

Patient Experience Case Studies

Matthew's Story:

A child's experience of cancer diagnosis and treatment



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Introduction

The Patient First Review was a landmark research study within the Province of Saskatchewan which explored the current health care system from a patient's perspective. The research involved speaking with patients, health care providers, and health system stakeholders in order to understand issues within the system, the potential causes of those issues, and what potential solutions might address them.

While the research provided a wealth of information that will be used by the Ministry of Health and the health care system to guide system planning, the Province was interested in doing a more detailed analysis on some of the key issues within the system in order to validate what was heard in the research. The case study approach was determined to be a useful tool for this analysis.

The purpose of Matthew's story is to:

- ▶ Present a patient story for what is a potential journey through the system for children with cancer and their parents;
- ▶ Engage patients and providers in a deeper discussion on the issues encountered in the system when a child is living with cancer;
- ▶ Validate the causes of the issues heard in the research;
- ▶ Explore potential solutions to address the issues that might be investigated further by the Ministry, health care providers and system stakeholders; and,
- ▶ Present the envisioned patient story when improvements have been made in the system.

The case study focuses on the experience of a child with cancer and his parents, as they go through the system trying to cope and manage the disease. The names are fictional; however, the experiences are real. Multiple patients interviewed during the Patient First Review provided an account of their experiences, which were combined to highlight common issues encountered throughout the health care system. Communities named in the study were used only as reference points. The providers referenced in this case are fictional and are not meant to depict any individuals who work in these communities. Any similarity to real people is purely coincidental.

Matthew's Story

Matthew is a 12-year-old boy who lives an hour outside Regina with his father, Jeffrey, and mother, Lisa. Matthew and his family have lived with cancer for most of their lives. Matthew and his father have Familial Adenomatous Polyposis (FAP), a large number of polyps that develop in the colon and rectum. FAP carries a 100% risk of developing colon cancer, usually by the age of 40, if the colon and possibly rectum are not removed. Patients must be examined regularly for the extent of their polyposis. Carriers of the gene that causes FAP are also susceptible to cancer in the intestines and stomach and must be watched for possible metastasis to the liver.

Years ago, when Matthew was too young to remember, his father had a tumor removed from his stomach. Jeffrey also had a colectomy to prevent colon cancer.

When Matthew was seven, he had a bowel resection to remove part of his colon. He has been in and out of hospitals since then, requiring frequent testing and visits with specialists.

Several months ago, Matthew started having slight pains in his stomach. He had a visit scheduled in a week with the family physician in their home town, an hour outside Regina, so Jeffrey asked Matthew if he felt it could wait until then. Matthew felt that it could.

A week later, the doctor examined Matthew and recommended that they should see the specialist in Saskatoon who had performed Matthew's previous surgeries. While he understood the complexity of Matthew's case, he hadn't received very many reports from those who had provided Matthew's hospital care. The doctor said he would send Matthew for tests and initiate the referral, and that the family should call the specialist in about a week to book the appointment in Saskatoon. Jeffrey took Matthew to the lab in Regina for his test before leaving.

Several days later, the physician's office called Jeffrey to indicate that Matthew's test results were abnormal and that a request would be sent to the specialist to perform an endoscopy. By this time, Matthew's pain had increased somewhat and his abdomen was tender. The doctor said he would expedite the referral and that Jeffrey could probably call the next day to book an appointment.

Jeffrey called the next day to book the appointment, but the specialist's office had not received the referral. The receptionist said she would book them in anyway, since Matthew was a regular patient, and would let Jeffrey know if anything had changed once they received the faxed referral from their family physician. They had an appointment available in four days. Jeffrey asked that the specialist call him, since he suspected his son may have the same type of stomach cancer he had, and he wanted Matthew's specialist to consult with his own specialist before performing an endoscopy on Matthew.

The next day, Jeffrey left another message with Matthew's specialist requesting that he speak with him. The following day, after still receiving no response, Jeffrey called the surgeon who had performed his own surgery and asked if he would be willing to discuss it with Matthew's surgeon before an endoscopy

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and possibly a biopsy was performed. His surgeon agreed, but indicated he would have to wait until Matthew's surgeon made the call.

Jeffrey had to work on the day Matthew was scheduled to go for his endoscopy in Saskatoon, so Lisa took him to the appointment. The surgeon performed an endoscopy and also did a biopsy of a small mass in Matthew's intestine. Learning of this, Jeffrey was upset that his calls went unanswered, and he phoned the surgeon. After a heated exchange, the physician told him that he would no longer deal with Jeffrey, and that if they wanted his services he would only interact with Lisa.

A little over a week later, Jeffrey and Matthew made the three-hour drive to Saskatoon to learn the biopsy results – only to be told that the pathologist's report was inconclusive, as were follow-up imaging scans. Their only option, they were told, was to wait and see how things progressed. Disappointed at receiving no definitive information, they headed to the car – just 45 minutes after arriving in Saskatoon.

Over the weeks that followed, Matthew's pain intensified and he found it increasingly difficult to sleep. Several months after the endoscopy, he came to his parents in the middle of the night crying, saying he couldn't sleep and was afraid he would never wake up.

That night, Jeffrey emailed the physician at Mount Sinai Hospital in Toronto who had removed his stomach tumor. Jeffrey was registered on the Familial Gastrointestinal Cancer Registry. In his note, he explained what had happened with his son to date and the frustration he felt. Later that morning, he received an email from the physician indicating that he was on vacation, but that he would respond immediately upon his return.

The following week, the physician at Mount Sinai asked that all of Matthew's test results be sent to them for a determination on next steps. This proved to be difficult when the Saskatoon specialist's office insisted on numerous authorizations and signed papers, which necessitated two more trips to Saskatoon before they agreed to send Matthew's results to Jeffrey's surgeon.

A few days later, Jeffrey's surgeon called to indicate that they couldn't make a determination with the test results they had, and told him they would speak with the hospital close to his home to arrange for an urgent CT scan. The following week, Matthew had a CT scan which was sent to Mount Sinai. Shortly afterwards, Jeffrey received a call: Matthew had a cancerous mass in his stomach, and would require an MRI for further investigation and analysis of his tumor.

Matthew was flown to Toronto to have his tumor removed. Since the family could not afford for both Jeffrey and Lisa to take time off work and pay travel costs, Lisa accompanied Matthew, leaving Jeffrey at home to wait anxiously and hope for good news. The surgery was successful and Jeffrey was overjoyed to see his son again upon his return to Regina.

When Jeffrey called Matthew's specialist in Saskatoon to arrange for post-surgical care, he was told the doctor would be reluctant to see Matthew since they had obtained a second opinion. Jeffrey was able to speak to the doctor and eventually the doctor agreed to continue to see Matthew.

The specialist in Saskatoon arranged an urgent endoscopy appointment to assess Matthew's progress from the surgery, and discussed the options for follow-up care that Matthew would have to undergo. Upon the recommendation of the surgeons at Mount Sinai, he would need radiation treatment. The surgeon said he would arrange for a series of tests and an

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Jeffrey himself was concerned about the amount of time he would miss at work, and how he and his wife would coordinate the significant number of follow-up visits that would be required.

appointment in the cancer centre in Regina if that was easier for them to access. He also gave Jeffrey a lab requisition and requested that they have tests completed so the results would be sent to the Cancer Centre before their first visit.

Two weeks later, Jeffrey took Matthew to his appointment at the Cancer Centre in Regina. They were greeted by a nurse, and then proceeded to meet with the pediatric oncologist. The oncologist examined Matthew, but hadn't received the test results from Saskatoon. He asked that Jeffrey take Matthew down to the lab to be tested again, and that based on the note from the pediatric surgeon, it was recommended he have follow-up radiation therapy. He would refer Matthew to the radiation oncologist in the next few days; from there, Matthew would meet with the radiation therapist a few times to prepare for the treatment.

The next week, Jeffrey and Matthew met with the radiation oncologist. He explained how the treatment would work, and that Matthew would have to come in three times a week for 12 weeks and meet with the radiation treatment team a few times.

Throughout the next week, the radiation therapist took measurements and calculated Matthew's dosage according to the oncologist's instructions. Jeffrey decided to bring in a home tutor for Matthew, since he would be missing so much school time during his therapy. Jeffrey himself was concerned about the amount of time he would miss at work, and how he and his wife would coordinate the significant number of follow-up visits that would be required.

The illness that Matthew suffered from is quite rare. The family's experience in interacting with providers and the system at each touch point, however, is not that rare as described by patients interviewed and revealed by the Patient First research. Jeffrey complained, for instance, that Matthew required an MRI every six months following his procedure to assess him for growth and metastasis. Jeffrey is constantly required to call and follow up with lost referrals and appointments that require a significant amount of work to schedule.

Overall, Jeffrey and Lisa thought the system worked well; however, it was the few instances as described in this story that didn't work so well. One aspect of care they felt was "phenomenal" was the nursing care they always received in the paediatric nursing units.

Key Questions the Case Raises

The following are some key questions that the case raises:

- ▶ How could Matthew's physicians have behaved differently to change his outcome?
- ▶ What are some of the incentives or disincentives that contributed to his physicians' behaviour?
- ▶ Is it reasonable to expect that a standardized care process could be in place to help physicians deal with rare diseases?
- ▶ How could Matthew's duplicate tests have been avoided?
- ▶ How could care have been more coordinated among his specialists and many providers?

Case Discussion

At its core, the issues experienced by Matthew and his family were the result of a system that was not designed as a system, where providers and organizations function in silos. It also speaks to a culture that has evolved as a result of overburdened providers and a lack of focus on the patient experience and the impact decisions have on that experience. "Patient" here is defined as Matthew and his family.

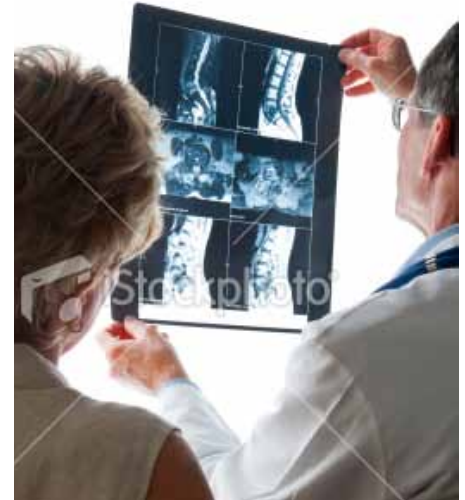
The experience as described is certainly not the experience of every patient and family. Many patients interviewed had high praise for the cancer system in Saskatchewan and the care they received. Many patients and their families specifically praised physicians and hospital staff working in the system, and reported that for the most part they felt cared for.

The aspects of care that frustrated patients the most were those that were uncoordinated. This feedback came from patients and providers interviewed for the case studies, but also came out through the research. These patients specifically described having to coordinate care between Saskatoon and Regina and sometimes points in Alberta. A patient living in Gull Lake, for example, who consults with a physician or oncologist in Regina, may require a CT scan for further investigation. The patient is booked into the CT scan at the hospital in Regina. Meanwhile, they pass by a facility with a CT scan on their drive home through Swift Current. In addition, they are sent for multiple tests and consultations requiring frequent drives back and forth to Regina and Saskatoon to accommodate provider schedules. In addition, patients often have to return to Regina or Saskatoon for a five-minute visit during which they learn that test results are "normal".

As in Matthew's case, patients also indicated that their family physician wasn't always involved in their care at a level they would like. They felt their family physician wasn't always informed about their care in hospital, which affected their overall care experience. Uninformed family physicians were a clear theme that resonated in the Patient First research.

The illness that Matthew was living with is rare. It is not unreasonable to expect that the highly specialized care he required would not be available in the province. However, there was no standardized process to deal with the unknown. This included ruling out all options, consulting with experts outside the physician's normal sphere, and communicating openly at each stage with the patient and their family. Patients and providers interviewed indicated that one of the primary drivers of concern for them during the care process was a lack of communication and not knowing next steps or how issues would be resolved.

Jeffrey felt helpless and alone, unable to help his son, and with no recourse. He ended up taking actions into his own hands by seeking care outside the province.



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Jeffrey had difficulties navigating the healthcare system and relied on what he knew from his own experience. Many patients indicated that the care they received was heavily reliant on the quality of their family physician, who acted as a system navigator and advocate. This came through very strongly in the patient interviews and the patient and provider research. Providers, however, did not feel fully involved in the patient's care, often not receiving the information they needed from other parts of the system, or receiving it late.

The requirements for follow-up care for patients who have cancer can be extremely intensive. Matthew required radiation treatment and continuous monitoring by a team of specialists in both Regina and Saskatoon. Matthew and his family experienced post-surgical care that was uncoordinated and potentially placed a strain on the family resources. From the patient viewpoint, there is a need to coordinate all aspects of follow-up care. Luckily for Matthew and his family, they lived only an hour's drive from Regina. Patients who live outside of Regina or Saskatoon and require intensive follow-up care are required to spend significant time travelling due to the level of uncoordinated care they experience.

Summary of Key Issues

- ▶ Lack of focus on the patient;
- ▶ Lack of access to specialist care;
- ▶ Long travel times for access to cancer care between Regina and Saskatoon;
- ▶ Lack of communication among providers;
- ▶ Lack of communication between providers and patients; and,
- ▶ Lack of system coordination.

Discussion on Causes

Some of these issues relate to a lack of coordination among providers and organizations within the system, others relate to a lack of communication between providers and between patient and providers. Underlying it all is a lack of focus on the patient experience and, at each touch point, an assessment of the impact on the patient.

Expectations for providers working in the system run high. In Saskatchewan, there is a shortage of healthcare professionals as compared to national averages. In 2007, there were 92 family physicians per 100,000 people in the province compared to 98 across Canada. The number for specialists was 72 per 100,000, compared to 94 in Canada, a much greater variance.

Additionally, the province has been losing professionals, with a net loss of 112 family physicians between 2004 and 2007 and a net loss of 27 specialists in the same time period. This constrained capacity is leading to high demands placed on providers trying to do their best within the system.

Providers don't necessarily have the tools to help them perform as may be expected. They lack the tools to communicate with one another through electronic health records or resource management scheduling applications.

Underlying it all is a lack of focus on the patient experience ...

As described by patients, and observed through interviews with providers, providers for the most part do a very good job for the task they have been assigned. Accountability is lacking, though, for the linkages between providers that contribute to a poor patient experience. It is also the aspects outside and around the care process that affect the patient experience but aren't always a factor in the design of the systems (e.g. travel times, parking, cost to the patient).

Each of the regions also has quality of care coordinators or client representatives that provide a valuable service to patients by providing them with information, someone to listen, or someone to help them navigate or resolve a system issue. This resource may be underutilized as the patients interviewed for the case studies, who had a range of difficulties with their care, were unaware of this resource and how it could have improved their care experience.

Linking It Back to the Research

Throughout the Patient First research, patients and providers relayed themes consistent to those presented in this case. The experiences and the causes of these experiences are described below and are consistent with the causes as described by patients and providers interviewed for these in-depth case studies and the data that has been presented to assess them.

The themes and causes as relayed by patients and providers consistent with this case include the following:

Theme –Quality of interaction between providers and patients

Description – Low-quality face time with physicians (e.g. lack of two-way communications, inattentiveness in examination, over-prescription).

Low-quality relationships are driven by:

- ▶ Rushed appointments
- ▶ Dismissive behaviours
- ▶ Lack of clarity in communications
- ▶ Over-prescription
- ▶ Lack of follow-up

Physicians' performance is affected by:

- ▶ Impact of fee-for-service compensation model
- ▶ Time crunch
- ▶ Stress

Theme – Effectiveness of communication channel between the system and patient

Description – Poor communication with patients from hospitals, facilities, doctors' offices (e.g. no updates on waits for service, test results, next steps); no one takes responsibility for the patient file:

- ▶ Not being kept apprised of updates and timing
- ▶ No advocate
- ▶ Lack of consistent standards for patient-provider communication of test results and diagnosis
- ▶ Inadequate sharing of information from providers on what to expect in terms of next steps or resolution

Theme – Quality of healthcare workforce

Description – healthcare workforce is perceived to be unstable and care is of unreliable quality:

- ▶ Lack of resources including staff shortages
- ▶ Difficulties retaining healthcare workers in the province, particularly in rural areas
- ▶ Healthcare workers that are burnt out
- ▶ Low staff morale
- ▶ Lack of supportive leadership

Theme – Management of health information

Description – lack of consistency in managing and sharing patient information among providers:

- ▶ Lack of accessible, centralized means of locating patient health information
- ▶ Fragmentation of health information throughout various parts of the system

Theme – Staff performance / behaviour accountability

Description – A sense of powerlessness to do anything about providers they encounter in the system that exhibit unacceptable behaviour:

- ▶ Poor supervision / accountability for provider behaviours
- ▶ Few channels to complain either directly or anonymously about observed problems with staff

Leading Practices

The following section provides a discussion of practices in other jurisdictions that have demonstrated success in improving the patient experience. In many instances, work is already underway at the Ministry of Health to develop these models for implementation in some form in the Saskatchewan healthcare system.

Patient-Centered Care

A common theme that resonates throughout each of the case studies is the requirement to change the way care is provided at each touch point throughout the system. Stewart et al (2000) found that patient-centered care influenced patients' health through the perception that their visit was patient-centered and through the perception that common ground was achieved with the physician. They also found that patient-centered care improved health status and increased health system efficiency by reducing diagnostic tests and referrals.

To begin with, a definition of the patient (typically including the patient's family of choice) and a definition of "patient-centered" are required. Don Berwick, the CEO of the Institute for Healthcare Improvement, defines patient-centered care as follows (Berwick 2009):

"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."

This definition has profound implications for every provider, administrator and policy maker in the system.

Changing the Culture of the Health System

To move care in line with this definition requires a cultural shift in how care is taught, how care is provided and the incentives and accountability structures put in place to monitor and change behaviour. This is no easy task. It is one that requires systematic planning and a sustained focus as a priority over an extended period of time.

From a systems/organizational perspective, this requires the following factors (Shaller, 2009):

- ▶ Top leadership engagement;
- ▶ A strategic vision clearly communicated to every person in the system;
- ▶ Involvement of patients and families at multiple levels;
- ▶ A supportive work environment that empowers employees;
- ▶ Systematic measurement and feedback;
- ▶ A quality built environment; and,
- ▶ Supportive information technology.

Patient-centered care influenced patients' health through the perception that their visit was patient-centered and through the perception that common ground was achieved with the physician. They also found that patient-centered care improved health status and increased health system efficiency by reducing diagnostic tests and referrals.

To truly create a patient-centered system, every touch point with the patient would require analysis, to assess the impact on the patient. This transformation of the system is described in detail in the Patient First Review Report on the Patient Experience Component.

The impact this would have, related to Matthew's case, would include the following:

- ▶ Coordinating appointment scheduling to prevent unnecessary travel;
- ▶ Engaging the family in a discussion on possible options and next steps at each stage of the care process;
- ▶ Involving his family physician in the care process and perhaps having him deliver test results and a discussion on options and next steps to prevent having to drive hours to Regina or Saskatoon; and,
- ▶ Telemedicine visits with the specialist where possible to reduce travel to the major centres for care.

These small changes would have meant a significant difference in the care and perceived level of care Matthew and his family received.

Providing Tools for Communication and Navigation

The use of information technology has been demonstrated to improve patient safety and reduce or eliminate duplicate testing (Shamliyan, 2008), but can also be used as a tool to help providers communicate with one another. Patients, including Matthew and his family, complained that their family physician was not involved in their care as intimately as they would have liked. Family physicians have multiple roles to play that include advocate, case manager, system navigator, and counsellor. To play these roles, family physicians require complete and timely information on the patient's condition.

This information can be shared through the use of Electronic Medical Records (EMR) that interface with other parts of the system including hospitals, labs, imaging, home care and others. The family physician is the one individual who should have a complete picture of the patient's health information to enable that provider to engage patients in fulsome discussions on their health and health outcomes.

The Ministry of Health is currently launching an Electronic Medical Record to support primary care physicians. This initiative will provide physicians with an ability to communicate with any future electronic health record.

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Matthew's Story Retold

When Matthew was seven, he had a bowel resection to remove part of his colon. He has been in and out of hospitals since then to monitor his disease, requiring frequent testing and visits with specialists.

Several months ago, Matthew started having slight pains in his stomach. He had a visit scheduled in a week with the family physician in their home town, an hour outside Regina, so Jeffrey asked Matthew if he felt it could wait until then. Matthew felt that it could. The doctor examined Matthew. He told Matthew and Jeffrey that Matthew would likely need to see the specialist, but that he wanted to send Matthew for some initial testing first.

The doctor told them that he would call them in a few days with the results and if needed, they would book Matthew into an appointment with the specialist. As usual, he would consult with the specialist to see if the visit would be appropriate using the telehealth equipment at the local hospital. Jeffrey and Matthew left the doctor and went to the closest lab 45 minutes away.

Several days later, the physician's office called Jeffrey to indicate that the test results were abnormal and that Matthew would require an endoscopy. The doctor told Jeffrey that he had sent the referral to the specialist and that they had an initial discussion about the procedure. They would be able to conduct the procedure using the Tele-endoscopy suite in Swift Current, 45 minutes from their home. Jeffrey asked his family physician if he could access his medical records and find the doctor who had helped diagnose his stomach cancer years before. Jeffrey was afraid Matthew might have the same cancer, as it is a risk factor for their illness. Jeffrey's doctor told him he would look into it and set up a conference with Matthew's specialist, and the specialist that had helped diagnose Jeffrey years before. They all agreed that it would be useful for Jeffrey's specialist to participate in the Tele-Endoscopy appointment.

During the appointment, the physicians confirmed that Matthew appeared to have a small mass in his stomach. A biopsy was performed and the sample sent to the lab for analysis. Jeffrey's specialist told the physicians that it was difficult to come to a definitive diagnosis for Jeffrey, and suggested sending the results to Jeffrey's specialist team at Mount Sinai, with his permission.

Matthew's family physician discussed this option with his family and suggested they wait to see if the pathology report revealed anything; if not, he suggested they send the results to the Gastrointestinal Cancer specialists at Mount Sinai where Jeffrey's tumour had been removed.

When the results came back inconclusive, Matthew's physician sent his test results to Mount Sinai for diagnosis. Matthew's doctor told him and his family that although the results did not show anything, it was possible they would find a result at Mount Sinai, where they deal with this disease more often. He told them he would stay in contact with the doctors there until they received a result.



... Matthew would likely need to see the specialist, but he wanted to send Matthew for some initial testing first.

The surgeon walked them through the details and risks of the surgery, and asked their family physician if he could coordinate the follow-up care that would be required.

Shortly after, the physicians from Mount Sinai asked for an additional CT scan and an MRI, for which Matthew and his family travelled to Swift Current and Regina. A few days later, Matthew's family doctor asked the family to come in to discuss the diagnosis and the options for Matthew. Through a teleconference with the specialist at Mount Sinai, they decided the best option was to travel to Toronto to have the surgery. The surgeon walked them through the details and risks of the surgery, and asked their family physician if he could coordinate the follow-up care that would be required.

Matthew was flown to Toronto with his parents to have his tumour removed. Because Jeffrey hadn't spent as much time off work travelling to Regina and Saskatoon for appointments, he could use vacation days for this trip to be there with his son. The surgery was successful and Matthew would make a full recovery.

The follow-up care for Matthew was pre-arranged by his physician's office. Shortly after his return, the specialist at Mount Sinai participated in a Tele-Endoscopy appointment for Matthew with his specialist in Saskatoon.

While this story has a similar ending, the experiences lived by Matthew and his family were quite different. The simple thing that changed the experience for them was a system that responded to their needs by engaging them in dialogue, providing open communication and facilitating the linkages among providers that create so much value for patients and their families.

The table below describes the touch points in Matthew's experience and how these touch points could have been different. The table also provides suggestions for how improvements could be made to each touch point, and links those aims with current/planned initiatives within the Province of Saskatchewan. It is important to reflect on each of the touch points through the case, because it is these touch points that can make or break the overall patient experience.

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Touch Point	Matthew's Story	Improvement Aim	Current MOH Initiatives
Accessing Primary Care	Difficulty accessing care close to home	Improve accessibility of primary care providers Improve appointment scheduling	
Linkages between referring providers	Lost or delayed referrals	Improve connections between providers	EMR
Provider Interactions	Rude or uncaring behaviour	Improve interactions so that patients feel supported and cared for Improve working environments so that providers feel supported and empowered to provide patient-centered care	
Cancer Specialists	Centralized Cancer care in Urban Centres	Improve connection points and options to reduce travel for cancer care Improve coordination of care among providers in the urban centres and providers in rural and outlying areas	EMR Telemedicine Community Oncology Program of SK
Receiving Results	Long distances required to hear results No standardized process for coming to a definitive answer No communication on what the options or next steps are when results are ambiguous	Involve family physicians in care process to deliver results and discuss options locally Standardize diagnosis that includes exhaustive decision points and communication with the patient and family at each stage	EMR

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