



JOURNEY MAPPING IN CANCER CARE

January
2019

Patient and provider experiences in receiving and delivering cancer care in British Columbia

This report is in memory of one of the patients who participated in the journey mapping session. Despite being very ill, the patient partner wanted their story to be heard and known. They passed away eight days after the mapping session. In honour of them, we hope that this report helps to inform and create system change for patients, patients' families and providers.

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Executive Summary

Cancer is the leading cause of death in Canada¹ and, with cancer rates rising, the health care system is under continual pressure to provide high-quality care to rising numbers of patients. Significant advances in research have allowed many patients to enter remission and live longer. To support patients and their families in receiving whole-person cancer care, the system requires a deep understanding of what matters to patients in their care and how the current system is experienced by patients.

In fall 2018, three journey mapping sessions with adult patients, families and health care providers were led by the BC Patient Safety & Quality Council (the Council), in partnership with BC Cancer and First Nations Health Authority (FNHA). The goals of the sessions were to inform whole-person cancer care throughout the entire care experience and improve transitions for patients receiving cancer treatment in British Columbia.

Each journey map reflects participants' steps, actions, thoughts and considerations, feelings and emotions, worries and concerns. The specific language used by the participants was retained whenever possible and direct quotes are incorporated throughout both the report and the maps. Change ideas generated from patients and providers are listed alongside each theme in the report.

The knowledge and information captured in this report provides an opportunity for policy makers, health care providers and patients to be inspired and take action towards creating a better, more person- and family-centred cancer care system.

The following themes emerged from the three mapping sessions:

- Both patients and providers are frustrated by the inconsistency and/or lack of communication as patients move through the system

- The current system is not operating in a shared care model, which leaves it up to patients to coordinate their care

- Cultural safety and humility is critical to the wellness of Indigenous patients

- Social and emotional support is integral (not just nice to have) to supporting patients and their families through cancer

- Patients in rural settings have trouble getting treatment close to home

- Patients desire a whole-person approach to care

- A sense of trust is often missing in the patient-provider relationship

- There is value in creating environments or networks for patients and providers to connect and collaborate to innovate and improve the system

Purpose

In summer 2018, the Council received a request from the Ministry of Health (MoH) to help inform whole-person cancer care and improve transitions for persons receiving cancer treatment in British Columbia. In partnership with BC Cancer and the First Nations Health Authority (FNHA), three journey mapping sessions were held in October and November to gather information from patients, family members and providers. This report summarizes their findings.

Scope

The scope of the mapping included the journey from before diagnosis through consultations in primary care (the General Practitioner (GP) or Nurse Practitioner (NP) typically); diagnosis; first oncologist appointment; supportive cancer care while under the care of BC Cancer, the regional health authority or services in First Nations communities; and transitions back to primary care.

Thematically, the mapping focused on exploring:

- Supports for patients to make informed choices about their cancer care that aligns with their preferences and wishes;

- Broader assessments for surgical oncology patients;

- Enhanced whole-person care for patients receiving cancer care; and

- Smoother transitions back to primary care which could include end-of-life or palliative services.

The Value of Patient Journey Mapping

Patient journey mapping is an effective way to explore and capture the emotional, mental and social experiences of individuals and groups interacting with a complex system.² The process has been successfully used by health systems around the world to engage the patient voice and assist with health care redesign initiatives.^{3, 4}

The mapping is collaborative and asks participants to describe a personal experience as a series of interrelated steps that are captured visually on a common drawing space. Unlike simple process mapping, which focuses on capturing steps in a workflow process, journey mapping also focuses on the mindsets, beliefs and emotions that mark each step. This approach highlights experiences around delivering and receiving care that are deeply personal and detailed, while allowing for common themes to emerge in an easy-to-understand and engaging graphic illustration.

In addition to highlighting opportunities for improvement or change, journey mapping can identify the reasons or drivers behind why patients, family members and health care providers respond as they do along the care journey and in transitions in care. The mapping sessions provide the opportunity for them to engage in a structured and safe environment focused on problem discovery and the mutual exploration of improvement opportunities.

Journey maps are snapshots in time that explore the mindsets, emotions and experiences of the participants that show up on the day, not comprehensive illustrations of the current state of the health care system. Readers of the maps can consider them critically and reflect on what is included as well as what is missing.

Journey Mapping Sessions' Participants

Non-Indigenous patient and family partners were recruited through the BC Cancer Patient and Family Experience Network, while Indigenous patient and family partners were recruited through FNHA. A total of 10 patient and family partners, including one Indigenous patient partner, attended the October session, with an additional 10 Indigenous patient and family partners attending a subsequent mapping session in November.

Patient and family partners had experiences with various types of cancers. Some participants had been cancer-free for several years; others lived with active tumours but were not actively in treatment and some were in active treatment for a current cancer. Participants represented a mix of rural and urban experiences and came from across British Columbia. For Indigenous patient and family partners, participants identified as First Nations (living at home and away from home) and Cree-Métis.

PATIENT AND FAMILY PARTNER SESSION

October 12, 2018

10 Patient and family partners

3 Organizational representatives from BC Cancer

INDIGENOUS PATIENT AND FAMILY PARTNER SESSION

November 20, 2018

10 Patient and family partners

3 Organizational representatives from BC Cancer and FNHA

PROVIDER SESSION

October 30, 2018

3 Allied health professionals

8 Physicians/Nurse Practitioners/Nurses

2 Organizational representatives from BC Cancer

Two observers from BC Cancer took part in the first patient and family partner session, while one observer from BC Cancer and one from FNHA took part in the Indigenous patient and family partner session. Their roles were to listen to the participants' experiences and ask clarifying questions as needed. A counsellor from BC Cancer was present at both sessions to offer support to participants.

For the provider session, BC Cancer played the lead role in recruiting providers. A total of 13 providers attended the session and included nurses from FNHA, allied health staff, GPs (urban and rural), NPs, oncologists, surgeons and organizational representatives from BC Cancer.

Understanding the Journey Maps

Three journey maps were created in the mapping sessions. This section provides context to help the reader interpret the maps. Specific change ideas and themes that emerged from the sessions are discussed in detail in the next section of the report.

For further details regarding how the mapping unfolded and key considerations when interpreting the maps, please see Appendices A, B and C.

High-resolution versions of the maps can be downloaded from [BCPSQC.ca](https://www.bcpsqc.ca).

Patient and Family Partner Map – October 2018

This map was created in a facilitated discussion where we asked patient partners to walk us through their cancer care journeys from pre-diagnosis, through diagnosis to treatment and into the next chapter after treatment was completed. Participants provided rich detail regarding not only the medical aspects of their journeys but also their mindsets and feelings

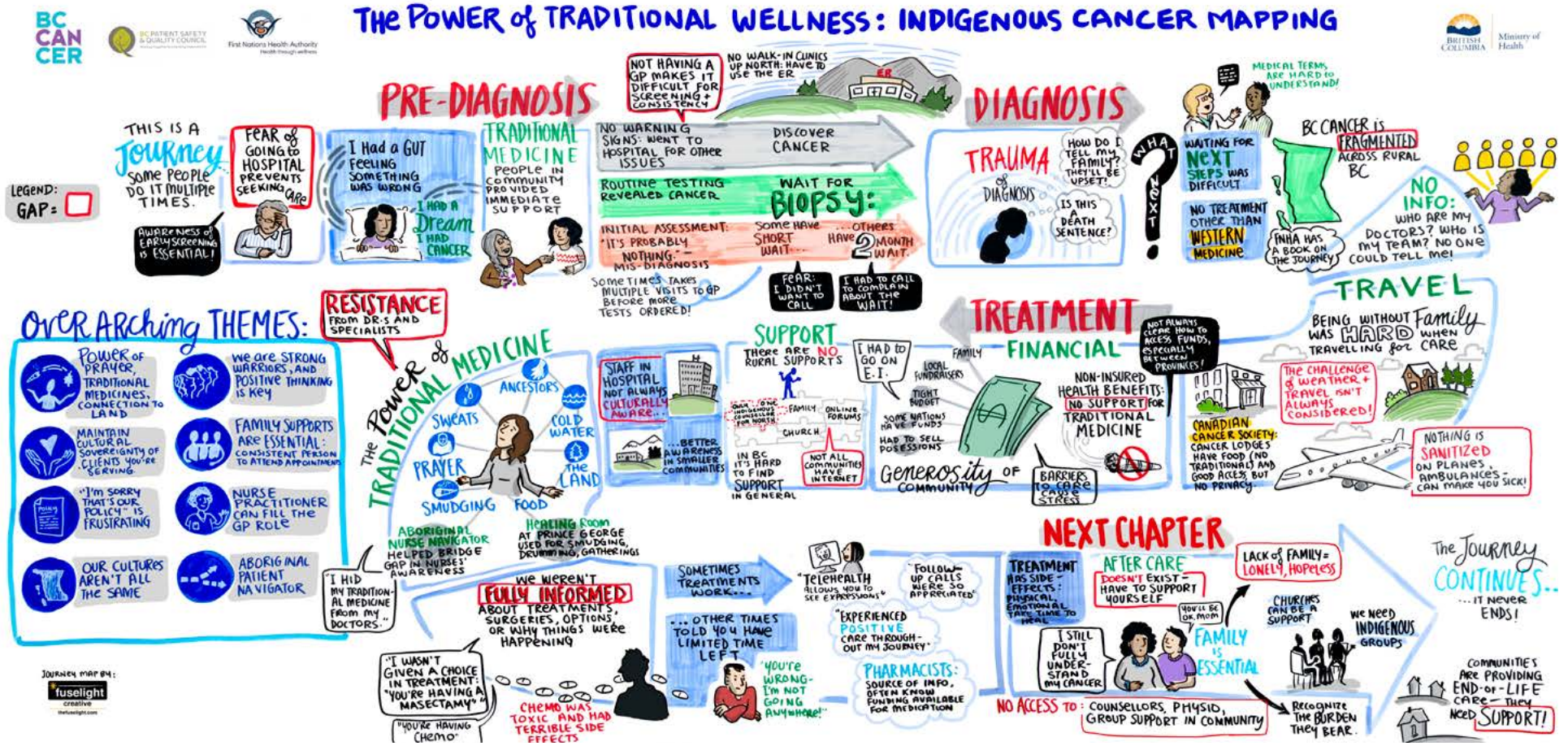
associated with various aspects of the care they received.

The patients' experiences were combined into a single, visual representation of their experiences. The patients' journey is depicted by a yellow "path" highlighting the different phases of cancer care.

Overarching insights that emerged from the discussion are listed on the left in blue. A legend, written at the top, identifies points along the patients' journey where there is a gap in services (red), a potential solution (blue), a key referral (green) or a significant barrier (purple) exists.



Indigenous Patient and Family Partner Map – November 2018



This map was created by asking patient partners to walk us through their cancer care journeys from pre-diagnosis, through diagnosis to treatment and into the next chapter. Participants provided detailed descriptions regarding their medical journeys as well as

insight into traditional approaches to wellness and traditional medicine in relation to cancer care. Participants also shared the emotional and psychological impacts of the journeys on themselves as well as their families and communities.

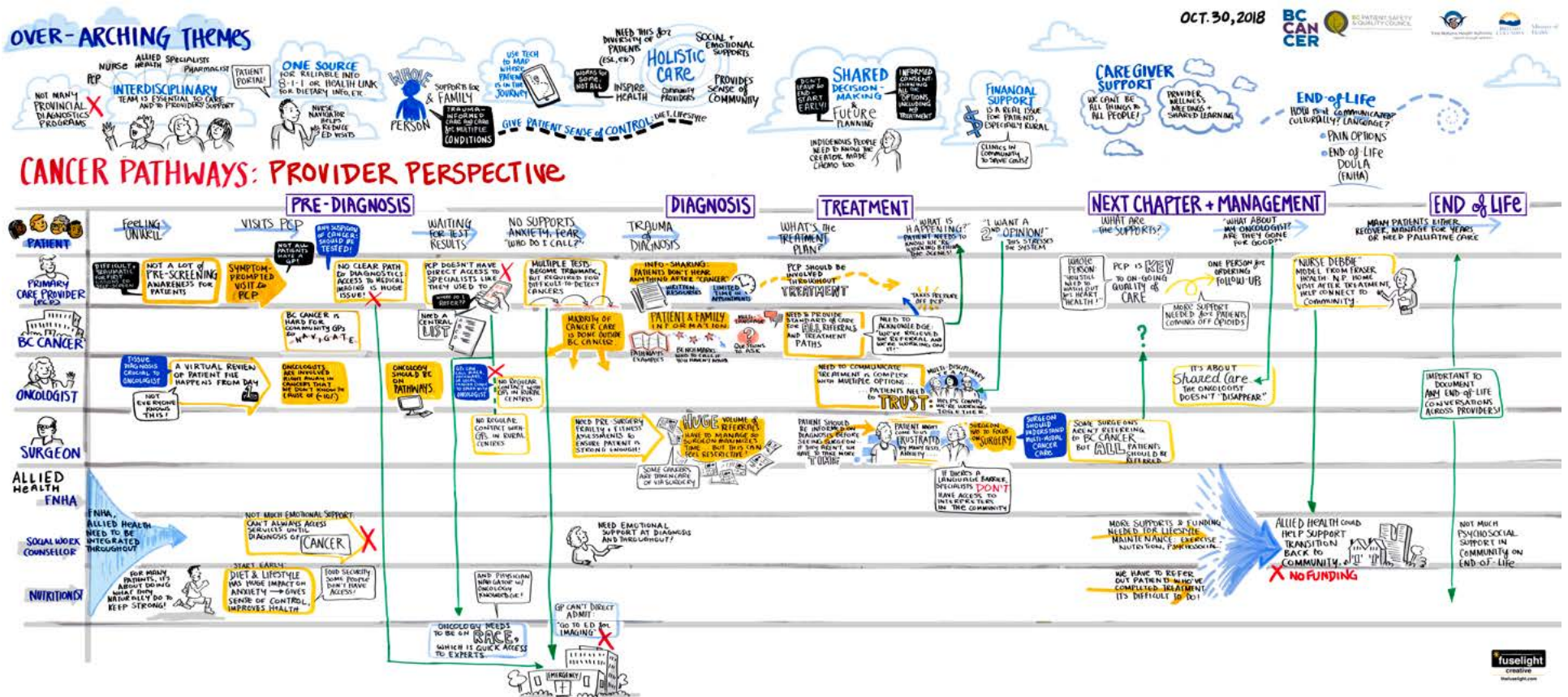
The map's key phases in the journey are depicted by a blue "path" through the different phases of the cancer journey. Overarching insights which emerged from the discussion are listed on the left in blue. Gaps in the system are identified in red.

Health Care Provider Map – October 2018

A “swim lane” approach was used to document the perspectives of health care providers. Each lane on the map represents a different provider’s perspective. The conversation began by asking primary care providers (PCPs) how they worked with patients when they first suspected the patient had cancer or found cancer due to a screening process. The conversation first explored specifics around how patients were referred to different

providers and programs, and then explored diagnosis, treatment and end-of-life care. Overarching themes and key insights based on input from the various providers are listed at the top of the map.

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Themes from the Maps

Eight themes emerged which were consistent across maps and highlight gaps, barriers and opportunities for improvement within the system.

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THEME 01

Both patients and providers are frustrated by the inconsistency and/or lack of communication as patients move through the system

“I had a FIT test and physical in November and received a letter from the Cancer Agency that my levels were approximately 30 times higher than the upper threshold value. I went to see my GP and was told my case was now under BC Cancer and my GP has nothing to do with it. Eleven months later I had a colonoscopy. I had a lot of mental distress.”

- Patient Partner

Patients said they feel anxiety and stress when care providers do not communicate well with each other. Patients were often not given a timeline for when they would hear back from various providers (“*Don’t phone us, we’ll phone you.*”) or how long it would take to complete tests and receive results.

There were multiple accounts from patients waiting weeks or months to get a confirmed diagnosis, which heightened their feelings of anxiety and not being in control of their care. Patients were frequently unable to find out where they were in the line-up for tests or results despite multiple efforts to find this information.

When patients had questions about side effects or treatment plans, some cited little guidance as to who to connect with about these questions. Many patients wanted to spend time with a nurse to talk about their concerns but often there was no nurse available in person or by phone.

“Open-ended waiting makes me crazy. I become foul, aggressive. It’s a swirling vortex of emotional crap. Standing in front of someone, advocating for myself, is the only way I know how to. You have to be demanding, boisterous, almost un-Canadian.”

- Patient Partner

“The oncology team in Terrace was amazing. I am grateful for them. They went above and beyond.” -

Patient Partner

“My doctor referred me to the surgeon. The surgeon asked if I had a biopsy, and I said, ‘No, that’s why they sent me here.’

He said, ‘The radiologist does the biopsy, so you need to ask him. I’m going to write down on a sheet of paper, you’re going to walk across the hospital, and you’re going to stand in x-ray until you get an appointment.’

Ten days later, I had the biopsy.”

- Patient Partner

Many patients did highlight that once they had a confirmed diagnosis, their care moved quickly, particularly at BC Cancer. Patients had very positive experiences when their treatment plan was clearly laid out and well-communicated. This positive experience had a lasting impact on subsequent aspects of their care.

Providers echoed this sentiment, saying that when a patient has experienced a long wait or when their diagnosis journey has not gone well, *“The patient is so traumatized and that never goes away. I spend more of my time with them trying to reassure them and build trust in the system.”*

Providers mentioned that in some of their practices they told patients when they will hear from their clinic and providing this timeline has reduced follow-up phone calls by patients wondering when they will hear back from the system.

Patients voiced how they were often given inconsistent information from various providers, there did not seem to be a standard way of receiving care in the system, and there was an overall lack of care coordination. Providers echoed this sentiment, saying that some physicians like certain tests to be done in advance of seeing the patient, while others order the tests once they see the patient.

“The Cancer Agency stepped up, worked through lunch hours, after hours, to get me in shape before my 35 consecutive days of radiation and three weeks of chemo. It was like a conveyor belt, which is good because that means they know what they are doing.”

- Patient Partner

Patients also noted that there is no standard way of receiving the diagnosis. Some patients received their diagnosis from their GP in their office, while others received it on the phone or heard it from a specialist.

“I need access to dedicated people with rapid access to quick advice because I have a test result that has scared me. So, what are my next steps?”

- Provider

“I got to my friend’s house and I received a call and he (the doctor) said I have cancer. I was at my friend’s house, but what if I was driving on the road when I got the information? Or on the phone while living alone?”

- Patient Partner

Providers agreed that there should be a more standardized approach across all physicians/NPs when referring a patient to a specialist, including providing a complete medical history with the referral. Providers voiced that there is a lack of consideration for how sick someone is when expediting their need for further testing.

Some providers tell patients to go to the emergency department to get diagnostics done (“It’s a workaround that everyone is doing out of necessity.”) because of the wait for diagnostics. Other providers are able to expedite a patient’s testing based on personal relationships they have with specialists.

Diagnostics are typically only available five days a week, which does not help ease the backlog. Patients voiced concerns about why diagnostic

tests were not done seven days a week when machines are sitting idle and patients are waiting. Operating rooms also mostly operate only five days a week, which limits the number of cancer surgeries that can be done.

GPs noted that as they have lost their hospital privileges, they no longer have a personal connection with the specialists, which GPs thought left them unable to expedite care for a patient. GPs mentioned that they want to be able to talk to an oncologist to get advice about how the referral should proceed when they are concerned about a patient. Patients also wanted to know what number they should be calling when they had questions, as this information was often missing from their discharge or treatment instructions and no one was coordinating their overall care.

Providers suggested that including oncology as part of Rapid Access to Consultative Expertise (RACE)ⁱ would help PCPs ensure that referrals were being made to the appropriate place. Access to RACE would also ensure that PCPs offer the latest treatments to patients which they may not otherwise be aware of due to rapid advances in cancer care. Also, ensuring that GPs were using the Pathwaysⁱⁱ system would help them make referrals to the appropriate specialist.

CHANGE IDEAS

Communicate expected wait times and potential treatment options to patients at every step of the journey.

Create consistent referral processes to ensure all GPs know what tests need to be completed before seeing a specialist.

Create consistency in where, when and by whom patients are given their diagnosis.

Provide patients with an information guide and outline next steps to help them process their diagnosis.

Develop a system for care coordination which works with patients as they go through the cancer process.

Add oncology to RACE.

Promote the use of the Pathways system to GPs for making oncology referrals.

Provide diagnostic imaging and surgery seven days a week.

ⁱ RACE is an innovative model of shared care where primary care providers can call one phone number and choose from a selection of specialty services for real-time telephone advice. In the model, the telephone call is routed directly to the specialist's cell phone or pager for "just in time" advice.

ⁱⁱ Pathways is a web-based directory that connects family doctors and specialists to streamline referrals. Pathways was developed by the Fraser Northwest Division of Family Practice, where it was piloted successfully and found to offer genuine solutions to GP-specialist referral issues. Through a password-protected portal, GPs can see the accurate wait times for each specialist on the Pathways system. There is work ongoing to enable electronic referrals through Pathways but at this time, it is only possible to see the wait times for each specialist registered in the system.

THEME 02

The current system is not operating in a shared care model, placing the onus on patients to coordinate their care.

“I really think people are doing the best they can with what they have. Everyone isn’t communicating. I was expected to keep the thread of communication, but I didn’t always. I was 32 and had a lump. The GP said I was young and it was probably an ingrown hair.”

- Patient Partner

Throughout the mapping sessions, patients expressed frustration and shock at how much they would need to advocate for themselves and coordinate their own care. Patients were particularly troubled by the transition between their PCP and specialists, and noted that they needed to repeatedly inform their PCPs about their care. Furthermore, there is a gap in the system to support patients with providing organized and consistent care coordination.

As one patient said, “I have to take 100% responsibility for my care.” This ties in closely to the first theme regarding a lack of communication. Providers noted that strong communication is needed to determine which health care provider is coordinating the overall care. This is particularly important when patients are transitioning from one health care provider to another. The patient is the only person at every appointment and is often expected to carry information between providers.

“Unless the oncologist lists the potential impact of the treatments, the GP won’t know to look for them.”

- Patient Partner

“A care plan gives the opportunity for information triggers.”

- Patient Partner

When patients are discharged from their cancer care team, they often return to the care of a PCP who has not been kept up to date with their care. Patients told stories of their discharge reports not being sent, being sent to the wrong doctor, or signing up for clinical trials because they wanted to stay connected to their oncologists. Patients were worried that PCPs would not know what to look for in their post-treatment if they were not given a proper continuing care plan. Patients advocated that a checklist should be given to PCPs, so they would be aware of the treatment that patients had received, and what to look for regarding ongoing care and side effects – including long-term side effects which patients may experience many years after their treatments.

“A lot of our people don't complain and that scares the hell out of me because they just get shuffled around like nothing.”

- Lisa Bourque Bearskinⁱⁱⁱ

One of the risks of not having centralized care coordination is how, when patients do not advocate for themselves, or are unable to, they can often be left with many unanswered questions. Due to historic and current negative encounters with health care professionals, some Indigenous patients said they do not feel comfortable questioning, or advocating for, their care.

ⁱⁱⁱ Please note, this patient requested to be identified in this report and signed a consent form to this effect.

“[BC Cancer] never impressed on him the need to meet with his GP. He died of heart attack one-year post cancer surgery.”

- Provider

Providers wanted to stress the importance of keeping the PCPs in the circle of care for patients as they move through the cancer system. Providers said that the cancer system is looking after the patient from a cancer perspective, whereas a PCP is still responsible for the rest of their care. Regular screening, immunizations, and check-ups should continue to be done by the PCP.

It must be acknowledged that many patients do not have a PCP, which creates a major barrier in being able to receive continuing care between a specialist and a PCP. In the Indigenous session, one-third of participants did not have a PCP and others would soon lose theirs as their providers were close to retirement. As one patient said, *“I didn’t have a GP to loop back to after. I’m completely alone now.”*

Patients indicated that the discharge back to primary care felt *‘like jumping off a cliff’* as they were concerned there would be no continuity of care from their cancer team to primary care. Some NPs in the community are trying to fill the gap by providing ongoing follow-up care to patients with cancer once their acute treatment with the oncologist is complete.

Providers were resounding in their support of a shared care model for patient care to better support patients. A true team-based approach to care would allow each provider to know their role throughout the journey and help to increase trust with patients. Providers mentioned the increasing frequency of interdisciplinary care conferences for complex cases and the value that they provide both the health care team and patients and families. Some patients voiced the need to have more decision aids available, rather than general cancer information, to help inform decisions about treatment options. A good example of interdisciplinary care came from several patients who had excellent relationships with their pharmacists, who worked with the patients' care teams and found ways to cover medications for them when the costs became prohibitive.

Providers suggested that having a patient portal available would *“revolutionize the patient experience.”* A patient portal would allow patients to see their cancer journey, where they were at in the stages of treatment as well as their appointments, reports and images. It may also open the opportunity to explore virtual appointments with providers, thereby reducing the need for patients to travel to all appointments.

“I was so impressed by the Indigenous patient navigator in the hospital. She was amazing.”

– Lisa Bourque Bearskin

Patients also raised the idea of having a way to track where they were in the health care system. Just like one can track a package sent in the mail, patients wanted to be able to see where their case was in the queue at each point in the journey.

The role of a patient navigator (sometimes called a nurse navigator or system navigator) came up in every mapping session. Some clinics have already implemented the role of the patient navigator which ensures that the proper connections and treatment are being provided for the patient.

In many cases, a navigator has allowed patients to move through the system faster and, as one provider stated, *“Nurse navigators are life changing.”*

CHANGE IDEAS

Create a way for patients to track where they are in the cancer journey system. Patients want to know that their case is being processed, even if there is going to be a wait time.

Ensure every patient and their PCP is given a continuing care plan with triggers for what to look for post-treatment.

Encourage the widespread adoption of patient navigators in the cancer system.

Develop a patient portal for patients to track their appointments, progress and treatment in the system.

Ensure all patients know the importance of continuing to see their PCP for their health during their cancer treatment and upon discharge from their cancer team.^{iv}

Create mechanisms to support true shared care models to support patients, including GPs, NPs, specialists, nursing, and allied health professionals.

^{iv} It is recognized that attachment to a PCP remains an ongoing issue for many patients in BC and there are strategies working on this issue in the province.

THEME 03

Cultural safety and humility is critical to wellness of Indigenous patients

“Every time I went to the room where they did the radiation, I closed my eyes. Every time I closed them, I could feel my ancestors with me and supporting me.”

- Patient Partner

Indigenous patients and their families noted that the importance of the role of traditional wellness and healing in their cancer journey cannot be overstated. Indigenous patients repeatedly referenced the support received from ancestors and families as well as their belief in the significance of spiritual practice in helping stay positive and resilient throughout treatment.

Many patients identified specific practices such as sweats, connecting with the land, being brushed with cedar, praying with Elders, taking cold water baths and using traditional medicines as practices which were important in supporting their health and wellness.

Patients identified how important it was to include their families in their cancer journeys in order to gather strength and positivity to make it through the treatment. For many, family members were advocates in the system, while others relied on families to ensure they were given traditional foods known to provide strength.

“We had a family sweat. We prayed at every meal. The prayers really work in helping to stay positive.”

- Patient Partner

“I ended up not communicating with my health care team about the traditional medicine I was taking. There was a serious side effect of my silence. With radiation, I used bear fat to keep my skin moist, but I was starting to burn. The nurse said, ‘You’re not using cream?’ and I said, ‘No, I’m using bear fat.’

Bear fat wasn’t good because it was actually intensifying the radiation and I ended up getting a permanent burn on my lung.”

– Lisa Bourque Bearskin

Many patients noted they used traditional healing to support their chemotherapy and radiation treatments, and some who did chose not to disclose it to their health care providers. Patients thought they were typically not supported by providers in conversations about traditional healing and many had experiences where they felt judged and, therefore, remained silent.

There can be significant risks to patient safety when patients feel they must stay silent about their use of traditional healing and medicine when also receiving Western treatments. Patients also noted that one cannot just take traditional medicines like you would a Western therapy. Traditional medicines must be incorporated into a system of beliefs and closely integrated with spiritual practices in order to be effective.

“The doctors scared me. I had a whole case of medicine from my aunties. I used it a few times, but the doctors said it might interact with my (Western) medication so it’s been sitting in my fridge for the past six months.”

- Patient Partner

Indigenous patients had a variety of experiences of being supported in their decisions to incorporate traditional wellness and healing into their care. Some were unaware that they could discuss traditional wellness with their health care provider, while others had to push and advocate for these practices to be included in their cancer treatments. For example, one patient was able to include smudging before each chemotherapy treatment.

It was identified that many hospitals and cancer centres have spaces where traditional wellness and healing practices such as smudging can take place, although patients were not always aware or told of them. An Indigenous patient navigator is often familiar with how to access these spaces and can help support patients in their traditional wellness and healing needs.

Several patients also noted instances of discrimination as well as problematic experiences around identification as an Indigenous person, in particular, during registration and check in for treatment. For instance, a patient wanted to identify as Cree-Métis, however the registration form did not list Cree-Métis as an option.

Many patients were interested in traditional wellness and healing and having these conversations with their health care providers; however, the process of self-identification and then discussing how health care providers can provide Indigenous specific supports can be problematic.

There is considerable opportunity to ensure that Indigenous patients are treated with dignity and respect in every encounter with the health care system. Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances in the health care system. Cultural humility is the process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Ensuring that all patients have the opportunity to integrate their belief systems and traditional approaches to medicine and wellness in clinically-safe ways would be a good outcome of culturally-safe care.

CHANGE IDEAS

Support Indigenous patients and health care providers in having conversations about the integration of traditional wellness and healing practices while receiving cancer treatment.

Ensure all health care providers have received training in cultural safety and humility.

Support organizational-level changes that support cultural safety and humility.

Provide Indigenous patient navigators to those going through cancer care to support the incorporation of traditional practices into their care.

THEME 04

Social and emotional support is integral (not just nice to have) to supporting patients and their families through cancer

“My sister-in-law found my suspicious mole when we were at the beach. When I heard the diagnosis ‘Melanoma Stage 1’ on the phone, I went numb and I stayed that way until after my surgery. The ‘all clear’ phone call didn’t bring me jubilation. Instead, all the stored-up emotions started pouring out. In crisis, I drove to the Canadian Cancer Society and asked for help. They told me to go across the street to BC Cancer and I got help there.”

- Patient Partner

Patients and providers were emphatic that patients and their families need social and emotional support throughout their cancer journeys. Patients discussed how the word “cancer” has been “demonized” in our society and is still often associated with death. This causes patients to immediately be fearful of receiving the diagnosis.

Patients recalled how traumatic the diagnosis was not only for them, but for their family and friends too. For some, they did not know where to turn for help, while others connected to Patient and Family Counselling through BC Cancer, their First Nations community or Elders for support. Patients repeated that they needed support and to know who to connect with before and after diagnosis, as well as during and after treatment.

“If you have cancer, you’re going to have anxiety, so you just deal with it. Seeking regular emotional support isn’t what people normally do. I did a cancer chat with a counsellor in Victoria, and I really felt like she [got] it. She knows what it feels like.”

- Patient Partner

“PTSD – you are never post. There is always some trauma. I call it my two-month horizon, when my next CT scan is. I have to plan my life around that short horizon.”

- Patient Partner

Patients mentioned that even after treatment is over, there is a lingering concern and worry about recurrence. Some patients found various services to be particularly helpful in providing support, such as BC Cancer Patient and Family Counselling, programs run by not-for-profit organizations and connecting with online peer groups who were experiencing the same types of cancer.

Other patients identified a significant gap in the emotional and social supports that are available once they finished treatment and many said they could not find them. Some Indigenous patients mentioned that there are few support services available in their communities.

“It’s hard to ask my family for support. I didn’t grow up with them because I grew up in a foster home. I stick to myself pretty much. It would be nice to have counsellors for cancer patients in different (First Nations) communities. There are quite a few people in my community that have cancer.”

- Patient Partner

Providers indicated that patients want to feel ownership over their health and that giving them key activities to work on related to diet, exercise and lifestyle changes can often help put them at ease when they are first diagnosed. Providers often hear good feedback from programs not offered in the health system, including programs run by not-for-profit organizations, which offer supports related to lifestyle.

Physicians noted that *'they can't be all things to all people'* and don't always have the proper amount of training to support patients' social and emotional needs. As cancer rates rise, providers increasingly feel the impact of the lack of emotional and social supports in their practices.

Physicians (GPs, oncologists and surgeons) often spend time in their appointments on the emotional needs of patients, rather than their medical needs. Patients may be better

"I often spend the first 15 minutes of the appointment dealing with the anger or trauma from how their diagnosis went...I don't have the skillset for the emotional support."

- Patient Partner

served by someone who has specific training in that area such as a social worker, counsellor or nurse navigator who can better support the patient.

Patients and providers also highlighted how little support is available to family caregivers to help them cope. Many patients were struggling to find supports for their partners, children and extended family following their cancer diagnosis. Cancer affects more than just the patient receiving care and the family care providers' needs are often forgotten.

CHANGE IDEAS

Ensure that patients are connected to (or at a minimum, aware of) social and emotional support services from the beginning of their cancer journey (before/at diagnosis) to ongoing support after treatment is completed.

Integrate emotional and social support into all stages of cancer care to ensure patients are receiving support from a health care provider with the appropriate skillset.

Ensure patients are aware of supports available to their family members to help them deal with the emotional impact of caring for a family member with cancer.

THEME 05

Patients in rural settings face logistical and financial challenges when accessing treatment

Both patients and providers noted the inequality in access to cancer care across the province and the greater financial burden suffered by patients who live in a rural community. Patients must travel further for care and are often away from their home communities and families for long lengths of time. Patients noted that there were even fewer emotional and social supports available to them when they live in a rural community.

Providers advocated for more clarity regarding what can be done in a patient's home community and what care needs to be provided away from home.

Indigenous patients highlighted how far they had to travel to receive care. Patients shared that they had to make daily and weekly trips to regional care centres which were hours away, and some had to move to a different city and live alone in order to receive care. This travel can create a significant financial burden. For some Indigenous patients, their communities were able to fully support the cost of travel, while others did not have any community support and were left to pay these costs themselves.

One rural patient had a particularly discouraging journey through the cancer system:

“We went to Kelowna on August 30, thinking we would be back in a week. I went home on May 11. We were away from home for nine months.”

No matter where you live in BC you should still get the same treatment anywhere...Is it possible to get all the information and get the treatment close to home? The oncologist told me, ‘No it’s not possible, you have to be at the cancer centre to get chemo,’ and I [found] out later that’s not true. I found out nine months later. The radiation has to be at the centre, but the chemo could be at home.”

- Patient Partner

“I almost lost my house.”

– Lisa Bourque Bearskin

“My husband was able to hold down the fort. My band is fortunate economically, so they helped us out.”

– Patient Partner

“Most of my family was working. Sometimes I would have to drive myself to chemo. I had to pull over to the side of the road because I didn’t know what I was doing. It was quite an ordeal for me.”

– Patient Partner

“People used to go to Grand Prairie, Alberta which was 1.5 hours away. Now it’s been cut off. So, the closest place was Kelowna.”

– Patient Partner

Patients needing to raise funds to support themselves through treatment was a common theme. Some received help from community or workplace fundraisers. One patient mentioned recruiting help from their networks on Facebook to help them pay for their living expenses while in treatment.

Cancer lodges run by the Canadian Cancer Society were identified as good accommodation options when needing to travel. Unfortunately for those who had limited funds, even these accommodation options were too expensive.

The impact on patients having to arrange travel to receive care was a theme amongst patients from rural or small towns. Some told of experiences hitchhiking to appointments or putting a call out on Facebook to find rides to get care, while others drove themselves when they probably should not have. Others mentioned shuttles could take them to a regional cancer centre from their town but doing so made for an exceptionally long travel day and was difficult given the effects of the treatments.

A patient from Northern BC noted that up until a few years ago, patients were able to travel to Alberta to receive care, which was much closer than many BC care centres. Patients noted that changes in policies meant that they are no longer able to access services in Alberta, which has resulted in longer travel to receive care.

Providers echoed this sentiment and indicated that intermittent mobile clinics which could travel to rural communities may be less costly to the system than having patients travel to a central location.

Patients noted how wonderful their experiences with Telehealth had been. They appreciated being able to view the physician on the screen and see their reactions and emotions. They also appreciated having this service available as it alleviated the need to travel for appointments.

Providers also noted that primary care providers in rural communities need to be better supported to help those with cancer. For example, providers mentioned that once a GP or NP has a suspicion of cancer, there should be a way to directly connect with oncology expertise so that they can begin to counsel the patient more effectively from the first steps in the process.

CHANGE IDEAS

Ensure that all providers in rural communities know what cancer treatments can be given in their home community versus a BC Cancer centre.

Continue to expand Telehealth access around the province and in First Nations communities to support person- and family-centred cancer care.

Develop mobile clinics for specialists to visit rural communities.

Support rural family physicians and nurse practitioners, possibly through a mobile app, technology, RACE or rapid access to oncology expertise through BC Cancer, to allow them to better support their patients from the beginning of their diagnosis until the end of their cancer journey.

THEME 06

Patients desire a whole-person approach to care

“My oncologist said, ‘Tell me about you, not your cancer, who you are.’

I’m so grateful for that. It was profound for me as a person.”

- Patient Partner

“The thing that really frustrates me, is that I made a list of questions on the day I started chemo, but I never got any answers. In general, they don’t want to stress you out so they are controlling your access to information because they don’t think you can handle it. I don’t think that’s their decision to make.”

- Patient Partner

Patients want to be seen as a whole person, rather than a file number or simply a case to be treated. Patients felt that they were often being treated with a “cookie cutter approach” rather than being seen as a unique individual.

Patients want to help direct their own care. In many cases, information was withheld from them in order to decrease their anxiety about the treatment. In reality, patients were vocal that this only increased their sense of worry.

Patients want to be asked about how much they would like to know at the start of every care experience. While some will want to know everything, others will want to know little or need more time to process information.

Patients recognized how overwhelming it can be to receive all the information at one time and suggested “giving information to patients in digestible chunks.” Providers were aware that “once you tell a patient they have cancer, they don’t hear anything after that” and, therefore, patients needed to have written instructions or another appointment to help them process the information.

“I was in so much pain. [The oncologist] was asking me questions and I just started to cry. He started to cry and we both cried. I was so devastated of what I was going through. I thank god for the people that have compassion.”

- Patient Partner

“I want to have enough information to make an informed decision. In my treatment, I wasn’t given the choice. I felt information was being withheld from me.”

- Patient Partner

“If you tell me the clear picture, and that picture is grey, at least we’re both working in the grey.”

- Patient Partner

“True informed consent includes all options, including no treatment.”

- Provider

“Often family members will filter the information they are telling their loved one. They are not always 100% honest that they have cancer.”

- Provider

Patients were clear that even if their providers were unsure about the exact course of treatment, they wanted to be presented with all the “grey areas” or options and know that they were going to figure it out together.

Providers acknowledged that giving patients information and receiving true informed consent was imperative to excellent patient care and a way to build trust between patients and providers. This includes discussing the option of not receiving any treatment and difficult topics such as end-of-life care. Only when patients have the full picture of information are they able to make truly informed decisions about their care. Some patients noted a lack of decision aids when they were trying to make choices about their care.

Providing whole-person care means acknowledging past cultural traumas and offering care that is culturally-safe and trauma-informed. As one provider mentioned, many Indigenous patients have had negative experiences with institutions and are fearful when entering the cancer system. Use of language such as “survivor” can be very upsetting to Indigenous people as it can be a trigger relating to residential school trauma. Overall, the patient partners highlighted that part of providing culturally-safe care involves honouring Indigenous spirituality, traditions, beliefs and history.

Providing whole-person care also includes ensuring that patients understand the information in their language of choice. Patients and providers worried for patients who could not speak or read English. Some health care institutions are built with English-only signs, and patients mentioned seeing other patients looking “glazed over” while walking around BC Cancer, as they could not read the signs. Providers stressed the importance of having professional translators, not just family members, present when delivering health information. Providers noted a dire shortage of translators in the community to support patients. Translation services are now available to GPs through the General Practice Services Committee, however, specialists do not have the same access.

Patients also mentioned that they do not always understand written information and look for alternative tools such as videos. Providers suggested creating a video outlining what patients should expect when they come to BC Cancer as a way to help patients understand the system and ease their anxiety about treatment.

“They gave me pamphlets but it’s hard for me to read and understand. I go on the Internet and see if there are any videos of people talking instead of me reading. It’s just hard because now I don’t know much about my cancer.”

- Patient Partner

Providers mentioned that a lack of funding for allied health within home and community care services greatly limits the care that they are able to provide to patients in the community once they are home. For example, there are limited supports for patients who are receiving cancer treatment and require a feeding tube. Providers noted that an increase in support for home and community care would allow for extended patient care in the community.

CHANGE IDEAS

Receive true informed consent from all patients, including discussing no treatment and end-of-life planning.

Ensure that patients are receiving culturally-safe and trauma-informed care.

Ask patients how much information they want to know about their care and provide it to them in easy-to-understand chunks.

Provide patients with written care pathways of what to expect along their care continuum.

Ensure all patients have access to a translator where and when they need one.

Create a video outlining what patients can expect at BC Cancer to teach them about their care and ease their anxiety about receiving treatment.

Increase funding to home and community care to be able to fully support cancer patients in the community.

THEME 07

A sense of trust is often missing in the patient-provider relationship

As a result of the patients' experiences, there was a general sense of mistrust in cancer care and in the health care system as a whole. Providers emphasized that when a patient has not had a positive experience early on, there was often a palpable sense of mistrust that had repercussions, particularly in how patients and providers communicated with each other going forward.

For instance, providers indicated that an oncologist reviews every file that goes to BC Cancer within 24 hours of receiving a referral, but this practice is not commonly known by patients and providers in the system. From a patient's perspective, all they know is that they have been referred to an oncologist and they hear nothing back from the system for a long time. Providers thought it may help to build trust if patients are notified that their file is reviewed within 24 hours of receipt.

Indigenous patients raised concern that some health care providers and hospital staff did not always provide culturally-safe care and that interactions with these staff were negative. When patients filed a complaint, they felt they were subsequently punished by the staff. These experiences further fueled mistrust between patients and providers.

Patients were frustrated with the lack of avenues to address problems with their health care team. Patients want to connect with their health care team and make decisions together; there were instances, however, where patients and providers did not get along. Several patients raised concerns that the only way to be assigned to another oncologist was to talk to their current provider. Patients said they had a "fear of not being treated" and felt awkward raising the issue of switching care providers directly with their current provider.

"I asked if there are any other options (another physician available). He said, 'You can walk out that door.'"

- Patient Partner

Building trust comes through transparency and by ensuring patients feel that their concerns have been heard. Providers raised potential solutions such as offering to take a patient's file to an interdisciplinary care conference or a tumour review board when patients are not happy with the type of care they were experiencing or wanted to have multiple opinions regarding their care going forward. These types of approaches have been successful and may help to build trust between patients and providers.

CHANGE IDEAS

Raise awareness with patients and GPs that a BC Cancer oncologist looks at all referral cases within 24 hours of receipt.

Provide a way for patients to change specialists without having to speak with their current provider.

Offer interdisciplinary care conferences to patients if there are concerns about the current care plan.

THEME 08

There is value in creating environments or networks for patients and providers to connect and collaborate to improve the system

Patients mentioned that it was therapeutic and beneficial for them to connect with others who had experienced cancer. Some patients mentioned how crucial a peer support network (either in person or online) was during and after their treatment. In particular, some Indigenous patients mentioned how hard it was to find a support group that made them feel comfortable and welcome.

This mapping session provided an opportunity for support. Patients mentioned their appreciation of being able to connect with others who had been through the cancer system. The sentiment of the importance of having a venue to connect with other patients was echoed in the participant evaluations as well as comments made during the various reviewing periods of this report.

“I am currently on a clinical trials committee...It allows me to connect with others going through [cancer treatment].”

- Patient Partner

“We need a place to come together and talk about experiences. These experiences stay with us forever.”

- Provider

For providers, there are few areas where allied health, family physicians, nurse practitioners, oncologists and surgeons from different areas in the province can come together and talk about issues in care. Caring for patients with cancer is important and emotional work. This takes a toll on providers who may not have an outlet to discuss their experience with others.

Provider fatigue and burnout are real issues in health care and were mentioned several times during the mapping sessions. Providing opportunities for providers to come together to talk about their experiences, process the emotional impact of their work and facilitate improvements in the system would be hugely beneficial.

CHANGE IDEAS

Create a regular venue for patients and family partners to come together to discuss ways to improve the system.

Create a regular venue for health care providers from all points in the cancer care journey to come together to discuss ways to improve the system.

Create a regular venue for patient and family partners **and** health care providers to come together and discuss feasible solutions for the continual improvement of patient- and family-centred care.

Next Steps

The experiences of patients, family members and health care providers captured in this report provide a snapshot of the current state of cancer services between primary care and specialty cancer services in BC. Patients and providers offered valuable insight into where communication, shared care, social and emotional support, a whole-person approach and equity in services changes could make a real impact on how cancer care is delivered and experienced.

The knowledge gained through this process provides an opportunity to inform policy direction and future strategic and operational planning to help advance person-centred cancer care at the local, regional and provincial levels. Journey maps are not comprehensive illustrations of the current state; they are snapshots in time that explore the mindsets, emotions and experiences of the participants that are present at the sessions. Readers, whether they are patients, caregivers, policy

makers, administrators or clinicians, can consider them critically and reflect not only on what is included, but also on what may be missing. As such, these maps have the potential to be used as a starting point for further discovery.

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Appendices

Appendix A: Structure of the Journey Mapping Days

Patient and Family Partner Sessions (October 12, 2018 and November 20, 2018)

The patient and family partner journey mapping sessions were held on the traditional and unceded territories of the Musqueam, Squamish, and Tsleil-Waututh First Nations in Vancouver, BC. The Indigenous patient and family partner session opened with a prayer by an Elder participant in the group. In both sessions, the day started by setting the context for the work and having participants agree on the way they wanted to be able to work together.

Participants were then asked to share how they found out they had cancer. Over the course of the morning, participants shared their cancer journeys with the group. The conversation evolved quite organically with the facilitators and observers asking very few questions. The graphic facilitator themed the ideas and stories that were emerging from the discussion. Participants were encouraged to write additional information on sticky notes and provide them to the facilitator should they not wish to speak up. Many participants also shared different elements of their journey with the graphic facilitator during breaks. A Council staff member took detailed notes to capture specific quotes, programs, gaps or change ideas which emerged from the conversation but were too detailed to be pictured on the map. These notes have been used to provide additional information throughout this report.

As each mapping day progressed, themes emerged from the patient stories. Excellent aspects of care were identified, as well as gaps and possible solutions. By the end of the day, a graphic map (see Appendices C and D) had been drawn. The last portion of the day was used for patient and family partners to validate the map to ensure that the conversation was accurately captured. Despite the map being drawn in ink, revisions were made by placing white paper over different areas and making changes. After the session, the maps were digitized, validated and refined by participants via email to ensure their experiences were accurately reflected. The Indigenous patient and family partner session closed with a prayer circle with all participants and the facilitators.

Health Care Provider Session (October 30, 2018)

The health care provider session was also held on the unceded territories of the Musqueam, Squamish, and Tsleil-Waututh First Nations in Vancouver, BC. Three participants joined the session by video conference technology and the rest were in the room. The session took four hours.

Facilitators opened the day by setting the context for the work and having participants agree on the way they wanted to be able to work together during the session. Facilitators then walked through the patient journey maps so that providers had a sense of what transpired at the patient and family sessions and the barriers and opportunities identified by the patient partners. Providers had also been given a copy of the patient map in advance of the session. Providers noted that there was no mention of end-of-life or palliative care services on the map. It was noted that for many patients this may not have been part of their journey and this may be better captured from a family member retrospectively after someone's death.

Facilitators opened the conversation by asking the family physician and nurse practitioners, primarily, to describe their experiences with screening patients for cancer or determining if they have the disease. The conversation evolved organically into a discussion around wait times for diagnosis and to see different specialists. The conversation moved through the diagnosis and treatment phases of the journey, and to necessary supports once treatment is complete. Barriers, gaps in the system and opportunities for improvement were noted in various aspects of the journey and are fully explained in this report. The map can be viewed in Appendix E.

After the session was complete, a copy of the digital map was emailed to all participants and edits were made based on participants' comments.

Appendix B: Key Considerations

It is crucial to continually have the patient voice involved in the redesign of health care service delivery. It is extremely valuable to have the comprehensive story of an individual's entire journey – not only where they touched the health system and what services and care they accessed, but also their emotional states, unmet needs, feelings, experiences and perspectives on the system.

Journey maps capture the experiences and mindsets of participants on a specific day. As such, they are meant to be a snapshot rather than a comprehensive, validated landscape of existing services. Journey maps focus on capturing experiences rather than soliciting specific ideas for improvement or planning a future state. They are most helpful when utilized as a foundation for subsequent consultations and strategic planning sessions.

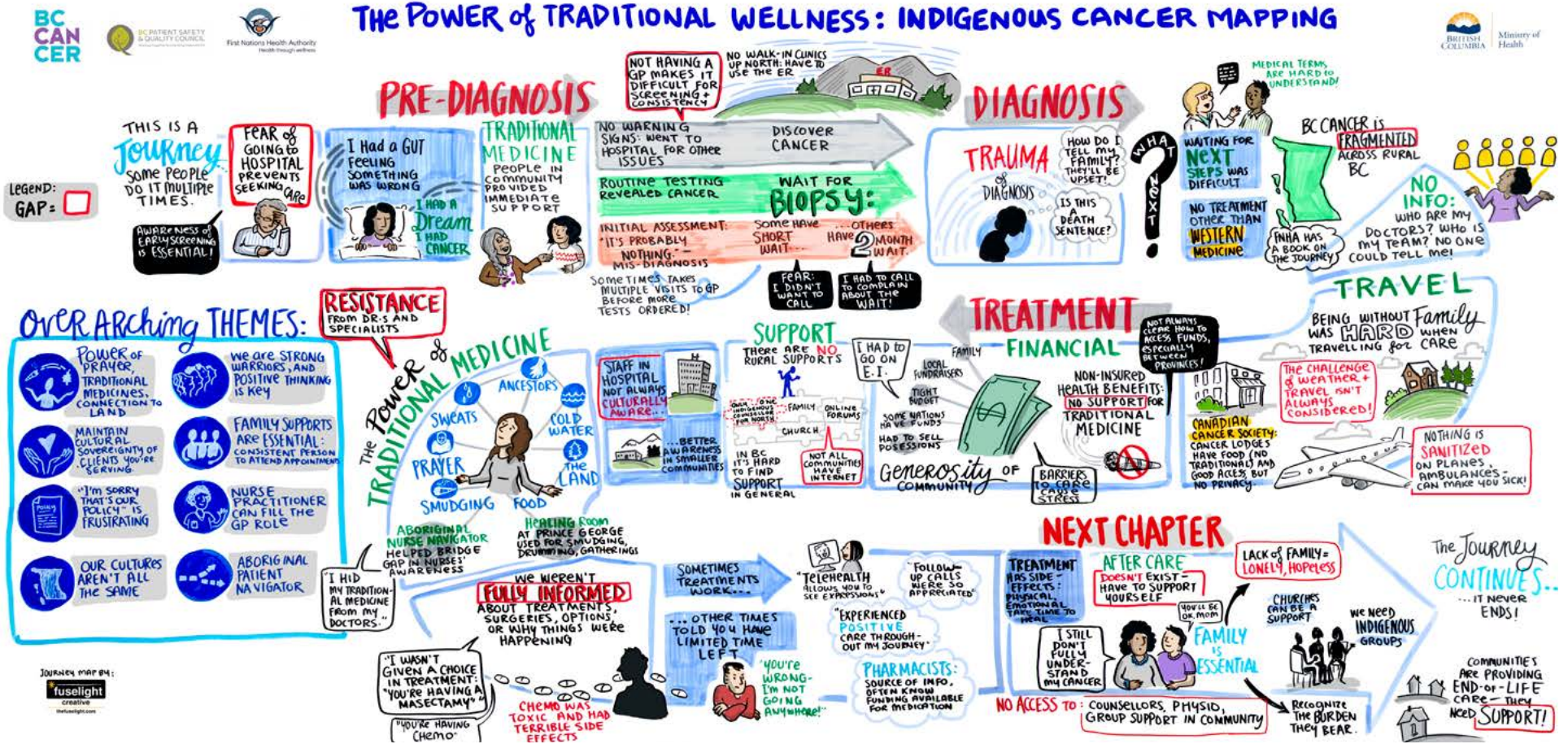
The language and content of the maps are reflective of the participants' discussions. As a result, terminology may be inconsistent or inaccurate. As a viewer, it is important to see each map as a unique perspective. Resulting questions about why certain elements were emphasized or excluded are valuable triggers for future consultations. For example, the experience of young people is absent from this report, as all participants were over the age of 18.

Appendix C: Cancer Pathways Patient Journey Map | October 12, 2018



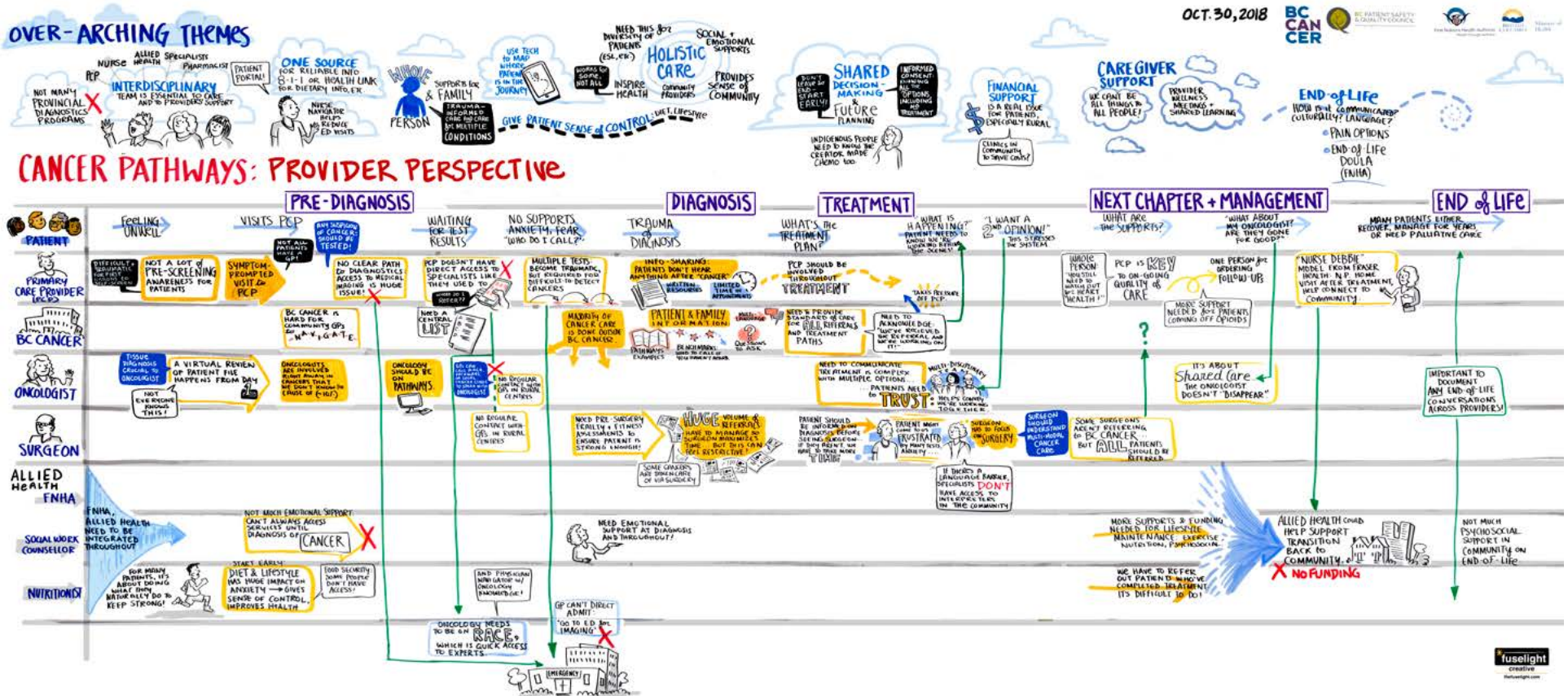
Download a high-resolution map from BCPSQC.ca

Appendix D: Cancer Pathways Indigenous Patient Journey Map | November 20, 2018



Download a high-resolution map from BCPSQC.ca

Appendix E: Cancer Pathways Provider Journey Map | October 30, 2018



Download a high-resolution map from BCPSQC.ca

