HQCA
Health Quality Council of Alberta

PATIENT PERSPECTIVES ON AN ELECTRONIC REFERRAL SYSTEM FOR ALBERTA

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ACKNOWLEDGEMENTS

The participation of patients and family members of patients in identifying where improvements are needed, and how they might occur, is critical to making effective change in our healthcare system. We wish to acknowledge the Albertans who participated in this project, sharing their perspectives on an electronic system to refer patients for specialized tests, procedures, or consultations. Many Albertans gave their time in focus groups and interviews, and related their experiences with referrals and their thoughts on how a province-wide electronic referral system might best serve the needs of patients and families. We thank them for their thoughtful contributions.

BACKGROUND

Patients receiving care in Alberta's healthcare system are commonly referred from one service provider to another for specialized consultations, tests, or procedures. For this care to be well co-ordinated, patients depend on reliable, accurate information being exchanged among providers and between providers and patients, and on reasonable periods of time for follow-up and treatment. Breakdowns in care are more likely to occur when patients require a referral for specialized healthcare services[i] from providers outside of their usual primary care team. The basic steps in the referral process are outlined in the HQCA's *Continuity of Patient Care Study*, published in 2013 (see figure, Appendix I).

From this study the HQCA concluded that all patients' continuity of care is at risk of breaking down when they are referred for specialized healthcare services because structures and processes to mitigate this risk are lacking. Without clear practices and confirmations, the system is based on assumptions that referrals are transmitted successfully, that information is received, and that patients will be contacted within a reasonable time frame.

The first recommendation made in the *Continuity of Patient Care Study*, as follows, concerned the need for a single, standardized, electronic process for referrals (e-referral):

> 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 follow-up 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 follow-up) that were not completed successfully according to the scheduled completion time.

[i] We define specialized healthcare services as those for which a patient must be referred by a healthcare provider (most often a physician); a waiting period for the service occurs, which often involves a process of triaging (prioritization); an appointment time is assigned; and, after the service, a report is generated that 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.

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 follow-up procedures.

    iii. Lab results, DI [diagnostic imaging] 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 follow-up 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.

Since its 2013 *Continuity of Patient Care Study*, the HQCA has become aware of a number of e-referral systems that are either in development or being piloted in Alberta. A project was therefore initiated by the HQCA in 2015 to gather patients' perspectives on their experiences with referrals in general and on an e-referral system specifically to inform ongoing work on e-referral systems. The purpose of the project was not to evaluate the strengths and weaknesses of any particular e-referral system, but to understand from the perspective of patients how their care is helped or hindered by the referral process overall and to identify the needs of patients, as related by them, in ensuring continuity of care.

Methodology

Referral processes in general and select e-referral systems in use within Alberta were explored; comparisons between systems were not made.

The HQCA was guided by an ethics screening tool – A Project Ethics Community Consensus Initiative (ARECCI)[ii] – which is used to evaluate the potential risks to people and their information when they participate in a non-research project of this kind. The screening tool determined there was a minimal ethical risk.

Literature review

A systematic literature search was conducted using multiple databases (e.g., PubMed, Medline, etc.) to identify relevant articles from peer-reviewed journals. National and international research spanning the previous 10 years was included. A first search for the concept and measurement of 'continuity of care' (and related terms) was supplemented by additional searches filtering for related concepts of 'integrated care', 'co-ordination of care', 'patient-centred care', as well as 'medical home'. These original searches were further expanded in the course of the work through cross-references and additional citations in the grey literature.

Focus groups

Five focus groups were used to explore patient experiences with the referral process overall and to gather perspectives on how an e-referral system could be designed to support patients throughout the referral process. A purposive sampling strategy – namely, maximum variation – was used to recruit participants who would bring a diversity of perspectives on the referral process. People living in urban and rural centres and of different ages, genders, and ethno-cultural backgrounds were sought. Due to time constraints, convenience sampling was also used by recruiting participants with help from members of the HQCA's Patient/Family Safety Advisory Panel. [iii] Panel members also served as members of the first focus group.

Participants were required to have some experience with referral processes in the Alberta healthcare system, such as referrals for specialized tests, procedures, or consultations for themselves or a family member. Participants consented to joining in focus group discussions and answering a short questionnaire.

A total of 35 people participated in the focus groups (one held by teleconference, four held in person in Peace River, Edmonton, Calgary, and Lethbridge) between mid-July and early August 2015. Skilled facilitators followed a semi-structured guide to lead discussions with the group (see Appendix II), and participants completed a questionnaire (see Appendix III). The data collected in the focus groups and questionnaires were analyzed using constant comparative analysis, a commonly accepted qualitative data-analysis method. This was done to identify key themes and differences by participant

[ii] http://www.aihealthsolutions.ca/arecci/guidelines/

[iii] The mandate of the Patient/Family Safety Advisory Panel is to identify study, review, advocate, and advise the HQCA on patient safety and quality issues from a citizen, patient, and family perspective. Members are drawn from all parts of the province.

characteristics (age, gender, ethnicity, geographic location, and extent and nature of their experience with referrals).

Individual patient interviews

In a separate process, a sub-set of patients participating in an e-referral system pilot project at one primary care network in Alberta consented to being contacted by the HQCA to participate in one-on-one interviews to discuss their experiences with the pilot project e-referral system. Thirty-seven consent forms were collected by the clinic and forwarded to the HQCA. Patients were randomly selected from those who had consented and were invited to participate in a short telephone interview.

Interviews were scheduled with 12 patients who replied to the invitation; seven of the interviews were completed successfully (five participants were unable to participate as planned). Telephone interviews were conducted during late August and early September 2015 by the HQCA, and lasted between 15 and 20 minutes each (see Appendix IV). Qualitative data were collected during the interviews and are summarized in the Findings section.

FINDINGS

Literature review

A literature review revealed that the concept of continuity of care is described as the quality of care over time[1] in terms of how an individual's healthcare is connected across healthcare events (i.e., various interactions with the healthcare system). It describes the experience of a smooth progression of care from the patient's point of view.[2]

Reviews of international literature have identified three major types of continuity across healthcare settings: relationship, information, and co-ordination/management continuity.[2,3,4,5] For the purposes of this study, information continuity and management continuity are relevant. *Information continuity* concerns the timely availability of relevant information through shared medical records, but also includes knowledge about the patient's preferences, values, and context usually accumulated in the memory of healthcare providers.[5] *Management continuity* involves the communication of patient-related information across team, institutional, and professional boundaries, and between professionals and patients. This concerns continuity across the secondary-primary care interface, for example, when referring from generalist care to specialist care, or when planning discharge from specialist or hospital care to generalist care.

Continuity of care is the process by which the patient and his or her physician-led care team are co-operatively involved in ongoing healthcare management toward the shared goal of high-quality, cost-effective medical care.[6]

Focus groups

Many of the experiences described by participants in the five focus groups were common among them. That is, they had similar stories to tell about their encounters with the referral process in Alberta. While participants had some positive comments to share, they had more to say about how the referral process could be improved. Their comments are grouped under five broad headings:

1. Experience with the referral process in general.
2. An ideal referral process.
3. Important information throughout the referral process.
4. Perspectives on an electronic referral (e-referral) system.
5. Online access to referral status and information.

Experience with the referral process in general

Lack of information

Many participants complained of a lack of information, of not knowing what was going on behind the scenes at various points in the referral process or how to follow up. Some people described this as feeling like their referral had gone into a 'black hole' leaving them to hope it would emerge. For example, one woman waited three to four months to get a call from a specialist's office to advise of an appointment, and then waited an additional three to four months for the appointment itself. This lack of information was described by focus group participants as frustrating, making it difficult to plan other life events: "They say, well we'll let you know when it happens. Well it's not good enough. We all have lives."

Many participants, across the focus groups, expressed surprise that the healthcare system still uses fax machines for referrals.

As well, people described not having access to information such as the following:

- **Where the referral has been sent** (e.g., for an MRI; for a specialist consultation), and whom to follow up with if there's been no response or acknowledgement within a reasonable time period.
- **How to reach a specialist to discuss an appointment date,** with participants describing it as sometimes impossible to reach a specialist to follow up, either because the specialist is not listed in the phone book or because the office has an answering machine that won't take messages.
- **What blood work and/or other tests are required before surgery**, which in one case almost led to a cancer surgery being cancelled.
- **When an appointment date has been scheduled.** For example, one person was on holiday when a hospital called to confirm an appointment; when he returned home he received a call saying that he had missed the appointment.
- **How cancellation lists work**, and what the requirements are to get placed and stay on the cancellation list.

People described feeling guilty about having to return to their family doctor for information about the status of their referral, which some people described as taking time and costing the system money. A number of people felt that the 'no-news is good news' approach currently prevalent in the system doesn't work, as things get missed. They would prefer to be notified of test results, regardless of the findings.

Participants felt the 'no-news is good news' approach currently prevalent in the system doesn't work.

Problems during the referral process

Specific problems with the referral process were experienced by a number of people. These included:

- **Referrals being sent to the wrong specialist,** which was experienced by an adolescent who was referred to an orthopedic specialist who "didn't treat kids," a person with macular degeneration who was referred to an ophthalmologist who didn't treat this disorder, and a person who was referred to a specialist who didn't treat the patient's particular kind of brain tumor. In each case, the error was identified months after the referral, when the patient attended the specialist appointment. This delayed diagnosis and treatment.

- **Referrals not arriving at their intended destination,** and patients only discovering this when they tried to follow up, often after some time had passed.
- **Urgent referrals not being treated urgently**. It took seven months for one individual to get a diagnosis of spinal stenosis, for example. The person had severe pain and disability and ultimately required emergency surgery to prevent permanent nerve damage. An elderly woman in severe pain with gastro-intestinal concerns was referred for a colonoscopy, for which she would have waited many months had her daughter not intervened. Participants said that their family doctors often struggled to get an urgent referral treated urgently, and advised them to keep going back to the emergency room.
- **Requirements prior to the referral appointment or changes in the referral not communicated to the patient.** One person spoke about the added burden placed on rural patients when they travel into a city for an appointment and find out the appointment was changed or that test results had not arrived.

Positive experiences with the referral process

Although difficulties with the referral process were described by more people, some participants shared positive experiences, such as:

- Being called back with an appointment date sooner than expected.
- Wait times for an appointment being shorter than expected.
- The referral being made to an appropriate specialist.

People with these experiences felt that perhaps their family doctor contributed to good outcomes by being thorough or well connected to needed services

An ideal referral process

Recognizing that conversion to an electronic referral system does not necessarily mean that the overall process will be improved, focus group participants were asked to describe how an ideal referral process should work before talking about an e-referral system. The characteristics of the ideal referral process that emerged were notably consistent across the five focus groups; these are summarized in **Table 1.**

Table 1: Focus group participants' views of the characteristics of an ideal referral process

Characteristics	Description
Transparency	▪ Knowing what's going on throughout the process, and being able to track your referral at all times (i.e., referred, received, current status, time frame). ▪ Patients should be informed at each step in the referral process. It was noted that consumers are able to track mail and online purchases from many places.
A "paper trail"	▪ A "paper trail" of the referral process should be available to patients, something that can either be printed or referred to electronically. ▪ Some said they want to be able to bring a copy of the appointment date with them as proof that they are supposed to be there at a particular time.
Information	▪ Knowing whom to contact if there is a need to negotiate appointment dates. ▪ Being informed quickly of the appointment date. ▪ Knowing what the referral is for and the next steps. ▪ How to reach people to follow up on a referral.
Mechanisms to ensure the patient has received information	▪ A mechanism to ensure that the patient has received and understands whether any pre-appointment tests are required, any special preparation, etc. ▪ A mechanism to ensure that the patient is aware of an appointment.
Indication of urgency	▪ An indication of urgency for the referral.
Fair	▪ Perceptions exist that workers' compensation cases get in for tests and consultations with specialists more quickly, and that elderly people are often put at the end of the queue.
Flexible	▪ Have an option to change appointment times that don't work, particularly in non-urgent situations. ▪ Be able to choose how you want to be communicated with, and provide permission for another person to have access to the information and/or be copied (e.g., family member, other supporter). ▪ Have some choice of where you get referred; for example: o Would like to see a list of possible doctors to be referred to, so you could make a choice. o Where (in what town or city) and to whom you want to be referred. If referrals had comparable wait-time information, that could be taken into consideration when making a choice. ▪ Be able to co-ordinate referrals, so it is possible to have more than one appointment in a day, especially if travelling from out of town. ▪ Have the option to be placed on a cancellation list for a chance at an earlier appointment; receive an email or text alert if there is a cancellation.
Access to test results online	▪ Be able to see test results online, as this would enable access to results as soon as they are available.

Focus group participants also described additional healthcare system features that were felt to be important for an ideal, patient-centred referral process:

- **A central repository where all the referrals and test results are available** would be helpful. The family doctor could see where the patient has been over the past year(s), so the initial problem doesn't get lost as information becomes decentralized.
- **Access to your own health information, so you can share it if you are seeing a physician who doesn't know you** (e.g., for Albertans who are out of town or province). This was felt to be particularly important for patients living with ongoing health issues, who end up being the experts on their own medical conditions.
- **Having help with the follow up from healthcare providers (e.g., primary care clinic),** as this is time-consuming for people, particularly those in the so-called 'sandwich generation'. Notifications to patients at different stages in the referral process would ease the burden of following up.
- **A robust and easy to use system, so that patients do not have to spend an extraordinary amount of time navigating and advocating.** For the vast majority of people who can and who want to be strong advocates, being able to track and follow up on referrals is important.

Important information throughout the referral process

Focus group participants were also given a supplemental questionnaire to gain feedback in two broad areas: people were asked to rank the importance of being notified when each step in a referral process had occurred, and to rank the importance of different kinds of information related to their referral. The findings align with the participants' ideal referral process described above.

Most participants rated being notified of each step in a typical referral process[iv] as 'very important'. Two of the steps were rated as 'important' or 'very important' by all participants: a referral has been received and accepted, and the status of the referral is clear (i.e., appointment is being arranged, or appointment has been set).

With respect to the importance of the kinds of information related to the referral process overall, the ones rated most frequently as 'very important' were:

- Whom to follow up with if you have not heard back about an appointment date.
- How long it's likely to take to get an appointment.
- What to do if you have been given an appointment time that does not work for you.
- How, or what to do, to get ready for the referral (e.g., blood work, fasting).

[iv] These were identified as: (1) a healthcare provider has sent the referral to an appropriate, clearly identified, provider or facility; (2) the health service provider or facility has received and accepted the referral; (3) the status of the referral is clear – either in progress (appointment being arranged) or completed (appointment has been made); (4) a report from the appointment, test, or procedure has been generated; (5) the requesting healthcare provider is aware of the report and has acknowledged receiving it.

- If you need to make an appointment, and with whom, to find out about the report findings (e.g., test or procedure results; specialist's recommendations).

Participants also described:

- Having a lack of information about the referral process, noting that once a referral has been initiated it often seems like it has disappeared into a 'black hole'.
- It is important to follow up with patients about test results, regardless of whether they are positive or negative.

An additional step was identified by some participants: the referring healthcare provider is in touch with the patient to discuss results from tests or procedures, or to arrange an appointment to do so.

Perspectives of an electronic referral (e-referral) system

Focus group participants shared their perspectives about an e-referral system, discussing concerns, benefits, online access to referral status and information, communication preferences, and implementation. The key themes that emerged in each of these areas are summarized below.

Concerns

Although participants expressed overwhelming support for moving forward quickly with e-referrals in Alberta, when asked directly if they had any concerns they raised two key issues: (1) privacy of health information and the security of the e-referral system; and (2) the availability of other options, especially for those without access to technology (i.e., computers, email, and smartphones).

1. Privacy of health information and the security of the e-referral system.

There were some concerns voiced about privacy and security, particularly if medical records were to be shared as part of the e-referral system. Participants noted the need for due diligence to ensure that access is tightly controlled. At the same time, participants recognized that there can be no absolute guarantee that the system would be secure, and they did not want this concern to outweigh the importance of moving forward with an e-referral system. Specific comments included:

- "My biggest concern is just who has access to that and can hack into it." There was also recognition that ultimately everything was 'hackable' ("even the Pentagon"), and that "the only safe computer is one that is unplugged and in the ground."
- Some participants noted that health information is a less likely target for hackers than banking information.
- Of greatest concern was the security of more sensitive health information such as mental health referrals and certain test results (e.g., HIV status).

> *"Extraordinary concerns with security should not be used as an excuse to hold up implementation for a lengthy period of time."*

- Good back-up systems were felt to be necessary to protect against 'crashes' and loss of data.
- Some felt that the current paper system, particularly the use of fax machines, already lacked security. As one person said, "It is easier for me to go into a doctor's office and grab a file than it is to get into their computer."

2. Availability of other options, particularly for those without access to technology.

Participants felt it was important to keep other options to supplement an e-referral system:

- Seniors, and those without family members to help them, may need an alternative to technology, such as phone calls followed up with letter mail.
- People with health conditions that deteriorate during a referral process would still need the ability to call someone to discuss any needed changes to their care.

> *"I think we have to take into consideration different populations…seniors, people [who] are homeless, people [who] don't have computer access or don't understand."*

Benefits

All of the participants, even those who did not have or use computers, felt that the benefits of an e-referral system far outweigh any concerns; specifically, the convenience and access to information offset their concerns about privacy. Participants said: "This is a no-brainer," "Just do it," and "It's time, it's time."

Additional benefits described by participants are:

- If people could track their own referrals online, a lot of stress and time associated with following up could be removed from the healthcare system.
- A referral process that is transparent to patients would eliminate many of the phone calls to healthcare workers from patients wondering about the status of their referral.
- Improved communication strategies and the ability for patients to track their referrals and appointments would likely decrease the number of no-shows and ultimately save the system money.

Online access to referral status and information, and any limitations to that access

Focus group participants were asked directly whether they would want online access to track their referral status and see relevant medical information. Participants expressed considerable support for this. Providing online access to medical information was seen by some as a way of building patient capacity to become more involved in their health and healthcare. Some felt there's a mixed message being sent by the healthcare system today: "It's your body (and we'd like you to take responsibility for it) but you don't get to know anything."

There were mixed perspectives, however, on the types of information that people wanted access to:

- It was felt that some patients would want to view "bad" test results online as soon as they're available and then see their doctor, while others would prefer getting that news from their doctor.
- Considerable support was expressed for allowing people to choose what kinds of information they see online. For example, patients who wanted to see test results could consent to that level; others could choose to see only that the results are available and then follow up with their doctor to receive them.
- Others felt online access should provide patients and their healthcare providers with access to information on both physical and mental health, including all medications being taken.

Communication preferences

Almost everyone identified email or text messaging as their preferred communication mechanism. A few said they would appreciate an app on their mobile devices to manage referrals and enter appointments into their calendars. One participant who did not have a computer acknowledged that she preferred phone and letter mail. In every focus group it was agreed that it is important to ask patients and their families about their preferred communication mechanism. Specific recommendations and examples included:

- Receiving appointment dates and reminders via their cellphones to track their referrals. This was seen to be cost effective for the healthcare system, as considerable health professional time could be freed up.
- Email, so that patients can print off a copy. The practice of dental offices providing appointments and reminders via email and/or phone was cited as an effective method.
- Being able to print emails reduces confusion about dates and times and provides 'proof' for patients when they arrive at an appointment.
- Small adhesive appointment cards.
- Electronic meeting requests that patients can accept or reject.

Implementation

Across all focus groups, people stressed a desire to see an e-referral system implemented in Alberta as soon as possible. They shared some ideas about how this implementation could occur:

- It was emphasized that an e-referral system is simply a tool, and that the processes that drive use of the tool need to be well thought out.
- Some caution was expressed about improving referrals through an e-referral system without also improving other aspects of the referral process that are problematic, including communication across transitions, listening to the patient and family, and ensuring that referrals are sent to the most appropriate place.

> *"Is this really going to change the quality of our referrals? Is the problem really the fax machine or is it the whole process?"*

- Different security or access levels would be useful for including family members or others who are helping a patient navigate the system. The type of accessible online information might need to be modified based on the situation.
- The need for patient feedback into the system as it is developed was emphasized, so that problems can be identified early.
- The question was raised whether a doctor is more likely to look at a referral if it is sent electronically. Some participants wondered whether monetary disincentives could be used to ensure doctors respond to referrals within a specified period of time.

Individual patient interviews

In addition to the literature review and focus groups, the HQCA in a separate process conducted interviews with a subset of patients who were participating in an e-referral pilot project at one primary care network (PCN).

In general, most patients who were interviewed reported positive experiences with the e-referral system. Most found the system fairly easy to use and they had no concerns about their privacy or the security of their information. Positive comments that were shared included:

- Patients appreciated the ability to receive information about their referral via text or e-mail.
- Most patients indicated the process was efficient and worked very well.
- The majority of patients indicated they were informed as to how their referral was classified (i.e., normal, semi-urgent, or urgent). This helped to set expectations around wait times for an appointment with the specialist.
- The process to respond to notifications (e.g., confirm scheduled appointments) was relatively straightforward, with few problems encountered.
- Patients received the information they needed to attend the appointment with the specialist or to undergo special diagnostic tests or procedures, including the name of the specialist and contact information (clinic location and phone number).
- Patients understood what to do if they needed to change an appointment scheduled by the specialist's office.
- Most patients received contact information for the specialist; most did not need to contact the specialist because the e-referral system provided them with the information they needed in a reasonable time frame.

Interviewees also suggested ways to improve the functionality of the e-referral system. Their comments are grouped according to key themes that emerged in the interviews (**Table 2**).

Table 2: Comments on the functionality of a pilot e-referral system at one primary care network

Function	Summary of comments
Tracking a referral	Most patients were unaware they could log into the e-referral system to track their own referral, and they indicated they would be interested in doing this rather than only relying on notifications sent to them. Most patients indicated they thought a mobile app on a smartphone would be useful in tracking their referrals and managing their appointments.
Wait times	Most patients understood what is meant if their referral is "normal" or "urgent" and expected to wait many months for the appointment itself to occur. Few patients, however, understood how long they should expect to wait before being *notified* that the appointment was scheduled. Some patients indicated they would appreciate information on expected wait times for notification of a scheduled appointment, as well as a process to follow if they are not notified within that time frame.
Method of notification	Many patients expressed an interest in being able to receive a calendar invitation to an appointment that they could easily add to their own personal electronic calendars. While all patients interviewed seemed comfortable using technology (e-mail, web application, or smartphone) to participate in the referral process, some concern was expressed that the process may disadvantage patients who lack access to, or are uncomfortable using, technology. The electronic referral process would still need to include phone and traditional letter-mail communication for these patients, it was suggested.
Multiple referrals	Some patients reported confusion with the status of referrals when referred to more than one specialist at a time. Some patients reported it would be beneficial to have additional tools to help them understand the different specialists and expected wait times for each appointment.
Appointment times and opportunities to reschedule	Most patients indicated that when they were notified about an appointment with a specialist, they were given the option to reschedule. Most reported that the scheduled time was inconvenient; however, most did not reschedule the appointment as they were "afraid to wait too long for the next available appointment." Some patients indicated they are "at the mercy of the specialist," they are "happy with whatever they get," and "just do as they are told." Some patients indicated they had to take considerable time off work to attend appointments, which could have been avoided if appointments were scheduled at the start or end of the day. Almost all patients interviewed indicated they would prefer to be able to log into a website and have the ability to choose their own appointment time with the specialist. Some patients also said they would prefer to be given options for appointments (e.g., three different dates/times), with the ability to choose the most convenient option. Of note, one patient reported having had this experience and found it to be very helpful.

Notifications and reminders	Notifications about a referral can be sent to only one person (i.e., the patient or the patient's proxy/decision maker). In a situation in which multiple family members are helping a loved one with appointments, it would be preferable if more than one person could receive e-mail/text messages about their family member's referral (i.e., redundancy in the system would be helpful). Most patients would appreciate a reminder about upcoming appointments. Those who have received reminders indicated they were almost always phone calls. Most patients suggested they would prefer text or email reminders (similar to the notification process for scheduling the appointment).

Patients also commented on the follow-up after a consultation, test, or procedure. All patients interviewed indicated they would like to be notified of the outcome of an appointment with a specialist.

Specifically:

- Patients would like to see the specialist's report to the referring physician that summarizes the appointment and treatment plan. Patients would like a copy of this report or be able to obtain it through a web-based application (e.g., a patient portal).
- Patients want instructions on what to do next (e.g., book a follow-up appointment with the specialist or referring physician).
- While electronic notifications are helpful, patients may still need to contact a specialist's office for more information. Some patients reported difficulty reaching someone to talk to when they called a clinic number for more information. Patients suggested it would be helpful to be able to e-mail or message (through the e-referral system) the referring and/or specialist physician directly with questions related to their referral to further reduce communication gaps that are still apparent in the e-referral process.

Even though patients indicated that in general they have more information about their referral, many still experienced challenges and some frustration with the e-referral process, as shown in these first-hand accounts:

- One patient received an e-mail notification about a scheduled appointment; the time was inconvenient so the patient did not confirm the appointment. Instead, the patient followed instructions to reschedule (i.e., called the specialist's office) and received a new appointment time. The patient later received a phone call from the specialist's office indicating the patient had not yet confirmed the original appointment time.
- At the time of these interviews, one patient was still waiting to be notified of an appointment time after being referred to a specialist several months previously. The patient chose not to call the specialist's office as the patient was told to expect an e-mail notification about the referral. The patient expressed frustration with the lack of information about expected wait times and the status of the referral, as well as the length of time that had passed waiting for an appointment date.

- Another patient received an appointment notification via email and confirmed the appointment following the instructions in the message. When the patient attended the appointment, the specialist had been called out on an emergency and was unavailable. The patient was instead seen by another physician. The specialist did not receive this information and attempted to follow up with the patient about rescheduling an appointment but was unsuccessful in reaching the patient. The specialist's office reported to the referring physician that it was unable to locate the patient and would be therefore cancelling the referral.
- One patient related the frustration of being told by both a referring physician and a surgeon that a specialized procedure was required before the patient's upcoming surgery. The patient was scheduled for the procedure *after* the surgery, however. The patient informed the referring physician's office and was told to contact the specialist's office. The patient was unable to expedite the test appointment through the specialist's office. The patient underwent the surgery as scheduled (there was some concern that without the information needed from the procedure the treatment plan had to be altered), and went to a rescheduled appointment with the specialist following recovery from surgery. This individual commented that "the patient should not be the only one with the complete picture"; "it was not clear if anyone else knew what was going on." The patient reported the referral experience to be stressful and 'bumpy'; when the patient was eventually able to reach someone on the phone, the person couldn't help and didn't understand the urgency of the patient's concern. "I was the only go-between between my referring MD, the surgeon, and the specialist."

SUMMARY

From the patient perspective, an ideal overall referral process should include transparency, access to information through all steps of the process, and the ability for patients to refer to and share information with health professionals. This model is supported by the findings from the literature review highlighting the importance of relationships, information, and communication.

The widespread implementation of an electronic referral (e-referral) system is seen as highly desirable among the cross-section of Albertans who participated in this project. Focus group participants and interviewees expressed in clear terms their frustrations with the current referral system, describing it as a 'black hole' in which information can be delayed, lost, or misdirected, and in which they feel powerless.

The benefits of an e-referral system in terms of access to information and the efficient use of healthcare resources are seen to address many of the participants' current concerns about referrals, provided efforts are made to improve the referral process generally.

Those interviewees with direct experience of an e-referral system at the one primary care network in this project said they felt the system provided them with adequate information to help them understand the status of their referrals and what was required of them to prepare for any special tests or appointments. They found the system efficient and easy to use.

Interviewees and focus group participants suggested ways to make the most of an e-referral system's functionality. They stressed the usefulness of:

- Tracking all steps in the referral process.
- Information about wait times and the ability to contact specialists.
- Notifications and alerts at each stage of the referral process via email or a smartphone app.
- Confirmations from patients and providers that create a real or virtual 'paper trail' to minimize missed appointments and improve transparency.
- Flexibility in where and when specialist appointments are made, including the ability to change appointment times, choose an appointment from a few options, or book their own appointment from an online calendar.
- Allowing multiple people online access to referral information so that different family members can help a loved one with managing tests and appointments.
- Online access to health information, medical records, and test results and other follow-up information, with provisions to safeguard sensitive health information.

The need for patients to be able to choose their preferred method of communication with healthcare providers was stressed. An e-referral system should include electronic (e.g., email, text messages, calendar invites) and alternative methods of communication (e.g., phone call, letter mail), for those who do not have or use technology.

With this report, the HQCA provides the unique viewpoint of the patients and their family members who are the focus of the referral process and whose continuity of care is reliant on a system that meets the needs of both patients and providers. Organizations looking to either improve the overall referral process or implement an electronic referral system can benefit from considering the patient perspective.

HQCA
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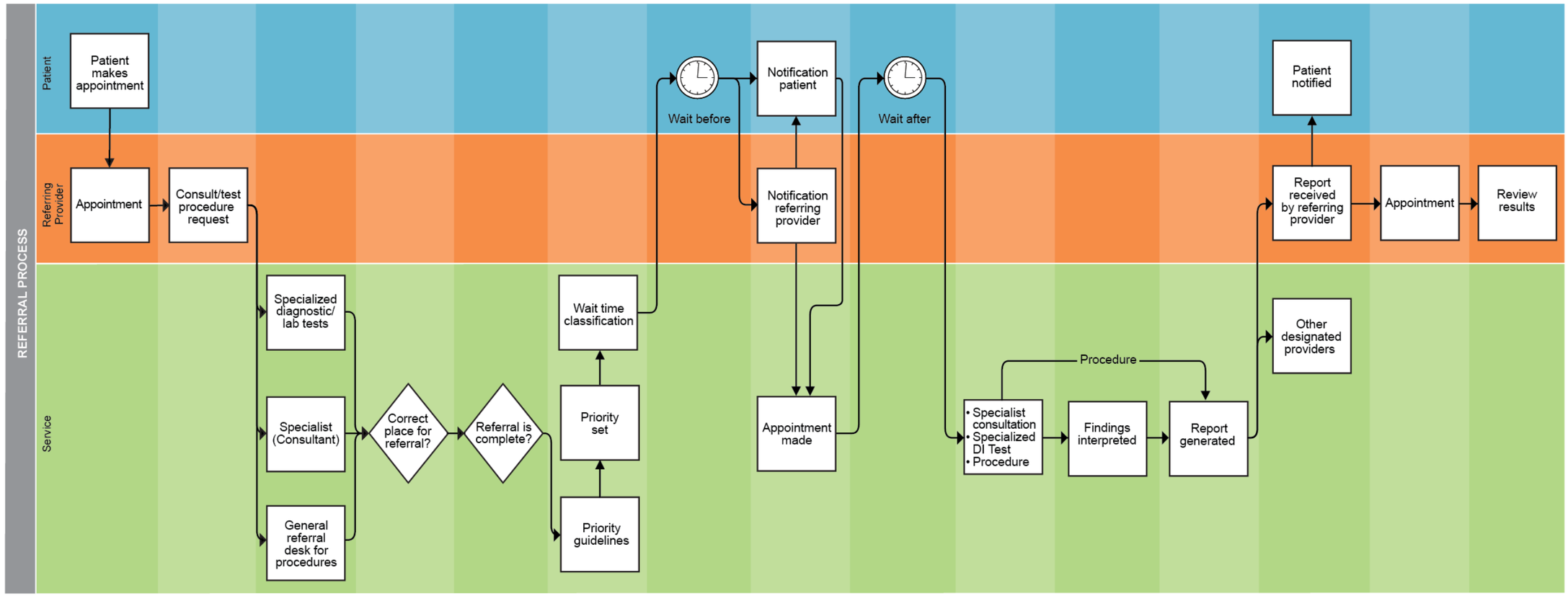
APPENDICES

Appendix I: Basic process steps for obtaining specialized healthcare services for patients



Inputs	• Referring provider contact information • Referring provider availability	• Who to refer to • Referral documentation • Priority documentation			• Results from tests received • Referral requirements met			• Patient contact information					• Patient contact information		
Outputs	• Time of appointment • Appointment address • Appointment reminder	• Average waiting time • Where is the patient in process • Information on procedure	• Acknowledgement of referral recieved	• Notification if referral is delayed/denied	• Notification if referral is delayed/denied		• Status update: current priority • Average wait time • Exceed wait time notification • Acknowledgement of appointment queue • Contact us if…	• Status update	• Status update: current priority • Average wait time • Exceed wait time notification • Acknowledgement of appointment queue • Contact us if…	• Status update	• Average wait time • Exceed wait time notification	• Status update	• Acknowledgement of report received • Positive/negative notification • Time of appointment • Address of appointment • Appointment reminder		• Follow up steps

*Details one potential path to highlight inputs and outputs

Appendix II: Focus group guide

Introduction

- Go over the information form (attached) and answer any questions the participants might have
- Go over the consent form and answer any questions the participants might have
- The information that you provide through this discussion is confidential. Anonymous quotes may be used in the final report to illustrate important points. No names or identifying information are used in any reporting.
- Ask for permission to audio-tape the session
- The audio tapes will be destroyed once the final report has been prepared.
- Go over ground rules
- This focus group will last 90 minutes. Please feel free to get up and stretch, go to the washroom, and/or replenish your refreshments at any time.
- Any questions before we get started?

Roundtable introductions

Ask people to introduce themselves and say why they are interested in participating in this focus group

Questions for discussion

<u>About the referral process generally</u>

1. What has been your experience with being referred to specialists and/or for specialized procedures (e.g., endoscopy, colonoscopy)? Describe the process, as you've experienced it.
   a) What has worked well?
   b) What hasn't worked so well?
2. Describe an ideal referral process. How would it work?
3. What do you want to know throughout the referral process?

Activity handout: Hand out the referral process questions, and give people a few minutes to complete it. Then we'll take a few minutes to discuss as a group.

- How do you prefer to be communicated with regarding appointment times and location, any other instructions (i.e., phone, email)
  - What about appointment reminders (i.e., phone, text message, email)

About e-referral

Brief description – Currently most referrals from a physician's office or walk-in clinic are done via fax or phone. That is, the office or clinic will call the specialist's office to make the referral, or send the referral request via fax. There is work underway to develop an electronic referral system. In an e-referral system, referrals would be done online, and there would be the ability for the referring physician's office or clinic to submit, track and manage referrals online throughout the referral process. Also see information sheet.

- How would you feel about an e-referral process?
- What do you see as some possible benefits?
- What are some concerns?
- How would an e-referral system help or hinder the ideal referral process we talked about earlier?
- How would an e-referral system help or hinder your access to important information?
- If there was the opportunity for patients/families to have online access to their own referral status, would you want this access? Why or why not?
- Are there any limitations to access that you would want?

Closing

- Roundtable: Is there anything else that you would like to say that we haven't had an opportunity to talk about yet?

THANK YOU!

Appendix III: Focus group patient questionnaire

Question #1

Outlined below are the typical steps in a referral process. Using the following scale, please indicate how important it is for you to be informed that this step has taken place, by circling the appropriate number.

1	2	3	4
Not at all important	**Somewhat important**	**Important**	**Very important**

Referral step	Level of importance Least → Most				Don't Know
1. A healthcare provider has sent the referral to an appropriate, clearly identified, provider or facility	1	2	3	4	☐
2. The health service provider or facility has received and accepted the referral	1	2	3	4	☐
3. The status of the referral is clear – either in progress (appointment being arranged) or completed (appointment has been made)	1	2	3	4	☐
4. A report from the appointment, test, or procedure has been generated	1	2	3	4	☐
5. The requesting healthcare provider is aware of the report and has acknowledged receiving it	1	2	3	4	☐
6. Any additional steps (please specify)	1	2	3	4	

Question #2

Outlined below are other kinds of information that you might want to know when you, or a member of your family, have been referred for a test, procedure or consultation with a specialist. Using the following scale, please indicate how important it is for you to get this type of information, by circling the appropriate number.

1	2	3	4
Not at all important	**Somewhat important**	**Important**	**Very important**

Type of information	Level of importance Least → Most				Don't Know
▪ When to expect to hear back about an appointment date	1	2	3	4	☐
▪ Who to follow up with if you haven't heard back about an appointment date	1	2	3	4	☐
▪ How long it's likely to take to get an appointment	1	2	3	4	☐
▪ Whether the place to which you have been referred has a cancellation list, and how to get on it	1	2	3	4	☐
▪ What to do if you have been given an appointment time that does not work for you	1	2	3	4	☐
▪ If it's possible to change the location of a test, procedure or specialist consultation (e.g., if you are from a rural area or smaller city do you absolutely need to travel to a large centre)	1	2	3	4	☐
▪ How, or what to do, to get ready for the referral (e.g., blood work, fasting)	1	2	3	4	☐
▪ If you need to make an appointment, and with who, to find out about the report findings (e.g., test or procedure results; specialist's recommendations)	1	2	3	4	☐
▪ Other (Please specify)	1	2	3	4	

Appendix IV: Patient interview guide

Name of Participant: _____

Name of Interviewer: _____

Date/time of Interview: _____

Background

- In 2013, the HQCA undertook an in-depth single case study review of a young man's journey through the health care system in southern Alberta. The purpose of this study was to highlight system issues related to continuity of care.
- The HQCA's *Continuity of Patient Care* study, published in December 2013, reported several problems with co-ordination of care, including the referral process for tests or procedures and consultations with specialists.
- The HQCA made a number of recommendations that aim to improve co-ordination of care in Alberta's healthcare system.
- One of the recommendations was that additional investments be made in an electronic referral or e-referral system.
- In follow up to this study, the HQCA is undertaking a project to look at e-referral processes, with an important aspect being to capture Albertans' perspectives on incorporating an e-referral process into the healthcare system.

The purpose of this interview, then, is to discuss the new e-referral system being piloted in select medical clinics in Alberta; your experience with the referral process; the acceptability of such a process; and how the e-referral system might be improved from a patient perspective.

Participation and confidentiality

Your participation in this interview is completely voluntary. We are asking for your permission to document the discussion which will help ensure that we have access to a record of information you share during the interview. All documentation of our discussion will be destroyed after we have reported the findings.

The information that you provide through this discussion is confidential. Anonymous quotes may be used in the final report to illustrate important points. No names or identifying information are used in any reporting. We will not be collecting information about any medical condition you may have or the reasons for referral to a specialist; questions will be restricted to your experience with the e-referral process.

Understanding of the participant

Your agreement to be interviewed today confirms your willingness to participate in this discussion. It also means that you understand and agree to what has been said above. You are free to refuse to participate, to decline to answer a particular question and/or to stop the discussion at any time.

Can you please confirm that you agree to participate in this brief interview?

Yes/No

Interview questions

1. Notifications

- Did you receive any notifications in regards to your referral?
- If so, how many notifications did you receive/at which steps in the process? Examples may include:
    - Referral received by the Specialist's office
    - Appointment booked by Specialist's office
    - Any other notifications
- How did you receive your notifications (e.g. email, text, phone)?
- Did you receive notification to let you know if your referral was accepted or declined by the Specialist? If so, how did you receive this notification?
- Were there other points in the referral process that you would have liked to receive notifications for?
    - Example: Report from Specialist regarding appointment, test results, etc. sent to referring physician
- Would you be interested in being able to access information about your referral in another way?
    - Example: Log in to a website or mobile app and retrieve information when convenient (in addition to or instead of receiving notifications)?

2. Appointment booking: confirmation and rescheduling

- If you received an appointment notification from the Specialist's office by voicemail, text or email, did you confirm the appointment notification? If so, how did you confirm?
- Did you experience any difficulties responding to the request for referral/appointment confirmation?
- Was the appointment date/time convenient for you as scheduled by the Specialist?
- Did you know how to reschedule the appointment?

- Did you need to reschedule the appointment?
  - If so, were you successful in rescheduling your appointment to a more convenient time?
- Did you receive a reminder about your appointment with the specialist?
  - If so, how did you receive this reminder?
  - If not, would you have liked to receive a reminder? By what means (email, phone, text)?
- Would you prefer to be able to schedule your own appointment rather than the Specialist's office just providing you with an appointment date/time?

3. Information about your referral and appointment

- Were you provided with pre-appointment information/suitable instructions (including clinic location, phone numbers, etc.) from the Specialist's office in order to be prepared for your visit with the Specialist?
- Did you know if your referral was classified as "urgent", "semi-urgent" or "normal"? If not, would it be helpful to know this information and the expected wait-time for these different categories of referral?

4. Patient phone calls

- Did you phone your referring physician to discuss your referral? If so, please provide reason for phone call and if your questions/concerns were resolved.
- Did you phone the specialist's office to discuss your referral? If so, please provide reason for phone call and if your questions/concerns were resolved.

5. Information security

- Do you have any concerns about privacy/security of your personal/health information with this process?

6. General comments

- Please share any comments related to overall experience with the e-referral system.

Would you like to receive notification via email (with a link to our website/report) when our report is finalized?

Would you be interested in being contacted in the future by the HQCA to invite you to participate in other projects (provide patient perspective)?

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