues, emotional needs;
- Finding common ground on the problem(s), and mutually agreed to courses of action and management;
- Communicating with them at every touch-point and in-between touch points to keep them informed about the ongoing care journey; and,
- Enhancing the continuing relationship with care providers.

This transformational shift requires a long term commitment with the supporting infrastructure to enable the change. This transformational agenda has been described in detail in Section 6.4. It provides a framework under which the Province can engage providers and patients in a renewed discussion about patient care in the Province. At its core, it will examine all aspects of care delivery from basic patient-provider interactions right up to administrative and policy decisions and how those decisions impact on the patient experience. This transformational shift will not be achieved over night.

In addition to this focused effort, as described in the implementation section earlier, there are strategies that can be employed over the long term to help respond to the concerns of patients raised in this study. Some of them are listed below:

- Expand access to inter-professional team-based care;
- Expand the use of Electronic Health Records;
- Develop cross-continuum programs that focus on specific populations;
- Optimize flow in the Emergency Department and Surgical and Diagnostic areas; and,
- Develop strategies to address gaps in rural, First Nations and Métis and Mental Health and Addictions services.

In the short to medium term, there are also initiative that can be taken up to show results more rapidly to address the issues raised by patients that include the following:

- Communicate estimated wait times for surgery and in the Emergency and support patients while they wait;
- Reform performance appraisal systems to measure, and reward patient-centered behaviours;
- Expand head nursing roles to provide greater access to that important supervisory and mentorship role; and,
- Support and improve management training to broaden and strengthen the leadership skills within the system.

While many recommendations for system change have come forward throughout this study, there are some initiatives that could be launched immediately to start the slow process of system change. These initiatives may be new, but some of them are also adjustments to work that are currently underway. These initiatives are coming from the voice of patients and in response to their concerns. They will also help to lay the foundation for a more patient-centred system until longer term projects can take hold. These initiatives include the following:

- Include patients in the design of the new children's hospital in Saskatoon, and all other health facilities thereafter;
- Include patients in the design / redesign of patient care processes, potentially involving them in the current use of Lean in the Province;
- Expand the use Lean to design care processes between organizations to create patient-centred linkages;
- Adopt a patient-centred policy lens for use within the MOH that evaluates every new policy developed with an eye for impact and effect on the patient;

- Develop patient advisory committees that advise the Regional Health Authorities and the providers within them;
- Use the Health Quality Council's Accelerating Excellence initiative to launch system wide patient-centered training;
- Develop performance measures with the Health Quality Council for each region that track patient satisfaction with the care they receive, and start thinking about appropriate incentives tied to these measures; and,
- Through participation in the Institute for Healthcare Improvement's Triple Aim initiative, ensure patients are included in the project team or in an advisory capacity, and use the results of that initiative to leverage change across the system.

These initiatives combined will help to create a more patient-focused healthcare system. One that engages patients in a discussion on their care and makes them feel included in the decisions that are made about their care. It will help patients navigate their way through the system to eliminate feelings of being lost in the system and it will improve access to care, overall improving the way patients feel about their healthcare system and underlying it all, improve health outcomes.

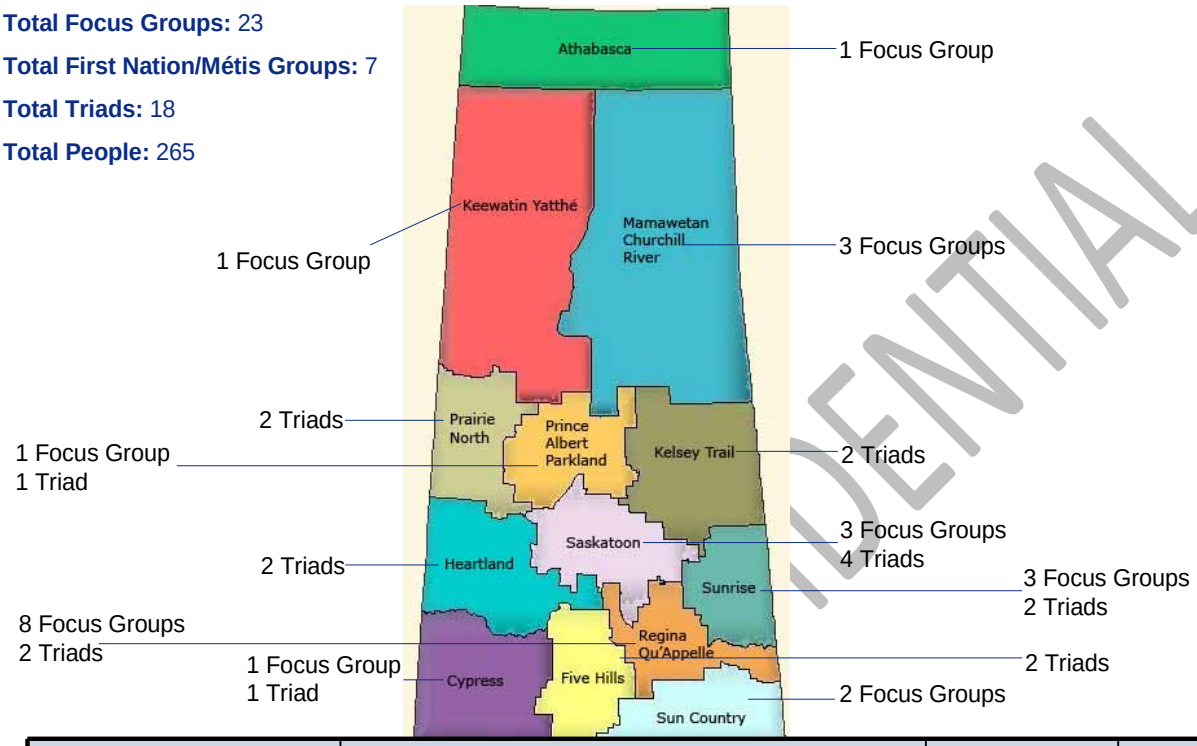
APPENDIX A: Comprehensive Summary of Patient Research Process

Total Focus Groups: 23

Total First Nation/Métis Groups: 7

Total Triads: 18

Total People: 265



Who	Where	# Participants Recruited	# Participants Participated
11 Mixed Demographic Groups	Regina (2), Saskatoon (1), Prince Albert (1), Swift Current (1), Yorkton (2), Kipling (2), La Ronge (1), Ile a la Cross (1)	10 per group	Average: 8 per group
4 First Nation/Métis Groups	Saskatoon (1), La Ronge (1), Fort Qu'Appelle (2)	10 per group	Average: 8 per group
'Intense Episodic' Triad	Saskatoon (1), North, Prince Albert (1), Rosetown (1),	15	11
'Chronic Illness' Triad	Saskatoon (1), North Battleford (1), Assiniboia(1),	15	15
'Women' Triad	Saskatoon (1), Rosetown (1), Melfort (1)	15	15
'Episodic 55+' Triad	North Battleford (1), Saskatoon (1), Assiniboia (1),	15	13
'Parents/Guardians' Triad	Regina (1), Swift Current (1), Canora (1)	15	12
'Care of the Elderly' Triad	Melfort (1), Regina (1), Canora (1)	15	14
2 'At Risk Mothers' Groups	Yorkton (1), Regina (1)	20	16
3 Homeless Groups	Saskatoon (1), Regina (2)	20	17
3 On-Reserve First Nations Groups	Standing Buffalo (1), Black Lake (1), Sandy Bay (1)	10 per group	Average: 8 per group
4 'Mental Health'	One-on-One phone interview	4	4
4 'Activity Limitations'	One-on-One phone interview	4	4

DRAFT - CONFIDENTIAL

APPENDIX B: Moderator's Guide

PATIENT FIRST REVIEW FOCUS GROUPS

Points for moderator to Address:

- Introduce self and role of the moderator
- Confidentiality and recording
- Two-way mirror
- Purpose of Note taker
- Incentives

INTRODUCTION TO THE PROCESS: Welcome to the Patient First Review. The Saskatchewan Minstry of Health has put together a commission to review how health care is working here in Saskatchewan. I have been engaged by this commission to facilitate discussion groups for the review - and we are starting with you, the patients and the public. The Patient First Review is about listening to patients, and the public to learn about the patient experience and to explore ways to improve health care in the Province. We are starting the review with you, the public. We want to hear from you on how the the Saskatchewan health care system should change/ develop in the future. Collecting experiences through randomly selected groups like this one is one way to do that.

This dialogue is going to take several months. Group discussions being held across the Province, like tonight's group, are just the beginning and they are very important.

KEY OBJECTIVES*:* We have 3 key objectives tonight. Eventually we will be building three lists that tie-in with these objectives.

1. **Build a list of experiences:** The first step toward finding out how the Saskatchewan health care system should develop in the future involves finding out how it has worked for you in the past. Tonight I would like to develop a list of good and bad experiences that you have faced in the health care system. **IMPORTANT NOTE ON TIMING**: Since we only have two hours, you might not have time tonight to fully explain your experiences in detail – you might only be able to share a little of some of your stories. Don't worry because there is another way to tell us. There is an online version of questions from this discussion – an interactive guide - that you can complete online on the website. If you prefer, you can complete a paper version of this interactive guide and mail it in to us. This can be downloaded online.

2. **Build a list of causes:** The second thing I would like to do tonight is to talk about the *causes* of your positive and negative experiences. I would like to discuss the key factors within the health care system that you believe are supporting your positive experiences, as well as the key factors that you believe have created more negative experiences.

3. **Build a list of "what can be done":** The third priority tonight is to build a list of "what can be done" to make sure positive experiences continue and are spread throughout the system and that negative experiences do not continue.

4. **Building a List of Potential Case Study Participants:** We also have a fourth objective. In the next few weeks we will be conducting a small number of follow-up interviews to explore some common positive and negative experiences in greater detail. Tonight when you leave, you will have the option of indicating whether you would like to be contacted for a possible follow-up interview. If you are interested in this possibility, there will be a place to leave your contact information as you sign out.

PARTICIPANT INTRODUCTIONS – Participants will introduce themselves.

SECTION 1: BUILDING A LIST OF EXPERIENCES

- **Section Objective:** To build a list of causes of good and bad experiences *(e.g. "friendly hospital staff"; or "no family doctor*

BEGIN WITH THE POSITIVE SIDE:

- Thinking about your experiences as users of the health care system here in Saskatchewan, what are some of the good things you've come across? What are some positive things you could say about the health care you have received here in Saskatchewan?
  - **Move around the table to ensure many voices.**
  - ***Ask the Group:*** How well does this type of situation match your experiences as users of the health care system?

NEGATIVE SIDE:

- And what hasn't been so good? Thinking about your experiences, what hasn't worked well?
  - **Move around the table to ensure many voices.**
  - ***Ask the Group:*** How well does this type of situation match your experiences as users of the health care system?

- *MODERATOR NOTE:* As each patient tells a story, be sure to understand where in the system this story occurs *–e.g. Family doctor, ED, other health care facility etc.*

SECTION 2: BUILDING A LIST OF CAUSES

Go through the list of GOOD EXPERIENCES. PROBE: What "made this experience good" (e.g. patient staff, quick paramedics, knowledgeable family doctor, availability of services, timeliness of care,

empathy understanding of staff). You can probe directly: What do you think was the reason for that experience? What factors in the health care system supported this experience.

- ***Probe individual impressions of the "cause":*** Was this a unique experience or do you think it is a common thing– could it happen to you or someone else again?

Go through the list of BAD EXPERIENCES. PROBE: What "made this experience bad" (e.g. patient staff, quick paramedics, knowledgeable family doctor).

- ***Probe individual impressions of the "cause":*** Was this a unique experience or do you think it is a common thing– could it happen to you or someone else again?

SECTION 3: EXPLORING CAUSES + SOLUTIONS:

MODERATOR TO EXPLAIN THE STICKER EXERCISE: I have provided you with a number of red stickers and blue stickers. **For the RED STICKERS:** I want you to place red stickers next to the problems and challenges on this list that you think are most important for the government to address right now (on the problems/challenges flipchart). You can place all of your stickers on one problem/issue if you wish. Or you can distribute your stickers to different problems and challenges. The bigger a priority you think something is, the more stickers it should have. **For the BLUE STICKERS:** Put the blue stickers next to the positive things on this chart that you think are most important for the Saskatchewan government to continue or begin doing. Put more stickers next to things that you value the most – that you think should get continued emphasis.

AFTER THE STICKERS HAVE BEEN DISTRIBUTED: for the red stickers, working from the issue with the most stickers down to the issue with the least stickers, the moderator should ask:

1. Why is this one important?
2. What needs to happen to solve this problem?
3. Does solving other problems here help to solve this problem? Is there a shared solution?

If money is answer given as a "solution"– *Probe:* If there were an unlimited amount of money available, would this problem go away? Are there other reasons this may be occurring/continuing to occur outside of a money-based reason? **If at the end a number of proposed solutions relate to money management - *Probe*:** Do you see any opportunities to spend the money currently in the system better? Also, how should "more money" be spent (e.g. more nurses) and how would that spending make a difference.

For the BLUE STICKERS: How do we make sure this continues? What needs to happen to ensure that this kind of experience is not threatened?

WRAP-UP FROM PARTICIPANTS

Time for closing comments from Participants

APPENDIX C: Patient Workbook Flow

Phase 1 of the Patient First Review involved posting an interactive guide on the Patient First Website that was for Patients and the General Public. The workbook had the following steps:

Step 1: 'Tell us about your experiences in the health care system'

The workbook asked respondents to share their experiences as a patient and user of the health care system, both positive and negative.

Step 2: Exploring causes and solutions enabling positive experiences

Participants were asked to share their ideas to help ensure such positive experiences continue in the future.

Step 3: Exploring causes and solutions for negative experiences

Respondents were asked to share their ideas as to what they believed caused the negative experience they had encountered. Additionally, they were encouraged to share solutions that they felt could help to solve those negative experiences and prevent them from continuing in the future.

APPENDIX D: Comprehensive Summary of Provider Research Process

Total Participants across the continuum of care: 94

General/Family Physician: 8

Physician-Specialist: 5

Nursing Personnel: 18

Pharmacist: 4

Home care Aide/Special Care Aide: 8

Environmental services, Housekeeping: 4

Psychologist/Social Worker: 5

Rehabilitation/Therapist: 5

Paramedic: 5

Diagnostic Personnel: 6

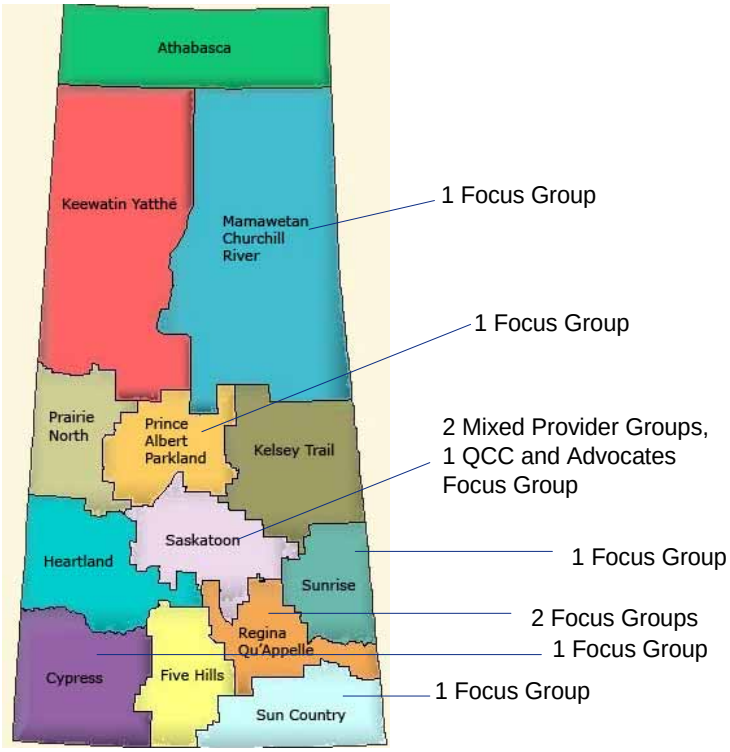
Health Care Administrator/High Level Support: 5

Dietician/Nutritionist: 2

QCC: 14

Patient advocate or volunteer: 5

Total Focus Groups: 10



WHERE	WHO WAS RECRUITED	WHO DID NOT SHOW
Saskatoon (3)	(2) General/Family Physician, (2) Physician-Specialist, (4) Nursing Personnel, (1) Dietician/Nutritionist, (1) Pharmacist, (1) Home care Aide/Special Care Aide, (1) Health Care Administrator/High Level Support, (1) Environmental services, Housekeeping, (1) Diagnostic Personnel, (1) Psychologist/Social Worker, (2) Rehabilitation/Therapist, (2) Paramedic, (9) QCC, (5) Patient advocate/volunteer	(1) Nursing Personnel, Psychologist/Social Worker, (1) QCC
Prince Albert	(1) General/Family Physician, (1) Specialist Physician, (2) Nursing Personnel, (1) Paramedic, (1) Health Care Administrator/High Level Support, (1) Environmental services, Housekeeping, (1) Psychologist/Social Worker, (1) Rehabilitation/Therapist, (1) Pharmacist, (1) QCC	Environmental services, Housekeeping, Pharmacist
La Ronge	(1) General/Family Physician, (3) Nursing Personnel, (1) Home care Aide/Special Care Aide, (1) Paramedic, (1) Psychologist/Social Worker, (1) Health Care Administrator/High Level Support, (1) Environmental services, Housekeeping, (1) Diagnostic Personnel, (1) QCC	N/A
Regina (2)	(3) General/Family Physician, (1) Specialist Physician, (2) Nursing Personnel, (2) RN/LPN from ANHH, (1) Pharmacist, (1) Paramedic, (1) Dietician/Nutritionist, (1) Home care Aide/Special Care Aide, (1) Health Care Administrator/High Level Support, (1) Diagnostic Personnel, (1) Environmental services, Housekeeping, (2) Rehabilitation/Therapist, (1) QCC, (1) Representative from SK Cancer Agency	(1) Rehabilitation/Therapist
Swift Current	(1) General/Family Physician, (2) Nursing Personnel, (1) Pharmacist, (1) Paramedic, (1) Home care Aide/Special Care Aide, (1) Psychologist/Social Worker, (1) Diagnostic Personnel, (1) Health Care Administrator/High level support, (1) QCC	N/A
Weyburn	(1) General/Family Physician, (2) Nursing Personnel, (2) Home care Aide/Special Care Aide, (1) Environmental services, Housekeeping, (1) Paramedic, (1) Pharmacist, (1) Psychologist/Social Worker, (1) Diagnostic Personnel	General/Family Physician
Yorkton	(1) General/Family Physician, (1) Specialist Physician, (2) Nursing Personnel, (2) Home care Aide/Special Care Aide, (1) Rehabilitation/Therapist, (1) Pharmacist, (1) Psychologist/Social Worker, (1) Diagnostic Personnel, (1) QCC	General/Family Physician, Psychologist/Social Worker

APPENDIX E: Moderator's Guide

PROVIDER GROUPS

MODERATOR INTRODUCTION

The Patient First Review is about listening to patients, providers and stakeholders about how to make meaningful improvements to the health care system in Saskatchewan. In the first of four distinct research stages of the Patient First Review, individuals across Saskatchewan were invited to share their experiences as users of the health care system with the Patient First Review team. Patient consultations have included focus groups, target patient discussion groups, one-on-one interviews, and responses to our first interactive guide. Phase One has provided the Patient First Review team with feedback concerning what is working well and what is not working well in the health care system from the patient perspective.

- You are the first to receive the findings.
- Findings should be taken into confidence – will be shared with the public beginning next week.
- Please do not mark up or keep the materials we give you tonight, they will be re-used.

TONIGHT WE HAVE THREE GOALS:

SHARE →Over 260 Saskatchewan residents from across the Province have participated in interviews and focus groups about their health care experiences. Over 1400 residents have completed our Patient Experience Workbook: Interactive Guide, with more responses arriving every day. We learned that most of the time, most patients have positive interactions with the health care system. Many patients are very proud of the Saskatchewan health care system and shared positive stories. However, negative experiences were also common. In this focus group, we will share with you some of the positive and negative experiences that Saskatchewan patients have told us about. Please note that findings from qualitative research (e.g. focus groups, interviews, workbooks) should not be extrapolated to the Saskatchewan population as a whole.

CHECK → We will check in with you about whether we are missing any common positive and negative experiences on our list.

EXPLORE → There is a clear bias for action from patients to improve the system so that it consistently delivers in practice what it promises in theory. **How do we protect the best while we fix the rest**? We will discuss some of the underlying reasons for positive and negative patient experiences and your ideas about what can be done to make meaningful improvements to patient experiences in Saskatchewan.

PART 1 – SHARE

First I will circulate a list of the positive and negative experiences that we have heard most commonly from patients.

- Patients "experiences" were arrived at after analysis of interview notes, focus group notes, and workbooks. The ones presented here are those that came up with a high level of frequency. Topics that came up less frequently have not been lost and will be revisited as more patient stories are examined from other avenues *e.g. patient experience workbook still available online.*
- "Experiences" articulate the patient perspective – not the system perspective.
- Patient quotes are illustrative only and show only one face of the patient experience.

PART 2 – CHECK

- Is this list what you would have expected?
- Were there any surprises?
- Are there any other positive patient experiences that you feel are common but have not been mentioned?
- Are there any other negative patient experiences that you feel are common but have not been mentioned?
- Does anyone think any of these suggestions actually do fit into some of the experience categories provided?

PART 3 – EXPLORE

Limited time means that we will look at a selection of experiences in detail.

- These flip books *include a brief description of the experience and a patient* story. Stories are based on real patient experiences but details have been changed to conceal patient identity. Some of the stories combine details of 2 or 3 real stories. Again, these stories only represent one face of the patient experience, so try not to get bogged down in specific details of a story when we discuss the experience in more detail.

FOR EACH EXPERIENCE COVERED, ASK:

- How common is this experience in Saskatchewan?

Build a List of Causes and Building a List of Solutions for Positive Experiences:

- **CAUSES:** What would you say are some of the key factors that enable this positive patient experience?

Note: focus on the "experience" generally rather than the specifics of the connected patient story.

- **SOLUTIONS:** How do we make sure that patients continue to have this positive experience in the health care system?

Build a List of Causes and Building a List of Solutions for Negative Experiences:

- **CAUSES:** What would you say are some of the key factors that lead to this patient experience? *Note: focus on the "experience" generally rather than the specifics of the connected patient story.*

  ***PROBE:** Would the problem go away if there was unlimited money or staff? Or is there another cause here?*

- **SOLUTIONS:** How do we avoid repeating this negative experience in the future?

  - *Of the solutions we have discussed for this, which would you say should be the highest priority?*
  - *Which solution would you say is most feasible/most do-able to implement in the very near future?*

WRAP-UP

- I want to encourage you to continue participating in the Patient First Review by visiting our website at www.patientfirstreview.ca. You will find a workbook that you can complete online - or download and complete by hand – that will allow you to elaborate on the experiences we have discussed and to provide your thoughts and ideas to us in writing.

- I would also like to remind you that **if** you are interested in the *possibility* of participating in a future interview to discuss your experience in more detail, you can indicate this when you sign-out and collect your incentive. Members of the Patient First Review research team will be conducting a small number of telephone interviews with some interested patients in the coming weeks.

APPENDIX F: Provider Workbook Flow

Phase 2 of the Patient First Review involved posting an interactive guide on the Patient First Website for Providers and the General Public. The workbook had the following steps:

Step 1: SHARE - Present positive and negative patient experiences

The workbook shared the positive and negative experiences as identified by the patients in Phase 1.

Step 2: CHECK - Gather "new" patient experiences

Respondents were encouraged to add any other experiences that they encountered as users of the health care system. The workbook provided respondents the opportunity to contribute new positive and negative patient experiences that they believed to be missing.

Step 3: EXPLORE - Explore "causes" and ideas for improving patient experiences

Respondents were invited to pick a selection of positive and negative experiences to explore in greater detail. They were asked to think about:
•What would you say are some of the key factors that enable this patient experience?
•What changes would you suggest to improve this patient experience?

APPENDIX G: Stakeholder Breakout Group Format

Selecting Categories of Improvement

Stakeholders were given the following instruction for their breakout group sessions:

- **Talk about ways to improve patient experiences by focusing on the categories of improvement that the research has identified.**

Generating lots of ideas → Harvesting Ideas and Picking the Best → Report Back to the Group

Be creative, while sticking to what you know.

Which ideas will impact patient experiences in the most meaningful way?

Consider the barriers to implementing these ideas

Top ideas for improvements

APPENDIX H: Stakeholder Session Guide

Introductions

- **Moderator to Introduce Self & Review Session Goals**
- **Session Goal:** To report back on some creative, actionable ideas that will improve patient experiences and advance the categories of improvement in a meaningful way. A 'report back' session will be a chance for each breakout group to highlight three or four good ideas from their discussion.
- Each participant says their name, role, organization

Main Activity: Ideas Exercise

Step 1: Selection of Categories of Improvement to discuss

- Group votes on first three of six categories of improvement to discuss (show of hands – each person has 3 votes)
- ***Note:*** Discussion of any category of improvement will be limited to 30 minutes. If 3 categories are discussed in less than 30 minutes, the remaining time can be used towards a 4th or more categories.
- Each group to report a session Reporter (who will present in the "Report-back")

Step 1: Generating ideas (One category at a time)

- Participants use sticky notes to write down ideas for solutions that would help to advance the category of improvement selected
- Rules for Participants:
  - 1 idea per sticky note. 1 sticky note per idea.
  - Be creative! *It's OK to have only one good creative idea rather than many, many ideas.*
  - Think about ideas that will have a meaningful impact on patient experience
  - **Start with ideas that come from what you know best** – ideas that you could see being implemented in your area.
  - Give people about 3 minutes for idea generation per category.

- **Notes to Moderator:** Remind participants that the "report back" will probably focus on one or two ideas BUT stress that you will keep track of the whole list and no ideas are being thrown away.
  - Moderator to place all the sticky ideas onto a flip chart - group all ideas in terms of their similarity – like with like.

Step 2: Discussing and harvesting ideas (One category at a time)

- As a group, evaluate each of the ideas according to 2 criteria. What makes a good idea:
  - Ask about how well the idea creates a benefit for the patient/improves the patient experience

- Ask about the **practicality/implement-ability** of each idea in terms of the types of barriers to implementation (emphasize that we want to stretch our thinking - at the same time, we need to be realistic e.g. ideas that require lots of new money or rely on major technological breakthroughs may not be "good").

- If an idea is particularly **good**, the moderator should set it aside as a candidate for the report-back session.

Repeat the steps above for each of the categories selected.

Step 3: Voting on Ideas

- Moderator to place all the ideas that were "set aside" for being "good" on a flip chart together
- Participants will be given 4 votes. Votes will be coloured dots (stickers).
- The participants will place their votes next to the ideas that they feel are best, using the criteria of: 1) Patient Experience Benefit; and 2) Implementability/consideration of barriers.
- Settle on the ideas for the "report- back" - About 3 or 4 ideas per group. The report back should reference the "category of improvement" from which each idea came. It's OK if you end up going with ideas that all were derived from the same category of improvement so long as they are your best overall ideas.

Step 4: Pick a report back spokesperson to describe ideas back to the broader group. **The reporter should focus on how the idea works within a category of improvement, how it improves patient experiences and how it can be implemented.**

APPENDIX I: Stakeholder Workbook Flow

Phase 3 of the Patient First Review involved posting an interactive guide on the Patient First Website for Stakeholders, Providers and the Public. The workbook had the following steps:

Step 1: Introducing Categories of Improvement

After a brief review of patient experiences, the workbook introduced respondents to the proposed Categories of Improvement. Respondents selected which categories of improvement they wished to explore further.

Step 2: Exploring ideas for categories of improvement

Participants were asked to share their ideas for making meaningful improvements within selected categories. They were encouraged to be creative, but also practical. Their ideas should: 1) Create a benefit for the Patient First; 2) Be actionable – possible to imagine implementing given current resources and scientific limitations. Participants were also asked to discuss potential barriers to implementing their ideas.

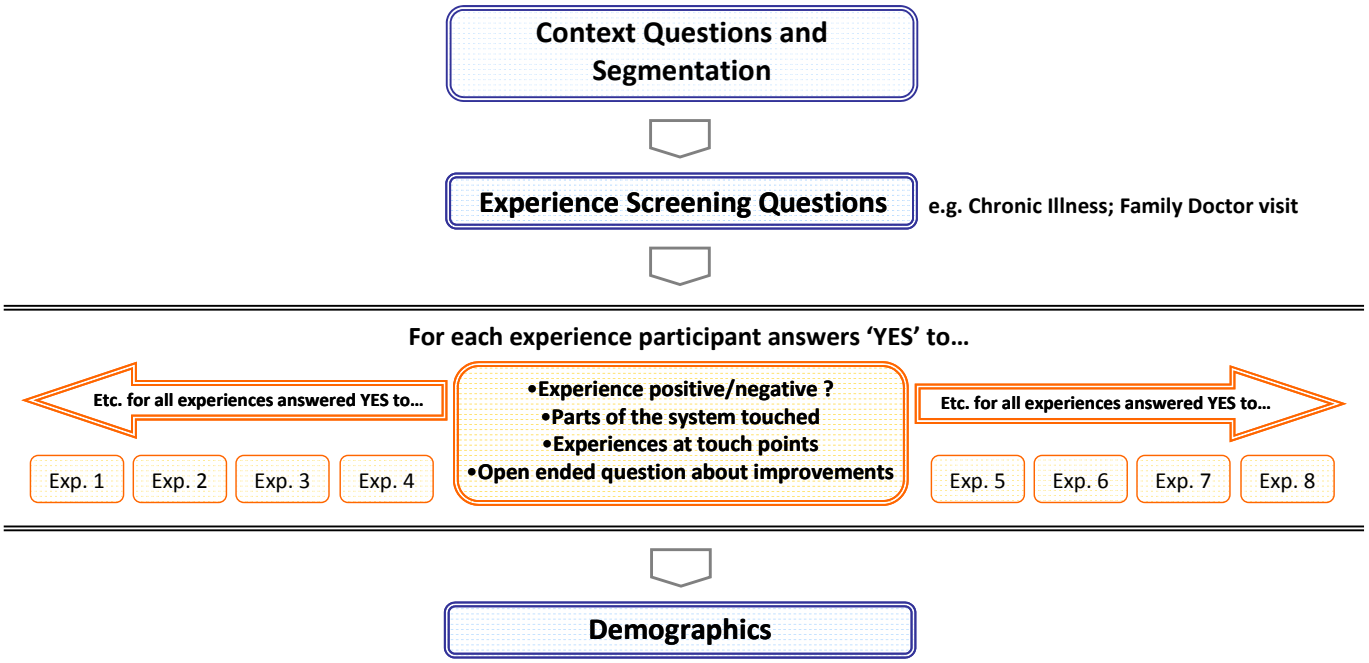
Step 3: Other ideas

Respondents were encouraged to share any other ideas that they have for making improvements to the health care system that would have a meaningful impact on patient experience (e.g. that do not necessarily line up with a category)

Step 4: Review of ideas and core debates

Participants were asked to provide feedback on some ideas heard through the PFR process so far.

APPENDIX J: Survey Flow and Design



APPENDIX K: Questionnaire

PFR PHASE 4 ENGAGEMENT

TELEPHONE SURVEY

N=1000

Quotas:

- 50/50 male/female;
- Representative regional and age samples;
- Min of 50 Métis respondents;
- Min of 100 First Nations respondents.

Hello, this is ____ calling from Innovative Research Group, a national public opinion research firm. Tonight we are contacting Saskatchewan residents about their opinions of the way health care services are delivered and to explore ways to improve patient experiences in the Province.

(If necessary read: This survey is being conducted as part of an initiative called the Patient First Review)

Would you mind if I asked you some questions? All your responses will be kept strictly confidential.

Yes - Continue	1	
Not available now **(ARRANGE CALLBACK)**	2	=> /INT
Refuse – LOG **(THANK AND TERMINATE)**	9	=> /INT

MONIT This call may be monitored or audio taped for quality control and evaluation purposes.

PRESS TO CONTINUE 1

S1 Have I reached you at your home phone number?
INTERVIEWER NOTE: IF NO SAY: May I speak to someone who does live here?

Yes - SPEAKING, CONTINUE 1

YES - TRANSFERRED – **(GO BACK TO INTRODUCTION)**	2	=> HELLO
No - NOT AVAILABLE – **(ARRANGE CALLBACK)**	3	=> /INT
Refused – LOG **(THANK AND TERMINATE)**	9	=> /INT

S2A. Are you a Canadian citizen 18 years of age or older who normally resides in Saskatchewan and resides at the location I have reached you at?

Yes	1	=> SEX
No	2	
Don't Know/Refused - LOG	9	=> /INT

S2B. Can I speak to anyone else who lives at this residence who is a Canadian citizen 18 years of age or older who normally resides in Saskatchewan?

Yes - **REPEAT INTRODUCTION WITH NEW RESPONDENT & CONTINUE**
1 => HELLO

No Eligible respondent resides in household **THANK & TERMINATE – LOG** 2
=> /INT

No, Eligible respondent is not available - **ARRANGE CALLBACK** 3
=> /INT

Don't Know/Refused - **LOG** 9
=> /INT

*SEX **** DON'T READ - RECORD GENDER BY OBSERVATION ****

Male	1
Female	2

Q1Aa Which of the following age groups do you fall into?

18-24	1
25-34	2
35-44	3
45-54	4
55-64	5
65+	6
Refuse **(VOLUNTEERED)**	9

WORK. Does anyone in your household work for... **(READ LIST)**

A marketing research firm - **LOG**	1	=> /INT
A newspaper, radio, or TV station (media) - **LOG**	3	=> /INT
An advertising agency - **LOG**	5	=> /INT
NONE OF THE ABOVE	7	
(DO NOT READ) - Don't know/Refused	9	=> /INT

METIS/FIRST NATION. Canadians come from a variety of backgrounds. Would you describe your own family background as First Nations, Métis or neither?

Yes, First Nations or Inuit	1	(min n=100)
Yes, Métis	2	(min n=50)
No, neither First Nations or Métis	3	(max n=850)

QUAL ***➔ INTERVIEWER NOTE: THE RESPONDENT HAS NOW QUALIFIED FOR THE SURVEY***

PRESS TO CONTINUE 1

Section 1 (Post Qualification) – Context Questions

1. How would you describe the overall quality of health care available in your community today? Is it excellent, good, acceptable, poor, or very poor?

Excellent	1
Good	2
Acceptable	3
Poor	4
Very Poor	5
Have not used any health care services	6
Don't know	8 (Volunteered)

2. Generally speaking, how would you describe the quality of the health care services provided to you and your family in the last 12 months? Is it excellent, good, acceptable, poor, or very poor?

Excellent	1
Good	2
Acceptable	3
Poor	4
Very Poor	5
Have not used any health care services	6
Don't know	8 (Volunteered)

3. Generally speaking, how would you describe your ability to access health care services for yourself and your family in the last 12 months? Is it excellent, good, acceptable, poor, or very poor?

Excellent	1
Good	2
Acceptable	3
Poor	4
Very Poor	5
Have not used any health care services	6
Don't know	8 (Volunteered)

4. Do you currently have a family doctor in Saskatchewan?

Yes	1	(SKIP TO Q6)
No	2	

Don't know	8	(Volunteered)

5. (If NO/DK to Q4) Which of the following statements is most true for you? (READ AND RANDOMIZE LIST. ACCEPT ONLY ONE RESPONSE)

It is not important to me to have a family doctor	1	
I don't need a family doctor right now	2	
I have looked for more than a year but I cannot find one in my community that will meet my needs	3	
My family doctor has left my community or retired, and I am looking for a replacement	4	
I have moved, and am currently looking for a family doctor in my new community	5	
Don't know	8	(Volunteered)

6. At the present time, how do you access health care services most often for yourself or your family when you require them, do you …. (READ AND RANDOMIZE LIST. ACCEPT ONLY ONE RESPONSE)

Visit your family doctor	1	
Visit a walk in clinic	2	
Go to the emergency room of a hospital	3	
Call the HealthLine	4	
Visit a Nurse practitioner or an advanced clinical nurse	5	
Visit a Naturopath or Homeopath	6	
Visit a Traditional Healer	9	
Other (specify)	10	
Don't know	8	(Volunteered)

7. In general, would you say that the health care that patients receive in Saskatchewan is better or worse than the health care that patients receive in the rest of Canada? Would you say it is much better, somewhat better, about the same, somewhat worse, or much worse?

Much better	1
Somewhat better	2
About the same	3
Somewhat worse	4
Much worse	5
Don't know (Volunteered)	8

8. In general, would you say that the health care that patients receive in Saskatchewan is better or worse than the health care that patients receive in the United States? Would you say it is much better, somewhat better, about the same, somewhat worse, or much worse?

Much better	1
Somewhat better	2
About the same	3
Somewhat worse	4
Much worse	5
Don't know (Volunteered)	8

9. Do you have any chronic medical problems like asthma, diabetes, or any physical disabilities?

Yes – a chronic medical problem	1
Yes – a physical disability	2
No	3
Don't know	8 (Volunteered)

10. Do you or a member of your immediate family work in the health care field?

Yes – I work in the health care field	1	
Yes – A family member works in the health care field	2	
Both – I and a family member work in the health care field	3	
No – Neither I nor a family member works in the health care field	4	
Don't know	8	(Volunteered)

11. Is there anyone in your life, such as a friend or family member, with a medical problem or disability for whom you are at least partially responsible for providing care, not as part of your paid work?

Yes	1
No	2
Don't know	8 (Volunteered)

Section 3 (Agree/Disagree Statements)

For each of the following statements about healthcare please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree?

Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Don't know	8	(Volunteered)

12. The Saskatchewan health care system puts patients first
13. I feel that I have a say in decision-making about my health care
14. In general, health care workers in my community care about patients and treat them with respect
15. My personal health care information seems to get lost in the health care system
16. I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour

17. (If 'Strongly Agree' or 'Somewhat Agree'to 16) How often do you experience rude or dismissive behaviour from health care workers? Is it never, sometimes, usually or always?

Never	1	
Sometimes	2	
Usually	3	
Always	4	
Don't know	8	(Volunteered)

SEGMENTATION QUESTIONS

For each of the following statements about healthcare please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree?

Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Don't know	8	(Volunteered)

18. I am confident that if I had a medical problem I would receive the treatment I needed in Saskatchewan as soon as I needed it.

19. The health care system is so complex that I worry that if I become seriously ill I will not be able to find the help I need.

20. I like to do my own research before I take my doctor's advice.

21. I am in pretty good shape for someone my age.

22. We put too much faith in medical doctors and conventional, western drugs and treatments.

23. With the technology we have these days, I am confident we will find cures to diseases like cancer sooner rather than later.

24. I worry about illness and disease more than most people I know.

25. I am more careful about what I eat than most people.

Section 4–Experience Screening Questions

I am going to ask you a few questions to understand how you might have used the health care system in Saskatchewan ~~in the last 5 years~~. Please be assured your answers will remain confidential. Please tell me if you have used the health care system in Saskatchewan for any of the following reasons in the last 5 years. Have you used the health care system to …

Yes	1	
No	2	
Don't know/Prefer not Say	8	(Volunteered)

A SECTION : 26A- 33A

26. To receive treatment for a serious medical incident such as a heart attack, a serious injury such as a motor vehicle accident, a major surgery, or a sudden serious illness? ← exclude "such as…." for future piping

27. To ask for advice or to receive treatment for one or more chronic illnesses such as diabetes, arthritis or asthma? ← exclude "such as…." for future piping

28. To ask for advice or to receive ongoing treatment or care for [your / someone else's] a dependent child with a serious chronic illness, a physical or developmental disability, or a mental health condition? ← exclude "with a …." for future piping. Instead say: "with a serious health issue"

29. To ask for advice or to receive treatment for one or more long-term medical conditions that has reduced the amount or kind of physical activity you can do either often or all of the time? ← exclude "that has …." for future piping

30. To ask for advice or to receive treatment for one or more mental or emotional health conditions?

31. To ask for advice or to receive treatment for one or more addiction issues?

32. To have a baby or to receive treatment or advice for one or more family planning or reproductive health issues?

33. To ask for advice or to receive treatment or care for an aging family member or friend for whom you are at least partially responsible for providing ongoing care? ← exclude "for whom …." for future piping

For 26-33, all respondents will be asked the "A" and "B" batteries. In terms of which mini-survey to apply to a participant, "YES" responses in the A battery will always trump "YES" responses in the B battery.

- Respondents should only be asked a "B" mini survey if they do not have 2 "YES" responses in the A battery.
- Respondents with zero "YES" responses in the A battery, or just one "YES" response in the A battery, will be eligible for mini-surveys from the "B" category.

The hierarchy applies within each battery (e.g. not between batteries).

B SECTION: Have you assisted someone such as a friend or family member in using the health care system to….? (REPEAT BATTERY 26-33)

Section 5 – MINI-SURVEYS

If 'YES' to any of 26-33 A or B, the respondent is eligible to participate in a mini-survey.

No more than 2 mini-surveys should be administered per respondent.

For respondents eligible for more than 2 mini-surveys, apply the following hierarchy to determine which 2 surveys to pick**: 31, 33, 28, 30, 32, 29, 26, 27. A should always trump B.**

We will verify and check incidences after the first 100 surveys are complete.

MINI-SURVEY 1

NOTE ON 'PIPE-IN"s BELOW:

If 'YES" to 26-33A, pipe in text as it appears in the questions 26-33.

If 'YES' to 26-33B, **WHEN PIPING IN RESPONSES, ADD THE FOLLOWING TEXT BEFORE THE PIPE-IN:** *to assist a family member or friend* (PIPE IN TEXT TO 26-33).

34. When was the last time you used the health care system to (PIPE IN RELEVANT ISSUE 26-33)

Within the last 3 months	1	
Within the last 6 months	2	
Within the last year	3	
Within the last 3 years	4	
Within the last 5 years	5	
Don't know	8	(Volunteered)

35. Overall, how would you describe your experience using the health care system to (PIPE IN RELEVANT ISSUE 26-33)? Would you say excellent, good, acceptable, poor, or very poor?

Excellent	1	
Good	2	
Acceptable	3	
Poor	4	
Very Poor	5	
Don't know	8	(Volunteered)

Thinking about your experience using the health care system to (PIPE IN RELEVANT ISSUE 26-33), which of the following parts of the health care system did you connect with? Did you connect with….

Yes	1	
No	2	
Don't know	8	(Volunteered)

36. A primary care practice, such as your family doctor's office or a walk-in clinic
37. Diagnostic testing services, such as MRIs or X-rays
38. Emergency care services
39. Hospital services for an overnight stay or longer

40. Surgical services
41. A specialist physician, such as dermatologist or psychiatrist, or a specialized treatment service, such as dialysis or cancer treatment services
42. Physical rehabilitation services, such as physical therapy or occupational therapy
43. Home care services
44. Long-term care services
45. Other services (VOLUNTEERED – SPECIFY)) _____

Based on your experience using the health care system to (PIPE IN RELEVANT ISSUE 26-33), how would you describe each of the following? Excellent, Good, Acceptable, Poor, or Very Poor?

Excellent	1	
Good	2	
Acceptable	3	
Poor	4	
Very Poor	5	
Don't know	8	(Volunteered)

46. The length of waiting times to access care
47. Transitions from one part of the system to another
48. Knowledge of health care staff
49. Listening skills of health care staff
50. Courteousness of health care staff
51. Communication of next steps by health care staff

POOR RATING PROBES

NOTE: FOR EACH STATEMENT IN 46-51 where response was "POOR" or "VERY POOR", ASK THE QUESTION BELOW. DRAW FROM PARTS OF THE SYSTEM USED IN Qs 36-45 FOR LIST

DO NOT ASK IF THE RESPONDENT ONLY USED ONE PART OF THE SYSTEM IN Qs 36-45.

ONLY IF 46=4 OR 5

52. In which part of the system did you have the greatest problem with the length of waiting times to access care...was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45. ACCEPT ONLY ONE RESPONSE)

ONLY IF 47=4 OR 5

53. You indicated that you had experienced a problem with transitions from one part of the system to another. I would like to understand which part of the system were you coming from and which part of the system you were going to when you experienced your greatest problem. (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45 ACCEPT TWO RESPONSES ONLY. ONE response for **"FROM"** and ONE response for **"TO"**)

ONLY IF 48=4 OR 5

54. In which part of the system did you have the greatest problem with knowledge of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45. ACCEPT ONLY ONE RESPONSE)

ONLY IF 49=4 OR 5

55. In which part of the system did you have the greatest problem with listening skills of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45. ACCEPT ONLY ONE RESPONSE)

ONLY IF 50=4 OR 5

56. In which part of the system did you have the greatest problem with courteousness of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45. ACCEPT ONLY ONE RESPONSE)

ONLY IF 51=4 OR 5

57. In which part of the system did you have the greatest problem with communication of next steps by health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45. ACCEPT ONLY ONE RESPONSE

FINAL QUESTION PER MINI- SURVEY 1:

58. From your point of view, what one thing could the health care system do differently that would make the biggest improvement for people who use the health care system to (PIPE IN RELEVANT ISSUE 26-33)? (OPEN)

MINI-SURVEY 2

NOTE ON 'PIPE-IN"s BELOW:

If 'YES" to 26-33A, pipe in text as it appears in the questions 26-33.

If 'YES' to 26-33B, **WHEN PIPING IN RESPONSES, ADD THE FOLLOWING TEXT BEFORE THE PIPE-IN:** *to assist a family member or friend* (PIPE IN TEXT TO 26-33).

59. When was the last time you used the health care system to (PIPE IN SECOND RELEVANT ISSUE from 26-33)

Within the last 3 months	1	
Within the last 6 months	2	
Within the last year	3	
Within the last 3 years	4	
Within the last 5 years	5	
Don't know	8	(Volunteered)

60. Overall, how would you describe your experience using the health care system to (PIPE IN SECOND RELEVANT ISSUE from 26-33)? Would you say excellent, good, acceptable, poor, or very poor?

Excellent	1	
Good	2	
Acceptable	3	
Poor	4	
Very Poor	5	
Don't know	8	(Volunteered)

Thinking about your experience using the health care system to (PIPE IN SECOND RELEVANT ISSUE from 26-33), which of the following parts of the health care system did you connect with? Did you connect with….

Yes	1	
No	2	
Don't know	8	(Volunteered)

61. A primary care practice, such as your family doctor's office or a walk-in clinic
62. Diagnostic testing services, such as MRIs or X-rays
63. Emergency care services
64. Hospital services for an overnight stay or longer
65. Surgical services
66. A specialist physician, such as dermatologist or psychiatrist, or a specialized treatment service, such as dialysis or cancer treatment services
67. Physical rehabilitation services, such as physical therapy or occupational therapy
68. Home care services
69. Long-term care services
70. Other services (VOLUNTEERED – SPECIFY)) _____

Based on your experience using the health care system to (PIPE IN SECOND RELEVANT ISSUE from 26-33), how would you describe each of the following? Excellent, Good, Acceptable, Poor, or Very Poor?

Excellent	1	
Good	2	
Acceptable	3	
Poor	4	
Very Poor	5	
Don't know	8	(Volunteered)

71. The length of waiting times to access care
72. Transitions from one part of the system to another
73. Knowledge of health care staff

74. Listening skills of health care staff
75. Courteousness of health care staff
76. Communication of next steps by health care staff

POOR RATING PROBES

NOTE: FOR EACH STATEMENT IN 71-76 where response was "POOR" or "VERY POOR", ASK THE QUESTION BELOW. DRAW FROM PARTS OF THE SYSTEM USED IN Qs 61-70 FOR LIST

DO NOT ASK IF THE RESPONDENT ONLY USED ONE PART OF THE SYSTEM IN Qs 61-70.

ONLY IF 71=4 OR 5

77. In which part of the system did you have the greatest problem with the length of waiting times to access care…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q61-70. ACCEPT ONLY ONE RESPONSE)

ONLY IF 72=4 OR 5

78. You indicated that you had experienced a problem with transitions from one part of the system to another. I would like to understand which part of the system were you coming from and which part of the system you were going to when you experienced your greatest problem. (READ LIST OF PARTS OF THE SYSTEM USED AT Q36-45 ACCEPT TWO RESPONSES ONLY. ONE response for **"FROM"** and ONE response for **"TO"**)

ONLY IF 73=4 OR 5

79. In which part of the system did you have the greatest problem with knowledge of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q61-70. ACCEPT ONLY ONE RESPONSE)

ONLY IF 74=4 OR 5

80. In which part of the system did you have the greatest problem with listening skills of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q61-70. ACCEPT ONLY ONE RESPONSE)

ONLY IF 75=4 OR 5

81. In which part of the system did you have the greatest problem with courteousness of health care staff…was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q61-70. ACCEPT ONLY ONE RESPONSE)

ONLY IF 76=4 OR 5

82. In which part of the system did you have the greatest problem with communication of next steps by health care staff …was it? (READ LIST OF PARTS OF THE SYSTEM USED AT Q61-70. ACCEPT ONLY ONE RESPONSE)

FINAL QUESTION PER MINI- SURVEY 2:

83. From your point of view, what one thing could the health care system do differently that would make the biggest improvement for people who use the health care system to (PIPE IN RELEVANT ISSUE 26-33)? (OPEN)

Section 8 – END - DEMOGRAPHICS

DO NOT READ LIST; RECORD ONE RESPONSE

Now I'm going to ask you a few questions to help profile your responses. Please be assured your answers will remain confidential and are only used for analysis purposes.

84. What is the highest level of schooling that you have completed?

Public/Elementary (Grade 1-8)	1
Some High School (9-12 OR 13)	2
Graduated High School	3
Some Vocational/Technical/College/CEGEP	4
Completed Vocational/Technical/College/CEGEP	5
Some University	6
Graduated University	7
Post Graduate	8
REFUSE **(VOLUNTEERED)**	98

85. Which of the following best describes your current job status? Read list

Working at your own business within your home	1
Working at your own business outside of your home	2
Working at an employer's business full-time	3
Working at an employer's business part-time	4
Currently unemployed	5
Student	6
Retired	7
Homemaker	8
Don't Know / No Response / Refused [DO NOT READ]	98

86. Was your **TOTAL HOUSEHOLD INCOME** for last year under or over $40,000?

UNDER $40,000	1	(**CONTINUE**)
OVER $40,000	2	=> Q87B
REFUSE **(DO NOT OFFER)**	9	=> END

READ LIST

87A. And would that be...?

Under $20,000	01	=> skip over q87b
$20,000 to under $30,000	02	=> skip over q87b
$30,000 to under $40,000	03	=> skip over q87b

UNDER $40,000 UNSPECIFIED **(DO NOT READ)**	04	=> skip over q87b
REFUSE (DO NOT READ)	99	=> skip over q87b

87B. And would that be...?

$40,000 to under $50,000	5
$50,000 to under $60,000	6
$60,000 to under $70,000	7
$70,000 to under $80,000	8
$80,000 to under $100,000	9
$100,000 to under $120,000	10
$120,000 or more	11
OVER $40,000 UNSPECIFIED **(DO NOT READ)**	12
REFUSE **(DO NOT READ)**	99

88. Which of the following best describes you.

Single, divorced or widowed and living alone	1
Single with children at home	2
Married or living with someone with children at home	3
Married or living with someone with no children at home	4
Refused/won't say	99

APPENDIX L: Solutions