

CONTINUITY OF PATIENT CARE STUDY

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FOREWORD

The Health Quality Council of Alberta (HQCA) hears concerns from Albertans through surveys and personal stories about the difficulties they experience as patients needing care that involves multiple providers in different settings. The overall experiences and outcomes for patients are improved when this care is well co-ordinated. Too often, however, breakdowns occur. Lost information or poor communication between providers is frustrating for everyone who cares about patient outcomes.

This report shares the story of one man who died unexpectedly, soon after being diagnosed with cancer. During the time between the onset of his symptoms and his death, he and his family experienced numerous frustrations in trying to obtain co-ordinated care for his serious and time-sensitive condition. We examine and share this man's story, with the permission of his family, because we believe it is representative of the experiences of others.

This is not an easy story to read. We learn of a patient who was burdened with co-ordinating his own care when problems arose, and with being made to wait longer than he should have for potentially life-saving care. Probing this case lets us look closely at specific problems in the system. More importantly, however, it helps us remember that people are at the centre of the healthcare system.

While breaks in continuity of care are far from infrequent, we hope our study stimulates constructive engagement without eroding morale among the caregivers who are passionate about their work and the health and wellbeing of the patients they serve. We believe that this report and its recommendations can move us in the right direction, so that healthcare providers are enabled to ensure co-ordinated care, and all patients experience a seamless journey throughout the healthcare system.

Dr. Tony Fields, HQCA Board Chair
Edmonton, Alberta

EXECUTIVE SUMMARY

A patient's experience in the healthcare system is greatly improved with continuity of care, which can be defined as "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context". Breakdowns in care are more likely to occur when patients require specialized tests or procedures or the services of providers who are not part of their usual primary care team. In these situations patient care is critically dependent on (1) reliable, accurate information being exchanged between providers and between providers and the patient; (2) maintaining continuity among providers in the management of a patient's condition(s); (3) providers understanding and agreeing on their individual responsibilities for the aspects of a patient's care; and (4) patients' awareness of who to contact for assistance with their healthcare needs, especially for emergencies or unexpected complications.

Over the years, the Health Quality Council of Alberta (HQCA) has learned about Albertans' concerns with breakdowns in the continuity of care many times and in several ways, such as through surveys and people contacting the HQCA with their stories. These help to identify common barriers to continuity of care.

In the spring of 2012 the HQCA learned about a particular individual's unfortunate experience that appeared to typify many of the challenges faced by Albertans who require specialized healthcare servicesⁱ and who experience breakdowns in their continuity of care. The HQCA decided to study this single case so as to reveal opportunities to improve Alberta's healthcare system for patients and, importantly, to also underscore that breakdowns in the system are not merely problems on paper – they affect real people. The case involves a man diagnosed with testicular cancer who died unexpectedly and within a short time of his diagnosis. The patient's family obtained his healthcare records and made them available to the HQCA. Supplemental information about his case was gathered in interviews conducted with healthcare providers and managers. The HQCA thanks the family for its assistance with the study and for providing written consent for the man's first name, Greg, to be used. Using his name rightly keeps him, and other patients like him, at the centre of the issue of continuity of care.

Information and analysis

The information gathered during the study was analyzed to look for system problems. The focus was not to find fault with individuals but to identify factors in the system that may compromise patient safety and health service quality.

ⁱ In this report 'specialized healthcare services' have been defined as those where a patient must be referred by a healthcare provider (in most circumstances, a physician), there is a waiting period for the service that often involves a process of triaging (prioritization), assigning an appointment time and following the service – generating a report by the person or clinic providing the service, which is sent back to the healthcare provider who made the original request. Typically, specialized healthcare services would include physician specialists, advanced diagnostic imaging studies (e.g. MRI, CT, and PET scans), and procedures.

Information about this patient's case strongly suggested that there were multiple breaks in the continuity of his care as he underwent investigations and treatment in several healthcare settings including two primary care clinics, a private diagnostic imaging (DI) clinic, Alberta Health Services DI facilities, a specialist's office, a hospital operating theatre, and an emergency department. For this study, HQCA examined what happened at the transition points among non-AHS facilities and between non-AHS facilities and AHS facilities.

Condensed chronology

The following is a condensed account of the patient's experience in the healthcare system leading up to, and following, his diagnosis. The events are recounted in more detail in the Chronology section of the report.

Greg had a routine exam at a primary care clinic, during which a thickening of the epididymis (a tube in the testicles) was noticed on one side. No followup was planned. Many months later he saw a second physician at a walk-in clinic for a minor skin condition. A month after that, he returned to the first physician who repeated the testicular exam and noticed the thickening of the epididymis was still present, but unchanged. The patient was referred to a general surgeon for an opinion. It would be three months before he heard from the surgeon's office about an appointment. In the meantime, he returned to the walk-in clinic complaining of lower back pain. A number of tests were done about a week later, including x-rays and an ultrasound, resulting in the detection of a large abdominal mass. This was the first indication that he had a serious condition and it was at this point that the possibility of cancer was discussed. The radiologist who reviewed the test results recommended an urgent chest, abdominal, and pelvic CT scan to confirm the diagnosis. An urgent CT scan was requisitioned by the walk-in clinic physician and the CT was performed weeks later. After the CT scan, with no call from the walk-in clinic about the results, Greg called the clinic. He was told the physician whom he had seen had left to join another practice, and an appointment was made for him to see a different physician. Based on the recommendation of the radiologist who interpreted the CT scan, an ultrasound of the scrotum was carried out the next day, which confirmed a testicular mass consistent with cancer. A referral to a urologist who would remove the cancerous testicle was completed. A week passed during which Greg heard nothing from the urologist's office. The walk-in clinic advised him to call the urologist's office himself, located at the Southern Alberta Institute of Urology. When he did, a recorded phone message stated that the urologist was away and not due to return for an extended time. Arrangements to see another urologist were quickly made. At that appointment, surgery was booked for two days following and plans were made to involve the Tom Baker Cancer Centre (TBCC). The surgery was completed uneventfully but within two days Greg had increasing concerns about swelling of his legs. He was unable to reach the urologist and went instead to an emergency department. The physician there examined him and confirmed an appointment with the TBCC was being arranged, and the patient returned home. The next morning, three days after his surgery, he lost consciousness and needed life-saving resuscitation. These efforts were unsuccessful and he died.

Findings

This patient's experience featured four breaks in continuity of care, and a fifth difficulty perceived as a break because he and his family were unaware of what was being done on his behalf 'behind the scenes':

1. The patient was referred to a general surgeon for an opinion about 'abnormal thickening' of his epididymis. The referring physician believed this appointment would take place within a few weeks; however, it actually took three months before the patient was notified about the appointment. There was no mechanism in place for the surgeon's office to alert the referring physician or the patient about how long the waiting time would be for an appointment; there were no procedures in place to inquire how long it would take to obtain the surgeon's opinion.
2. The patient underwent a CT scan for suspected cancer. The test was believed to be necessary before sending him to an appropriate specialist for definitive treatment. Despite this test being critical to his care, a followup appointment was not made to review the results of the scan and refer him to a specialist. This break in continuity of care was likely compounded when the primary care physician who ordered the CT scan left the walk-in clinic to join another medical practice. When the report of the abnormal CT findings was received by the clinic the patient was not contacted; instead, he called the clinic to obtain an appointment with another physician.
3. The patient was referred to a urologist for an urgent appointment. Neither the referring physician, the walk-in clinic, nor the patient knew this urologist was out of the city for an extended time. One week later, when he had not yet been contacted about an appointment, the patient phoned the walk-in clinic that had initiated the referral. He was told to speak directly with the urologist's office. When he discovered that he would have to wait several weeks to see the urologist he had been referred to, he re-contacted the walk-in clinic, which led to another referral to a different urologist.
4. After his surgery this patient was concerned about worsening lower limb swelling and pain. Although it was during normal business hours on a weekday, he was unable to reach the urologist who had performed his surgery, two days previous, to discuss what the implications were and to obtain advice about what to do. He decided that his only option was to go to an emergency department.
5. The patient had been referred to the medical oncology service at the Tom Baker Cancer Centre (TBCC) by the urologist. Behind the scenes the TBCC was organizing an urgent outpatient appointment with an oncologist who specialized in the treatment of testicular cancer. The patient and his family were unaware that any of this was taking place; all they knew was that an oncologist had been spoken to and that they would hear from the TBCC. They had no way to confirm this or to understand the timeframe.

This patient was in the care of two, and then three, primary care physicians, none of whom knew or had access to his whole history. He experienced delays in receiving important tests, difficulties contacting the specialists providing his care, insufficient communication from providers about appointments and results, and confusion about the process for booking appointments. Through all of this, the patient found himself having to make numerous followup phone calls when no one was calling him. Indeed, he assumed a great deal of responsibility in trying to manage his own continuity of care.

Over and above the breaks in his care continuity described above, there were missed opportunities to expedite his care. Once it was understood he likely had cancer with serious complications it took nearly two months to complete the diagnostic tests he required, refer him to a specialist, and operate.

Issues

Several key issues were identified following an analysis of the findings. These are discussed in the Issues, Analysis, and Recommendations section and are briefly identified here:

1. **Reliable continuity of care when patients are referred for specialized healthcare services.** There is a risk that patients' continuity of care will break when they are referred for specialized healthcare services (specialist consultation, advanced diagnostic imaging tests, invasive or semi-invasive procedures). Procedures and standards to mitigate this risk are lacking.
2. **Radiologists expediting additional diagnostic imaging studies and the next level of care for patients with time-sensitive health conditions.** When a patient is discovered to have a time-sensitive health condition that is first established through a diagnostic imaging study, valuable time can be lost when patients are required to return to the healthcare practitioner who requested the study, to arrange followup appointments and order additional recommended specialized health services (advanced diagnostic imaging studies, specialist consultation, or procedures).
3. **Prioritization criteria for outpatient CT scans.** Current prioritization criteria for outpatient CT scans do not take into account patients with time-sensitive health conditions who have not yet been diagnosed with a malignancy, when the CT scan may be necessary to move on to a procedure that would confirm the diagnosis.
4. **Formal transfer-of-care responsibilities for time-sensitive health conditions and availability of responsible healthcare providers.** Patients with a time-sensitive health condition may not be able to obtain timely medical attention from responsible healthcare providers for that condition because there is no clear understanding about whom to contact when the healthcare provider who is responsible for managing a patient's condition cannot be reached.
5. **Co-located practice groups: co-ordinating services and clarifying relationships.** When healthcare providers co-locate, particularly when they practise a specialized type of healthcare, members of the public and broader healthcare community may be led to believe the services that are provided are fully co-ordinated between members of this 'practice group'. The name 'Southern Alberta Institute of Urology' implies an overarching organizational structure that supports and co-ordinates the activities of the 17 private-practice urologists and the two centres (Prostate Cancer Centre and the Alberta Bladder Centre) that are located within the Institute. In fact, the Institute has limited infrastructure and provides no co-ordinating function – the urologists and the centres function independently.

Recommendations

Recommendations were developed to mitigate problems in quality and patient safety related to breakdowns in the continuity of patient care. A full discussion of the issues, analysis, and recommendations appears in the main report. The HQCA's Quality Assurance Committee that conducted

the study identified 10 recommendations to address the issues highlighted above and an additional three recommendations to address a supplementary issue that was identified while reviewing this case.

Recommendation 1

Alberta Health and Alberta Health Services should strongly consider making additional investments in the provincial electronic health record and e-referral system to standardize workflow processes for all specialized healthcare services so that the following functionality is available for all patients and practitioners in Alberta:

1. Electronic referrals confirmed as 'received' by the service provider.
2. Management of appointment scheduling including booking confirmation and patient notification.
3. Report generation and transmission back to the referring provider.
4. Confirmation that the patient has completed a followup appointment with the referring provider.
5. Notification to the referring provider about referrals that are incomplete, delayed, or denied when submitted to the service provider.
6. Notification to the referring provider about known or projected waiting times for tests, consultations, or procedures that are outside specified limits.
7. Notification to the referring provider and the patient about important processes (referral, appointment scheduling, patient notification, appointment completion, patient followup) that were not completed successfully according to the scheduled completion time.
8. A patient portal for viewing:
 - i. When the key steps in the referral, appointment time, and report generation process for specialist consultation, special diagnostic imaging studies, and procedures have been successfully completed and notifications when they have not.
 - ii. Appropriate contact information for patients when they detect a problem with the special health service, referral, appointment booking, or followup procedures.
 - iii. Lab results, DI reports, pathology reports, procedure findings, hospital discharge summaries, other diagnostic information (e.g., EKG, echocardiograms, pulmonary function tests).

When a reliable electronic referral system is developed and functioning, the net benefit to Albertans will not be realized until all healthcare providers are using the system to manage the referral and followup processes for patients who require specialized healthcare services. Given that, Alberta Health will need to work with Alberta's healthcare providers to ensure that when the system is operational and reliable, it becomes the only accepted approach for managing patients who require these services.

Recommendation 2

The College of Physicians & Surgeons of Alberta and other relevant healthcare colleges amend their Standards of Practice, and Alberta Health Services amend its policies and procedures, related to co-ordination and provision of services. In so doing, healthcare professionals and clinics that provide specialist consultation, advanced diagnostic imaging studies, or semi-invasive and invasive procedures would confirm completion of those studies, services, or procedures and be required to track critical

process steps (transactions) between a referring provider and a service provider such that both know and have documented in a patient record that the following steps have been completed:

1. A request for service has been sent and received.
2. A specific appointment date and time for the service has been made.
3. The requesting provider and the patient have been notified of the appointment details (and the patient has accepted the appointment).
4. The report of findings has been successfully sent to (and received by) the requesting provider.

Step 4 will only be possible when there is a complete provider registry that is continuously maintained and updated; this is particularly essential when service providers have a critically important result that needs to be communicated urgently to the requesting provider who is therefore responsible for managing the result for the patient.

Recommendation 3

The Alberta Society of Radiologists (ASR) in collaboration with Alberta Health Services (AHS) and the College of Physicians & Surgeons of Alberta (CPSA) develop policy and procedures that would support radiologists to expedite the care of a patient whom they find has a time-sensitive health condition by:

1. Directly ordering the next logical DI test if one is required.
2. Directly referring a patient who has a time-sensitive health condition to a clinical service when it is obvious the patient requires that expertise to move to the next level of care.

This should be accompanied by a discussion with the patient and notification to the primary care physician (or the healthcare provider who requested the initial diagnostic test) about what actions the radiologist has taken on behalf of the patient.

The ASR, AHS, and the CPSA should consider developing parameters (criteria) that would assist clinicians to properly identify conditions and circumstances that could be considered 'time sensitive'.

Recommendation 4

Alberta Health Services revise the current criteria for prioritizing outpatient CT scans to take into account patients with time-sensitive health conditions who do not yet have a confirmed diagnosis of malignancy. Consideration should also be given to reviewing criteria for MRI scans and PET scans to ensure that criteria for these outpatient studies are aligned and consistent with those for CT scans.

As with Recommendation 3, operational parameters that assist clinicians in identifying 'time-sensitive health conditions' will need to be developed.

If the processes used for patients with time-sensitive health conditions are changed in accordance with Recommendation 3 and Recommendation 4 it could shorten considerably the time taken to transition the care of these patients to the services they require for definitive treatment.

Recommendation 5

The College of Physicians & Surgeons of Alberta (CPSA) amend its Standards of Practice, and Alberta Health Services (AHS) revise its Medical Staff Rules and Bylaws, as required to ensure that the following issues are addressed:

1. A physician who provides care to a patient with a time-sensitive health condition must make it clear to the patient and all other healthcare providers involved in that patient's care who the responsible physician is for helping the patient manage his or her condition; and, that this information is documented in the patient's chart(s) and all consult/referral notes.
2. The responsible physician(s) for a patient with a time-sensitive health condition, or a patient who has recently undergone a procedure defined to be invasive or semi-invasive, be available (or designate another physician with similar expertise to be available) to deal with complications the patient may experience from the condition or following the procedure. Patients should only be referred to an emergency department in situations where the patient's condition has suddenly changed and is likely to be potentially life, organ, or limb threatening (see also Recommendation 7).
3. Availability should be specifically defined for (a) weekday, and (b) after hours, including evening, weekend, or holiday. Weekday (or normal business day) availability should include at least an office phone that is answered (or answering machine responded to the same day) for a minimum of seven hours. Evening, weekend, or holiday availability for patients with time-sensitive health conditions means the physician can be contacted directly by phone or paging system or indirectly through Health Link Alberta.
4. The transfer of responsibility from one physician to another for managing a patient's time-sensitive health condition should be a formal process that is acknowledged and documented by both physicians and ensures notification to the patient.

A working definition of 'responsible physician' must be developed; the physician who has the expertise or who has most recently managed the patient for a time-sensitive condition, especially if it involves performing an invasive or semi-invasive procedure, should under most circumstances be considered as the 'most responsible'. An operational definition for 'invasive and semi-invasive procedure' that can be used with the CPSA's Standards of Practice and the AHS Medical Staff Bylaws may also need to be developed.

Recommendation 6

The Alberta Medical Association in collaboration with Alberta Health Services and the College of Physicians & Surgeons of Alberta, and with public consultation, develop a document that outlines specific physician commitments to patients who have time-sensitive health conditions (or who have recently undergone an invasive or semi-invasive procedure), to be available and responsive to concerns patients may have about their condition or possible complications from a procedure. Such a document, which would be congruent with the Canadian Medical Association (CMA) Code of Ethics, could be planned such that it becomes a key part of the new Alberta Health Charter or a stand-alone declaration.

Recommendation 7

The Alberta Medical Association and Alberta Health Services investigate how to partner with Health Link Alberta so that patients who believe they need to contact a specialist (or designate) responsible for their care after hours have a mechanism by which to do that.

Recommendation 8

The College of Physicians & Surgeons of Alberta (CPSA) should develop a proactive process to monitor physicians' compliance with the CPSA's After Hours Access to Care Standard.

Recommendation 9

All (adult-treating) private-practice urologists in Calgary, the Prostate Cancer Centre, and Alberta Health Services enter into discussions to review the business and organizational model for the Southern Alberta Institute of Urology so as to provide infrastructure support that will ensure better co-ordination of services including central referral and triage, call answering, and the ability for patients and referring physicians to easily contact a urologist when there is an urgent patient concern.

Recommendation 10

The Southern Alberta Institute of Urology and Alberta Health Services review their websites and written communication with a view to clearly communicating to patients, the public, and referring physicians the relationship between the SAIU, the Prostate Cancer Clinic, the Alberta Bladder Centre (Vesia), private-practice urologists, and Alberta Health Services.

Supplementary finding

Following the patient's death, because it was sudden and unexpected, his case was referred to the Office of the Chief Medical Examiner (ME Office) by the healthcare providers at the hospital. When the ME Office becomes involved there are at least two additional consequences for family members: (1) it may create expectations that detailed answers regarding the circumstances of a person's death will be provided, which is in fact unlikely; and (2) the final report may take more than six months to be completed which has important implications for families having to make final arrangements for the deceased's estate.

The ME Office's goal in conducting an investigation is to determine the cause of death and the mechanism of death. When the ME Office decides to investigate a death, an ME (who is a physician) completes an autopsy and reviews additional health information about the patient to gain an adequate understanding about the patient's past medical history. This information can come from many sources but initially the most important source is medical files the patient may have in one or more hospitals or one or more physician offices or clinics. The most comprehensive source of diagnostic imaging results, laboratory results, and drug information on patients is contained in the province's electronic health record – Netcare. However, MEs and other healthcare personnel associated with their office are not allowed access to Netcare.

Although the purpose of a death investigation is clear to the ME Office, it may not be as clear to surviving next-of-kin, who may have questions about the person's death that involve more than cause and mechanism. After waiting many months for the final report the family were disappointed to learn that

their questions regarding an explanation for the delays in care the patient experienced and the many breaks in the continuity of his care were unanswered and were far beyond the mandate of the ME Office.

Recommendation 11

Alberta Health amend the definition of “health service” in the *Health Information Act* so that medical examiners are able to become “authorized custodians” and obtain access to the provincial electronic health record, Netcare.

Recommendation 12

The Chief Medical Examiner arrange for a comprehensive process improvement review to find efficiencies in the ME Office investigations so that surviving family members receive the final report in a more timely fashion. By establishing performance standards that can be audited on an ongoing basis, the Chief Medical Examiner will be taking steps to reassure the public that investigations are being conducted efficiently.

Recommendation 13

The Office of the Chief Medical Examiner review the written information and its verbal communication provided to surviving family members about expected outcomes of an ME Office’s investigation so as to minimize the risk of misunderstandings. The Office of the Chief Medical Examiner should consider consulting with community members while it develops its communication strategy to obtain feedback as to the effectiveness of this strategy. And, it should consult with grief experts to better understand how best to communicate with grieving family members who may, understandably, be less capable than usual to process much information during the initial meetings with death investigators.

PROJECT OVERVIEW

Background

Obtaining needed healthcare services can become complicated for Albertans when they require specialized tests or procedures or the services of providers who are not part of their usual primary care team. Breakdowns in care continuity that jeopardize optimal outcomes are more likely to occur when these more complex healthcare needs arise. In these situations continuity of patient care is critically dependent on (1) reliable, accurate information being exchanged between providers and between providers and the patient; (2) maintaining continuity among providers in the management of a patient's condition(s); (3) providers understanding and agreeing on their individual responsibilities for the aspects of a patient's care; and (4) patients' awareness of who to contact for assistance with their healthcare needs, especially for emergencies or unexpected complications. In this report continuity of patient care is defined as "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context".¹

When a patient requires specialized healthcare services their experience should not include disjointed, uncoordinated episodes with unfamiliar care teams. Responsibility for connected care – assuring continuity – rests with many players: health care providers, health professional and regulatory organizations, government, health delivery systems, and patients themselves.

Physicians value continuity of care with patients because of their belief that it improves trust and communication; this enables physicians to provide better care to patients.² Breakdowns in the continuity of patient care in situations where patients are moving from an acute care setting to a primary care or community-based setting are common, and lead to poor quality care, patient safety problems, and dissatisfaction among primary care physicians.^{3,4}

Over the years the HQCA has learned about Albertans' concerns with breakdowns in the continuity of patient care through multiple surveys and people contacting the HQCA with their stories.

The HQCA Satisfaction and Experience with Healthcare Services Surveys are a point-in-time evaluation of adult Albertans' self-reported experiences and satisfaction with the quality of healthcare services. Through six surveys, spanning almost a decade, Albertans have consistently reported the following barriers to continuity of patient care:⁵

1. Fewer than 50% felt that healthcare professionals' efforts to co-ordinate their care were excellent or very good.
2. A substantial number of people believed that their physician was often not informed about treatment, care, or tests they had received elsewhere in the system. For example:
 - Approximately 50% reported their personal family doctor was not informed about care they had received in an emergency department.
 - About 35% of Albertans reported their personal family doctor was not informed about care they had received from a specialist or care they had received while in hospital.
 - Between 10 and 15% of Albertans reported their personal family doctor was not informed about results of diagnostic imaging tests and MRI scans they had undergone.

3. Nearly 10% reported an experience where healthcare professionals had failed to share important information about the patient with each other (question asked in the 2012 survey only).

Stories of breakdowns in information exchange or in continuity of patient care that undermine patient and family experience have been provided by Albertans to the HQCA, such as:

- A patient's death was not communicated to all parts of the healthcare system so his family was contacted months later about an appointment the patient was to attend.
- A patient knew she was on a surgical waitlist but had to phone the hospital to see if the staff could "give her an idea" of when the surgery might be performed.
- A patient required a yearly followup with a specialist; when the patient's specialist retired the family doctor's office faxed a referral to another specialist. When the patient inquired about the appointment 10 months later (and after not being contacted) she was told there was no record of a faxed referral.
- A patient's palliative care plan was not shared among the various points in the healthcare system where the patient was treated. When the patient suffered a cardiac arrest she was resuscitated, which was against her wishes as documented in her plan.

A physician contacted the HQCA to discuss a patient she was concerned about. The patient had undergone an abdominal ultrasound that was ordered by his primary care physician for vague back and abdominal complaints. A possible mass in one of his organs was reported and the radiologist recommended the patient have a CT scan of his chest, abdomen, and pelvis. The patient was not contacted with an appointment, did not followup with his physician, and therefore did not have the scan. Several months later he developed shortness of breath and went to an emergency department. There, a CT scan showed a small amount of fluid around one of his lungs. He was advised to followup with his primary care physician; however, before he could arrange for that he went back to the emergency department with worsening shortness of breath. He was admitted to hospital and additional testing showed that the original mass in one of his abdominal organs was a cancer that had spread to his lungs. At this point his treatment options were limited. Phone calls were placed to the diagnostic imaging centre regarding the original CT scan requested several months before; however, staff at the diagnostic imaging centre could not find any record that the referral was received.

Surveys and stories are helpful in highlighting the experiences of Albertans with their healthcare system; however, they are not detailed enough to understand all the factors in the system that contribute to breakdowns in patients' care continuity and hence do not point to solutions.

In the spring of 2012 the HQCA learned about another individual's experience that appeared to highlight many of the challenges faced by Albertans who require specialized healthcare servicesⁱⁱ and who

ⁱⁱ In this report 'specialized healthcare services' have been defined as those where a patient must be referred by a healthcare provider (most often a physician), there is a waiting period for the service that often involves a process of triaging (prioritization), assigning an

experience breakdowns in their continuity of care. The HQCA decided to study this single case, felt to be representative of what many experience, so as to reveal opportunities to improve Alberta's healthcare system for patients and, importantly, to also personalize the issue of breakdowns in continuity of patient care.

Scope

The HQCA determined that the patient had received care across jurisdictions, in the community at large and in acute care settings. Alberta Health Services (AHS) does not have the authority to review the care of patients that takes place in settings beyond its own facilities, such as in the community, a doctor's office, or private clinic. Most, but not all, of this patient's healthcare took place in the community. A preliminary review of the information about his case strongly suggested there were multiple breaks in the continuity of his care as he underwent investigations and treatment in several healthcare settings including two primary care clinics, a private diagnostic imaging (DI) clinic, AHS DI facilities, a specialist's office, an AHS hospital operating theatre, and an AHS emergency department.

Because some of the care that this patient received was in facilities owned and operated by AHS, the HQCA contacted AHS. In collaboration both organizations decided to do independent studies; AHS would focus on the care that the patient received in its facilities, while the HQCA would study the transition points among non-AHS facilities and between non-AHS facilities and AHS facilities.

The HQCA's quality assurance committee (QAC) studied the implications for quality and patient safety with respect to the continuity of patient care across the healthcare continuum. This specific patient's journey was used to study the healthcare system, including but not limited to:

1. Referral processes both in the community and to AHS facilities and healthcare providers.
2. Patient engagement with the healthcare system.
3. Availability and exchange of patient information between healthcare providers/organizations/institutions and with the patient.

To enhance the quality and safety of healthcare in Alberta the HQCA set out to make system-level recommendations for improvement. The QAC did not evaluate specific management (diagnostic or therapeutic) decisions. This study was limited to the investigation of a single patient's journey through the healthcare system in Alberta as a representative case. The assessment of other patient's experiences was not within the scope of this study. Terms of Reference are in Appendix I.

appointment time and following the service – generating a report by the person or clinic providing the service, which is sent back to the healthcare provider who made the original request. Typically, specialized healthcare services would include physician specialists, advanced diagnostic imaging studies (e.g., MRI, CT, and PET scans), and procedures.

Methodology

The HQCA conducted its study under Section 9 of the *Alberta Evidence Act*⁶ with the sole purpose to gain insight into the many factors that contributed to breakdowns in continuity of care, and with the goal of developing system-level recommendations that could help improve the quality of care for patients in the future.

The *Systematic Systems Analysis: A Practical Approach to Patient Safety Reviews* (SSA:PSR) was used as a guide.⁷ The methodology encourages a systemic view of the healthcare system; that is, “how all parts of the healthcare system play a role”, rather than a focus on “only one particular factor in isolation”. A model of the healthcare system was used, which is made up of the five major components of the health system: patients, personnel, equipment/environment, organization(s), and regulatory agencies.^{7,8} The model also considers the quality assurance fundamentals of structure, process, and outcome.

The following describes the approach taken to collect and analyze information and to develop recommendations.

Collection of information

The QAC gathered information from a number of sources:

- Interviews
- Patient health records
- Patients and families, through the HQCA’s Patient/Family Safety Advisory Panel
- Detailed flow-mapping of specific processes
- Documents and files
- Review of the literature
- Other healthcare organizations
- Information technology experts

Analysis of information

In the analysis phase each piece of information was organized according to which part of the healthcare system it came from, among the five components described above from the SSA:PSR. Then, all the information for each of the five major system components was analyzed to identify system problems. Finally, the findings of the analysis were reviewed and examined to ensure that the perspective of the QAC focused on the entire system, not individuals. The focus was not to find fault with individuals but to identify factors in the system that may contribute to patient safety problems.

Presentation of the findings

Findings and lessons to be learned for users of the healthcare system, healthcare providers, and the healthcare system as a whole are presented, including lessons to be learned as described by the patient’s family and from the perspective of the QAC.

Development of recommendations

Recommendations were developed to mitigate the quality and patient safety problems related to breakdowns in the continuity of patient care.

Project governance

The study was conducted by the HQCA's Quality Assurance Committee (QAC) in accordance with Section 9 of the *Alberta Evidence Act*.⁶ The Continuity of Patient Care Study Quality Assurance Committee included:

- W. Ward Flemons MD FRCPC, Quality Assurance/Quality Improvement Expert Consultant – Study Lead
- Donna MacFarlane RN, Patient Safety Lead – Administrative Lead, HQCA
- Margot Harvie RN BN MEd, Quality & Safety Education Lead, HQCA
- Carmella Duchscherer RRT BHS(RT) MPA, Quality & Safety Review Team Lead, HQCA

The following people provided helpful input into the report. Their contributions are appreciated:

- The HQCA Patient/Family Safety Advisory Panel
- Charlene McBrien-Morrison RT (CSLT) MBA, Executive Director, HQCA
- Jeanette Jackson MSc PhD, Health System Data Analyst, HQCA
- Lisa Brake, Communications Lead, HQCA
- Eric Wasylenko MD BSc MHSc, Health Ethics and End of Life Expert Consultant
- Michael Wong, Business Analyst, Arcurve Inc.
- Christiane Langtry, Administrative Assistant, HQCA

The assistance of the family of the patient whose experience is recounted here, and others involved with his case, is gratefully acknowledged.

CHRONOLOGY OF EVENTS

The facts for this chronology were generated primarily from the patient's healthcare records created by the primary care clinics that provided services to him and from interviews conducted by the QAC with healthcare providers and managers. The patient's healthcare records were obtained by the patient's family, who then made them available to the QAC.

This report, with the written permission of his family, uses the patient's first name: Greg. This decision was intentionally made to keep patients such as him at the forefront of our thinking about the healthcare system. Not speaking of him personally would risk having Greg lost in the report, as he was lost in the healthcare system when he received care.

Week 1, Greg went to see a primary care physician (PCP1) for a routine physical examination. During the exam an abnormal thickening of one of his epididymides (the epididymis is a tube in the testicle) was detected; testicular exam was noted to be normal. No history of injury or infection was reported. Routine lab results were normal and no plans for followup from this visit were made.

In **week 37**, he started noticing intermittent back discomfort that he believed to be related to muscle strain or possibly sciatica.

In **week 42**, he went to a walk-in clinic that he had not previously attended, for a minor skin condition. He was assessed by a primary-care physician (PCP2) and received a prescription.

In **week 45**, he returned to PCP1 for a second opinion about his skin condition; while he was there, a repeat exam of the epididymis was performed and once again it was noted to be thickened but unchanged from the previous exam. The testicular exam was once again recorded as normal. A decision was made to refer Greg to a general surgeon for an opinion about the epididymis issue. He was asked to pass the referral request to the surgeon's office in the same building; when he did that he was told he would be called to book an appointment at a later date. Greg was contacted three months later, in **week 59**; PCP1 was unaware of this waiting period.

In **week 51**, he went back to see PCP2 for a complaint of lower back pain. Following an exam some routine lab tests, x-rays, and an ultrasound exam were ordered. Approximately one week later Greg had the x-rays and ultrasound at an outpatient (non-AHS) radiology centre. Although the x-rays were normal, the ultrasound showed a large abdominal mass. It was unclear what the cause was but it was suspected that the mass was due to enlarged lymph nodes that contained cancer. The radiologist discussed the findings of the ultrasound in-person with Greg (the technician had the radiologist review the ultrasound immediately); the radiologist also called PCP2 and recommended that an urgent chest, abdomen, and pelvis CT scan be performed (at one of AHS's diagnostic imaging facilities). PCP2 requested the walk-in clinic staff contact Greg and make an appointment for him to be seen urgently the following day; however, he was unable to make that appointment time. Another appointment was scheduled the following week.

At the followup appointment (which took place in the evening) one week later, **week 53**, PCP2 and Greg discussed the possibility of cancer. A decision to proceed with a CT scan was made and the requisition (marked urgent) was completed by PCP2. The following day the medical clinic staff faxed the CT requisition to an AHS diagnostic imaging centre. The CT requisition was triaged by an attending radiologist as priority 2.ⁱⁱⁱ Within 24 hours of receiving the faxed CT scan request, the diagnostic imaging centre confirmed an appointment for the scan that was 19 days from the date that the request was received (this was within provincial diagnostic imaging guidelines for priority 2 requests). The appointment confirmation was faxed back to PCP2's walk-in clinic and Greg was notified about the date and time of the scan.

During the time that Greg was waiting to have the CT scan, PCP2 left the walk-in clinic to join a medical practice in another city.

Week 56, The CT scan was completed and confirmed the ultrasound finding and raised the question of stage III testicular carcinoma, with spread (metastases) to abdominal lymph nodes. The radiologist who reported the findings on the CT scan recommended an ultrasound of the scrotum.

In **week 57**, one week after the CT scan was completed, when he had not yet heard of a followup appointment at the walk-in clinic where he had seen PCP2, Greg called the clinic to inquire why an appointment to review the results from the CT scan had not yet been scheduled. An appointment to be seen later that same day by another primary care physician (PCP3) was made because PCP2 had left the clinic. At that appointment PCP3 reviewed the CT scan results with him and completed a requisition for an outpatient ultrasound of his scrotum. The ultrasound was completed the following day and revealed a testicular mass that was consistent with cancer. The next day he returned to see PCP3. A referral to a urologic surgeon (urologist) was discussed and agreed to. The following day a referral letter was faxed to a urologist's office. The walk-in clinic staff and PCP3 did not know the urologist (Urologist1) to whom the referral was faxed was away for an extended period of time.

One week later, **week 58**, when he had not yet been notified about the surgical appointment, Greg called the walk-in-clinic to determine the status of the urology referral; he was advised to call the urologist's office directly. When he phoned the urologist's office a recorded phone message informed him that the urologist was out of the office and not due to return for an extended period of time. Greg called the staff at the walk-in clinic and advised them. The walk-in clinic staff faxed his referral to a second urologist (Urologist2). At about this same time the first urologist, who had been alerted to the nature of the patient's problem despite being away, reviewed the consult request online through his electronic medical record and advised his office assistant to arrange for the patient to be seen by a colleague (Urologist3). Urologist1 was unaware that the walk-in clinic had sent a second referral request, and Greg received two appointments to see two different urologists within a very short period of time. He chose

ⁱⁱⁱ CT scans are assigned a priority 1 if they are requested for patients with known cancer and priority 2 if they are requested for patients with suspected cancer.

to see Urologist3 because he was able to see him within one business day (Urologist2 had offered an appointment within two business days).

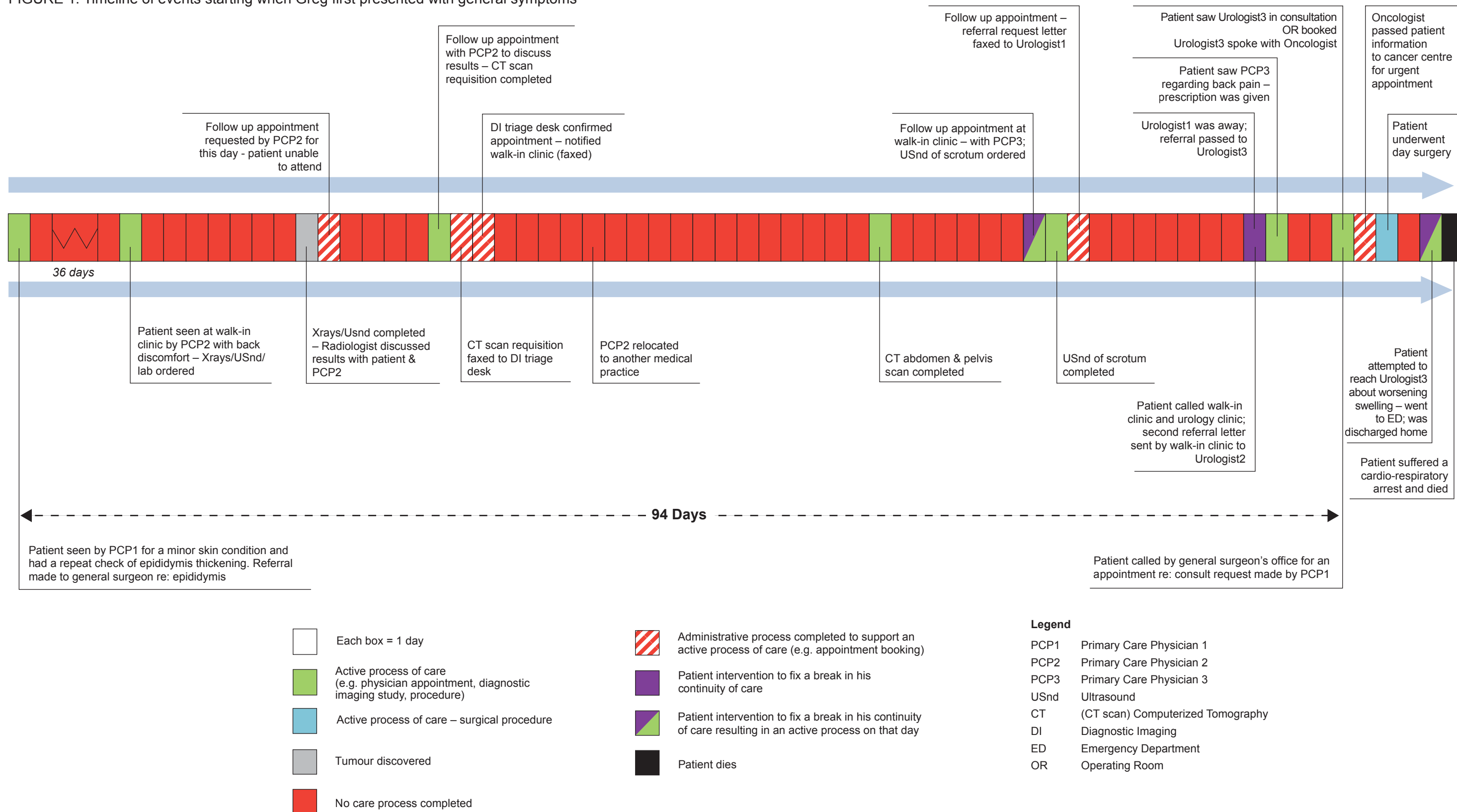
At the same time, he went back to see PCP3 for increasing back pain and was given a prescription for pain medication.

During **week 59**, his final week, when he attended the urgent surgical appointment with Urologist3 he was, according to a family member who went with him, complaining about swelling in both of his legs. Plans were finalized for a day surgical procedure to remove the cancerous testicle two days after this initial appointment. After seeing Greg, Urologist3 called an oncologist to expedite the cancer clinic's involvement. The oncologist passed the information to the cancer clinic's triage centre; the centre began organizing an extra appointment time so Greg could be seen as soon as possible after his surgery.

Two days after his appointment with Urologist3, Greg underwent removal of his testicle (orchidectomy). At that point he had not yet been told of a cancer clinic appointment. The day following his surgery, he and his family were concerned because he was experiencing lower leg swelling, which the family believed was getting worse. One day later (two days after the operation) Greg and his family tried to reach Urologist3 to discuss his worsening condition but were unsuccessful. Eventually they were able to reach a receptionist at the Prostate Cancer Centre^{iv} who was able to confirm that the urologist's office was not open. Greg decided to go to an emergency department. In the emergency department the physician who reviewed his case believed that the swelling was a result of his inferior vena cava being compressed by the metastatic tumour. A call was placed to the oncologist (whom Urologist3 had contacted earlier in the week) to confirm that the cancer centre was aware of Greg and that an appointment was being arranged. When this was confirmed, Greg was discharged from the emergency department and returned to his family's home where he was recovering after his surgery. The following morning when he got up, Greg suddenly lost consciousness. His family called 911 and Emergency Medical Services arrived shortly thereafter. After initial resuscitative efforts Greg was transported to a hospital; unfortunately the resuscitation was unsuccessful and he died at the hospital.

^{iv} The Prostate Cancer Centre is co-located within the Southern Alberta Institute of Urology with the individual urologic surgeon's offices.

FIGURE 1: Timeline of events starting when Greg first presented with general symptoms*



*An asymptomatic abnormality of the epididymis was discovered as part of a routine physical exam by PCP1, 10 months before this chronology starts.

Breaks in the continuity of patient care

The continuity of patient care ‘broke’ four times in this case; there was a fifth experience during which Greg and his family felt there was break in continuity because they could not see what was happening ‘behind the scenes’. Although these are the experiences of a single patient, the QAC believes they typify many other patients’ experiences with Alberta’s complex healthcare system.

1. PCP1 elected to refer Greg to a general surgeon for an opinion about ‘abnormal thickening’ of his epididymis. Greg and his doctor believed this appointment would take place within a few weeks; however, it actually took three months for Greg to be notified about the appointment. There was no mechanism in place for the surgeon’s office to alert PCP1 or the patient about how long the waiting time would be for an appointment; there were no procedures in place for PCP1 to inquire how long it would take to obtain the surgeon’s opinion.
2. Greg underwent a CT scan for suspected cancer. The test was believed to be necessary before sending him to an appropriate specialist for definitive treatment. Despite this test being critical to his care, a followup appointment was not made to review the results of the scan and refer him to a specialist. This break in continuity of care was likely compounded when the primary care physician who ordered the CT scan (PCP2) left the walk-in clinic where Greg had been seen to join another medical practice. Greg reported to his family that he was not told the physician had left.^v When the report of the abnormal CT findings was received by the clinic Greg was not contacted; instead, he called the clinic to obtain an appointment with another physician (PCP3).
3. Greg was referred to a urologist for an urgent appointment. Neither the physician (PCP3), the walk-in clinic, nor Greg knew this urologist was out of the city for an extended time. One week later, when he had not yet been contacted about an appointment, Greg phoned the walk-in clinic that had initiated the referral. He was advised by the walk-in clinic to speak directly with the urologist’s office. When he discovered that he would have to wait several weeks to see the urologist he had been referred to, Greg re-contacted the walk-in clinic, which led to another referral to a different urologist.
4. After his surgery Greg was concerned about worsening lower limb edema and pain. Although it was during normal business hours on a weekday, he was unable to reach the urologist who had performed his surgery two days previous to discuss what the implications were and to obtain advice about what to do. He decided that his only option was to go to an emergency department.
5. Greg had been referred to the medical oncology service at the local cancer centre by the urologist who had seen him urgently and performed his operation. Behind the scenes the cancer centre was organizing an urgent outpatient appointment with an oncologist who specialized in the treatment of testicular cancer. The centre was in the process of booking an extra appointment in an already

^v The walk-in clinic had posted signs indicating that this physician was leaving however, the details about where the signs were posted and for how long are not clear.

full oncologist's schedule. Prior to calling the patient the cancer centre's usual process is to confirm that they have all of the patient's information available for the oncologist, which would include the pathology report of the surgical specimen. Greg and his family were unaware that any of this was taking place; all they knew was that an oncologist had been spoken to and that they would hear from the cancer centre. They had no way to confirm this or to understand the timeframe.

Missed opportunities to expedite care, once it became known that the patient had a time-sensitive health condition, are highlighted elsewhere in this report.^{vi}

^{vi} The QAC, for the purpose of this report, defined 'time-sensitive health condition' as one that requires definitive diagnosis and treatment within days to one or two weeks (maximum) because there is known compromise of vital limb or organ function (or there is a high probability of this developing).

FINDINGS & LESSONS TO BE LEARNED

There are important lessons that many patients, providers, and administrators of Alberta's healthcare system can learn from the analysis of the challenges that this one patient faced trying to navigate his way through a complex healthcare system. In high-performing health systems patients would not be burdened with the responsibility to be so vigilant and to advocate so strongly for themselves as this patient was required to be.^{vii} Given how healthcare systems in Canada operate, however, it is important for all stakeholders to understand what is currently required so that each Albertan can protect his or her continuity of care.

'Lessons to be learned' are shared in this section, from the perspective of the patient's family and from the perspective of the QAC. The HQCA obtained permission from the family to quote from a document they had prepared about their son's and brother's experience. These comments are included here because they provide insight into the users' experiences and the perceptions they have about how Alberta's healthcare system operates. The QAC has identified lessons to be learned for patients (Users) of the healthcare systems, for individual healthcare providers (Providers), and for the larger healthcare system (System).

The College of Physicians & Surgeons of Alberta (CPSA) has published Standards of Practice that are "the minimum standard of professional behavior and good practice expected of Alberta physicians".⁹ The standards are applicable in several of the situations that were reviewed in this report. The relevant standards are quoted where they apply.

Referral to specialists – knowing the process and timeframe

This patient was initially referred by a primary care physician (PCP1) to a general surgeon for an opinion and management suggestions about an abnormal finding in the epididymis. The process used to obtain an appointment with this surgeon was for the PCP1 to hand the patient a note written to the surgeon requesting that he see the patient in consultation with the intent that the patient would give this to the surgeon's office assistant located in the same office building. This process was completed successfully. The patient was told he would be contacted with an appointment time but was not told what timeframe to expect, nor did PCP1 have a way to determine the timeframe for the appointment. An assumption was made by PCP1 that the appointment would take place within a few weeks. In reality it took three months for the surgeon's office to contact the patient with an appointment.

The CPSA's Standard 6 covers the Referral Consultation Process and among other points states, "A consultant or service must respond verbally or in writing to a request for a non-urgent consultation from a referring physician within thirty (30) days of the receipt of a request."⁹

^{vii} High-performing healthcare systems have very little or no waiting times for specialist appointments, advanced diagnostic imaging studies, or procedures. Therefore, triaging requests for such services is not required and patient referrals do not have to be managed as intensely. Opportunities for patients' continuity of care to break down when being referred are substantially reduced.

Lessons to be learned – Family perspective:

“Never assume that when a referral is made to another doctor that the case will be treated with any particular priority.”

Lessons to be learned – QAC perspective:

Users: *If you have not heard about an appointment followup with the physician or clinic you have been referred to, or the physician/clinic who referred you.*

Providers: *When a physician is referring a patient for a specialized healthcare service there needs to be a clear understanding of; (1) how it will be confirmed that the referral has actually been received; (2) who will contact the patient with the appointment time; and (3) the timeframe in which the patient will likely be seen. If a patient needs to be seen within a certain timeframe, this should be clearly highlighted on the consultation letter or form together with the rationale for the request.*

Co-ordinating patient care – having more than one ‘quarterback’

The services of two primary care physicians (PCP) were accessed in two different settings. One PCP was aware of a problem this patient had with an abnormality in his epididymis; the other PCP was aware of the patient’s back pain. There were no electronic systems in place to share this information, and there was no obvious connection between the two issues in the mind of the patient. Moreover, the information about the epididymis abnormality was not highlighted on the ultrasound or the CT scan request form that PCP2 completed because the physician was unaware of the abnormality. It is possible that if the epididymis abnormality had been included on the original abdominal ultrasound requisition, the radiologist would have completed a scrotal ultrasound on the same day and discovered the patient’s testicular cancer six weeks sooner.

Lessons to be learned – QAC perspective:

Users: Avoid using more than one primary care physician so that a complete file of your medical information is available in a single location. If you do access the services of a different primary care team inform them of your history and of other healthcare providers you have seen.

Providers: Ask about other healthcare providers the patient may have seen and where you might find potentially important healthcare information about your patient.

System: An integrated electronic health record would ensure that important patient healthcare information is available regardless of where a patient obtains care.

Expediting diagnostic imaging studies for patients with time-sensitive health conditions

This patient underwent an ultrasound of the abdomen to investigate his complaint of back pain. The ultrasound showed a large mass that was seen to be pushing on a large vein (inferior vena cava) in his abdomen. The radiologist spoke with the patient, notified the PCP who ordered the test and then recommended an urgent CT scan. The ultrasound clearly showed that the patient had a serious, time-sensitive health condition (compromise of a vital body structure). Yet, by the time a CT requisition was completed and faxed to an AHS facility where it was reviewed and protocolled by a radiologist there, and by the time a CT appointment was given and the scan was completed, 26 days had elapsed before the patient returned to the PCP's office for a followup appointment.

CT scans are performed almost exclusively within publicly funded facilities that are managed by Alberta Health Services (AHS), although private facilities exist where CT scans can be performed via a user-pay mechanism. When a CT scan requisition for an outpatient is received it is assigned a priority level by a radiologist based on CT Prioritization Guidelines.^{viii} Criteria exist for the following conditions or anatomical areas (1) common conditions; (2) chest, abdomen, and pelvis; (3) musculoskeletal; (4) neuro, head, and neck, (5) pediatric, and (6) cardiovascular. The criteria that apply to an abdominal mass include the following with the relevant maximum waiting times:

Priority 1 – CT scans ordered for staging or metastatic workup in a patient with known malignancy – within 7 days

Priority 2 – CT scans ordered to characterize a known mass (but where it is not known yet if it is malignant or non-malignant) or to search for a primary malignancy (presumably in situations where metastatic disease has been diagnosed) – within 30 days

Priority 3 – CT scans ordered for patients with an incidental finding of an adrenal mass – within 60 days

Priority 4 – CT scans ordered for routine scheduled followup

^{viii} Alberta Health Services Provincial CT Prioritization Guidelines September 21, 2011

Although the radiologist who interpreted the ultrasound identified a serious time-sensitive health condition that was very likely malignant (cancerous) and recommended an ‘urgent’ CT scan, and the requisition was marked ‘urgent’ by the patient’s PCP, the patient did not yet have a confirmed diagnosis of cancer. Therefore his CT scan was assigned a priority 2 by a second radiologist and the appointment time was 19 days from the date that the CT requisition was received. This was within the guidelines for maximum time limits. It is common practice that if one diagnostic imaging test, like an ultrasound, demonstrates an abnormality that requires additional imaging studies, it is the responsibility of the original requesting physician to order these. The radiologist who interpreted the ultrasound was in a private DI clinic and was not responsible for, or involved with, the process for establishing the CT scan priority.

Radiologists are a unique type of consultant; their participation in the care of most patients they are asked to ‘consult on’ is limited to the interpretation of the diagnostic imaging study that the patient has undergone. Because they are consultants, however, the CPSA’s Standards of Practice should be assumed to apply. Standard 6 addresses the Referral Consultation Process; subsection 21 states, “If the consultant requires further investigations before reaching a definitive diagnosis, the consultant must not delegate arrangement and followup of those investigations to the referring physician without prior agreement”.⁹ However, this is not common practice for most radiologists and could result in a perceived conflict of interest (see next section – Radiology self-referral).

Lessons to be learned – Family perspective:

“‘Urgent’ in the healthcare system doesn’t mean urgent! It is very difficult for us to understand how something classified as urgent takes 19 days to become actionable. Urgent to the radiologist meant not only sending the report but personally calling the doctor that requested the tests the same day and making sure that the information made it in person all the way to the doctor examining Greg’s health. In our investigations we were told by well-respected doctors that times approaching three weeks after an “urgent request” is made is not uncommon. In fact it was classified as ‘normal’. It was explained that it is in part because many doctors classify their requests as urgent to try and move their patient up the waiting list. We also were given the impression that because it was normal, we shouldn’t expect anything more and it was not the fault of the system. Clearly the system is broken if the necessary resources are not available on a priority basis, related to the patient’s real critical needs. The fact that doctors are not working within a disciplined process of prioritization is bad news but the worst part is their position that because it is ‘normal’, it is ok, regardless of the outcome.”

Lessons to be learned – QAC perspective:

Users: *If you have a serious medical issue and it is not being addressed in a timeframe that you believe is acceptable, it is quite appropriate to ask your healthcare provider to reconsider the urgency of your care needs.*

Providers: *‘Urgent’ lacks a standard definition in the healthcare system. If a patient with a time-sensitive health condition needs an appointment for a test, procedure, or consult within a very short period of time, the only reliable way to ensure this happens is to speak directly with a person who has the authority to appropriately expedite the appointment. No other approach or process can reliably take the place of direct provider-to-provider communication.*

System (Radiologists): *In situations where one diagnostic test for a patient indicates a clear need for additional diagnostic imaging studies in a timely fashion, radiologists are acting within their professional duties if they order the required test or tests on behalf of the patient as soon as possible. Ideally, the radiologist should attempt to consult with the referring physician, and discuss the reasons for and merits/risks of further diagnostic tests. In the absence of opportunity for direct consultation with the referring physicians, professional courtesy dictates that radiologists should notify the physician who ordered the original test about what will be done for the patient. Professional courtesy does not mean that radiologists have to send the patient back to the ordering physician merely for the purpose of having them order the additional imaging studies. Indeed, the CPSA Standards of Practice for the ‘Referral Consultation Process’⁹ (Standard 6) stipulates that if a consultant requires further investigations before reaching a definitive diagnosis, the consultant must not delegate arrangement and followup of those investigations to the referring physician without prior agreement.*

System: *The current criteria that are used to prioritize scans such as CTs and MRIs are incomplete since they do not take into consideration cases where ultrasounds or x-rays suggest with a high probability that a patient has an underlying cancer. In situations where there is clear evidence that a patient has a time-sensitive health condition, CT or MRI studies for these patients should be top priority regardless of whether malignancy has been confirmed.*

Radiology self-referral

Radiologists provide publically funded services and are paid in different ways depending on whether they work in a private clinic or in an AHS facility. Private diagnostic imaging clinics submit a claim to the Alberta Health Care Insurance Plan (AHCIP) for studies they perform on patients. The AHCIP reimburses the clinic for the cost of performing the test, and reimburses the radiologist for interpreting the test and preparing a report that is sent back to the ordering physician. The fee that is claimed and paid is

established in the Schedule of Medical Benefits that the Government of Alberta sets in negotiation with the Alberta Medical Association. Advanced diagnostic imaging exams that are publically funded (e.g., CT scans, PET scans, and MRI scans) are only available in facilities owned and operated by AHS (hospitals and treatment centres).^{ix} For interpreting these advanced imaging studies, radiologists are paid an interpretation fee by AHS; no claims are submitted to the AHCIP. Some radiologists only practise in private clinics but a substantial number work both within private clinics and AHS facilities.

Radiologists are cautious about directly arranging for patients to have diagnostic imaging studies because of the perception that this appears to be ‘self-referral’ within the profession. The CPSA’s Standard 29 addresses Conflict of Interest Involving Financial or Personal Gain by Physicians. Subsection 4 of this standard states, “A physician must not have a direct or indirect interest in a healthcare business to which the physician refers a patient or to which a patient may be expected to attend due to geographic proximity or necessity unless permitted by the Registrar”.⁹ Whereas this Standard and the perceived conflict of interest created by radiology self-referral may be a legitimate concern for routine diagnostic imaging studies in a private setting where a radiologist or the group that he or she works within might directly benefit from additional diagnostic tests being performed, it should not be a concern in cases where a patient has a time-sensitive health condition and the recommended test (e.g., CT scans, MRI scans, PET scans) will be performed in an AHS diagnostic imaging facility.

Followup and review of test results

Between the time that the patient’s urgent CT scan was ordered by PCP2 and the time it was completed, the ordering physician left the clinic to join another medical practice in a different city. Seven days elapsed from the time the CT was completed until the patient received a clinic appointment with another physician to review the results of the CT scan. The clinic had signs posted stating that the physician was leaving his practice at this walk-in clinic and providing patients with options for continuing their care with the walk-in clinic or with the departing physician at his new location.^x According to his family, the patient did not receive direct information from the walk-in clinic that the physician he had been seeing had left and the patient himself had to call the clinic to get a followup appointment with another physician so he could learn what the CT findings were and what type of specialist he would need to see. This was a critical step in his journey to get to a surgeon and ultimately to an oncologist for definitive, potentially life-saving treatment.^{xi,10}

Two of the CPSA’s Standards of Practice are relevant to this break in the patient’s continuity of care. Standard 22 addresses situations where a physician is leaving, closing, or moving a medical practice. In these situations, in addition to notifying the CPSA a physician must provide a minimum of ninety (90)

^{ix} CT scans and MRI scans are also located in a few private clinics and patients can pay privately (out-of-pocket) for them. Occasionally, when waiting lists are extensive for MRI scans, AHS will contract with private clinics for some patients on the waiting list to have their MRI scan in a non-AHS facility. In this case the publically funded healthcare system pays for the cost of the MRI.

^x The HQCA could not confirm when the signs had first been posted or the exact location of the signs.

^{xi} Patients with metastatic testicular cancer have a greater than 50 per cent chance of long-term survival with chemotherapy treatment.¹⁰

days' notice of the medical practice closure or relocation to patients with whom there is an expectation of ongoing care (subsection 5).⁹

Standard 24 (Preventing Follow-up Care Failures) requires a physician who orders a diagnostic test or makes a referral to another health professional to (subsection 1): (a) have a system in place for review of test results or consultations and arrangements for followup care when necessary, (b) have a system in place to contact the patient when followup care is necessary, (c) document all contacts and attempts to contact the patient,^{xii} and (d) make arrangements for responding to "critical" diagnostic test results reported by a laboratory or imaging facility for urgent attention after regular working hours or in the absence of the ordering physician.⁹

Lessons to be learned – Family perspective:

"Never, ever assume there is a critical smooth hand off between doctors."

Lessons to be learned – QAC perspective:

Providers:

- 1. When a provider's office knows the date and time of an appointment for an important test like a CT scan, staff should book the patient's followup appointment for one or two days following the scan (results will be available on Netcare), rather than rely on the arrival of a paper report to trigger the booking of the next appointment. This is especially important for a patient with a time-sensitive health condition.*
- 2. Providers who are leaving a practice and transferring the care of patients to another physician, should ensure there have been adequate attempts to notify patients about the change in their healthcare provider. Additional efforts should be made to speak with patients who are in the process of undergoing investigations for serious disorders that could be life-threatening.*

Ensuring that a patient's transition of care has been successful

In the case reported here, the patient required an urgent appointment to see a urologist. The referral was faxed to a urologist at the Southern Alberta Institute of Urology (SAIU) who happened to be out of the city for an extended time; therefore, this first referral request was not reviewed right away. The only way the walk-in clinic that sent the referral could have known that this specific urologist was away was if clinic staff had phoned the urologist's office. That is not usual practice. Referring-physician offices usually assume that their faxed requests for a consult are received and processed. In this particular case,

^{xii} According to the Standards of Practice this documentation must be included in the patient record.

that assumption was incorrect. This patient waited for one week to hear about an appointment and when he had heard nothing he contacted the walk-in clinic. He was told to contact the urologist's office directly, which he did. When the patient learned that the urologist to whom he had been referred was away for an extended time he called the walk-in clinic staff again and notified them. Shortly after making these inquiries the patient received two appointments (to see two different urologists) – one initiated by the urologist who was away, who had been alerted to the referral's urgency, and the other by the walk-in clinic, which faxed a second referral to a different urologist. If he had not called after waiting a week, the patient would have experienced an even longer delay.

Although all the urologists have their offices in the same building they function independently; there is no central or shared referral system in place. Therefore there was no way for any other urologist to know that a patient who required urgent assessment and treatment had been referred to a colleague who was away or, that once this information eventually became available, which other urologists the patient had been referred to.

The CPSA's Standard 6, The Referral Consultation Process, subsection 17 states that a consultant or service must make information available to referring physicians (and other referring practitioners, if applicable) respecting the process by which referrals are accepted (e.g., by telephone, facsimile, secure e-mail, or verbally) and a consultant or service should generally be available to respond to requests for consultation. Subsection 9 (in reference to the referring physician) states that in the case of a referral for emergency care, the physician must discuss the referral with the consultant or the emergency physician (if referral to an emergency department is being made) or otherwise ensure acceptance of care by the consultant or service.⁹

Lessons to be learned – Family perspective:

"If you are referred to the 'Urology Centre' (Southern Alberta Institute of Urology) located next to the Rockyview Hospital in Calgary, do not assume that this is a centre where a team of doctors work together when in fact they work independently and therefore it appears they don't collaborate together very closely."

Lessons to be learned – QAC perspective:

Users: *Whenever you are referred from one healthcare provider to another, or for an advanced diagnostic imaging test or a procedure, make sure you understand who will contact you with the appointment time, when you should expect to hear of the appointment, and whom to contact if you do not hear within this timeframe. The handover of your care may not happen smoothly; therefore, it is important to remain vigilant and followup with an appropriate person if you have not heard about an appointment within a reasonable time.*

Providers:

1. *Specialists' offices (or clinics that offer specialized healthcare services) that are closed for an extended time need to ensure there is a way for referring doctors to know this if their usual practice is to fax referrals. Arrangements should be made for these referrals to be seen and promptly reviewed by someone so any patient who has a time-sensitive health condition is seen and dealt with as soon as possible.*

2. *Physicians needing to refer a patient with a time-sensitive condition to a specialist or clinic should call and speak to someone directly who can expedite the referral. This will ensure a more reliable transition of care.*

3. *For all patients, but especially those with time-sensitive conditions, physicians who are referring them for a specialized healthcare service should have a process in place to ensure that a faxed referral was received by the specialist's office (or clinic) and that an appointment is being scheduled in a timely fashion. Anything less exposes a patient to a number of imperfect processes, which, if one or more of them fail, compromises the transition of, and therefore delays, the patient's care.*

System: *Current processes for managing the complex dealings between referring physicians and specialists or clinics offering specialized healthcare services are variable and not sufficiently reliable to protect patients' continuity of care. An electronic referral system that allows referring physicians and patients to verify that each step of the referral process has been completed and to alert them otherwise, is likely the only system-level change that can be made to improve patients' safety and the effectiveness of specialized healthcare referrals.*

Co-located practice groups: co-ordinating services and clarifying relationships

When healthcare providers co-locate, particularly when they practise a specialized type of healthcare, members of the public and broader healthcare community may be led to believe the services that are provided are fully co-ordinated between members of this 'practice group'.

The Southern Alberta Institute of Urology (SAIU) is office and clinic space for 17 urologists and two centres: the Prostate Cancer Centre (PCC) and the Alberta Bladder Centre (also known as Vesia). The Institute has no infrastructure and provides no co-ordinating function – the urologists and the centres function independently. The SAIU is situated next to the Rockyview General Hospital (RGH), on the top level of its new parkade. Capital funding for developing this space, which opened in 2010, came from generous philanthropists and the Prostate Cancer Foundation. The fact that the SAIU is physically located on Alberta Health Services (AHS) property may lead patients to incorrectly conclude that the SAIU is an AHS facility. AHS leases the space to the PCC and subsidizes some of the building costs, such as maintenance, heating, electricity, and security. Urologists are in private practice and each of them

subleases office space from the PCC. A private diagnostic imaging clinic also subleases space and provides onsite prostate biopsies for patients who attend the PCC.

The two centres, Vesia and PCC, provide specialized urological health services. Vesia provides diagnostic and treatment services for men and women with lower urinary tract disorders and women with pelvic floor dysfunction. The PCC provides services to diagnose and treat men with prostate cancer.

Established in 1999, the PCC is a non-profit advocacy group. Funding for the PCC is provided by a charitable fundraising organization, the Prostate Cancer Foundation. The Foundation and the PCC have Boards of Directors that oversee each organization.

Each urologist at the SAIU is an independent practitioner with separate office space and staff. Some urologists share an electronic medical record; however, there isn't a single SAIU medical record. The urologists, like all independent physicians, have distinct referral processes; except for Vesia, there is no central process for managing referrals for patients requiring urological care. The urologists being located together may give the appearance that the SAIU has a role in co-ordinating patient referrals and transitions of patient care from physicians in the community to the urologists in Calgary; however, this is not the case.

Patients requiring access to services provided by the PCC require a referral to a urologist. Patients deal individually with the urologist they have been referred to. The urologist refers the patient to the PCC services. In contrast, Vesia accepts direct referrals (fax or online submission) from physicians in the community, thereby providing a central referral process. Vesia also publishes on its website a mechanism for making urgent referrals (a phone number to contact the urologist on duty is provided.).

Post-operative care – physician responsibility for patients

This patient had an operation to remove the primary source of cancer. The operation was a short, straightforward day procedure that would enable him to proceed to a medical specialist (an oncologist) who could provide definitive treatment for his metastatic cancer. After his surgery, the patient was provided by hospital staff with standard discharge instructions for orchidectomy (removal of testicle) on what to do if he was experiencing complications from the operation. The patient had concerns about the symptoms he was experiencing (back pain and lower limb edema) and when these worsened post-operatively he wanted to discuss his concerns with either the urologist he had seen or the medical oncologist he was to see. Unaware of the status of his cancer clinic appointment, he tried to contact the urologist about the change in his symptoms to obtain advice about what should or could be done. The only way this patient could reach the urologist was to call his office. Despite it being a weekday during normal business hours, the urologist's office was closed and there were no instructions on the recorded answering message about how to reach him or someone who was covering for him. He tried to contact the Southern Alberta Institute of Urology (SAIU) but learned, as described above, that the SAIU does not have a central phone number to call. He did find a number for the Prostate Cancer Centre and was able to reach a receptionist there. The receptionist was able to confirm, after some inquiry, that the urologist was not available that day. After confirming there was no way to contact the urologist who had operated on him two days ago, or another physician covering for him, the patient elected to go to an emergency department where he saw a physician he had not met before and who did not know the details of his case. The experience of needing to go to an emergency department due to an inability to contact the attending physician, is reflective of the experiences of many Albertans.

In Alberta, patients are frequently informed by physicians' recorded answering systems that if the office is closed, and a patient believes they cannot wait until the office reopens, they should attend an emergency department. This widespread practice among physicians throughout the province correctly addresses situations where patients have life-threatening or emergent health conditions; it does not, however, address situations where patients have a time-pressing concern but do not know if it is life-threatening.

Two CPSA Standards are applicable in situations where a patient has been referred to one or more specialists and needs to contact a physician on an urgent or semi-urgent basis because of a change in his or her condition (especially following some type of procedure). The questions most patients have are, "who should I contact" and "how do I reach them"? The College's Standard 6 (Referral Consultation Process) partially addresses the 'who' question. Subsection 22 of this Standard specifies what should be in a consultant's report back to the referring physician after seeing a patient. Beyond some basic information it states that a consultant's report must include, when applicable, recommendations for followup by the referring physician, recommendations for continuing care by the consultant, recommendations for referral to other consultants, and the advice given to the patient.⁹ This standard does not address the responsibility of the consultant to be available to address patient concerns.

Standard 32 specifies the following expectations of physicians to provide after-hours care for patients:⁹

1. A physician who provides care on an ongoing basis must ensure that care is continuously available to the patients in his or her medical practice.
2. When a physician is unavailable, the physician must make specific arrangements with another physician or physicians or with an appropriate coverage service with which the physician has an agreement.
3. If requested by the CPSA, a physician must demonstrate the existence of an agreement described in subsection (2).
4. A physician must make information available to the physician's patients about the arrangements in place for after-hours coverage of the physician's medical practice.
5. It is not acceptable for a physician's answering service to direct patients to attend an emergency room or other episodic care facility unless the physician has a formal agreement with the specific facility or with a physician working in that facility.
6. Notwithstanding subsection (5), a patient with an emergent or life-threatening condition must be immediately referred to an emergency department if a physician is unable to render care.

The Canadian Medical Association Code of Ethics lists a series of guidelines for physician activities and conduct.¹¹ Guideline 19 addresses one of the core responsibilities physicians have to patients. It states: "Having accepted professional responsibility for a patient, continue to provide services until they are no longer required or wanted; until another suitable physician has assumed responsibility for the patient; or until the patient has been given reasonable notice that you intend to terminate the relationship."

Lessons to be learned – Family perspective:

“Never, ever let your doctor leave you without a surefire method of contacting them (or someone you and they both trust) 24 hours a day. We did not know that the urologist’s office wouldn’t be open on Friday when we had talked to the urologist pre-surgery. We also were guilty of assuming that post-surgery, among the instructions there would be special notations of what to do and who to talk to in the event of concerns arising. These were multiple erroneous assumptions we made. Experiences since have shown in some instances some doctors do indeed provide this kind of instruction and contact information and actively encourage calling them if anything worries the patient or family involved.”

Lessons to be learned – QAC perspective:

Providers: *When patients have undergone a procedure following which there could be complications, and/or you have responsibility for providing care to a patient with a serious health condition, you should provide patients with detailed information (written or on your website if that is an effective option for patients) about how to reach you (or a colleague if you are unavailable) for a reasonable time period following the procedure. This should include contact information for regular ‘business hours’ and after hours. Providing patients with the sole option of going to an emergency department to see a physician whom they have never seen before and who will not have access to all of the patient’s information does not meet the CPSA’s Standard of Care.*

System: *It should become a standard practice that when patients are discharged following a procedure they are provided information about when and how to contact the physician who performed the procedure or an appropriate delegate (e.g., a colleague who may be on-call).*

‘Jousting’ in healthcare – how it affects trust and confidence in handovers of care

‘Jousting’ is a term that has been used to describe situations in which different healthcare providers contradict one another with the information they provide to patients or when a healthcare worker is critical of another in front of a patient. This patient and his family were informed (by the urologist) that his appointment at the cancer centre would be expedited. Further, they were told that because of the tumour compressing his inferior vena cava that the oncologists would consider starting chemotherapy as soon as possible after the orchidectomy, possibly even before the final pathology report was available. Although this is not often done it was considered an option by the oncologist with whom the urologist spoke, not only because of the complications and symptoms the tumour was causing but also because of the source of cancer (testicular).

On his second post-operative day, the patient and his family were concerned that they had not heard about the scheduling of his cancer clinic appointment. In attempting to reach Urologist3 they were able to speak to someone at the Prostate Cancer Centre who then placed a call to the Tom Baker Cancer Centre (TBCC) for them. A person at the TBCC called the patient back and informed him that the clinic was waiting for the final pathology report to be completed, which would likely take between seven and 10 days, before booking a definitive appointment. When this patient responded that he had been told by Urologist3 that he could be started on treatment before the final pathology report was available he was

told by the TBCC representative that this “never” happened. Suddenly he and his family did not know what or whom to believe – this statement contradicted what Urologist3 had told them. During this transition of care between the urologist and the TBCC the patient and his family expected a consistent story. When this wasn’t the case it shook their confidence in the caregiving team. The patient never had the opportunity to clarify the contradictory information he had been given by the TBCC representative.

Lessons to be learned – Family perspective:

“Don’t simply trust your doctor’s judgment and recommendations unless you have a long enough history with them to be certain, or else make sure you have checked on those things yourself to see that they in fact are valid.”

Lessons to be learned – QAC perspective:

Providers: *It is important that patients have trust in their healthcare providers. This trust is easily broken when healthcare providers contradict or criticize other healthcare providers or the information they provided to patients. When you are speaking with patients be aware of the context of the interactions and the information patients have received from other healthcare providers.*

Electronic health records – patient access to important health information

When patients interact with the healthcare system, the information that is generated from those interactions can be stored in paper format or electronically; the latter is referred to as an electronic medical record (EMR). When patients access different health providers or clinics, each of these providers likely has a separate EMR, meaning that patients have multiple electronic records or files. For example, if a patient went to one physician who ordered some lab tests, the results would be available for that patient in that physician’s EMR. If the same patient went to a different physician who ordered an ultrasound, the result of that test would be in that physician’s EMR. Neither physician would have access to the other physician’s test results or records. The patient would have records in two separate EMRs and both would be incomplete.

Electronic health records (EHRs) aggregate information from multiple data sources (including hospitals, pharmacies, diagnostic imaging facilities, laboratories, and some clinics) so that there is a more comprehensive patient record that can be automatically updated. Core components of an EHR include the following: client registry (a list of all patients and their relevant personal information), provider registry (a list of healthcare professionals who are authorized to use the EHR), diagnostic imaging information, drug information, and laboratory information.¹² EHRs allow access to important patient information by multiple providers in the health system regardless of which type of health facility they are located in. Alberta’s provincial EHR is called Netcare and Internet-based access is available to authorized health service providers. Netcare is automatically updated with certain types of information about patients. The main types of information in Netcare include diagnostic imaging test interpretations (and in some cases the actual images), laboratory results, and drug information (prescriptions dispensed), as well as some hospital discharge summaries.

Personal Health Records (PHRs) provide patients access to their health information and tools to help them manage their health. The functionality of PHRs varies widely; they can be stand-alone or linked to

EHRs. Stand-alone PHRs allow patients to have an electronic site for storing their health information; however, patients have to enter the data themselves. Alternatively a PHR can be linked to an EHR so that patients are able to view healthcare information through a ‘patient portal’. There isn’t yet a functioning PHR system in Canada linked to a provincial EHR that would allow patients to view their own health information.

PHRs that have been developed for healthcare systems in the United States highlight the functionalities that are currently possible and demonstrate how this can allow patients to become more engaged in their own healthcare. Some of these functionalities include:^{xiii,12}

- scheduling appointments
- secure messaging (providing patients an ability to contact their healthcare providers)
- decision support (providing access to trusted sources of health information)
- viewing laboratory and diagnostic imaging results
- pharmacy information

In most healthcare systems there are certain healthcare services (e.g., specialist consultation, advanced diagnostic imaging studies, and invasive or semi-invasive procedures) that require a referral from a healthcare professional, on behalf of a patient, in order to obtain the service. For this to occur successfully, several process steps need to be completed reliably, including the referral process, assigning a priority to the referral (to manage the waiting period), appointment scheduling, patient notification, completing the service, report generation, report transmission, and report review between the requesting healthcare provider and the patient (Figure 2). There are currently no patient portals that allow patients to see what stage they are at in the specialized healthcare service referral process.

Alberta’s current and planned future state for personal health records

In Alberta, patients currently have access to their own medical information only if they ask individual healthcare providers or a hospital for printed copies. They can obtain lists of their prescription medications from their physician or pharmacist. If the list comes from an EMR it may be incomplete if the patient has more than one physician or pharmacy; the information is more likely to be complete if it comes from Netcare.

[MyHealth.Alberta.ca](http://myhealth.alberta.ca) is an Alberta Health initiative that provides health information to Albertans including summaries of health conditions, wellness, medications, health alerts, health services, decision aids, and health checkup tools as well as electronic links to an AHS website that allows people to view emergency department wait times (<https://myhealth.alberta.ca/Pages/default.aspx>). In the near future [MyHealth.Alberta.ca](http://myhealth.alberta.ca) will introduce a Personal Health Record (PHR) that will allow Albertans to enter and track information on their own such as weight, blood pressure, heart rate, blood sugars,

^{xiii} These are functionalities described in an AHS white paper and are not currently operational in all PHRs, but it provides a vision of the possibilities of PHRs in Alberta.

cholesterol, allergies, medication lists, exercise routines, and wellness goals and maintain an appointment calendar. Plans are under way to link the PHR with the province's electronic health record (Netcare) so that patients will gain access to their lab results and diagnostic imaging results as well as their prescription dispensing history. Eventually there are plans to offer secure messaging (e.g., email) to patients' healthcare providers through the PHR.

Alberta Health Services is preparing to implement a limited production rollout of an e-referral system. This system is being developed using the Netcare platform. This system will allow physicians to refer patients electronically to a limited set of specialized healthcare services (cancer clinic, for breast cancer and lung cancer patients; bone and joint referrals, for hip/knee replacement surgery; and later, advanced diagnostic imaging studies, such as CT and MRI scans). This will allow standardization of the referral process and will include process steps up to the point that the patient receives an appointment for the service and receives that service. Healthcare providers should be able to track a patient's progress through the e-referral system. At this time e-referral will be available on a voluntary basis to physicians and other healthcare providers who choose to use it. A long-range vision for integrating the e-referral system with the PHR that could allow patients the opportunity to track the status of their specialized healthcare services exists but it is too early to estimate a timeframe of when Albertans can expect this level of functionality.

Patient portals and continuity of patient care – literature review

Literature review see Appendix II

There are several ways to view the continuity of patient care; in general, three dimensions have been described in the literature:^{1,13,14,15}

1. Relationship continuity, particularly important in primary care, is described as the relationship between a single practitioner and a healthcare user (expressed as 'physician attachment'). Patient portals have the potential to improve primary care patient-provider communication¹⁶ by integrating personal health records owned by the patient, medical records owned by primary care centres, and electronic health records owned by the health system. In Denmark, such a system provides patients with same-day access to primary care, electronic prescribing systems connected to local pharmacies, as well as 'off-hours' healthcare services based on patient's health registry information (referred to as electronic health records).¹⁷
2. Information continuity is the timely availability of relevant information through shared medical records but also knowledge about the patient's preferences and values. Core functions of existing patient portals include:
 - Secure messaging (providing patients an ability to contact their healthcare providers).
 - Access to medical and health records to receive personalized health information tailored to health condition and to preventive health topics.^{18,19} Many clinicians are concerned that patients might misunderstand test results or become anxious or distressed when accessing complex medical information. However, when this has been evaluated in specific patient populations (e.g., breast cancer patients), access to personal health information has not been found to increase anxiety levels).²⁰ Healthcare organizations establish policies that limit type and timing of available test results. For example, this could entail categorizing test results into three groups: results displayed as soon as available, results displayed after seven days to

allow time for a provider to review results and contact a patient directly, and highly sensitive results that are never displayed).¹⁸

- Administrative tasks such as scheduling appointments and bill management.
3. Management continuity involves the communication of facts and judgments across team, institutional, and professional boundaries, and between professionals and patients. Patient portals are owned, administered, documented, and managed by a healthcare institution. Institutions may offer access to selected clinical data (basic function) as part of the patient's electronic health record, which can then be integrated into any type of patient-owned record.²¹ It is possible to integrate personal health records with clinical information systems from multiple vendors.²² To date, however, it does not appear as though most electronic health records have the ability to capture data for measuring healthcare performance data or work flow actions.²³ Creating audit trails of provider actions within patient records (e.g., monitoring what was reviewed, added, or modified) could improve co-ordination of care.²³

A comprehensive patient portal integrated into primary care can increase patient-centredness, improve patient activation, enhance delivery of age- and risk-factor appropriate preventive services, and promote utilization.²⁴ No evidence was found, however, of a patient portal system being used to manage patient scheduling of specialized healthcare services (referrals, waitlist management) that would inform patients about the status of their referral and allow them to participate in that important management process.

State-of-the-art patient portal systems in North America

Three leading healthcare systems in the United States (Geisinger Health System, Mayo Clinic, and Kaiser Permanente) were interviewed to gain additional information on their experience using an Internet-based patient portal system and how that might inform the vision for a system in Alberta that could address some of the important issues that were factors in the case that was a focus of this report (see Appendix III for a complete description).

Geisinger Health System serves more than 2.6 million residents throughout 44 counties in central and northeastern Pennsylvania.^{xiv} It has three medical centres (approximately 1,100 inpatient beds in total) and 41 community practice sites. Geisinger is an integrated health services organization widely recognized for its innovative use of the electronic health record. Geisinger, like the Mayo clinic, is based on a group practice model with a common EMR (EPIC EMR System) used by all of its healthcare providers and institutions. It has used an Internet-based patient portal since 2001. Patients in the Geisinger system have access to the following functionalities through their patient portal:

- View lab results (almost all results in real time).
- View diagnostic imaging results.

^{xiv} <http://www.geisinger.org/about/>

- Message healthcare providers.
- View portions of the medical record, including outline of current health issues, medications, allergies, immunizations, and health reminders.
- Track chronic conditions and provide updates: Patients are able to enter their own healthcare data into their patient record (e.g., glucose values, blood pressure, and weights) which can be viewed by their healthcare providers.
- Schedule appointments with their primary care providers.
- Grant proxy access to the patient portal for family members to assist with their care.

The most common patient portal functions that patients use are viewing laboratory results, viewing diagnostic imaging results, and messaging to healthcare providers. In 2013 Geisinger provided access through the patient portal to 'open notes', which provides patients the opportunity to view healthcare provider notes. Patients are able to schedule appointments with their primary care providers through the patient portal. To date the experience has been that most patients do not take advantage of this functionality but those who do have a lower no-show rate. In 2014 patients will be able to complete pre-visit questionnaires and schedule lab tests before their scheduled appointments with providers. The functionality of the Geisinger patient portal is dependent on what is offered by the vendor.

Mayo Clinic is based in Rochester, Minnesota and has inpatient and outpatient facilities in Scottsdale, Arizona and Jacksonville, Florida as well as outpatient clinics in Iowa, Wisconsin, and elsewhere in Minnesota.^{xv} Mayo Clinic healthcare providers, clinics, and acute care facilities in Rochester use a common EMR (GE medical record). Scottsdale and Jacksonville use the same EMR system (Cerner), which is different and separate from the Rochester EMR. Patients in the Mayo system have access to the following functionalities through their patient portal:

- View lab results (all results in real time – no results are withheld).
- View diagnostic imaging results (currently reports only – in the future, images will also be available).
- View pathology results.
- Medication list, allergy list, immunizations.
- Pre-visit questionnaires and forms that can be completed online.
- Notification (reminders) of preventive health services to be completed (e.g., colon cancer screening).
- Requests to reschedule appointments (in the future patients will be able to book appointments online).

^{xv} <http://www.mayoclinic.org/about/>

- View of upcoming appointments.
- Messaging healthcare providers (just starting) – allows patients to contact their healthcare providers online.
- Administration – refilling prescriptions online, registration, insurance, authorizations.

Requests from primary care physicians for specialist consultation and scheduling of those appointments is handled within the EMR. It is possible for physicians external to the Mayo system to request an ‘e-consult’ with a Mayo specialist or refer a patient for an appointment electronically. Some functionalities have been custom built by Mayo and integrated within its EMR. Mayo has built most of its own mobile applications that allow patients to use mobile devices to view the same health information Mayo can see with the Internet-based patient portal. The ‘viewer’ Mayo has created to enable this functionality integrates information from multiple EMRs.

Kaiser Permanente is the largest managed care organization in the United States, operating out of nine states and the District of Columbia. It provides outpatient and inpatient care to more than 9,000,000 people from 37 hospitals and 611 medical office buildings.^{xvi} It initially started building its own EMR but changed to the EPIC EMR system. It created its first patient portal in 1996, which had limited functionality; however, it now uses EPIC’s ‘MyChart’ that has multiple functionalities, including the top four that patients use most often and view as most important:

- Email my doctor
- Test results – lab / DI
- Prescription refills
- Appointment scheduling

Mobile applications make it possible for patients within the Kaiser system to use their mobile devices to access their health information and perform the functions that are possible using the Internet-based patient portal.

In none of the above described systems is it possible for patients to track the status of their referrals for specialized healthcare services. Similar to Alberta, in these health systems, specialized healthcare services must be requested for a patient by a healthcare provider who works within the healthcare system. However, unlike in Alberta, waiting times for most of these services are not long so there is little impetus for or interest in building a view for patients that allows them to monitor their status in the process of ‘referral management’.

^{xvi} <http://xnet.kp.org/newscenter/aboutkp/fastfacts.html>

ISSUES, ANALYSIS, AND RECOMMENDATIONS

Reliable continuity of care when patients are referred for specialized healthcare services

Issue

There is a risk that patients' continuity of care will break when they are referred for specialized healthcare services (specialist consultation, advanced diagnostic imaging tests, invasive or semi-invasive procedures). Procedures and standards to mitigate this risk are lacking.

Analysis

Patients in Alberta, and their healthcare practitioners, have limited access to their own health information and are unable to track their transitions of care from one healthcare provider to another, to diagnostic centres that offer advanced imaging, or to facilities that perform invasive/non-invasive procedures.^{xvii} Without this information, patients are unable to be fully engaged as partners in their own care, unable to advocate for changes in their planned care if they do not believe it is appropriate or timely, and unable to detect when there have been breaks in their continuity of care.

When patients are referred for specialized healthcare services there are four critical steps that, if not successfully completed, can delay or prevent patients from obtaining the benefit of such services. Specialized healthcare services are those where (1) a healthcare provider must make a request, on behalf of a patient, for the service; (2) an appointment is required (typically involving some amount of waiting and some prioritization process); and (3) a report is provided about the service back to the healthcare provider who requested it. The most common examples of these are specialist consultation, advanced diagnostic imaging tests (e.g., CT scans, MRI scans, PET scans), and procedures – especially those that are invasive (e.g., surgery) or semi-invasive (e.g., biopsies, scopes).

The four critical processes where the continuity of patient care critically depends on shared workflows between the healthcare practitioner requesting the service and the one providing the service are (1) the request for service; (2) assigning an appointment date and time for the service; (3) notification to the patient of the appointment details (location, date, and time); and (4) report transmission back to the requesting provider (Figure 2). There are two additional steps required for successful completion: (1) the patient following through with the specialized healthcare service at the assigned appointment date and time; and (2) the patient meeting with the referring healthcare provider to review the results and discuss their implications.

There is no agreed-upon standard process for completing the critical shared workflow tasks required for successful completion of a specialized healthcare service. Different health service providers have

^{xvii} Patient's healthcare providers are also unable to track the status of their patients who have been referred for specialized healthcare services because this is not done electronically and the processes are non-standardized.

developed many different processes for completing these necessary steps. Because the processes for transactions between healthcare providers are not standardized, there is no way to systematically verify that a patient's continuity of care has not been compromised. Standard processes should be used whether the referral, appointment management, and report generation/transmission is accomplished using an electronic platform, fax machines, or traditional mail. The standards should be met for all patient encounters that involve specialized healthcare services but are critically important for patients with a time-sensitive health condition.

With thousands of providers of specialized healthcare services, the healthcare system is complex. In such a system, the only realistic way of improving the overall provision of these services so that patients' continuity of care is protected and can be systematically verified is to develop an electronic system to carry out all of the steps outlined in Figure 2. This would require an information and transaction system that all providers and requestors of specialized healthcare services use directly or that can be integrated with existing electronic medical records that are in use.

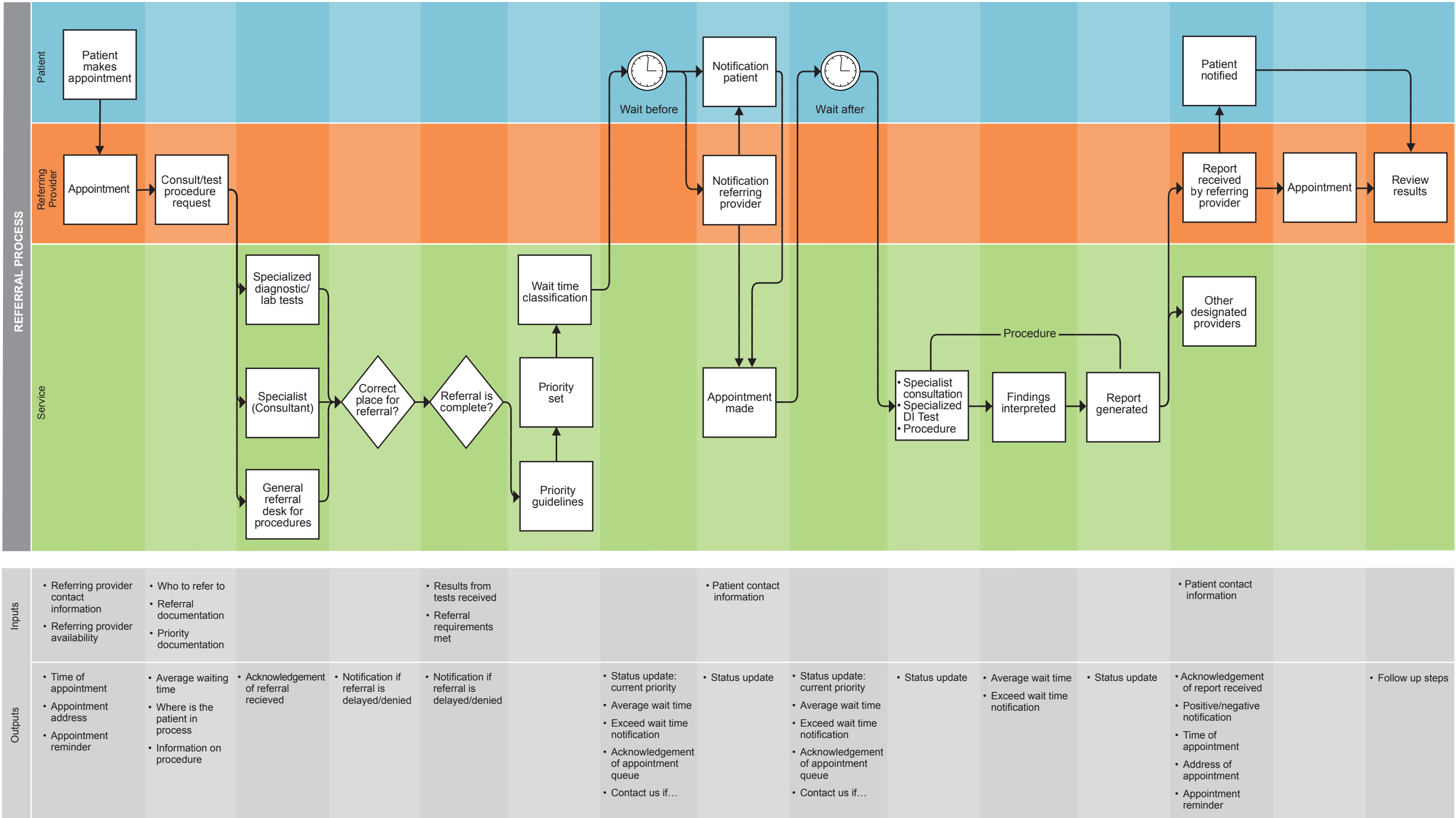
If patients are to be full partners in their own care, an Internet-based patient portal would be required that provides patients with access to their own health information and the ability to verify for themselves that the process steps listed below (and outlined in Figure 2) have been completed:

1. A healthcare provider has sent the request to an appropriate, clearly identified, provider or facility.
2. The health service provider or facility has received and accepted the request.
3. The status of the request is clear – either in progress (appointment being arranged) or completed (appointment has been made).
4. The requesting healthcare provider and patient have been notified of the appointment time (and it has been accepted by the patient).
5. The appointment, test, or procedure has been completed.
6. A report from the appointment, test, or procedure has been generated.
7. The requesting healthcare provider is aware of the report and has acknowledged receiving it.
8. The patient has completed a followup appointment to see the healthcare provider who requested the service and the process is completed.

Internet-based patient portals have become a standard feature of the more advanced healthcare systems in the United States and Europe. To date there has not been a wide-scale deployment across an entire healthcare region or province in Canada. Alberta has some of the technical infrastructure to allow for the functionalities of a patient portal to be introduced, and indeed the health information technology leaders in the province have taken some important steps in this direction. For patient portals to be truly useful in allowing patients to participate in their own continuity of care, however, they must be capable of letting patients track the status of their appointments for specialists, procedures, and advanced diagnostic imaging results. Some patient portal systems in the United States allow patients to book some types of healthcare appointments (e.g., with their primary care provider). However, appointments for specialized healthcare services in these systems still have to be booked by a referring healthcare provider on the patient's behalf, and patients are not able to view the status of the referral process. When an appointment has been booked for a specialized healthcare service it is possible for the patient

to view, through the portal, the details of that appointment. In the Alberta context it is critical that patients also be able to check on the status of the referral and appointment booking process because most specialized healthcare services need to manage waiting lists, which introduces opportunities for the patient to be 'lost'. Providing Albertans with a view of the many steps involved in the referral management process (Figure 2) will require a high level of functionality and integration across Alberta's healthcare system.

FIGURE 2: Basic process steps for obtaining specialized healthcare services for patients*



*Details one potential path to highlight inputs and outputs

This degree of functionality for patients will only be possible when electronic appointment scheduling becomes a standard of care, and all physicians, advanced diagnostic imaging facilities, and procedural facilities (e.g., operating theatres, endoscopy suites) in the province use this to manage the multiple transactions required for patients who are referred for specialized healthcare services.

Recommendation 1

Alberta Health and Alberta Health Services should strongly consider making additional investments in the provincial electronic health record and e-referral system to standardize workflow processes for all specialized healthcare services so that the following functionality is available for all patients and practitioners in Alberta:

1. Electronic referrals confirmed as 'received' by the service provider.
2. Management of appointment scheduling including booking confirmation and patient notification.
3. Report generation and transmission back to the referring provider.
4. Confirmation that the patient has completed a followup appointment with the referring provider.
5. Notification to the referring provider about referrals that are incomplete, delayed, or denied when submitted to the service provider.
6. Notification to the referring provider about known or projected waiting times for tests, consultations, or procedures that are outside specified limits.
7. Notification to the referring provider and the patient about important processes (referral, appointment scheduling, patient notification, appointment completion, patient followup) that were not completed successfully according to the scheduled completion time.
8. A patient portal for viewing:
 - i. When the key steps in the referral, appointment time, and report generation process for specialist consultation, special diagnostic imaging studies, and procedures have been successfully completed and notifications when they have not.
 - ii. Appropriate contact information for patients when they detect a problem with the special health service, referral, appointment booking, or followup procedures.
 - iii. Lab results, DI reports, pathology reports, procedure findings, hospital discharge summaries, other diagnostic information (e.g., EKG, echocardiograms, pulmonary function tests).

When a reliable electronic referral system is developed and functioning, the net benefit to Albertans will not be realized until all healthcare providers are using the system to manage the referral and followup processes for patients who require specialized healthcare services. Given that, Alberta Health will need to work with Alberta's healthcare providers to ensure that when the system is operational and reliable, it becomes the only accepted approach for managing patients who require these services.

Recommendation 2

The College of Physicians & Surgeons of Alberta and other relevant healthcare colleges amend their Standards of Practice, and Alberta Health Services amend its policies and procedures, related to co-ordination and provision of services. In so doing, healthcare professionals and clinics that provide

specialist consultation, advanced diagnostic imaging studies, or semi-invasive and invasive procedures would confirm completion of those studies, services, or procedures and be required to track critical process steps (transactions) between a referring provider and a service provider such that both know and have documented in a patient record that the following steps have been completed:

1. A request for service has been sent and received.
2. A specific appointment date and time for the service has been made.
3. The requesting provider and the patient have been notified of the appointment details (and the patient has accepted the appointment).
4. The report of findings has been successfully sent to (and received by) the requesting provider.

Step 4 will only be possible when there is a complete provider registry that is continuously maintained and updated; this is particularly essential when service providers have a critically important result that needs to be communicated urgently to the healthcare provider who requested the test and is therefore responsible for managing the result for the patient.

Radiologists expediting additional diagnostic imaging studies and the next level of care for patients with time-sensitive health conditions

Issue

When a patient is discovered to have a time-sensitive health condition that is first established through a diagnostic imaging study, valuable time can be lost when patients are required to return to the primary care physician who requested the study, arrange followup appointments and order additional recommended specialized healthcare services (i.e., advanced diagnostic imaging studies, specialist consultation, or procedures).

Analysis

When a patient needs to undergo a diagnostic imaging test the usual approach is for a healthcare provider (usually a physician) to request the test and then receive the interpretive report after it is completed. If the patient requires additional imaging studies then he or she would usually wait for a followup appointment with the physician before the studies are ordered. This process takes additional time – how much time depends on several factors.

Typically radiologists do not intervene in the relationship between the patient and healthcare provider who ordered the test. Radiologists have been sensitive to a real or perceived conflict of interest if they are involved in ordering or directly arranging for additional diagnostic studies. This is because in community settings radiologists are in private practice. If they were to directly arrange for additional testing they would receive additional fees, thus creating a potential conflict of interest. Therefore, it is rare for radiologists to order or directly arrange for additional testing for a patient. An exception to this rule is patients who undergo mammography or breast ultrasound who are found to have a breast lump – radiologists will often arrange for image-guided biopsies to be completed.

If a radiologist were to arrange for a special diagnostic imaging test in a facility owned and operated by Alberta Health Services there would be no direct financial benefit to the radiologist. Nevertheless, radiologists typically do not make these arrangements for patients, even in cases where they are the first to discover that a patient has a time-sensitive health condition and requires additional urgent

investigations. This is unfortunate, because radiologists are more likely than primary care physicians to understand how to obtain an expedited diagnostic imaging study for a patient when it is clinically indicated.

An even more unusual practice for radiologists is to directly refer a patient to a specialty service when it is obvious what the patient's condition is and what type of specialist is needed to provide the next level of care. When a patient has a time-sensitive health condition, expediting care means eliminating process steps that do not add value to the patient's healthcare journey. When a radiologist can clearly establish that the patient has a time-sensitive health condition and needs additional testing or a specific type of specialist there is an opportunity to eliminate unnecessary processes, such as having the patient return to a primary care provider to request the additional testing or specialist appointment.

Recommendation 3

The Alberta Society of Radiologists (ASR) in collaboration with Alberta Health Services (AHS) and the College of Physicians & Surgeons of Alberta (CPSA) develop policy and procedures that would support radiologists to expedite the care of a patient whom they find has a time-sensitive health condition by:

1. Directly ordering the next logical DI test if one is required.
2. Directly referring a patient who has a time-sensitive health condition to a clinical service when it is obvious the patient requires that expertise to move to the next level of care.

This should be accompanied by a discussion with the patient and notification to the primary care physician (or the healthcare provider who requested the initial diagnostic test) about what actions the radiologist has taken on behalf of the patient.

The ASR, AHS, and the CPSA should consider developing parameters (criteria) that would assist clinicians to properly identify conditions and circumstances that could be considered 'time sensitive'.

Prioritization criteria for outpatient CT scans

Issue

Current prioritization criteria for outpatient CT scans do not take into account patients with time-sensitive health conditions who have not yet been diagnosed with a malignancy, when the CT scan may be necessary to move on to a procedure that would confirm the diagnosis.

Analysis

Requests for outpatient CT scans are reviewed by a radiologist and assigned a priority. The current guidelines for prioritizing these CT scans relies on whether a diagnosis (malignancy) has been established (priority 1) or is just suspected (priority 2). Maximum waiting times, according to AHS guidelines, is seven days for priority 1 scans compared with 30 days for priority 2 scans. Some patients may be deemed to have a time-sensitive health condition based on existing diagnostic imaging studies or other clinical features but do not yet have a confirmed diagnosis. Current prioritization criteria hamper the timely completion of a CT scan for such patients. CT scans are often critical for physicians to review prior to planning diagnostic biopsies and/or therapeutic resections because of the detailed information they provide on the probable type and extent of disease. Delays in obtaining a CT scan often directly translate into delays in diagnoses, or starting definitive treatment.

Recommendation 4

Alberta Health Services revise the current criteria for prioritizing outpatient CT scans to take into account patients with time-sensitive health conditions who do not yet have a confirmed diagnosis of malignancy. Consideration should also be given to reviewing criteria for MRI scans and PET scans to ensure that criteria for these outpatient studies are aligned and consistent with those for CT scans.

As with Recommendation 3, operational parameters that assist clinicians in identifying 'time-sensitive health conditions' will need to be developed.

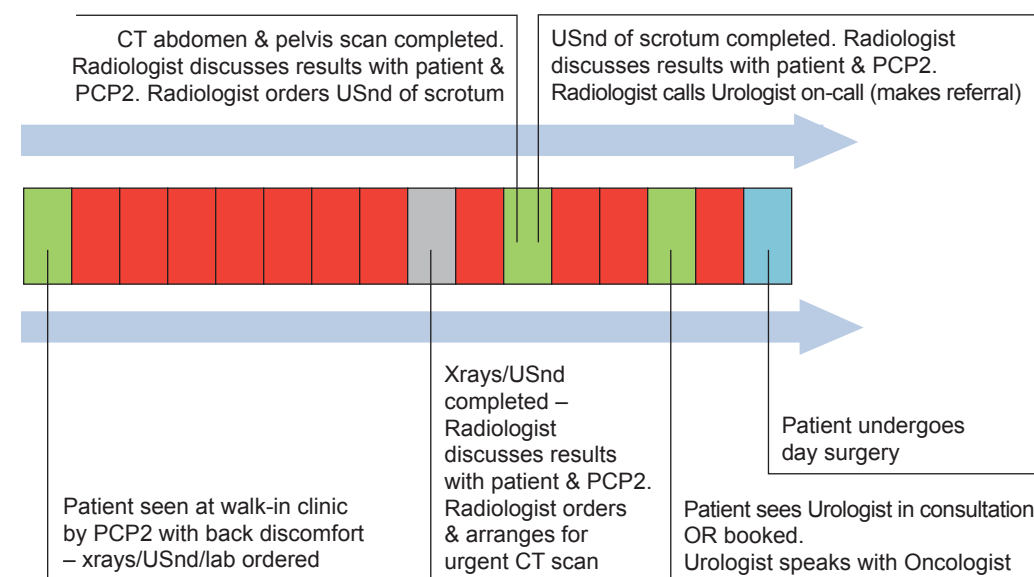
Figure 3A highlights the potential journey the patient described in this study might have experienced if the changes to the system as outlined in these recommendations had been in place.

Figure 3B is the journey that the patient actually experienced.

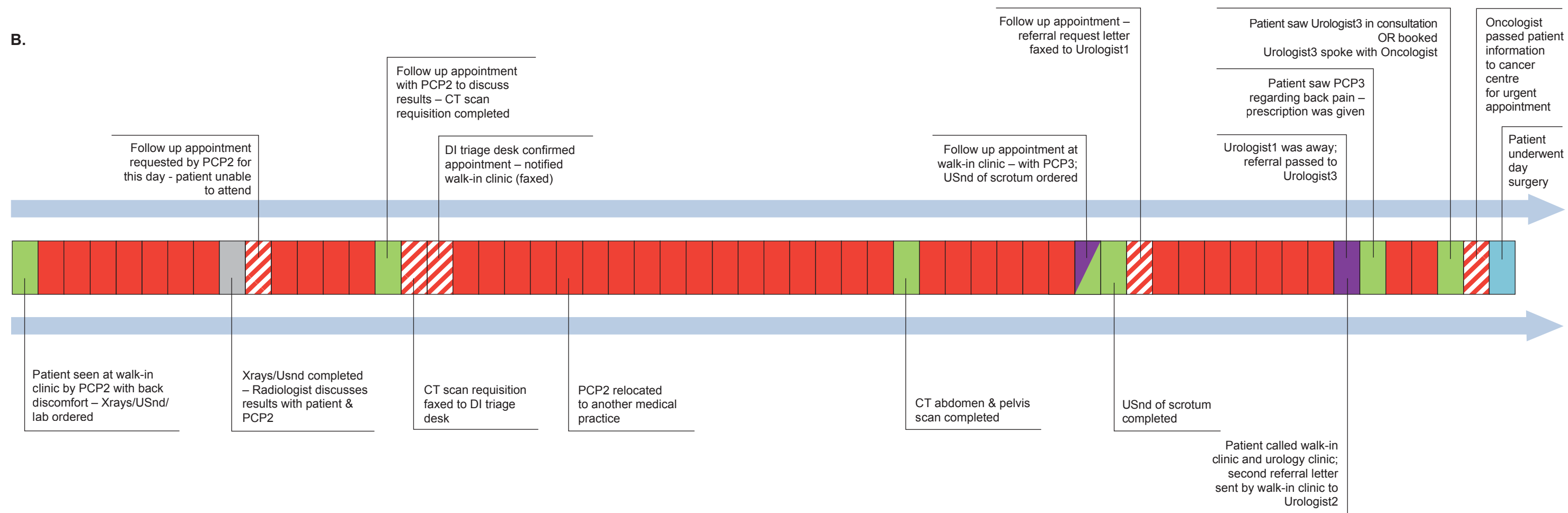
If the processes used for patients with time-sensitive health conditions are changed in accordance with Recommendation 3 and Recommendation 4, it could shorten considerably the time taken to transition the care of these patients to the services they require for definitive treatment.

FIGURE 3: (A) **Potential** timeline of events if the recommendations from this report had been in place. (B) **Actual** timeline of events from first presentation with back symptoms to surgical procedure

A.



B.



*See Legend on Figure 1

Formal transfer-of-care responsibilities for time-sensitive health conditions and availability of responsible healthcare providers

Issue

Patients with a time-sensitive health condition may not be able to obtain timely medical attention from responsible healthcare providers for that condition because there is no clear understanding about whom to contact when the responsible healthcare provider cannot be reached.

Analysis

Patients with time-sensitive health conditions, perhaps more than any other group, need to have their continuity of care protected. This means the patient and all healthcare providers share a clear understanding of which provider is responsible for managing this condition for the patient. The responsible provider needs to offer a reliable mechanism by which patients can easily contact the provider or someone of comparable expertise, who may be providing coverage, if the patient believes his or her condition has deteriorated. This is particularly important when a patient has undergone a procedure that may result in complications that need to be managed right away. It is common for patients to move between one type of healthcare provider to another depending on the nature of the patients' diagnosis and the type of treatment(s) they require; however, it is often not clear to the patients which healthcare provider they should contact if they experience an unexpected deterioration or complication.

There are currently no regulations that stipulate a process by which a provider is designated as the physician responsible for managing a patient's condition even if it is considered to be time-sensitive. Further, there are no guidelines or rules that specify how the care of a patient, or treatment of a condition that is time-sensitive, is transitioned from primary care physician to specialist or between specialists.

The College of Physicians & Surgeons of Alberta's (CPSA) Standards of Practice stipulate the requirements of physicians who offer care to patients on an ongoing basis. Yet, the Standards are not clear whether specialists, who may only have an intermittent, time-limited involvement with a patient, are considered to be providing care on an 'ongoing basis'. Further, the Standards do not specifically address situations in which a specialist physician may be deemed to be 'responsible' for a particular patient condition because of the special expertise required or because of having performed a recent procedure. It is particularly important for patients with a time-sensitive health condition to know whom they should call and how to reach that provider(s) during and after normal business hours if their condition worsens.

The CPSA's Standards of Practice do address the expectation that physicians provide after-hours access to care to patients for whom they provide 'care on an ongoing basis' (Standard 32). However, it is open to interpretation whether a specialist who has only seen a patient once or twice and may not plan to see the patient again would be considered to be providing 'ongoing care'. It is common practice in Alberta for a physician's office answering system to refer patients to an emergency department when the office is not open, despite the fact that the CPSA's 'After Hours Access to Care' Standard 6 states the following:

1. A physician who provides care on an ongoing basis must ensure that care is continuously available to the patients in his or her medical practice.

2. When a physician is unavailable, the physician must make specific arrangements with another physician or physicians or with an appropriate coverage service with which the physician has an agreement.
3. If requested by the CPSA, a physician must demonstrate the existence of an agreement described in subsection (2).
4. A physician must make information available to the physician's patients about the arrangements in place for after-hours coverage of the physician's medical practice.
5. It is not acceptable for a physician's answering service to direct patients to attend an emergency room or other episodic care facility unless the physician has a formal agreement with the specific facility or with a physician working in that facility.
6. Notwithstanding subsection (5), a patient with an emergent or life-threatening condition must be immediately referred to an emergency department if a physician is unable to render care.

There is no stipulation in the CPSA's Standards for what constitutes a 'normal business day' or how many hours per weekday a physician's office should provide access to patients to reach that physician 'same day'. Patients' continuity of care, especially if that care is for a time-sensitive condition, can be compromised if they cannot reach the physician who has been providing care to them when they need help.

Alberta Health Services' Medical Staff Rules state that each practitioner with AHS privileges "shall ensure safe and effective on-call coverage for patients for whom they are the Most Responsible Practitioner".^{xviii} Practically speaking the concept of Most Responsible Practitioner is only assigned within acute care and possibly long-term care facilities; it is not typically applied to patients outside of these facilities who are in a community setting. Alberta Health Services' Medical Staff Bylaws contain a provision that "Practitioners shall provide safe and effective on-call and service coverage."^{xix} Neither the Medical Staff Rules or Bylaws addresses the issue of a practitioner's obligation to be available to patients in situations where the practitioner would be considered the most responsible; nor do they mention any added accountability required by practitioners for patients with time-sensitive health conditions or those patients on whom a practitioner has recently performed a procedure (invasive or semi-invasive).

Most physicians share after hours, on-call responsibilities with their colleagues. On-call duties can be onerous, hence the tendency to recommend that patients visit an emergency department if they feel they need urgent medical attention. An alternative is for patients to call Health Link Alberta, which provides around-the-clock health advice and information through a toll-free phone number to all Albertans. Support is provided by experienced registered nurses and other healthcare professionals. Although it is currently not common practice for specialist physicians to partner with Health Link, it is a possible solution. Health Link could take calls from patients who have a relationship with a specialist

^{xviii} Alberta Health Services Medical Staff Rules. Approved and Effective 28 February 2011.

^{xix} The Alberta Health Services Medical Staff Bylaws. Approved and Effective 28 February 2011.

and who feel they need to reach that specialist or the person on call. Several issues would need to be addressed before this could become a viable solution to the lack of after-hours availability of some Alberta physicians. For example, physicians would have to develop criteria (algorithms) for Health Link nurses to use so that consistent advice could be provided to patients. Health Link would require contact information for the physician on call for the group in situations where the nurse believed that patients did need to speak to a physician within a short period of time.

Although the CPSA's Standards address most of what patients require from physicians, there is no 'charter of rights' for patients in Alberta. Such a charter could include what patients deserve with respect to access to healthcare providers, especially in situations where they have a time-sensitive health condition and need to reach the responsible provider(s) urgently. The concept of a patient charter was considered more than a decade ago in the Alberta legislature through a private members bill but was never adopted. There is a provision in the new *Alberta Health Act* (which will be proclaimed and come into force on January 1, 2014) for a 'Health Charter'. Consultations on what will be included in the Alberta Health Charter will begin in January 2014. The Health Charter is expected to set out expectations and responsibilities within the health system.

Recommendation 5

The College of Physicians & Surgeons of Alberta (CPSA) amend its Standards of Practice, and Alberta Health Services (AHS) revise its Medical Staff Rules and Bylaws, as required to ensure that the following issues are addressed:

1. A physician who provides care to a patient with a time-sensitive health condition must make it clear to the patient and all other healthcare providers involved in that patient's care who the responsible physician is for helping the patient manage his or her condition; and, that this information is documented in the patient's chart(s) and all consult/referral notes.
2. The responsible physician(s) for a patient with a time-sensitive health condition, or a patient who has recently undergone a procedure defined to be invasive or semi-invasive, be available (or designate another physician with similar expertise to be available) to deal with complications the patient may experience from the condition or following the procedure. Patients should only be referred to an emergency department in situations where the patient's condition has suddenly changed and is likely to be potentially life, organ, or limb threatening (see also Recommendation 7).
3. Availability should be specifically defined for (a) weekday, and (b) after hours, including evening, weekend, or holiday. Weekday (or normal business day) availability should include at least an office phone that is answered (or answering machine responded to the same day) for a minimum of seven hours. Evening, weekend, or holiday availability for patients with time-sensitive health conditions means the physician can be contacted directly by phone or paging system or indirectly through Health Link Alberta.
4. The transfer of responsibility from one physician to another for managing a patient's time-sensitive health condition should be a formal process that is acknowledged and documented by both physicians and ensures notification to the patient.

A working definition of 'responsible physician' must be developed; the physician who has the expertise or who has most recently managed the patient for a time-sensitive condition, especially if it involves

performing an invasive or semi-invasive procedure, should under most circumstances be considered as the ‘most responsible’. An operational definition for ‘invasive and semi-invasive procedure’ that can be used with the CPSA’s Standards of Practice and the AHS Medical Staff Bylaws may also need to be developed.

Recommendation 6

The Alberta Medical Association in collaboration with Alberta Health Services and the College of Physicians & Surgeons of Alberta, and with public consultation, develop a document that outlines specific physician commitments to patients who have time-sensitive health conditions (or who have recently undergone an invasive or semi-invasive procedure), to be available and responsive to concerns patients may have about their condition or possible complications from a procedure. Such a document, which would be congruent with the Canadian Medical Association (CMA) Code of Ethics, could be planned such that it becomes a key part of the new Alberta Health Charter or a stand-alone declaration.

Recommendation 7

The Alberta Medical Association and Alberta Health Services investigate how to partner with Health Link Alberta so that patients who believe they need to contact a specialist (or designate) responsible for their care after hours have a mechanism by which to do that.

Recommendation 8

The College of Physicians & Surgeons of Alberta (CPSA) should develop a proactive process to monitor physicians’ compliance with the CPSA’s After Hours Access to Care Standard.

Co-located practice groups: co-ordinating services and clarifying relationships

Issue

When healthcare providers co-locate, particularly when they practise a specialized type of healthcare, members of the public and broader healthcare community might assume that services are fully co-ordinated between members of this ‘practice group’. The name ‘Southern Alberta Institute of Urology’ implies an overarching organizational structure that supports and co-ordinates the activities of the 17 private-practice urologists and the two centres (Prostate Cancer Centre and the Alberta Bladder Centre (Vesia)) that are located within the Institute. In fact, the Institute has limited infrastructure and provides no co-ordinating function – the urologists and the centres function independently.

Analysis

When adult patients require the services of a urologist in Calgary they must be referred by a physician to a specific urologist. Despite the fact that all urologists treating adults have offices within the Southern Alberta Institute of Urology (SAIU) there is no mechanism for referring physicians to send a referral request to the SAIU and have the Institute arrange for the first available or the most appropriate urologist to see a patient (i.e., there is no centralized referral system). All of the urologists have independent practices, notwithstanding that small groups of them may share an electronic medical record. Patients requiring services from the Prostate Cancer Centre or the Alberta Bladder Centre must first be referred to a urologist. If a patient is referred to a urologist who is away there are no standard

processes in place to alert referring physicians to this situation, nor is it guaranteed that the referral will be forwarded to another urologist. When patients or referring physicians try to contact a specific urologist there is no reception function provided by the SAIU – the only option is to contact a specific urologist’s office directly. If the urologist’s office assistant is unavailable for any reason there is no other way to reach the urologist or to know if there is a colleague who might be covering for him. The exception to this general rule is the Alberta Bladder Centre (Vesia), which provides on its website a single fax number for referring physicians to use for sending referral requests, or an electronic referral option using the Centre’s electronic medical record. In addition, on this website a phone number is provided for referring physicians to contact a urologist if there is an urgent referral.

Although the SAIU provides for co-location of the urologists, the Prostate Cancer Centre, and the Alberta Bladder Centre, which affords a certain degree of efficiency and enhanced services, it also creates the impression that services offered within the Institute are integrated, which is not the case. This can cause confusion for patients and referring physicians who are not familiar with how the Institute functions. In addition, because the SAIU is located on AHS property at the Rockyview General Hospital and is referred to on the AHS website as the ‘Rockyview Urology Clinic’ a false impression can be created that the SAIU is owned and operated by AHS.

The organization and function of the SAIU was reviewed during this study; however, similarly structured healthcare organizations in Alberta can also learn and make improvements to their structures and processes to enhance continuity of patients’ care.

Recommendation 9

All (adult-treating) private-practice urologists in Calgary, the Prostate Cancer Centre, and Alberta Health Services enter into discussions to review the business and organizational model for the Southern Alberta Institute of Urology so as to provide infrastructure support that will ensure better co-ordination of services including central referral and triage, call answering, and the ability for patients and referring physicians to easily contact a urologist when there is an urgent patient concern.

Recommendation 10

The Southern Alberta Institute of Urology and Alberta Health Services review their websites and written communication with a view to clearly communicating to patients, the public, and referring physicians the relationship between the SAIU, the Prostate Cancer Clinic, the Alberta Bladder Centre (Vesia), private-practice urologists, and Alberta Health Services.

SUPPLEMENTARY FINDING

Issue

When a patient dies unexpectedly the Office of the Chief Medical Examiner (ME Office) may become involved. This can lead to at least two additional consequences for family members: (1) it may create expectations that detailed answers regarding the circumstances of a person's death will be provided, which is in fact unlikely; and (2) the final report may take more than six months to be completed, which has important implications for families having to make final arrangements for the deceased's estate.

Analysis

In the case described within this report the patient's death was referred to the ME Office because it was sudden and unexpected. The decision was made by the ME Office to perform an autopsy and additional testing. A 'death investigator'^{xx} from the ME Office contacted the patient's family and spoke to them on the phone. Based on this conversation, the family's understanding was that a full investigation into the circumstances surrounding the death would be conducted. Within a few days, the family was contacted by the ME Office with a preliminary verbal report about the apparent cause of death – massive pulmonary embolism (a large blood clot in the lungs).

Seven months later the family received the final report from the ME Office. The report confirmed the preliminary report that the 'mechanism' of his death was pulmonary embolism. The report contained no information about the challenges experienced with the patient's continuity of care nor any evaluation of the time that had elapsed from when it was first known that he likely had cancer until he was eligible to receive potentially life-saving treatment, despite the family's expectations that these matters had been investigated.

Death investigators, who are usually nurses, meet or speak with surviving family members when the ME Office becomes involved with the case of someone who has died suddenly and unexpectedly. The death investigator speaks with the family and provides them with information, including documents that explain the purpose of the ME Office involvement. When the ME Office decides to investigate a death, a medical examiner (who is a physician) completes an autopsy and reviews additional health information about the patient to gain an adequate understanding about the patient's medical history. This information can come from many sources but initially the most important source is medical files the patient may have in one or more hospitals or one or more physician offices or clinics. The most comprehensive source of diagnostic imaging results, laboratory results, and drug information on patients is contained in the province's electronic health record – Netcare. This would be a very efficient mechanism for the ME Office to collect essential information on patients whose deaths they are investigating. Yet, neither the medical examiners nor the death investigators who collect much of the medical information on cases are allowed access to Netcare. This is apparently because they come under

^{xx} This is the official job title.

a different Ministry (Justice and Solicitor General) that is not affiliated with Alberta Health. The ME Office can spend considerable time and effort tracking down the information from physician's office records and hospital charts that is already available in Netcare, adding to the delay of issuing a preliminary and subsequently a final investigative report.

The medical examiner's goal in conducting an investigation is to determine the cause of death and the mechanism of death. In addition to an autopsy, in most cases other tests are needed. These include microscopic (histological) examination and microbiological testing of relevant body tissues, and in some cases, toxicological testing – all of which may take several weeks to complete. In some cases, the results from initial testing may show a need for additional testing that would delay completion of the final report. In most cases, however, much of the testing can be performed concurrently and results can be available within weeks. For the case studied in this report, despite the fact that the autopsy, which was completed within a few days, provided the cause and mechanism of death, and additional testing consisted of histological testing, it took seven months for the final report to be issued from the ME Office.

Institutions such as banks and insurance companies usually require an official proof of death before claims and other dispositions may be settled. In cases where the ME Office has investigated a death, neither the family doctor nor the hospital may complete any documents. All documentation as to the cause and manner of death must be provided by the ME Office.

In British Columbia the target for time of completion of coroners' investigations is four and a half months.^{xxi} The College of American Pathologists' accreditation requirements stipulate that a final autopsy report must be submitted within 30 working days for routine cases and within three months for complicated cases.²⁵

While the purpose of a death investigation is clear to the ME Office, it may not be as clear to surviving next-of-kin who may have questions about the patient's death that involve more than cause and mechanism. In the particular case studied in this report the family was most concerned with gaining an understanding and an explanation for the delays in care the patient experienced and the many breaks in the continuity of his care. They understood, from their conversations with the death investigator that these bigger, and just as important, questions would be answered in the final report from the ME Office. After waiting many months for the final report they were disappointed to discover that none of these issues were investigated and were far beyond the mandate of the ME Office.

Recommendation 11

Alberta Health amend the definition of "health service" in the *Health Information Act* so that medical examiners are able to become "authorized custodians" and obtain access to the provincial electronic health record, Netcare.

^{xxi} <http://www.pssg.gov.bc.ca/coroners/publications/docs/annualreport2010.pdf>.

Recommendation 12

The Chief Medical Examiner arrange for a comprehensive process improvement review to find efficiencies in the ME Office investigations so that surviving family members receive the final report in a more timely fashion. By establishing performance standards that can be audited on an ongoing basis, the Chief Medical Examiner will be taking steps to reassure the public that investigations are being conducted efficiently.

Recommendation 13

The Office of the Chief Medical Examiner review the written information and its verbal communication provided to surviving family members about expected outcomes of an ME Office's investigation so as to minimize the risk of misunderstandings. The Office of the Chief Medical Examiner should consider consulting with community members while it develops its communication strategy to obtain feedback as to the effectiveness of this strategy. And, it should consult with grief experts to better understand how best to communicate with grieving family members who may, understandably, be less capable than usual to process much information during the initial meetings with death investigators.

APPENDICES

Appendix I: Terms of reference



Review of Continuity of Patient Care in Alberta

Terms of Reference

Purpose

Pursuant to section 16 (1) of the *Health Quality Council of Alberta Act*, the HQCA will conduct an independent quality assurance review under Section 9 of the *Alberta Evidence Act* of the Continuity of Patient Care in Alberta in conjunction with Alberta Health Services.

Objectives

The HQCA will conduct a quality assurance review of the implications for quality and patient safety with respect to the continuity of patient care across the healthcare continuum. A specific patient's journey will be used to review the healthcare system including but not limited to:

- Referral processes both in the community and to AHS facilities and healthcare providers
- Patient engagement with the healthcare system
- Availability and exchange of patient information between healthcare providers/organizations/institutions and with the patient

To enhance the quality and safety of healthcare in Alberta the HQCA may make system-level recommendations for improvement, based on the findings and analysis of this review.

This review will be limited to the investigation of a single patient's journey through the healthcare system in Alberta as a representative case; other patient encounters / journeys will not be investigated.

Stakeholders

Stakeholders that may be engaged in the review process include but are not limited to:

- Alberta Health Services
- Primary care
- Community health
- Alberta Health
- College of Physicians & Surgeons of Alberta
- Private diagnostic imaging facilities
- The Office of the Chief Medical Examiner

Review Sponsor

John W. F. Cowell M.Sc., MD, CCFP, FRCP, CEO of the HQCA



Deliverables and Timelines

- A full report of the issues, analysis and recommendations will be available in 2013.

Approved by the Board of the Health Quality Council of Alberta:



Dr. Anthony Fields
Chair



Date

Appendix II: Literature review

A literature search was conducted using multiple databases integrated in Web of Knowledge (e.g., PubMed, Medline, etc.) to identify relevant articles from peer-reviewed journals. A first search for ‘patient portal’ (and related terms) was supplemented by two further searches filtering for ‘patient experiences with portals’, as well as ‘portal functions or applications’. These original searches were further expanded in the course of the work through cross-references and additional citations in the grey literature resulting in a total of 29 reviewed papers.

Continuity of care

The concept of *Continuity of Care* emphasizes the healthcare user’s, caregiver’s and healthcare provider’s perspective on *integrated care* experienced as connected and coherent, as well as consistent with the healthcare user’s medical needs and personal context.¹ Publicly funded health services should be responsive to user needs, preferences, and expectations. The literature suggests approaches to increase responsiveness to patients’ preferences including online communication, same-day appointments, team-based care;^{26,27} interactive techniques to facilitate shared decision-making;²⁸ promoting patient access to electronic medical records to enhance provider-patient communication with minimal risks for patient worry, confusion, or anxiety;²⁹ and conducting patient surveys and acting on patient feedback.^{30,31}

Reviews of international literature have identified three major types of continuity across different healthcare settings:^{1,13,14,15}

Firstly, *relationship continuity* in primary care is mainly viewed as the relationship between a single practitioner and a healthcare user (expressed as *physician attachment*) and it fosters improved communication, trust and sense of responsibility. In the ideal world, patient-centered primary care covers computer-based guidance and communication systems to improve patient-provider relationships.¹⁷ Patient portals have the potential to improve primary care patient-provider communication¹⁶ by integrating personal health records owned by the patient, medical records owned by primary care centres and electronic health records owned by the health system. Within primary care, all Albertans should have a medical home which would improve continuity of care. For example the Danish style medical home provides same-day appointments, electronic prescribing systems connected to local pharmacies, as well as ‘off-hours’ healthcare services based on patient’s health registry information (referred to as electronic health records).¹⁷

Secondly, *informational continuity* concerns the timely availability of relevant information through shared medical records, but also knowledge about the patient’s preferences, values and context usually accumulated in the memory of healthcare providers. Core functions of existing patient portals include secure messaging, access to medical and health records to receive personalized health information tailored to health condition and to preventive health topics,^{18,19} as well as administrative tasks such as scheduling appointments and bill management. Osborn and colleagues¹⁸ designed a robust set of procedures and policies to promote efficient delivery of safe and secure functions of patient portals. A comprehensive patient portal integrated into primary care can increase patient-centeredness, improve patient activation, enhance delivery of age- and risk-factor appropriate preventive services, and promote utilization.²⁴ However, there have been mixed findings for the quality of health information technology in primary care, compared to acute care, suggesting that both patients and providers should be involved in the development, implementation and evaluation of patient portals and its functions.³²

Thirdly, *management continuity* involves the communication of facts and judgments across team, institutional and professional boundaries, and between professionals and patients. Patient portals are owned, administered, documented and managed by a healthcare institution and institutions may offer access to selected clinical data (basic function) as part of the patient's electronic health record which can then be integrated into any type of patient-owned record.²¹ Stolyar and colleagues²² explored the feasibility to integrate personal health records with clinical information systems from multiple vendors. All available patient documents could be viewed and shared across clinical information systems. In contrast, Jensen and colleagues²³ examined the implementation of quality indicators into electronic health record systems of 6 healthcare organizations. Most systems did not have the ability to capture data for more complex measures, particularly, work flow actions. The authors suggested that audit trails should allow tracking provider actions within patient records (e.g., monitor what was reviewed, added or modified) which in turn would improve co-ordination of care. There is an increasing need for patient accessible electronic health records; a workshop in Toronto with 45 nationally and internationally renowned experts explored issues related to providing access (e.g., maintaining privacy and confidentiality). The workshop participants identified the need for managing institutional change including a national infrastructure, as well as patient / professional education and navigation.³³

Patient portal users

Patient portals can be adapted to the patient's wishes and knowledge levels. Ammenswerth and colleagues²¹ reviewed 4 different patient portals (in vitro-fertilization treatment, diabetes mellitus patients, congestive heart failure patients and a general patient portal by Kaiser Permanente) showing that patients with chronic diseases and patients with intensive and long-time treatment were more willing to use patient portals. Similarly, Archer and colleagues³⁴ reviewed 130 studies and they found a higher adoption rate for disabled, chronically ill and caregivers for the elderly. In contrast, the minority of primary care patients were interested in using portals, for example, only 6% of members in the Kaiser Permanente NW region had registered which is comparable to an 11% utilization rate found by Weingart and colleagues.³⁵ However, primary care patients who had enrolled to a portal had different demographic characteristics, as well as different interest levels in selected portal functions.¹⁶ This was also evident in a randomized controlled trial showing that about 50% of the total sample (portal users and control group) were willing to pay for online correspondence with their physician.¹⁹ Moreover, a web-based patient portal focused on wellness, prevention and longitudinal health showed an adoption rate of 73% and almost all found the portal to be easy to use, a valuable resource, and helpful for participating in their own care.²⁴ In order to improve the quality of provided information exchange in primary care, patient outcomes should be targeted directly and systems should be adapted to patient needs.³² It is important to select and maintain portal functions of greater interest to certain patient user groups.¹⁶

Patient portal functions and their utilization

As mentioned above, core functions of existing patient portals include secure messaging, access to medical and health records to receive personalized health information tailored to health condition and to preventive health topics,^{18,19} as well as administrative tasks such as scheduling appointments and bill management.

The literature search revealed one publication specifically looking at referral management in 32 patients and how secure messaging can be structured into the workflow.³⁶ The results showed that almost all

were satisfied with the overall online referral process, physicians found the information detailed enough to triage requested referrals. Moreover, patients, providers and care co-ordinators reported enhanced communication and found the secure messaging component convenient to use. Lin and colleagues¹⁹ found that online messages contained more informational and psychosocial content compared to telephone calls. In addition, secure messaging has been frequently used for medication refills for patients with multiple sclerosis³⁷ and for diabetes patients.³⁸ Five years after implementing MyHealthAtVanderbilt, about 50% of portal users sent secure messages and this function is governed by a smart message triage system.¹⁸ That is, in order to maximize provider productivity, messages within this portal are sent to be answered by a multidisciplinary team (nurse, administrative assistant, allied health professional, etc.). However, clinical relevant messages are forwarded to the healthcare provider. Messages bounce back if they were not opened within a specific time period avoiding delay because of provider's absence.

Patients primarily review laboratory results when they have access to their clinical information system.^{38,39} There are clinical concerns that patients might misunderstand test results or might become anxious or distressed when accessing complex medical information. However, Wiljer and colleagues²⁰ showed that access to personal health information in breast cancer patients does not increase anxiety levels (not even in the chemo-therapy subgroup). Moreover, there are policies in place to limit type and timing of available test results. For example, Osborn and colleagues¹⁸ categorized test results into 3 groups: 1. results displayed as soon as available, 2. results displayed after 7 days to allow provider to review results and contact patient directly, and 3. highly sensitive results which are never displayed. Personalized health information promotes the adoption and active participation in health management.¹⁸ It is important to consider general and specific preferences of patients, for example, the majority (88%) of patients with advanced lung cancer wanted information on diagnosis, treatment, cure rate and life expectancy. In contrast, fewer patients wanted information about palliative care (64%) or information about end-of-life decisions.⁴⁰

About one third of portal users are using administrative functions such as scheduling or viewing upcoming appointments and managing medical bill.^{18,38} Turvey and colleagues⁴¹ found that 2 in 5 portal users print information and every third user self-entered medical information.

Overall, it has been shown that functions that typically prompt concerns about privacy and security are frequently used portal functions.¹⁸ Patient portal users perceive rather improved privacy and security of medical information, the understanding regarding health, and overall quality of care.⁴² However, there are barriers to patients adopting and using portals including the requirement of internet access and IT expertise.^{42,43} Moreover, several types of people do not tend to use patient portals, for example those without an educational degree.³⁸ Improvement in the portal itself can improve usability⁴⁴ and it is important to incorporate patient feedback to improve portal utilization and functionality.⁴⁵

Impact of patient portals on quality and patient safety

There is insufficient evidence to judge whether patient portals facilitate high quality care and assure patient safety.²¹ Inconsistent findings were also reported when reviewing studies examining positive effects of portals on patient satisfaction.⁴⁶ However, incorporating audit processes, formal evaluation of user experiences, as well as the measurement of quality and safety through the portal can improve user satisfaction, as well as quality and patient safety.¹⁸

Appendix III: Patient referral system

Patient Referral System:

Process, Technical and Implementation Study

Prepared for the
Health Quality Council of Alberta
by Arcurve Inc.

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INTRODUCTION

A technical and implementation review of some best of class Patient Portal Systems was undertaken to: 1) identify best practices used by these patient portals and 2) to determine if these portal systems had developed opportunities for patients to view the status of referrals that had been made on their behalf for specialized healthcare services. This part of the study was undertaken to understand what process and technical challenges existed, when implementing patient portal solutions. Once these best practices were identified, a set of suggestions for how specialized healthcare referral management could be improved was identified. This report is the output of this analysis including some suggestions for further developments of Patient Portal Systems in Alberta.

The study was completed jointly by the Health Quality Council of Alberta and Arcurve^{xxii}. Arcurve assisted in understanding some of the technical issues in developing patient portal systems. The process for conducting the study included:

1. A general review and assessment of the current patient medical referral process in Alberta.
2. Interviews with 3 U.S. health care providers on the functionality and implementation process and challenges of their patient portal solutions.
3. An Interview with the Alberta Health Services Personal Health Portal team to understand current Alberta patient portal initiatives.
4. Creation of a straw model process identifying required process steps, inputs and outputs to close gaps in the current specialty care referral process.

REVIEW OF U.S. PATIENT CARE PORTALS

To assess some of the best practices used when creating, implementing and managing Patient Care Portals, 3 major healthcare providers in the U.S. were interviewed. Each provider has invested significant resources in bringing a patient portal to market.

The goal of the interviews was to understand:

- Core functions and features provided by the portal
- Implementation strategies and challenges
- How specialty referral services currently worked in their environment
- Usage rates

^{xxii} Arcurve is an independent software development and services company, based out of Calgary. The business analysis was handled by Michael Wong, a Project Manager and Business Analyst working for Arcurve.

Kaiser Permanente

Kaiser Permanente is the largest managed care organization in the United States, with over 8 million health plan members. Kaiser Permanente operates in nine states and the District of Columbia.

Kaiser Permanente started their portal project in 1996. They started with a solution that was built in house, but later switched to Epic System's MyChart.

The initial functionality included:

- Ability to refill prescriptions
- Scheduling of appointments
- Nurse/Community Boards

After the switch to Epic Systems, the following functionality was added:

- Secure Messaging
- Proxy Access for dependents and family members
- Scheduling of Appointments
- Access to test results
- Prescription Refills

Key benefits identified:

- Secure Messaging – allowed patient to communicate with Doctors, without appointment requirement
- Test Results – immediate access to test results
- Appointment Scheduling – ability to manage appointments online
- Prescription Refills – money saved by automating process

Usage Rates:

- 65% of those who are eligible have accounts
- 4 million people registered (9 million members)
- 31 million visits to the portal site every quarter
- 25 million sign-on's per quarter
- 25% of users access services via mobile

Implementation Strategies/Challenges

- Large support infrastructure had to be put in place before portals were made available to clients.
- Efforts to standardize and reconcile data from existing systems were a significant effort.
- Implementations were handled on a region-by-region basis, when switching from the initial systems to Epic.
- The EMR and Patient Portal functionality are managed under one system, all under the control of Kaiser Permanente.

Referral Process:

- No systems exist to manage referral process internally from general to specialty services.
- Systems exist to handle referrals from outside of the organization.

Mayo Clinic

Mayo Clinic is a medical practice and research group based out of Rochester, Minnesota. It is the largest non-for-profit medical practice in the United States, seeing over 1 million patients a year coming from across the United States, and 150 countries around the world.

The Mayo Clinic started their portal project in 2005, with an initial focus on bill payment processing. In 2009, they shifted towards offering a suite of services for patients. The Mayo Clinic makes use of two different EMR systems; GE Medical Record for their Rochester services and Cerner, for their Jacksonville and Scottsdale services.

Core functionality includes:

- Ability to view full medical record (Displayed when transcribed)
- Preventive Service Reminders
- Lab Results – all results are displayed in real time and are not withheld
- Secure messaging with providers
- Proxy access for dependents and family members
- Pre-visit data collection
- Prescription Refills

Usage Rates:

- 100k active users
- 300k patients have accounts (out of a total of 600k unique patients)

Implementation Strategies/Challenges

- There were multiple EMR systems that needed to be integrated. These systems were all within the control of Mayo Clinic

Referral Process

- Internal specialty referral is handled using internal EMR
- Referral systems exist primarily to handle incoming patients from outside organizations

Geisinger Health System

Geisinger Health System is a physician led health care system based out of Danville, Pennsylvania. Geisinger provides more than 2.6 million people health care across the northeastern United States.

Geisinger implemented their patient portal starting in 2001. The Geisinger Patient Portal is based on Epic Systems MyChart software.

Core functionality includes:

- Viewing laboratory results
- Viewing diagnostic imaging results
- Messaging healthcare providers
- View portions of the medical record, including outline of current health issues, medications, allergies, immunizations, and health reminders

- Tracking chronic conditions and provide updates: Patients are able to enter their own healthcare data into their patient record (e.g. – glucose values, blood pressure, and weights), which can be viewed by their healthcare providers.
- Patients are able to schedule appointments with their primary care providers through the patient portal – to date the experience has been that most patients do not take advantage of this functionality but those who do have a lower no-show rate.
- Grant proxy access to the patient portal for family members, to assist with their care.

Key benefits identified:

- Access to Lab Tests – Patients are worried about test results and are happy to be able to access them immediately when available.
- Message a doctor – The ability to message a doctor and get an answer quickly, without having to wait for an appointment.

Usage Rates:

- 10k portal hits per day
- 60k unique patients per month
- 230k signed up (out of a total of 550k patients)

Implementation Strategies/Challenges:

- Any acquired health provider/hospital were converted over to the Epic EMS System.
- Implementations and conversions took on average 1-2 years to complete.
- Geisinger felt using one vendor for both the EMS and Portal System locked them into what functionality could be provided and what could be modified for the user experience.
- Geisinger believed that separate layers for the EMS data and user interface would allow for better options to customize the user interface and experience.

Referral Process

- No internal systems to manage referral process
- Use of Paper and Fax is still common for referring patients

ALBERTA INITIATIVES – PERSONAL HEALTH PORTAL (PHP)

The Personal Health Portal went live in 2011 with MyHealth; a non-personal health care information delivery portal for patients. Moving forward, the goal is to provide a personal health record that patients can maintain on their own. Microsoft Health Vault was acquired by Alberta Health Services to provide this functionality.

Core functionality includes:

- 1st pilot – Cardiac Wellness Institute
 - Access to drug dispensing information
 - Ability to record food, diet, journal, exercise information
 - Identity Management System in place to authenticate users
 - Goal was to improve clinical flow between patients and clinicians

Future planned functionality:

- Secure messaging with providers
- Access to all information in Netcare (diagnostic imaging/lab results)
- Allowing for health widget tie ins (e.g. Fitbit)
- Proxy Access for dependents and family members
- Integration with eReferral investigation underway
 - Functionality would include intercepting referral status messages and displaying them in the personal health portal
 - Goal is to be able to display referral data within a year

Implementation Strategy/Challenges

- Getting access to information that is ready to be consumed by the public is quite limited
 - Labs are not standardized by name or units
 - Other data points are not fully populated (immunization history)
 - Labs may not want to be sent before they've been reviewed by a clinician
- Supports need to be in place to manage the general public launch
- Marketing effort will need to be underway before launch, to educate the public
- The PHP team believes in a 2 pronged approach – a general public launch and specific program launches
- Implementation challenges lie more with data and process, rather than technical challenges

CURRENT SPECIALTY SERVICE REFERRAL PROCESS

To understand how the current specialty care referral process can be improved, it is important to review the existing process in use.

After a referring provider makes an assessment that a patient requires a specialty service, diagnostic or lab test, the following steps usually occur:

The referring provider makes a referral to the specialty service/diagnostics service.

- Referrals are usually made by phone or fax.
- Referrals can be handled by a specific provider or a central reservation desk for that specialty.
- Once the referral is received, the material is reviewed to ensure that the referral has all of the required documentation, is for the correct specialty, and meets any specific requirements to obtain the specialty service.
- Once the initial referral is processed, there may be waiting time before the appointment for the referral is made.
- The specialty service may or may not contact the referring provider when the appointment is made.
- Once tests or referring provider visits are completed, a time lag usually follows to assess/interpret the results.
- Once the report/results are completed they are sent to the referring provider.
- The referring provider contacts the patient to set up a followup appointment to review the results of the specialty referrer/diagnostic information.

GAPS IN THE SPECIALTY CARE REFERRAL PROCESS

1. The handoff process between referring and specialty providers is not well defined.
When a referral is made, there are no consistent and standardized process steps defined to document and acknowledge that a referral was received, accepted and/or processed. As such, it may be difficult to determine what the specific status of any referral is.
2. Lack of Status Information
As part the handoffs that occur between the referring provider and the specialty provider/diagnostic service, there is no consistent status information on where a patient is in the referral process. As such, to see if a handoff was successful or to determine what part of process a patient currently is in requires a manual followup with multiple parties in the process.
3. Followup steps
If a problem occurs during one of the process steps of a referral, there is a lack of information on what the appropriate followup is to resolve the problem. There may be different appropriate followup steps in the process if a wait time has exceeded an initial expected time, or if the referring provider does not followup after an appointment.

SUGGESTIONS

General Portal Functionality

After completing the patient portal provider interviews, there were consistent patterns for key functionality that drove both patient sign-ups and retention for the patient portal. These included:

- Ability to electronically message health providers
- Ability to renew prescriptions online
- Ability to see test results immediately
- Ability to make appointments
- Providing a mobile site version of the patient portal services

As well, the health providers found that the following functionality helped them provide better service and save costs:

- Ability to see test results – a number of health service providers saw the quality of care increase after test results were made available. This included patients being able to identify tests that were not associated to them, or results that required immediate followup.
- Ability to refill prescriptions – cost savings were introduced by allowing patients to refill their prescriptions online, through decreased doctor's visits.
- Ability to electronically message health care providers - patients wanted the ability to message a health provider, without having to make a visit.

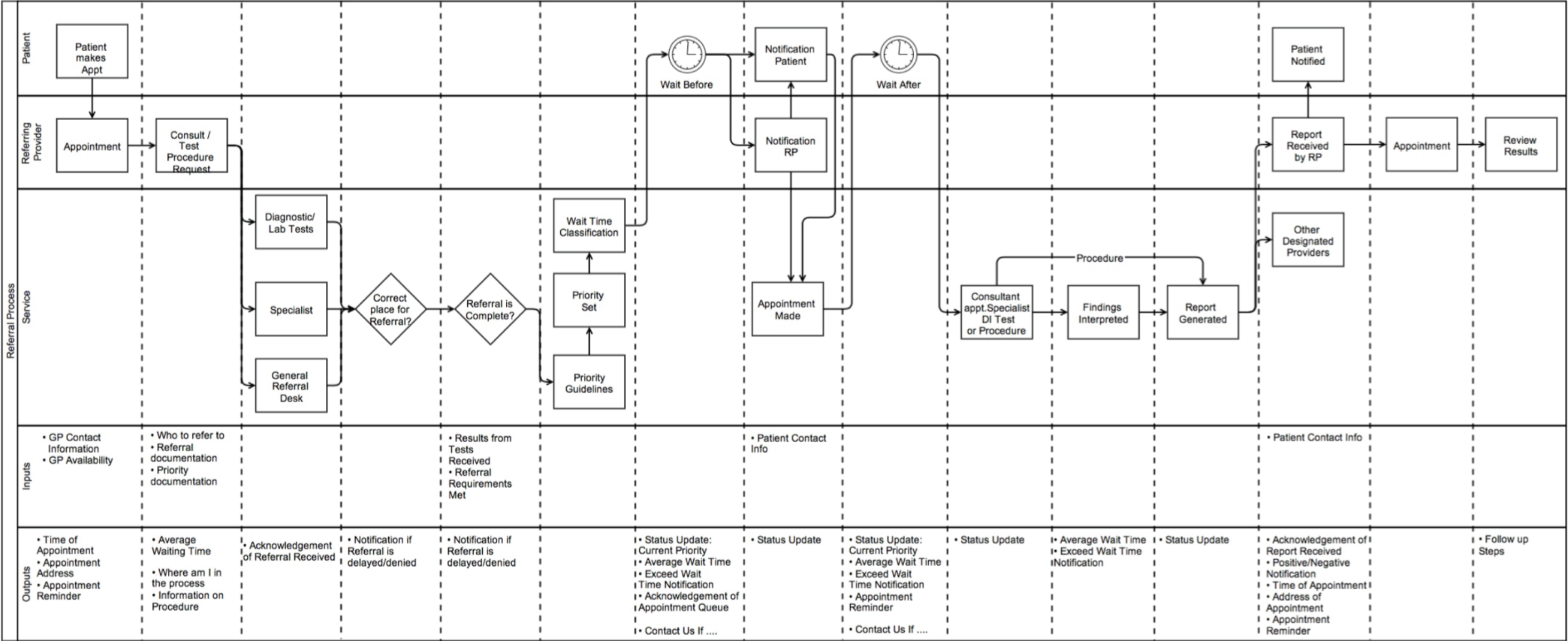
These key features should be examined for inclusion for any patient portal solution considered.

Patient Referral Process Modifications

To close the existing gaps in the current specialty care referral process, it will be important to define the requirements for successful handoffs at key points in the process between patients, referring providers, specialty providers and diagnostic services. This includes ensuring key inputs and outputs in the referral process are defined and delivered to required parties at the appropriate steps.

A basic required state was documented to provide the potential inputs and outputs needed, to close the key gaps as patients move through the referral process

Basic Required State



Note: Details one potential path to highlight inputs and outputs

Core Functionality

To support the process improvements, the following core functionality is required:

- **Status Information**
At each step of the process, all 3 parties in the referral transaction should be aware of the status of the referral. Status indicators should also display the complete chain of steps, to help educate patients on the required steps and to understand what's next in the referral process.
- **Handoff Acknowledgements/Confirmation**
At each of the specific hand off points where responsibility for the referral is passed between the referring provider, the specialist and/or the patient, a clear acknowledgement and confirmation should be recorded. This allows each party to recognize that the handoff was successful.
- **Notifications**
Notifications are key to provide patients or referring providers information on when the status in the referral process has changed and when a referral process has fallen outside of the accepted parameters. This allows patients or referring providers to take action if needed.
- **Document Management**
As reports, labs or diagnostic tests are completed, making the document transfer process secure and easily accessible will ensure that these results are available to the referring provider when needed. Any missing reports can then also be easily identified.
- **Mitigation strategy information**
Patients and referring providers need to be provided with information on what steps to take if their referral is delayed, denied or moved in priority to ensure they can act as advocates for their care.

IMPLEMENTATION

Two high-level implementation challenges were identified when reviewing how to improve the specialty care services provided can be improved. The challenges assume that multiple systems will be required to support the core functionality.

- Focus on patient care can be displaced with separate system initiatives
- Core functionality to support patient referral status required by one system is not prioritized in another system

Implementation Suggestions

To ensure the functionality required to support the ability to provide referral status and tracking information to patients, a number of implementation suggestions are included:

- **Ensure future planning for each of the systems includes the required patient referral functionality as part of their delivery plans.**
With separate teams building functionality that could be utilized to provide the required patient referral information it becomes critical that each team includes the core requirements needed to support the recommended workflows. As there are many stakeholders in the deliverables of the each of these systems, it will be important to ensure that the core requirements and functionality needed are included as part of the development roadmap.

- Include feedback and input from individuals focused on patient safety and advocacy as part of the development and strategy roadmaps.
Development roadmaps and project charters for systems such as Netcare, eReferral and the PHP should receive direct input from members of the health care community who are focused on addressing patient safety and advocacy. The additional input to the planning process will ensure that a patient focus is represented in the development of these systems.

Where required functionality could be implemented

To support the recommended modifications to the workflow processes, a number of additional suggestions can be made based on the review of the current medical record and portal projects in Alberta.

In reviewing the current systems in place, it is possible to add the recommended workflow processes by making adjustments to 3 current systems in development:

Personal Health Portal (PHP)

- The Personal Health Portal can act as the main access point to allow patients to get information on the status of their referrals and provide notification and alerts when needed.

This could include:

- Managing appointments and booking confirmations
- Status of current referral process
- Notification when status of referrals falls outside of normal parameters
- Contact information for appropriate followups

eReferral

- The Referral system can provide the required status information to provide updates on what state a referral is in.

This could include:

- Providing confirmation that a service provider has received a referral
- Confirmation that the patient has completed the followup appointment
- Notification of referring healthcare personnel about known or projected waiting time for tests / consultations / procedures that are outside specified limits

Netcare/EMR

- Specific reports or lab information could be retrieved from Netcare or a specific EMR if needed.

This could include:

- Access to relevant lab information
- Access to test / diagnostic or reports from specialty providers

TECHNICAL CONSIDERATIONS

1. Single System EMRs are not required to implement process changes
Although several of the portal providers interviewed used a single EMR/Patient Portal System, it was not identified as critical requirement to building a successful portal solution. A key criticism of using a single sourced solution was that functionality modifications were more difficult, if it didn't fall into the solutions provider's feature roadmap.
An alternate approach was to provide a multitier architecture, allowing for greater flexibility when developing the functionality of the portal solution.
2. Data Standardization across EMRs
Significant effort was required by a number of the Health Services, to standardize existing data, to make it presentable for user consumption. Any steps that can be taken to standardize the data entry of EMR data will provide beneficial when integrations are performed.
3. Shared Architecture Planning
To reduce the level of effort and modifications for planning and implementing integrations across the multiple record keeping systems in Alberta, sharing and co-ordinating the architecture planning for each system will be critical.

This could include:

- Reduction of data duplication across systems
- Creating or using a common security access model across systems
- Consistent APIs and data access to allow for greater reuse of functionality and extensibility of code

METRICS TO BE MEASURED

In order to determine the success of any modifications to the patient referral process and supporting systems, it will be important to measure the impact of modification to the systems. Some possible metrics could include:

1. Rate of completed Referrals
Measure rate of completed referrals pre/post referral process modifications.
2. General Patient Satisfaction
Measure pre/post satisfaction rates of patients who move through the referral process.
3. Patient Knowledge of Referral Process
Measure patients understanding of where they are in the process, what the next steps are and what they can do if something goes wrong.
4. Appointment Metrics
Measure number of missed/rescheduled referral and followup appointments.

Appendix IV: Acronyms

AHCIP	Alberta Health Care Insurance Plan
AHS	Alberta Health Services
AMA	Alberta Medical Association
ASR	Alberta Society of Radiologists
CEO	Chief Executive Officer
CPSA	College of Physicians & Surgeons of Alberta
CT	Computerized Tomography
DI	Diagnostic Imaging
ED	Emergency Department
EHR	Electronic Health Record
EKG	Electrocardiogram
EMR	Electronic Medical Record
GE	General Electric
HQCA	Health Quality Council of Alberta
ME	Medical Examiner
MRI	Magnetic Resonance Imaging
OR	Operating Room
PCC	Prostate Cancer Centre
PCP	Primary Care Physician
PET	Positron Emission Tomography
PHR	Personal Health Record
Providers	Healthcare Providers
QAC	Quality Assurance Committee
SAIU	Southern Alberta Institute of Urology
SSA:PSR	System Safety Analysis: A Practical Approach to Patient Safety Reviews
System	Healthcare System
TBCC	Tom Baker Cancer Centre
Users	Patients of the Healthcare System
USnd	Ultrasound

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