JOURNEY MAPPING **SUBSTANCE USE** TREATMENT

An Exploration of Health Care Provider and Peer Experiences in Delivering and Receiving Primary Care

BRITISH COLUMBIA | Ministry of Health
First Nations Health Authority
Health through wellness
BC PATIENT SAFETY & QUALITY COUNCIL
Working Together. Accelerating Improvement.
GPSC
General Practice Services Committee

Executive Summary

On April 14, 2016, Provincial Health Officer Dr. Perry Kendall declared a Public Health Emergency under the Public Health Act due to the unprecedented rise in deaths due to opioid overdoses in British Columbia (BC). While significant improvements in care have been made since this declaration, the number of people dying in BC has continued to rise. Improving access to appropriate and effective treatments and supports is critical to preventing overdoses before they happen. In order to increase the efficacy of primary care in addressing the needs of people who use substances, a shared understanding of how the current primary care system is experienced by both health care providers and patients/peers is required.

In the summer and fall of 2017, the BC Patient Safety & Quality Council partnered with the Ministry of Health, the Ministry of Mental Health and Addictions, the First Nations Health Authority and the General Practice Services Committee to host two journey mapping sessions to explore the current state of treatment options and support for people with substance use concerns in primary care settings – from both the health care provider and the patient/peer perspectives. Over 120 health care providers, patients and organizational representatives contributed to the creation of six distinct journey maps.

Each journey map reflects the steps, thoughts and considerations, feelings and emotions, worries and concerns, and actions of participants. Wherever possible, language accurately reflects that of the participants, and direct quotes are incorporated throughout. The following major themes emerged:

1. **Current care models don't always meet the full scope of peer needs** (treatment often does not fully address the cultural, financial, spiritual, physiological or social needs of peers).
2. **Both providers and peers felt lost or hopeless when navigating the current treatment system** (participants agreed that feeling lost and frustrated often led to avoiding or abandoning treatment).
3. **Trust is not always present between providers, peers and their families** (trust takes time to build but was noted as a key component of successful treatment).
4. **Access to treatment is not always available or offered when peers are ready** (low barrier, rapidly accessible treatment is often not accessible during key 'windows of opportunity').
5. **Current mindsets can perpetuate stigma and hinder access to treatment** (substance use disorder is not always seen as a chronic disease).
6. **There is significant variation in the type of care provided by treatment centres and recovery centres** (peers and providers said the variation in entry requirements and treatment protocols can make it difficult to feel confident in the effectiveness of the care being provided).
7. **Chronic pain is not always effectively addressed during treatment for substance use** (pain is often dismissed or not addressed, and non-pharmacologic options are not always offered).
8. **Strong communities are a key part of treatment and recovery** (providers and peers talked about the importance of connecting those in treatment with people who have lived experience with substance use, their families, community elders as well as cultural and community organizations).

Change ideas suggested by participants were also captured and are indicated alongside the theme they fit most closely within.

The knowledge and wisdom captured in these journey maps provides an opportunity for the perspectives of both peers and providers to be utilized as tool for future strategic planning. This can occur at the local, regional and provincial level to respond to the ongoing opioid overdose crisis and create a more effective and sustainable system for those experiencing problematic substance use.

Table of Contents

1 Executive Summary

5 A Public Health Emergency

6 Journey Mapping Experiences in Substance Use Treatment

The Value of Journey Mapping
Purpose
Scope
Participants
Structure of Journey Mapping Days
Key considerations

9 The Journey Map

Journey Maps – Primary Care Focus

- *Peer Journey Map*
- *Health Care Provider Journey Maps*

Journey Maps – Indigenous Perspectives

- *Indigenous Peer Journey Map*
- *Health Care Provider Journey Maps*

13 Discussion – Major Themes and Change Ideas

Theme 1: Current care models don't always meet the full scope of peer needs
Theme 2: Both providers and peers felt lost or hopeless in navigating the current treatment system
Theme 3: Trust and collaboration are not always present between providers, peers, and families
Theme 4: Access to treatment is not always available or offered when peers are ready
Theme 5: Current mindsets perpetuate stigma and hinder access to treatment
Theme 6: There is significant variation in the type of care provided by treatment centres and recovery centers
Theme 7: Chronic pain is not always effectively addressed during treatment for substance use
Theme 8: Strong communities are a key part of treatment and recovery

22 Next Steps

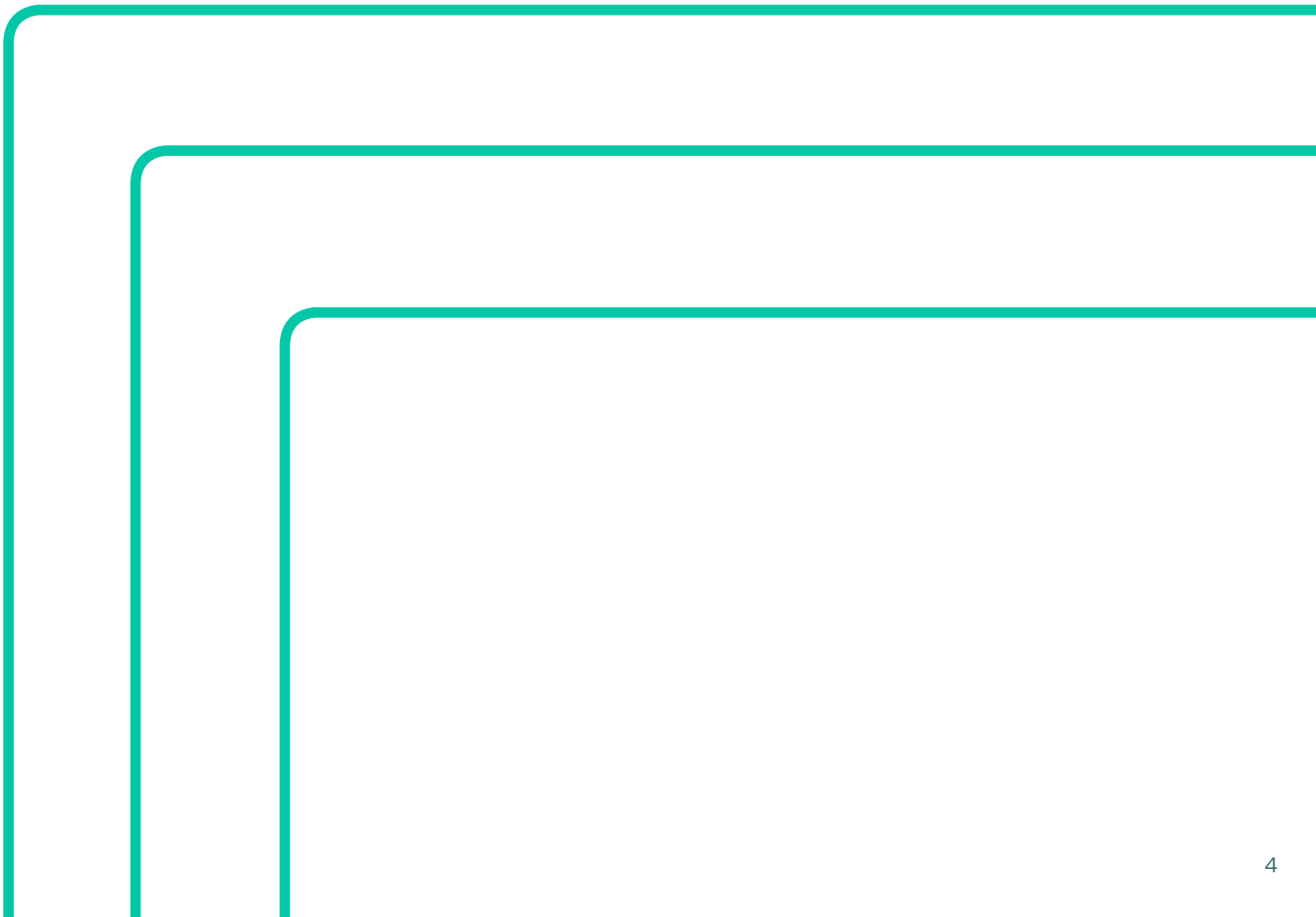
23 Reference List

24 Appendices

Appendix A: Substance Use Treatment Journey: Peer Experiences
Appendix B: Accessing Treatment: Provider Experiences
Appendix C: Primary Care Case Study: Provider Experiences
Appendix D: Overdose in the Park Case Study: Provider Experiences
Appendix E: Substance Use Journey: Indigenous Peer Experiences
Appendix F: Substance Use Journey: Providers Treating Indigenous Peers Experiences

Journey Mapping Substance Use Treatment

An Exploration of Health Care Provider and Peer Experiences in Delivering and Receiving Treatment in Primary Care



A Public Health Emergency

On April 14, 2016, Provincial Health Officer Dr. Perry Kendall declared a Public Health Emergency under the Public Health Act as a result of the unprecedented rise in deaths due to opioid overdoses in British Columbia (BC).

Despite significant efforts by people and organizations across the province to respond to and prevent overdoses and overdose deaths, the number of people dying from overdose in BC has continued to rise. In October 2017, there were 96 suspected drug overdose deaths – a 26% increase over the number of deaths occurring in the same month in 2016. To date, there have been over 1,200 illicit drug overdose deaths in BC in 2017[1].

	'91	'92	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10	'11	'12	'13	'14	'15	'16	'17
Deaths	117	162	354	308	217	301	300	400	272	236	236	172	190	183	230	229	202	183	201	211	294	269	333	269	519	985	1208
Rate	3.5	4.7	9.9	8.4	5.7	7.8	7.6	10.0	6.8	5.8	5.8	4.2	4.6	4.4	5.5	5.4	4.7	4.2	4.6	4.7	6.5	5.9	7.3	7.9	11.1	20.7	30.2

Figure 1: Illicit Drug Overdose Deaths and Death Rate per 100,000 Population in BC (data up to Oct 31 2017)[i]

Improving access to appropriate and effective treatments and supports is critical to preventing overdoses before they happen. In order to increase the ability of primary care providers and care settings to meet the needs of people who use substances, a shared understanding of how the current primary care system is experienced by both health care providers and patients/peers was explored.

[i] "Peers" is a preferred term for people with lived experience using substances (http://www.bccdc.ca/resource-gallery/Documents/PEEP%20Best%20Practice%20Guidelines.pdf). We will use the terms "patients" and "peers" interchangeably throughout this report, as both terms were used by the participants during the mapping sessions

Journey Mapping Experiences in Substance Use Treatment

The journey mapping process was designed to gather information to further understand the current state from both perspectives - not only what typically happens, but also to capture concerns, emotions, mindsets and beliefs. This information is critical to identifying strategic opportunities for improving the care. The purpose of this report is to share the findings from this process.

The Value of Journey Mapping

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 or process.[2] While there are a myriad of approaches, journey mapping is typically a collaborative process that asks participants to describe a personal experience as a series of interrelated steps that are captured visually on a common drawing space. Unlike process mapping, which focuses on capturing all possible steps in a process, journey mapping also focuses on the mindsets, beliefs and emotions that mark each step. This approach was selected as it enables us to explore how mindsets and belief systems interact with how we deliver and receive care, and results in a visual, easy-to-understand graphic illustration.

In addition to highlighting opportunities for improvement or change, journey mapping can identify the reasons or drivers behind why health care providers and patients behave as they do in the primary care system.

WHO ATTENDED?

JULY SESSION

27 health care providers

including family physicians; nurse practitioners; physician addictions specialists; emergency department physicians; paramedics; social workers; pharmacists & harm reduction workers

9 peers

with lived experience representing communities including Nelson, Victoria, Abbotsford and Penticton

18 organizational representatives

Including the Ministry of Health, Ministry of Mental Health & Addictions, Doctors of BC, Health Authorities, General Practice Services Committee, Specialist Services Committee and the BC Centre on Substance Use

Purpose

In the summer and fall of 2017, the BC Patient Safety & Quality Council partnered with the Ministry of Health, the Ministry of Mental Health and Addictions, the First Nations Health Authority and the General Practices Services Committee to host two journey mapping sessions to explore the current state of treatment options and support for people with substance use concerns in primary care settings – from both the health care provider and the patient perspectives. The first session, held in July of 2017, involved health care providers, peers and organizational representatives from across BC.

The negative consequences of colonization on Indigenous peoples have resulted in significant disparities in health outcomes. As a result, the opioid crisis has disproportionately impacted First Nations in BC. Therefore, the second session (held in October of 2017) focused explicitly on Indigenous perspectives and experiences when delivering and receiving care for substance use concerns.[3] Both sessions also aimed to build relationships across participant groups and foster shared agreement on key areas to move forward on.

Scope

Due to the added complexity and concomitant work led by the Ministry of Children & Family Development, the scope of this session was limited to adults. As the mapping focused on the experiences of accessing primary care treatment for substance use concerns, occasional and recreational drug users - a population also impacted by the overdose crisis – were not included.

Participants

Invitations were issued to representatives of key organizations (including Ministry of Health, First Nations Health Authority, Doctors of BC, BC Centre on Substance Use, and each Health Authority); providers (urban and rural family physicians and nurse practitioners, emergency department physicians, paramedics, social workers, nurses, pharmacists, community health and treatment center workers, National Native Alcohol and Drug Abuse Program [NNADAP] workers and Elders) and people with lived experience (family members, peer support workers, people who use drugs, and people in recovery). A total of 62 participants attended the July session; 55 attended the October session.

WHO ATTENDED?

OCTOBER SESSION

25 health care providers

including NNADAP workers, community support workers, treatment centre staff, Elders, Physician addictions specialists, General Practitioners and Nurse Practitioners.

15 peers

with lived experience representing communities including Mission, Abbotsford, Prince George, Quesnel and Kelowna

16 organizational representatives

Including FNHA Health Directors, the Ministry of Mental Health & Addictions, Doctors of BC, Health Authorities, the BC Centre for Disease Control and the BC Centre on Substance Use

Structure of Journey Mapping Days

The journey mapping sessions were held on the unceded territories of the Musqueam, Squamish and Tsleil-Watuth First Nations in Vancouver, BC. Both sessions had similar formats; after a traditional welcoming ceremony conducted by a Musqueam Elder and setting the context of the response to the opioid overdose crisis, participants were divided into two mapping groups. The **health care provider** mapping group focused on provider experiences and perspectives on how they have sought to navigate the primary care system to treat patients with substance use concerns. The **peer** mapping group focused on the experiences and perspectives of people who have sought treatment for substance use through the primary care system. Observers (organizational representatives with no specific role in delivering or receiving care) were assigned to each group. Observers were invited to listen in on the sessions and ask clarifying questions as needed.

Over the course of several hours, participants in each group shared personal stories and experiences about how they have interacted with and within the primary care health system. Facilitators noted specific steps in the journey, direct quotes, ideas for change and emotions/beliefs on sticky notes that were subsequently affixed to a large blank piece of paper on the wall. As the mapping progressed, participants identified natural themes and patterns that led to the sticky notes being re-arranged on the paper. At the end of the session, each group had created a single journey map that incorporated a variety of their experiences. At the end of the mapping, both peers and providers shared their journey maps with the larger group. This knowledge transfer assisted participants in identifying themes common to both maps and helped the providers and peers understand each other's perspectives.

At the conclusion of the mapping, facilitators worked with a graphic illustrator to transform the sticky notes into comprehensive visual representations of the day. These digital maps were then validated and refined by participants in order to ensure they were true reflections of their experiences.

Key considerations

Journey maps capture the experiences and mindsets of participants on a specific day. As such, they are meant to be snapshots rather than comprehensive, validated landscapes 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. Finally, the language and content of the maps are reflective of the participant discussions. As a result, terminology may be inconsistent or inaccurate. As a viewer, it is important to see each map as a unique perspective. Resultant questions about why certain elements were emphasized or excluded are valuable triggers for future consultations and explorations.

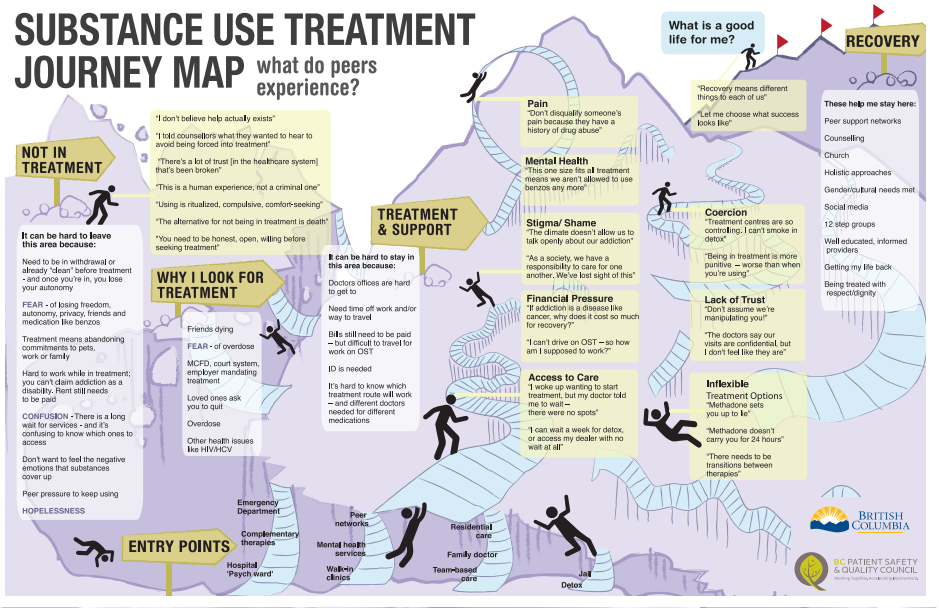
The Journey Maps

A total of six journey maps were developed; four from the session held in July 2017 that focused on primary care, and two from a session in October 2017 that focused on Indigenous perspectives. This section provides context that can help viewers interpret each map; a discussion of themes and ideas for change can be found in the next section. Large scale maps can be found in Appendices A-F. Digital versions are available for download at www.bcpsqc.ca.

Journey Maps – Primary Care Focus

Peer Journey Map

The peer mapping group began with small table conversations that helped elicit major steps in their personal journeys with substance use treatment. These touch points were then explored as a larger mapping group. Four main areas in participant treatment journeys emerged: (1) experiences when peers are not in treatment; (2) what motivates peers to seek treatment & entry points into treatment; (3) experiences with treatment; and (4) experiences with recovery.

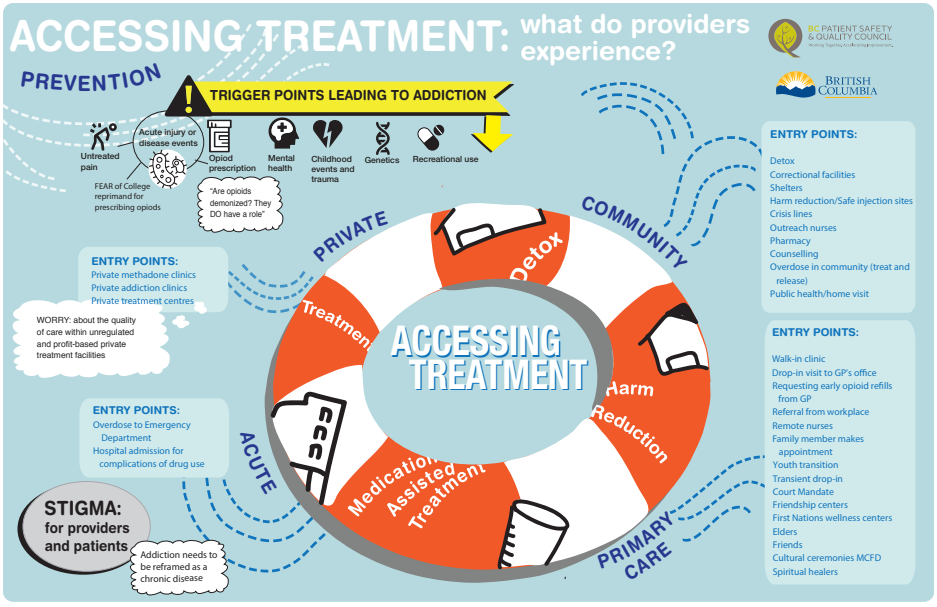


The map seeks to illustrate that the transitions between these areas are frequent and often unanticipated; the maze of fragile and broken bridges that peers navigate when they seek help was alternately described as "confusing", "unpredictable", "hostile" and "hopeless", and they emphasized how the complexity of this system made it easier to fall back into using drugs. In the words of one participant, "I didn't even know what [treatment options] were offered". Another participant emphasized, "One wrong step meant that I was back where I had begun". The direct quotes in the yellow text boxes highlight the experiences peers believe had "ejected" them from the treatment system. The grey text boxes associated with each stage summarize major findings.

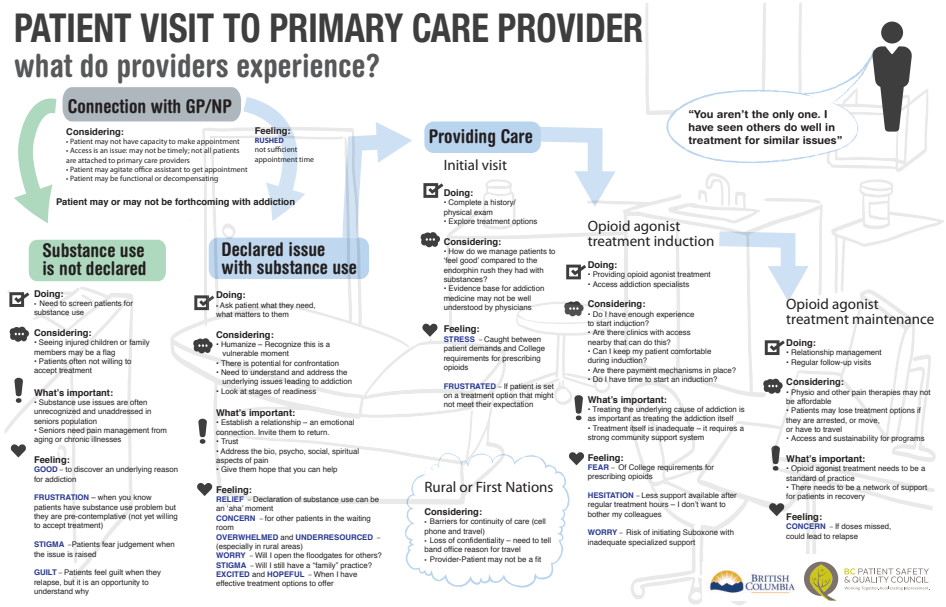
Health Care Provider Journey Maps

The provider mapping exercise began with a discussion highlighting the many ways patients can access treatment. Private, community, primary care and acute entry points were identified as part of a "life ring" of services. The fluid, non-linear design of the illustration and the multi-dimensional nature of the life ring emphasize that the options listed are only some of many, often disconnected services that providers are aware of. The provider experience trying to navigate these treatment options with and for patients is often one of frustration and confusion. Many providers voiced a lack of trust in the efficacy of current health system offerings; these options were alternately seen as "siloed", "inaccessible", "under-regulated" or "not responsive [to patient needs]".

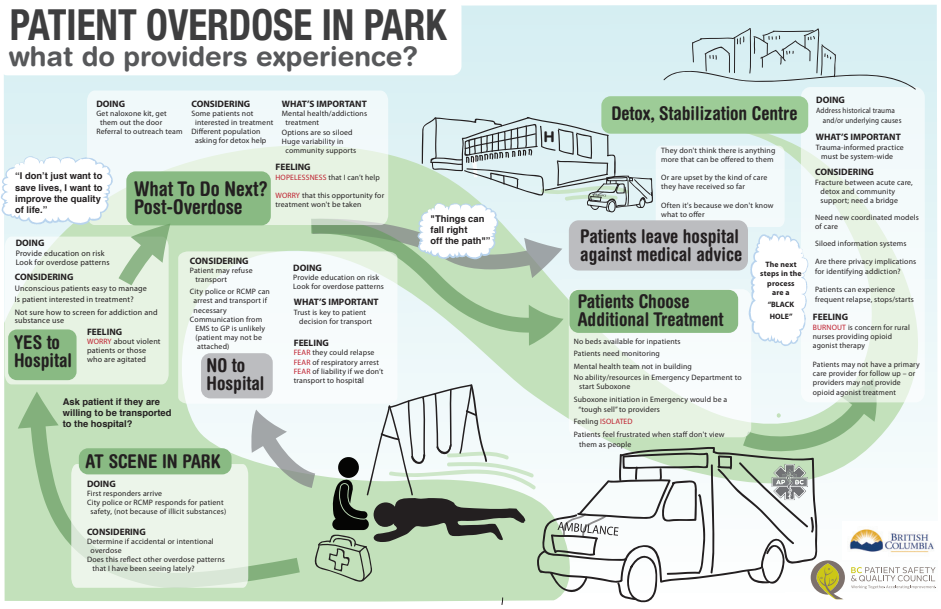
Once access points to treatment were identified, the provider group focused on mapping two fictional "case studies" to illustrate how they navigate the health care system. The first case study explored what happens when a patient with substance use concerns presents at a primary health care clinic or family physician's office. The map, when read from left to right, explores four elements of the provider experience as they engage with the patient. The first is what they actually *do* – what are



the concrete actions they take in the moment? The next is what they *consider* – what thoughts and ideas help focus their actions? The third is what is *important* – what priorities take precedence? The fourth is how providers *feel* in these moments. When viewed as a whole, the *Patient Visit to Primary Care Provider* journey map offers a snapshot of the lived experience of many providers seeking to provide appropriate care for those with substance use issues.

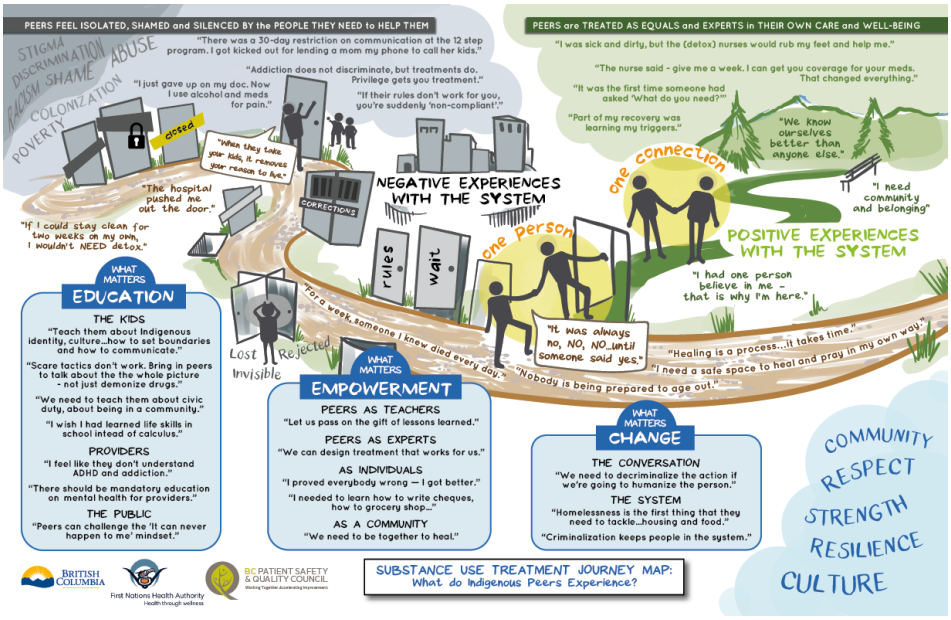


The second case study explored the experiences of various providers as a patient moves through the emergency and acute care health systems. This map begins in the lower quadrant with a scene at a fictional park, and moves through parts of emergency services, acute care wards and discharge planning. Providers spoke about the challenges in trying to provide substance use treatment beyond life-saving interventions in the emergency department environment, and used the term "black hole" to describe their lack of awareness of effective community treatment options for patients after discharge.



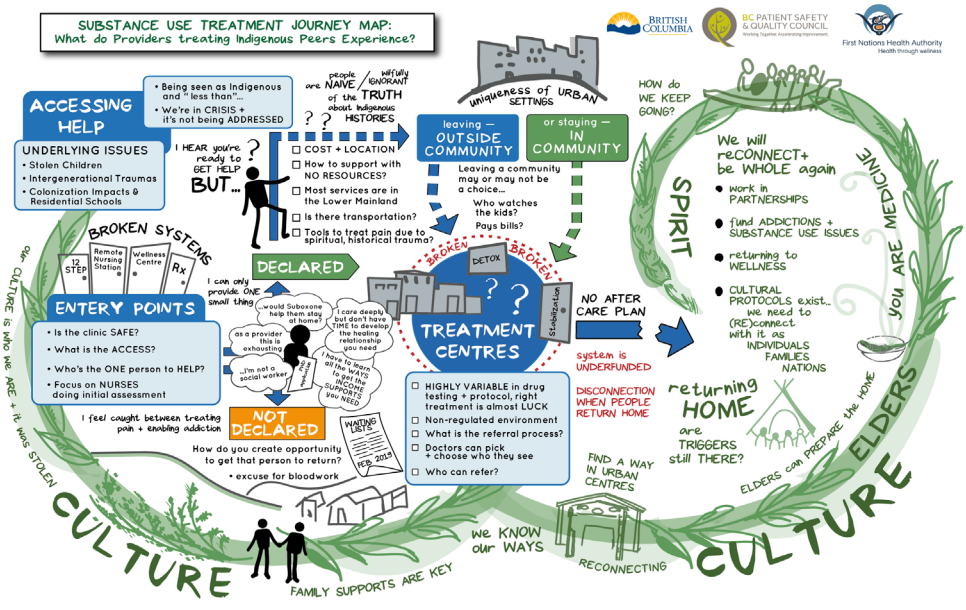
Journey Maps – Indigenous Perspectives

Indigenous Peer Journey Map



The Indigenous peer mapping session also began with informal small group discussions. Peers were encouraged to capture ideas on sticky notes; these were then transferred to a large wall during the main mapping session. A powerful metaphor of "doors" emerged early in the discussion; many peers shared experiences of being "locked out", having doors "shut in their face", being sent through "revolving doors" or accessing treatment only when doors were "held open" by someone else; this metaphor was captured in the digital journey map. Major themes also emerged, including the importance of education, empowerment and change to long-term recovery, the negative impacts of stigma, racism and poverty and the presence of trust and human connection in nearly all positive interactions with the substance use treatment system.

Health Care Provider Journey Map



Providers agreed early in the mapping session that the legacy of colonization, trauma, intergenerational trauma and internalized racism has contributed to the disproportionate impact the opioid overdose crisis has had on First Nations in BC. The journey map also shows that providers face significant barriers to offering effective substance use treatment to peers – particularly if they are operating in rural or remote areas that have no local treatment options. The map emphasizes how variability in referral protocols, entrance requirements, treatment options and discharge arrangements among treatment centers can often make it difficult to confidently refer peers to type of care that suits their needs. Finally, the map highlights the crucial role of traditional healing and culture across the treatment spectrum, and the potential for traditional medicines to be integrated into the current primary health care system.

Discussion – Major Themes and Change Ideas

While mapping occurred independently, there are a great number of parallels between provider and peer maps, as well as between the July and October sessions, that are worth exploration. This section examines successes and opportunities for improvement in the current health system from the perspectives of mapping participants. As each mapping day had distinct conversations, this section distinguishes between the July and October information and change ideas with the use of icons.

Theme 1: *Current care models don't always meet the full scope of peer needs*

Participants had a shared belief that "wrap around" models of care which addresses bio-psycho-social needs including housing, employment and positive social networks have the most potential for supporting both peers and providers in the long-term. Peers highlighted peer-to-peer support networks such as the Vancouver Area Network of Drug Users (VANDU), Society of Living Drug Users (SOLID) or Western Aboriginal Harm Reduction Society (WAHRS) as a key component of successful treatment models. Many emphasized that they are most drawn to treatment centres that offer comprehensive support including laundry, showers, child care, pet care, doctors and counsellors. Providers highlighted the value of integrating social workers, counsellors and case managers into their teams – and of successes they have seen where care is thoughtfully coordinated to respond to the particular needs of a patient.

Both peers and providers emphasized the importance of implementing alternative coping strategies before asking someone to change their drug use practices. This means providing adequate housing, food and childcare support prior to starting medical treatment. One peer explained,

"Addiction was my best friend – don't take away someone's way of coping without offering something else."

Both groups also agreed that "wrap around" care goes beyond having comprehensive treatment centers – it needs to include significant cultural, financial and spiritual support once someone is discharged from treatment. Providers commented on the "huge gap" in care once peers return to their communities; in the words of one provider,

"by not having resources for them [when they return], we are setting them up for failure.. this is the most vulnerable time of their lives."

The lack of existing resources in communities is exacerbated, for some participants, by inadequate handover between treatment centers and community providers.

Providers underlined the value of traditional ceremonies and cultural practices in aftercare; one Elder emphasized

"Elders can bring back cultural teachings to start the healing journey."

Another added that traditional ceremonial practices offer *"connection between mystical experiences and better mental health."* The value of empowering Elders to coordinate spiritual and cultural care throughout the substance use journey will be repeated in subsequent themes.

Theme 1: Change Ideas

- Support primary care home models that integrate social workers and psychologists
- Fund peer organizations so they can build their capacity to integrate into clinics
- Integrate cultural counsellors and Elders to provide spiritual and cultural care across whole journey
- Support programs that let women bring children with them to treatment
- Increase access to lawyers who have expertise in mental health & substance use
- Assist peers in obtaining pardons so they can return to work

Theme 2: *Both providers and peers felt lost or hopeless in navigating the current treatment system*

Both providers and peers had common experiences of feeling "lost" or "hopeless" as they tried to navigate the health care system. For peers, this often means that they will disengage with the health care system, and fall back into drug use as an easier and familiar path. For providers, this means they feel ineffective and unable to provide good care; this can lead to choosing not to treat people with substance use concerns.

Participants reflected on the difficulty of locating and accessing appropriate treatment services – and on how the responsibility of doing so often falls to peers and family members with limited financial or information resources. In the words of one provider,

"It's difficult for me as a physician to navigate the system – I can't imagine how it is for families."

All peer participants shared experiences of confusion and frustration when trying to access treatment. In one case, when the peer voiced this frustration she was accused of *"not wanting [treatment] badly enough"* by a frontline care provider.

The difficulty in navigating the current treatment system is intensified by how frequently the services themselves change; one provider reflected that

"resources come and go.. [peer] lives get lost in the jungle in terms of access to resources in the city [Vancouver]".

Other providers delivering care in rural and remote communities simply wish there were any treatment supports available locally. Participants also reflected on how varied the entry requirements and therapeutic approaches to treatment centres in BC are – and how it is difficult to know what would be a good treatment "fit" for a peer.

Finally, participants emphasized the human costs associated with the current treatment system; peers often assume treatment is not available and refuse to even begin looking, while others who start treatment are often lost when transitioning between services. Burnout is a major concern among providers. Remote nursing stations (wellness centres) experience high turnover, struggle to meet local demand with limited resources and are routinely frustrated by the health care bureaucracy. Many feel that the only way to really help peers is by assuring a level of financial stability; the only way many can do so is completing a PWD (Person With Disabilities) form. These applications are emotionally exhausting for both peers and providers – particularly because substance use doesn't qualify peers for medical welfare or PWD support. In the words of one provider,

"I'm tired of saying 'look after yourself'.. we are suffering". Another added, "As service providers, we are burned to the ground."

Theme 2: Change Ideas

- Encourage treatment programs & clinics to integrate peer navigators and peer support groups
- Fund positions that focus exclusively on coordinating care between services
- Challenge Health Authority boundaries to deliver more provincially accessible care
- Update criteria for disability support to include substance use concerns
- Support discharge planning for peers leaving acute care
- Train providers to help peers and families locate the next step in services; don't leave this responsibility to them alone

Theme 3: *Trust and collaboration are not always present between providers, peers, and families*

In some cases, peers and providers described the successes they have experienced when there is trust and collaboration between the two (or more) parties. This means treatment will be more versatile and responsive to peer needs, and providers are less worried about risks such as diversion (transfer of prescribed medication to another person for illicit use). Both groups agreed that trust takes time to build, and that strategies including longer clinic visits and longitudinal care relationships are necessary ingredients. In the words of one provider,

"Building engagement is as important as anything else providers do".

Many participants were acutely aware of the system pressures that can restrict the development of trust; one provider emphasized that "we need to receive adequate compensation for time in initiation", while another added

"not all clinics have the time [for longer visits] – either they won't, or they can't."

Many peers highlighted the difficulty of building trust with providers when their substance use concerns are so highly stigmatized; in the words of one peer, *"Don't assume we're manipulating you"*.

Peer participants shared numerous stories of positive interactions with the health care system that were prompted by, or included, others who use or had used substances. In the words of one peer, *"Nothing hits home like experience."* Receiving treatment exclusively from providers who have never personally experienced substance use disorder, she added, is

"like being taught parenting by someone who doesn't have kids."

Other peers reflected on the healing experiences they have had when helping other peers at women's shelters or organizations ranging from WAHRS (Western Aboriginal Harm Reduction Society), to VANDU (Vancouver Area Network of Drug Users). Participants agreed that empowering peers to help one another navigate to care services or embedding peer support at the point of care drastically increases the accessibility of primary care services by removing real and perceived stigma and judgement. Providers and peers also agreed that the families of peers are often highly motivated to support their loved one, but not equipped with the information or strategies to do so. Educating families about the rationale behind treatment pathways and encouraging them to create plans with their loved one to support them can make them valuable advocates and care providers.

Theme 3: Change Ideas

- Frame substance use as a medical condition – not a choice
- Increase medical appointment time to allow for trust to build
- Provide education & support resources for family members and caregivers
- Provide flexibility for peers to move between treatment options
- Post GP hours to assist peers in seeing same provider over time at walk-in clinics
- Fund programs that recognize the inner strength and drive of peers – and encourage them to develop into peer mentors and support workers as part of their recovery

Theme 4: *Access to treatment is not always available or offered when peers are ready*

Peer and provider mapping groups agreed that additional low barrier rapid access treatment options (specifically access to opioid agonist treatments like methadone and buprenorphine) are needed. There is a very small window of opportunity where peers are ready to access treatment – if they have to wait more than a day or two, they will often resume substance use. One peer explained,

"I can either wait a week for detox, or go to my dealer and wait no time at all".

Providers recognized the importance of offering services when and where patients need them – but struggle to respond to this need. *"We can't always access detox beds in a timely way"* explained one provider. Another added,

"Less support is available after regular clinic hours – and I don't want to bother my colleagues [to provide coverage]".

Participants emphasized there are windows of opportunity throughout the treatment journey; not just at the "point of entry". These almost always occur at transition points between services. One peer, for example, shared how she was stable on OAT while in a correctional facility, but after being released had to look for over a month to find a prescriber to continue the medication. Peers also shared strategies they employ to access services when in crisis; many shared "pulling the suicide card" in order to access a detox bed; others reflected on how they would *"call all the treatment centers you can – and just say you're living in the area"* in order to get either publically funded or private treatment beds.

Theme 4: Change Ideas

- Support rural nurses to initiate & manage buprenorphine
- Direct/self-referrals to more rapid access clinics
- Provide peer navigator at point of entry into treatment system.
- Outreach services by family physicians – rather than having patient come to clinics
- Strengthen ties between acute & community for better discharges
- Develop home detox programs that are supported by trained peer support workers
- Change the catchment-system approach to accessing treatment beds
- Develop human & print resources to help people find treatment and support in the 72 hours following release from a corrections facility

Theme 5: *Current mindsets perpetuate stigma and hinder access to treatment*

A common refrain throughout mapping was how prevailing mindsets of substance use as a "moral weakness" or "criminal activity" restrict access to treatment. Opportunities for early intervention are missed because peers worry about the consequences of disclosing use to their health care provider.

"The climate doesn't allow us to talk openly about our addiction",

one peer explained. Providers agreed; one said, *"Patients have a fear of judgement when the issue is raised"*. Both groups agreed that shifting the public discourse to substance use being a chronic illness is vital. This enables peers to disclose early and get access to preventative interventions, and providers to integrate peers into their practices as they would any other patient with chronic illnesses like heart disease or diabetes.

Participants agreed that Indigenous peers experience additional layers of systemic bias and racism that make it particularly difficult to access and remain in treatment for substance use. Many peers reflected that the experience of being labeled as a "lost cause" or

"just what we expected – a drunk Native"

had devastating impacts on their self-confidence. These experiences, for some peers, have been compounded by childhood trauma (adverse childhood experiences, including abuse, neglect, and household dysfunction), experiences in the social welfare system (particularly being placed in non-Indigenous homes or moved frequently between foster homes) and primary or secondary traumas associated with the residential school system. Both providers and peers emphasized the importance of trauma-informed practice[ii] and addressing concurrent mental health conditions including attention deficit hyperactivity disorder, bi-polar disorder and post-traumatic stress disorder as part of a successful treatment process. Providers and Elders also emphasized the importance of recognizing the impact colonization has had on many Indigenous peers and their communities – and that reconnecting with traditional culture and spirituality is an important part of a healing journey.

Several peers involved in mapping had given presentations and workshops about substance use and harm reduction in schools and community settings, drawing on their own life experience to "challenge the 'it can never happen to me' mindset". They agreed that effective education goes beyond "scare tactics" that focus exclusively on drugs as inherently "bad"; it needs to involve an honest discussion about how trauma, mental health, peer pressure and family life all contribute to people choosing substance use as a coping strategy.

Theme 5: Change Ideas

- Frame substance use as a chronic illness among both peers & providers
- Increase remote access to addictions specialists through telehealth
- Engage peers to participate in research and provide education to providers
- Attach peer navigator to GP clinics to help new patients navigate supports
- Increase availability of addictions training for GPs and NPs
- Train care providers in cultural humility and trauma-informed practice and use that approach for all people who present with substance use
- Provide specific education about relapse as part of the recovery process (challenge mindsets that relapse equals failure)
- Pursue decriminalization as critical part of reframing substance use as a medical (and not a criminal) issue
- Provide training, support and compensation to peers so they can be effective educators in schools
- Involve peers in revising health & civics curriculums to better represent the human face of substance use

[ii] Integrating an understanding of trauma into all levels of care, system engagement, workforce development, agency policy and interagency work. (From Ministry of Children and Family Development. Healing Families, Helping Systems: A Trauma-informed Practice Guide for Working with Children, Youth and Families. Nov 2016. https://www2.gov.bc.ca/assets/gov/health/child-teen-mental-health/trauma-informed_practice_guide.pdf)

Theme 6: *There is significant variation in the type of care provided by treatment centres and recovery centers*

The mapping process highlighted the myriad of publicly funded and private for-profit treatment and supportive recovery options currently available – and the lack of significant standardization or oversight among many private for-profit treatment centers. While paying out of pocket can increase accessibility – in the words of one peer,

"If you have money, you can get recovery services"

– many private clinics are "not evidence-based" (provider), "coercive" (peer) or even "abusive" (peer). Both groups voiced a desire to see increased government regulation of private for-profit clinics, and enhanced oversight of advertisement campaigns that mislead the public about participant recovery rates.

Referring providers shared the unease they often feel when trying to refer peers to appropriate treatment or recovery centers. They reflected that the variation in entry requirements and the absence of standardized treatment protocols make it difficult to feel confident in the quality of care provided in some treatment and recovery centers; these concerns are often validated by anecdotal feedback they receive from peers who share experiences of being shamed, ridiculed or subjected to treatments that do not reflect best practice. Providers representing treatment and recovery centers reflected that the rationale behind entry requirements (such as providing a "clean" urine sample prior to admission) vary; for some, it is a useful way to create peer-specific care plans that respond to the substances currently being used. For others, it is because they are not equipped to support peers through a "detox" process in-house.

Several peers shared experiences of arriving at recovery centres to discover that they do not offer the counselling, cultural, spiritual or mental health supports they need. In many cases, the only options available were Christian-based recovery homes or 30-day programs that employ strict admission criteria and regulations to remain in the program, including no contact with the outside world and absolutely no substance use (including cigarettes). One peer explained,

"In order to receive help, you have to play by 'their' rules."

For several of the peer participants, rules like complete abstinence and isolation from family and friends did not support their recovery.

Theme 6: Change Ideas

- Create a provincial peer advocacy body
- Explore regulating or accrediting private for-profit treatment centres and supportive recovery facilities
- Have public forum or website for peers and families to rate treatment centres according to pre-determined criteria
- Publish admission criteria, medical/ psychological support staff and lists of actions (such as phone use or drug use) that can result in expulsion
- Create standardized way to measure care quality in supportive recovery homes

Theme 7: *Chronic pain is not always effectively addressed during treatment for substance use*

Both mapping groups commented on the complex relationship between pain and problematic substance use. There is a perceived need to improve pain management while mitigating the risks of using pharmacological interventions. Many providers voiced concerns with enhanced regulation over opioid prescribing practices. One provider asked *"Are opioids demonized? They do have a role to play."* Another worried,

"If people can't have prescription opioids, do they go elsewhere? There is a risk of them going to the street."

Many peers at the mapping session also suffered from chronic pain – and emphasized that chronic pain needs to be addressed before they can secure housing, employment, or begin their path to recovery. Many commented that their chronic pain is often dismissed as "drug seeking" – which leads to looking elsewhere to manage pain. In the words of one peer,

"Methadone doesn't cover breakthrough pain – so I deal with that myself [and buy illicit drugs]".

Another added, *"Let us have a trial on proper pain medication [if we're in pain]."*

Mapping groups touched on the importance of establishing appropriate and effective chronic pain management treatment as part of all treatment for substance use. Some peers shared that they continue to use substances such as illicit opioids or alcohol to manage chronic pain; they were unable to find prescribers to assist them in accessing alternatives. In the words of one peer,

"After I left the recovery house, I was a lot better.. I live with friends, but I still drink for pain management."

Theme 7: Change Ideas

- Empower peer organizations to engage & educate at-risk patients
- Create more flexible guidelines for opioid prescribers
- Expand public access to complementary therapies (physiotherapy, massage therapy, etc.)
- Address chronic pain issues before addressing substance use issues (don't take away a coping strategy without providing something to replace it)

Theme 8: *Strong communities are a key part of treatment and recovery*

Peers reflected on the importance of being part of a positive, strength-based community in their recovery that can provide coaching, peer-to-peer counselling and support. They emphasized that there is no "one-size-fits-all" treatment or recovery community; some peers shared success with abstinence-based programming like 12-step groups, while others highlighted the support they experienced with harm-reduction programming that makes any drug use safer and enables them to maintain full-time employment. Peers all agreed that the community itself needs to include lived-experience experts who can educate new members about the drivers behind substance use and strategize on how to reduce triggers.

While both peer and provider mapping groups reflected on the value of community in treatment and recovery, each group focused on different types of communities. For many providers and Elders, it was the communities centered on reserve lands that had the potential to provide the cultural, spiritual and emotional support required for successful treatment. Providers emphasized the therapeutic value of "consistency and comfort", and Elders highlighted the value of traditional ceremonies for healing. Limited treatment options – often the result of housing shortages (no buildings available) or resource limitations (no staff or funding available) means that peers often have to leave their communities; this is often prohibitively expensive for the individual or the band and the cause of significant personal stress. One provider explained,

"If someone leaves the community – who watches the kids? Who pays the bills?"

Peers who contributed to the October mapping day largely lived "outside of community", or not on reserve lands. The communities most valuable to them consisted of other peers; individuals who have had their own experiences with substance use and could support them in their own unique recoveries. Peers agreed that the feelings of acceptance, support and camaraderie they experienced in peer-led harm reduction groups such as WAHRS, Sara for Women and VANDU led to longer associations with the groups and a better quality of life. One peer explained,

"We are judged everywhere else – but not here [at VANDU]. It means we come back."

Theme 8: Change Ideas

- Promote partnerships between peer support organizations and primary care clinics in the same region
- Help develop online peer support programs to reach geographically isolated areas
- Create mobile units to provide care in remote areas (so peers don't have to leave their communities)
- Promote linkages between NNADAP and community Elders
- Create clinical pathways for cultural care

Next Steps

The knowledge and wisdom captured in these journey maps provides an opportunity for the perspectives of both peers and providers to be incorporated in future strategic and operational planning. This can occur at the local, regional and provincial level to respond to the ongoing opioid overdose crisis and create a more effective and sustainable system for those suffering from problematic substance use. 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 show up on the day. As such, these maps have potential to be used as conversation starters; viewers – be they policy makers, peer support workers or physicians – can consider them critically and reflect not only what is included, but what is missing. How are ideas around conventional health care delivery reflected in the provider maps? What assumptions are being made about services that are and are not possible – and about the peers that will receive these services? How are peers embracing – and rejecting – current discourse about substance use? These questions can help direct future work, and encourage the type of curiosity and open-mindedness required to design services that respond to this public health crisis.

Reference List

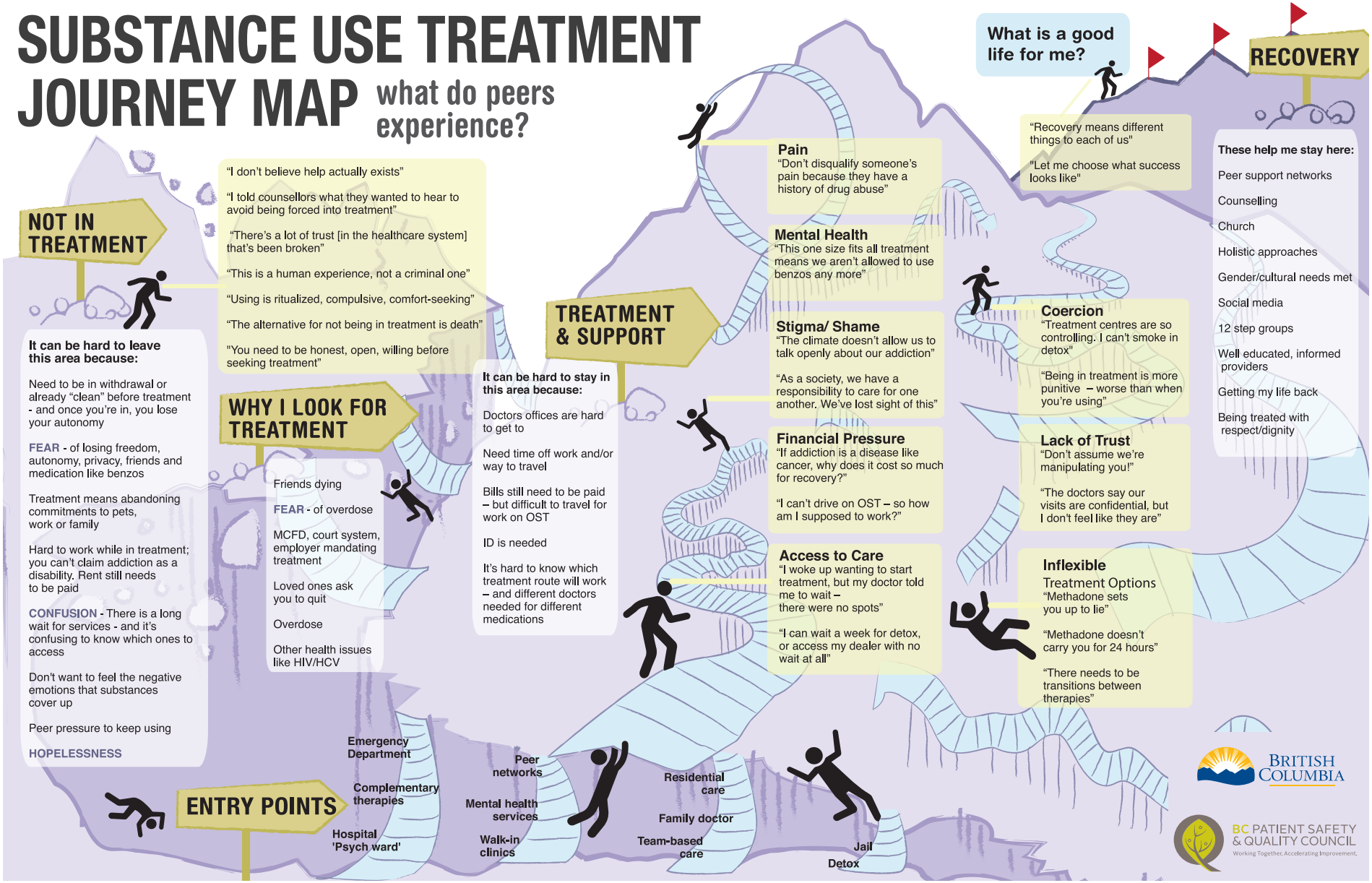
1. BC Coroners Service. Illicit Drug Overdose Deaths in BC: January 1, 2007 to October 31, 2017. Available from: https://www2.gov.bc.ca/assets/gov/public-safety-and-emergency-services/death-investigation/statistical/illicit-drug.pdf

2. Trebble Timothy M, Hansi Navjyot, Hydes Theresa, Smith Melissa A, Baker Marc. Process mapping the patient journey: An introduction. BMJ 2010; 341 :c4078. Available from: http://www.bmj.com/content/341/bmj.c4078.full

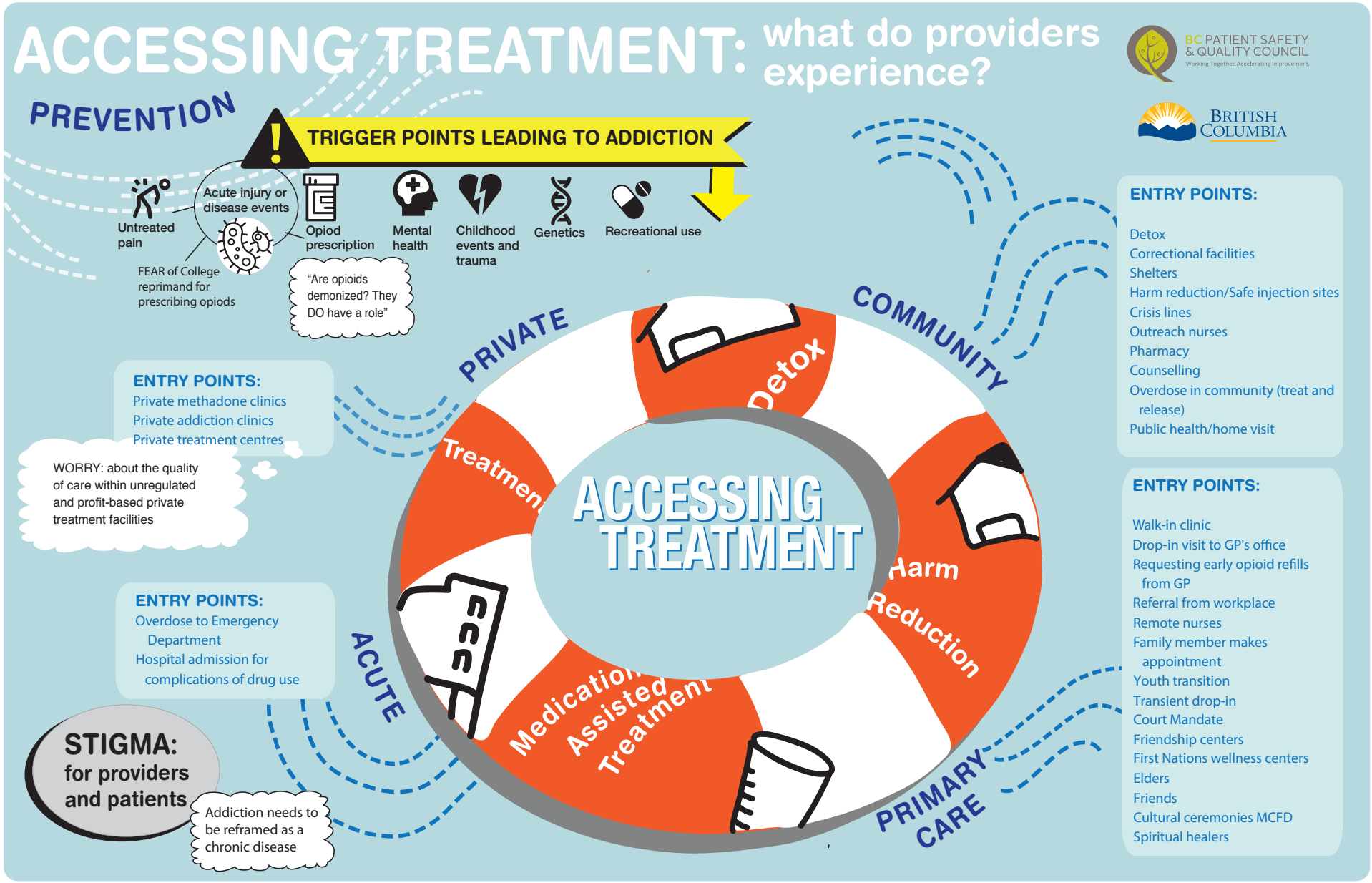
3. First Nations Health Authority. Overdose Data and First Nations in BC: Preliminary Findings. Available from: http://www.fnha.ca/newsContent/Documents/FNHA_OverdoseDataAndFirstNationsInBC_PreliminaryFindings_FinalWeb_July2017.pdf

Appendices

Appendix A: Substance Use Treatment Journey: Peer Experiences



Appendix B: Accessing Treatment: Provider Experiences



PATIENT VISIT TO PRIMARY CARE PROVIDER

what do providers experience?

Connection with GP/NP

Considering:
- Patient may not have capacity to make appointment
- Access is an issue: may not be timely; not all patients are attached to primary care providers
- Patient may agitate office assistant to get appointment
- Patient may be functional or decompensating

Feeling:
RUSHED
not sufficient appointment time

Patient may or may not be forthcoming with addiction

Substance use is not declared

Doing:
- Need to screen patients for substance use

Considering:
- Seeing injured children or family members may be a flag
- Patients often not willing to accept treatment

What's important:
- Substance use issues are often unrecognized and unaddressed in seniors population
- Seniors need pain management from aging or chronic illnesses

Feeling:
GOOD – to discover an underlying reason for addiction

FRUSTRATION – when you know patients have substance use problem but they are pre-contemplative (not yet willing to accept treatment)

STIGMA –Patients fear judgement when the issue is raised

GUILT – Patients feel guilt when they relapse, but it is an opportunity to understand why

Declared issue with substance use

Doing:
- Ask patient what they need, what matters to them

Considering:
- Humanize – Recognize this is a vulnerable moment
- There is potential for confrontation
- Need to understand and address the underlying issues leading to addiction
- Look at stages of readiness

What's important:
- Establish a relationship – an emotional connection. Invite them to return.
- Trust
- Address the bio, psycho, social, spiritual aspects of pain
- Give them hope that you can help

Feeling:
RELIEF – Declaration of substance use can be an 'aha' moment
CONCERN – for other patients in the waiting room
OVERWHELMED and **UNDERRESOURCED** – (especially in rural areas)
WORRY – Will I open the floodgates for others?
STIGMA – Will I still have a "family" practice?
EXCITED and **HOPEFUL** – When I have effective treatment options to offer

Providing Care

Initial visit

Doing:
- Complete a history/ physical exam
- Explore treatment options

Considering:
- How do we manage patients to 'feel good' compared to the endorphin rush they had with substances?
- Evidence base for addiction medicine may not be well understood by physicians

Feeling:
STRESS – Caught between patient demands and College requirements for prescribing opioids

FRUSTRATED – If patient is set on a treatment option that might not meet their expectation

Rural or First Nations

Considering:
- Barriers for continuity of care (cell phone and travel)
- Loss of confidentiality – need to tell band office reason for travel
- Provider-Patient may not be a fit

Opioid agonist treatment induction

Doing:
- Providing opioid agonist treatment
- Access addiction specialists

Considering:
- Do I have enough experience to start induction?
- Are there clinics with access nearby that can do this?
- Can I keep my patient comfortable during induction?
- Are there payment mechanisms in place?
- Do I have time to start an induction?

What's important:
- Treating the underlying cause of addiction is as important as treating the addiction itself
- Treatment itself is inadequate – it requires a strong community support system

Feeling:
FEAR – Of College requirements for prescribing opioids

HESITATION – Less support available after regular treatment hours – I don't want to bother my colleagues

WORRY – Risk of initiating Suboxone with inadequate specialized support

Opioid agonist treatment maintenance

Doing:
- Relationship management
- Regular follow-up visits

Considering:
- Physio and other pain therapies may not be affordable
- Patients may lose treatment options if they are arrested, or move, or have to travel
- Access and sustainability for programs

What's important:
- Opioid agonist treatment needs to be a standard of practice
- There needs to be a network of support for patients in recovery

Feeling:
CONCERN – If doses missed, could lead to relapse

"You aren't the only one. I have seen others do well in treatment for similar issues"

BRITISH COLUMBIA

BC PATIENT SAFETY & QUALITY COUNCIL
Working Together. Accelerating Improvement.

PATIENT OVERDOSE IN PARK
what do providers experience?

DOING
Get naloxone kit, get them out the door
Referral to outreach team

CONSIDERING
Some patients not interested in treatment
Different population asking for detox help

WHAT'S IMPORTANT
Mental health/addictions treatment
Options are so siloed
Huge variability in community supports

FEELING
HOPELESSNESS that I can't help
WORRY that this opportunity for treatment won't be taken

"I don't just want to save lives, I want to improve the quality of life."

What To Do Next? Post-Overdose

DOING
Provide education on risk
Look for overdose patterns

CONSIDERING
Unconscious patients easy to manage
Is patient interested in treatment?
Not sure how to screen for addiction and substance use

YES to Hospital

FEELING
WORRY about violent patients or those who are agitated

CONSIDERING
Patient may refuse transport
City police or RCMP can arrest and transport if necessary
Communication from EMS to GP is unlikely (patient may not be attached)

NO to Hospital

DOING
Provide education on risk
Look for overdose patterns

WHAT'S IMPORTANT
Trust is key to patient decision for transport

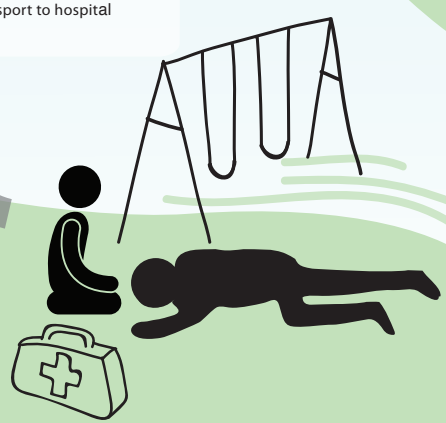
FEELING
FEAR they could relapse
FEAR of respiratory arrest
FEAR of liability if we don't transport to hospital

Ask patient if they are willing to be transported to the hospital?

AT SCENE IN PARK

DOING
First responders arrive
City police or RCMP responds for patient safety, (not because of illicit substances)

CONSIDERING
Determine if accidental or intentional overdose
Does this reflect other overdose patterns that I have been seeing lately?



"Things can fall right off the path""

Patients leave hospital against medical advice

They don't think there is anything more that can be offered to them

Or are upset by the kind of care they have received so far

Often it's because we don't know what to offer

Patients Choose Additional Treatment

No beds available for inpatients
Patients need monitoring
Mental health team not in building
No ability/resources in Emergency Department to start Suboxone
Suboxone initiation in Emergency would be a "tough sell" to providers
Feeling ISOLATED
Patients feel frustrated when staff don't view them as people

The next steps in the process are a "BLACK HOLE"

Detox, Stabilization Centre

DOING
Address historical trauma and/or underlying causes

WHAT'S IMPORTANT
Trauma-informed practice must be system-wide

CONSIDERING
Fracture between acute care, detox and community support; need a bridge

Need new coordinated models of care

Siloed information systems

Are there privacy implications for identifying addiction?

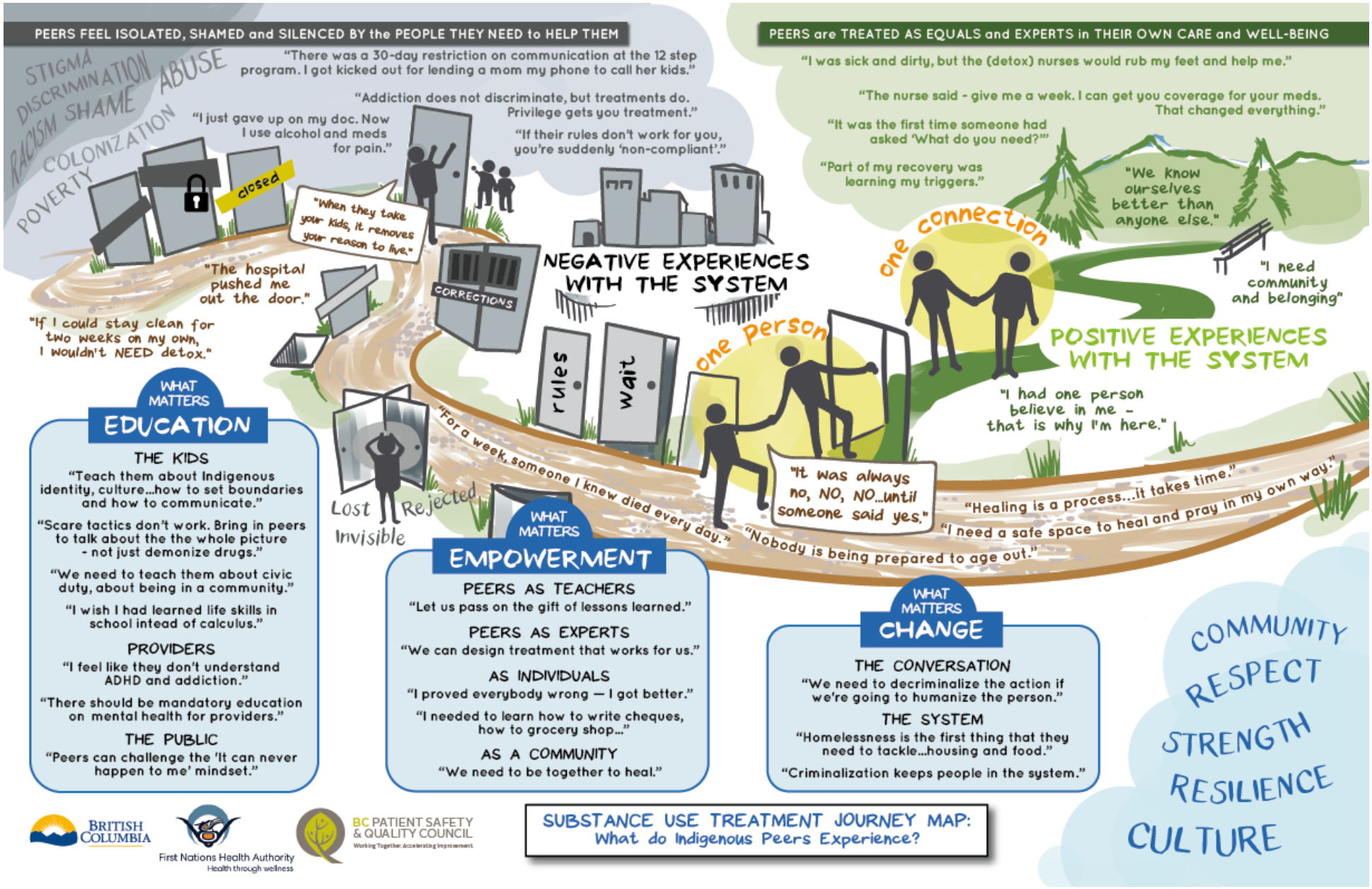
Patients can experience frequent relapse, stops/starts

FEELING
BURNOUT is concern for rural nurses providing opioid agonist therapy

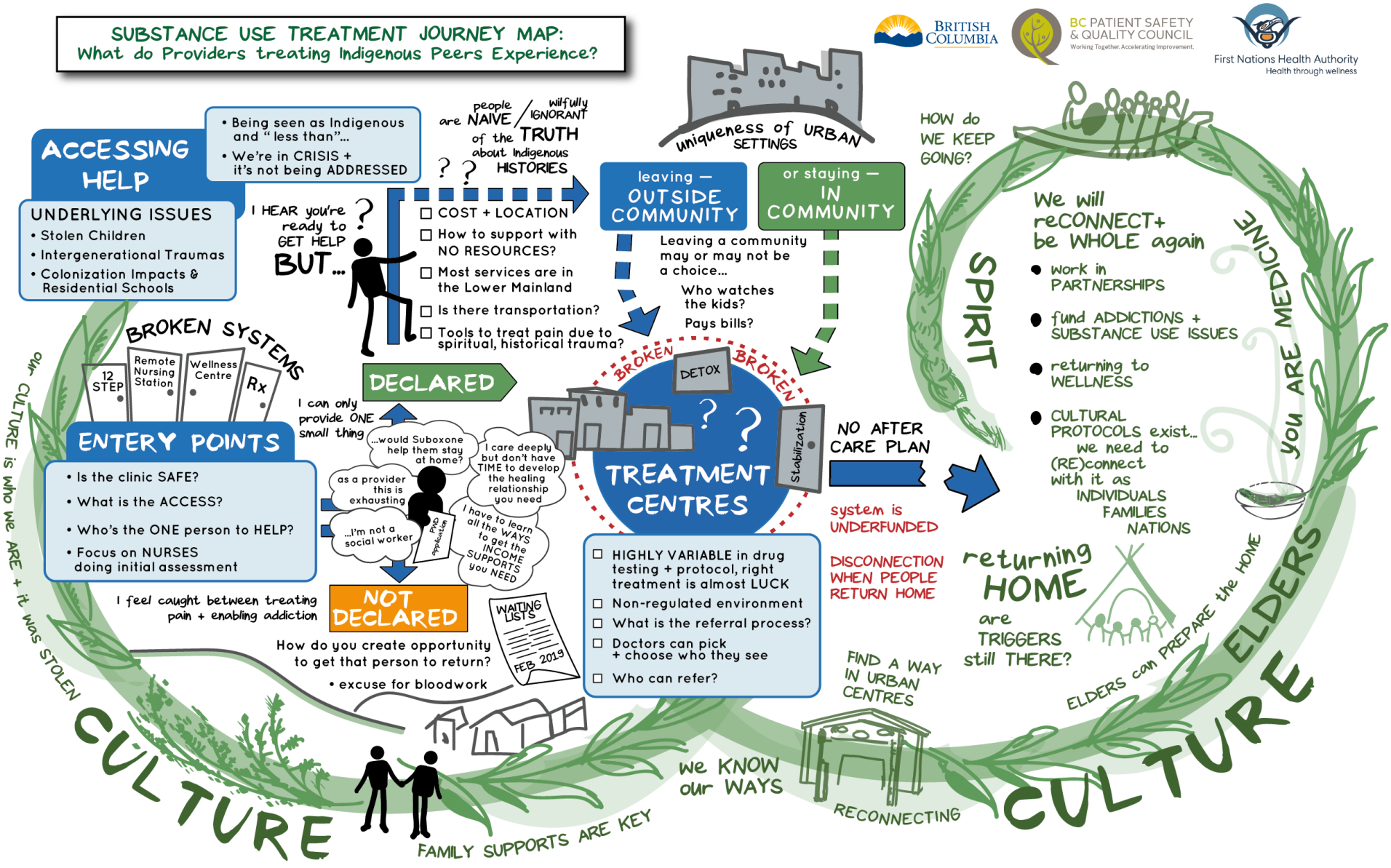
Patients may not have a primary care provider for follow up – or providers may not provide opioid agonist treatment

BRITISH COLUMBIA
BC PATIENT SAFETY & QUALITY COUNCIL
Working Together, Accelerating Improvement.

Appendix E: Substance Use Journey: Indigenous Peer Experiences



Appendix F: Substance Use Journey: Providers Treating Indigenous Peers Experiences



BCPSQC.ca
info@bcpsqc.ca
@bcpsqc

201-750 PENDER ST W
VANCOUVER, BC
V6C 2T8

604.668.8210
1.877.282.1919

BC PATIENT SAFETY
& QUALITY COUNCIL
Working Together. Accelerating Improvement.