

VCH Community Engagement



Substance Use System of Care Strategic Plan

Stakeholder Engagement Report

February 2017

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Background

In April 2016, Vancouver Coastal Health (VCH) and Providence Health Care (PHC) embarked on a process to develop a strategic framework for a, “client-centred and evidence-based system of care for substance use that aims to improve the quality of the treatment and care for our clients.” The goal was to develop a strategic plan that would complement other planning initiatives that were ongoing at VCH and PHC, such as the DTES 2nd Generation Strategy, Detox redevelopment and St Paul’s Hospital redevelopment, and was meant to be an overarching plan that ties together all of the addictions-related elements.

Once an initial draft of the strategic plan was complete, the project steering committee approached VCH Community Engagement to hear from clients, families and health care providers on the frontline for their feedback on the draft plan. Chiefly, they wanted to know:

- a) What did stakeholders think about the draft plan
- b) What would be their priorities for implementation
- c) What was missing from the draft recommendations

In January 2017, VCH Community Engagement, in partnership with PHC staff, held four two-hour focus groups with different stakeholders: One session for family members, one session for clinicians working within the substance use system of care, one session for people with lived experience of addiction who live in the Downtown Eastside and one session for people with lived experience of addiction who live outside of the Downtown Eastside. This report is a summary of what was heard during those four meetings.

In Memoriam

Laurie Preston, Treasurer of the BC Association of People on Methadone (BCAPOM), was registered to participate in a focus group for this project. Sadly, Laurie passed away just the week before. Laurie, like so many residents of the Downtown Eastside, volunteered her time and energy with the hope of improving the health and wellbeing of people who use drugs. Our sincere condolences go out to Laurie’s family and friends and to all our participants who shared stories of losing loved ones.

Who Did We Hear From?

Overall, thirty-four people participated in the four focus groups.

- Fourteen were people who have lived experience of accessing addiction services in Vancouver. Nine people participated in the session in the DTES. Only five people attended the session for people with lived experience with addiction who live outside of the DTES, despite registration for the session being full and running a significant waitlist. Of the fourteen total participants:
 - 6 identified as Aboriginal, 1 identified as Chinese, 7 were Caucasian
 - Average age was approximately 40 years old
 - Just over half (8) identified as women
 - 10 live in the Downtown Eastside, 4 live in other parts of Vancouver including Commercial Drive, Marpole and Shaunessy, or Surrey
- Ten were loved ones of people with lived experience of addiction.
 - Average age of 60 years old
 - Almost all (9) identified as Caucasian
 - Half live on the west side of Vancouver
- Nine were clinicians working within the substance use system of care. This included:
 - Four representatives of VCH-contracted agencies
 - Two VCH staff
 - One Providence Health Care staff
 - Two primary care physicians – one VCH physician and one private practice GP

Limitations

The information contained in this report is limited in the following ways:

Participants did not have the opportunity to read the entire strategic plan document and were basing their feedback merely on the recommendations, meaning they lacked the context and details of the whole plan. Note: The recommendations were also modified to plain language for the client and family focus groups.

While there were a number of Aboriginal participants and one participant of Chinese descent, other ethno-cultural groups were not represented. As such the feedback may have a blind-spot in regards to access to the system of care for specific cultural communities or for those who speak limited English. We are also unaware of participants' sexual orientation and none of the participants identified as transgender so feedback has additional gaps in regards to access for those who identify as LGBTTIQ.

What did stakeholders think about the draft plan?

Overall, participants in the four focus groups had a moderately positive response to the strategic plan's draft recommendations. Participants were pleased to see Vancouver Coastal Health and Providence Health Care planning to improve the system and the experience of care. Certain recommendations like increasing the capacity of existing services and developing guidelines for treating pain in conjunction with substance use were received very positively. Participants were also pleased to see VCH and PHC soliciting stakeholder input into the plan. However, participants across the focus groups raised some concerns with the direction of the plan. Participants' feedback on each of the draft recommendations is outlined in the appendix, but has been organized into the following themes:

- Caring for the whole person

Participants worried that the draft plan's emphasis on the medical model does not take a whole person approach and will not adequately address core issues like trauma. Participants across all stakeholder groups felt strongly that mental health must be treated concurrently with substance use, and were concerned with the lack of specific reference to mental health and trauma in the draft recommendations.

- Scepticism that family physicians can deliver quality substance use care

Participants, particularly clinicians, supported the notion of increasing the capacity of family doctors to provide basic addictions care. However, there is significant scepticism among all stakeholder groups about the ability of GPs to do this well because of: stigma among physicians and clinic staff; a shortage of GPs in the community; VCH and PHC's lack of influence over GPs in private practice; and a reluctance among some experienced doctors to change practice.

"People can't be honest with health professionals because they don't trust that they won't be penalized. I can't tell my doctor certain things because I'll lose my carries." - DTES Peer

- More choice in treatment and personalized treatment

Participants generally welcomed the idea of practice guidelines, a chronic disease approach to substance use and metrics to improve the quality of care. However, they were concerned that these would result in "checklist" or "cookie-cutter" approaches to care that are not client-centred. The issue of over-prescription of methadone and suboxone was raised by some clients as an example of a treatment that is not always client-centred. Clients wanted more choice in care, including different care for those who do want abstinence and those who do not have abstinence as a goal.

"Doctors are worse than dope dealers. They push you on methadone and give you no support to get off it. I had to go against my doctor's wishes to get off it." - Client

- More services, especially for complex clients

Participants frequently mentioned the need to be able to serve people immediately when they are ready for change. Lack of capacity, especially in residential services and transitional supports was identified as a significant problem and was resulting in people not seeking care or accessing unregulated recovery homes. Participants across stakeholder groups also spoke about the lack of capacity in the system to serve clients with concurrent disorders and complex needs.

“A lot of treatment centres and healthcare providers are not educated in treating concurrent disorders. Something like anxiety or depression, yes, but not the bigger ones like schizophrenia or bipolar. My brother is an addict and bipolar and he gets turned away.” - Client

Clinicians, particularly representatives from contracted agencies, worried that some of the recommendations contained in the draft strategic plan may have the unintended consequence of acting as a disincentive to service providers for taking on more complex clients, e.g. attaching outcomes metrics to funding.

- Involving clients and families as true partners

Clients and families feel strongly that their experience and knowledge can improve the system. Clients felt that people with lived experience should be involved to a greater degree in developing and delivering education to health professionals, developing clinical practice guidelines and designing and delivering services in a way that reduces barriers to care.

Family members view themselves as the, “default system of care” and feel that the health system needs to better support them to support their loved ones. Greater access to their loved one’s health information and information on how to navigate the system were frequently mentioned, as was the need for more support groups for family caregivers. Engagement of family members, they argued, must go beyond consultation towards collaboration.

- Removing barriers to care

Education for health care providers including paramedics and emergency department staff was discussed as crucial for reducing stigma and improving care.

Clinicians and clients both raised the issue of the cost as a barrier to care, particularly for people who earn too much to qualify for Income Assistance but are still lower income. Participants urged VCH and PHC to acknowledge the two-tiered system that exists and advocate with the Ministry of Social Development to address inequity of access.

Ending restrictive policies were encouraged by clients. In particular, clients and families raised the need for change in regards to policies that, “kick people out,” if they relapse while in care.

“My son was in treatment and relapsed once. He was in a publicly-funded bed. We had to pay \$8000 to move him to a private bed so that he could stay in treatment.” - Family member

One word:

At the end of each session, participants were asked to give one word to describe their overall reaction or feelings about the draft strategic plan. The words they used are listed below.

“Hopeful” x 2	“Concerned”	“Follow-through”
“Positive”	“Lacking”	“Education
“Caring”	“Limited”	“No discrimination”
“Grateful”	“Medical”	“Humanize”
“Direction”	“Cynicism”	“Beginning”
“Reflective”	“Craving”	“Helpline”
“Improvement”	“Work in progress”	

What would stakeholders prioritize for implementation?

At the end of each focus group participants were asked to identify one recommendation that would be their priority for immediate implementation. They were given the choice of selecting a recommendation that came from the plan or one that emerged during the conversation. Responses ranged considerably (Note: some participants appeared to use the exercise to highlight key messages rather than identify an action for implementation). They are listed here in order of amount of support. The number of participants who chose that recommendation as a priority is identified in brackets.:

- **Develop services that are efficient and have sufficient capacity to meet client need (8 participants identified this as their priority)**
- Amend restrictive policies that create barriers to accessing treatment (2)
- “Continuum of care” language is missing (2)
- Assess the current workforce and provide training opportunities on up-to-date current evidence-based practices throughout the health education continuum. (2)
- Any clinical practice guidelines developed need to be possible, practical and realistic (1)
- Reduce stigma to seeking and accessing services by improving the culture and environment of services (1)
- Services and treatments offered should be client-centred (1)
- Examine best practices from other jurisdictions (1)
- Conduct research on concurrent disorders (1)

- Amend the Mental Health Act to allow the system to mandate care for people practicing very risky substance use (1)
- Create computer systems to analyse addiction services and create reports (1)

What is still missing?

During focus groups, participants identified the following as important issues that were not addressed in the draft strategic plan:

Gap 1. Mental health

The lack of reference to mental health and concurrent disorders in the draft recommendations was noted by participants in every focus group. The urgent need for services to provide better care for those with concurrent disorders was repeatedly mentioned.

One participant felt strongly that VCH should advocate to have the Mental Health Act amended to allow mandated care for people engaged in extremely risky drug use.

Gap 2. Trauma-Informed Care

The absence of any reference to trauma-informed care was noted across all focus groups. Clinicians recommended that education on trauma-informed care and cultural competency be provided for all staff. One client spoke about the financial burden he faced trying to access private therapy for PTSD because counsellors available through VCH and contracted agencies were not able to provide an appropriate level of trauma therapy.

Gap 3. Cost as a barrier to care

The issue of cost, particularly for residential services, was raised across all focus groups. Clinicians in particular spoke about the two-tiered system of care, where those with the ability to pay have faster access to better quality private care. Clients noted that lower middle income earners cannot afford private services, but do not qualify for Income Assistance, creating a significant barrier to residential services. Clinicians mentioned that lower middle income populations also have difficulty paying for suboxone and methadone. VCH and PHC were urged to acknowledge this two-tiered system and address inequity in access in partnership with the Ministry of Social Development.

Gap 4. Including paramedics and Emergency Department staff in efforts to build capacity and reduce stigma

Ineffective or discriminatory treatment from paramedics was a common story among clients and family members. Participants urged that paramedics and emergency department staff be included in any health authority efforts to provide training or address stigma.

Gap 5. “Continuity of Care”

Clinicians and family members noted the absence of reference to “continuity of care” in the plan’s recommendations. Although they recognized that it was mostly captured in the recommendations under A and B, some felt that the concept was important enough to be explicitly stated.

Gap 6. Transitional care

Clients emphasized the need for more services that support people during transitions, i.e. while waiting for a bed in residential treatment, or when leaving residential care.

Gap 7. Family members as partners in care

Participants in the focus group for family members wanted the strategic plan to include greater recognition of family members as part of the care team. They felt that support groups for family members such as Parents Forever and opportunities for education should also be extended to all family members so that they too can facilitate entry to the system of care. It was suggested that an education portal be developed to allow family members to access information on substance use and where and how to access care.

Gap 8. Harm reduction

Clients and clinicians wanted to ensure that the definition of “recovery” adopted in this strategic plan was not strictly limited to abstinence. Many participants noted a lack of mention of harm reduction in the plan as it was presented to them. Families and clients felt it was important that services be available to support people for whom abstinence was not a goal. Clients suggested that non-abstinence based residential care could serve as a “stage one” for those not yet ready for abstinence and as a place for people to go if they relapse while in residential treatment in order to prevent further relapse and/or homelessness.

Gap 9. Regulation and clinical standards for recovery homes

Family members and clients repeatedly raised concerns about unlicensed recovery homes that were not providing safe environments or evidence-based care to clients.

Gap 10. Prevention and early intervention

Family members wanted to see reference to a plan for preventing substance use through early intervention during childhood.

Appendix

Summary of feedback on each draft recommendation

A. Provide the right services to the right clients at the right time

A1. Ensure clients are matched to the appropriate service intensity level when they enter the system.

- Clients and clinicians felt that services for concurrent disorders and very complex clients was very limited and therefore would make it difficult to achieve an appropriate match for most clients.
- Clinicians and clients questioned who would be doing the “matching” and suggested that mental health assessment should inform this matching. Clients suggested a peer-to-peer approach for service matching.
- This assessment needs to happen on-demand in a central place that clients, families and clinicians are all aware of.

A2. Develop services that are efficient and have sufficient capacity to meet client need.

- This was by-far the most supported recommendation in the plan. Seven participants selected this recommendation as their priority for implementation.
- Clients and clinicians felt that lack of capacity in existing services meant that people are not being matched well to services, e.g. being referred to detox because there is a bed available, not because they actually need detox.
- Representatives of contracted agencies were concerned about the use of the term “efficient.” The complexity of an agency’s clients at one time impacts the number of people they can serve effectively. If a contracted agency is expected to have their beds full one-hundred percent of the time, it acts as a disincentive to accept complex clients as they do not have the resources to serve them appropriately.
- Clients and family members both raised the issue of unregulated recovery homes and the need for evidence-based standards in these programs.

A3. Expand access and entry points through primary care and acute services.

- All of the stakeholder groups spoke about the lack of knowledge of addiction among primary care physicians. Clinicians spoke about the need to build capacity of primary care docs to provide basic addiction care. However, clients and family members were critical of the concept of primary care doctors as an “entry point” - citing a lack of access to GPs in the community, doctors’ tendency to over-prescribe methadone and experiences of stigma at the hands of doctors and clinic staff.

A4. Services should be specialized for certain groups, e.g. women, youth, Indigenous people, older adults, LGBT clients.

- There was very good support for this recommendation across focus groups.
- Clinicians suggested that high need/complex clients needed to be considered a subgroup as these clients tend to cycle through the system. Specialized services for pregnant women outside of the DTES and women with children was also suggested.

A5. Chronic disease management principles are required as part of a recovery oriented system of care to avoid cycling through acute services.

- Clinicians felt that this kind of medical model approach does not address core issues of trauma and noted that this chronic disease management approach needed to be trauma-informed in order to avoid the “checklist” approach that would be inappropriate for addictions care. Clients echoed reservations about “checklists” and being treated in a cookie-cutter fashion by health professionals.
- Clinicians spoke of significant silos between acute, primary care and chronic disease services. They felt that improving linkages between these services and increasing capacity of primary care doctors to provide addictions care would help to better manage cycling through acute services.
- Clients and clinicians spoke of the lack of long-term care available. For instance, clients felt that the eight counselling sessions available through VCH addictions teams was inadequate for long-term recovery. They also felt that after-care like second stage housing was important but lacking.

B. Removing Barriers

B1. Amend restrictive policies that create barriers to accessing treatment.

- Clinicians, family members and DTES peers spoke about the need for VCH to advocate with other organizations and ministries to amend problematic policies, e.g. College of Physicians and Surgeons guidelines around long-term opioid pain management.
- Representatives from contracted agencies worried that removing some barriers will force some programs to stretch beyond their capacity. Programs with fewer barriers to access tend to be overburdened with more complex clients.
- Clients recalled a number of restrictive policies they had encountered including long clean-time requirements (even for in-patient detox services), dress codes, and being forbidden from contacting intimate partners. Beyond policy, DTES clients mentioned that counsellors, “always want you to end your relationship,” which had discouraged them from seeking treatment.
- Clients and families spoke about the need for residential treatment facilities to have greater flexibility for clients who relapse in treatment in order keep people engaged in treatment and to prevent homelessness.

B2. Reduce stigma to seeking and accessing services

- Clients shared a number of experiences of stigmatizing treatment at the hands of physicians and clinic staff, including VCH-operated clinics, as well as EMTs.
- Clients suggested that peer involvement was key for designing and delivering safe, welcoming services.

C. Continuity and coordination

C1. Ensure patients are attached to primary care (patient medical home) with integrated and coordinated services

- All participants expressed scepticism that this recommendation would be possible due to the shortage of GPs in the community and the lack of structure currently in place to make patient medical homes possible. Clinicians noted that relying on walk-in clinics as patient medical homes won't work because they do not provide appropriate follow-up care.
- Families reiterated that addictions care under a family doctor needs to be trauma informed.
- Clients asked if, rather than relying on GPs to provide addictions care, addictions specialists could also provide primary care. A clinician noted that Crosstown Clinic, for example, provides primary care to many of its clients, which is outside of its mandate but necessary because of lack of other primary care resources in the community.

C2. Improve ease of navigation and referrals

- Clients recommended that nurses and other clinicians should be able to make referrals. Requiring a doctor's referral often means waiting for an appointment, which can be a deterrent/barrier.
- Family members felt strongly that VCH and PHC should better equip families to facilitate their loved one's journey through the system by developing resources like help lines, web portals or assessment/referral centres that would be accessible to clinicians, clients and family members.
- Clinicians warned against standardizing referral processes as this can be very cumbersome (e.g. existing examples of shared referral packages are very long) and can result in a "cookie cutter" approach that doesn't serve subgroups well.

C3. Improve communication between services so that patient information is shared with relevant providers by leveraging EMR systems.

- Clients had differing opinions on privacy when it came to information sharing between services, although all agreed that client consent was necessary before sharing information. Some were concerned about their personal information being shared due to stigma, while others wanted their information available to frontline service providers who were not clinicians in order to improve access to care.
- Family members wanted greater access to their loved ones medical information in order to facilitate care and called for greater education for doctors and the public, in plain language, on privacy legislation as the rules are inconsistently applied.

- Clinicians identified a need for greater consistency in language used across the system of care. E.g. clinicians attach different meanings to the term “treatment,” or some clinicians refer to “detox” as a place rather than a process. This inconsistency creates confusion and impedes communication.

D. Quality and consistency of clinical practice

D1. Develop therapeutic guidelines, pathways and supports for the evidence-based care of addictive disorders

- Clinicians and clients alike noted that clinicians will not necessarily follow guidelines, which may impede continuity of care for clients moving between services. Clinicians emphasized that any guidelines needed to be, “possible, practical and realistic” in order to enable adherence. Clients suggested that consequences be established for not following guidelines.
- Clients and families strongly suggested that people with lived experience be involved in the development of these guidelines.

D2. Develop guidelines and support for managing concurrent medical illness and substance use.

- Participants across all focus groups emphasized that the system of care must improve its capacity to serve people with mental health concerns, including serious and persistent mental illness.

D3. Develop practice guidelines and support for managing concurrent chronic pain and substance use.

- Clients and clinicians agreed that guidelines for pain management are urgently needed, particularly for clients who are in recovery and want to maintain their recovery. Emergency Department visits were mentioned as particularly problematic for prescribing opioids for people in recovery and even active treatment.
- Clinicians identified a specific need for guidelines pertaining to cannabis oil.

D4. Establish dissemination, knowledge translation and educational structures to support implementation of clinical guidelines that enable evidence-based best practices for all health providers.

- Clients and families recommend that people with lived experience of substance use be involved in the development and delivery of education to health care providers.
- Clinicians recommended that best practice and guidelines be disseminated not just to health care providers, but also families and clients.

D5. Services and treatments should be client-centred.

- The notion of client-centred care was well-supported by participants but all focus groups identified that guideline-based care would inhibit client-centred care because clinicians would adhere to guidelines rather than listening to the unique needs of each individual.

E. Workforce

E1. Assess the current workforce and provide training opportunities on up-to-date current evidence-based practices throughout the health education continuum.

E2. Invest in health care provider education through release-time funding for those in practice and salary support for primary care physician fellowships to develop a highly-skilled workforce.

- Clients, families and clinicians all emphasized that paramedics and ED staff needed to be included in any training provided. Beyond training, frontline workers and first responders also need to be supported to prevent the burn-out that participants viewed as contributing to discriminatory treatment.
- Clinicians felt that CCRS needed more content on addictions and trauma and that training on an ongoing basis, rather than one-off, needed to be made mandatory.
- Clients and clinicians agreed that additional education around substance use should be provided to health professionals while in school, particularly around trauma-informed care.

F. Performance evaluation and information technology

F1. Develop programs and implement metrics using a “cascade of care” framework for key programs (e.g. withdrawal management) as well as specific substance use disorders.

F2. Expand capacity and capabilities of the current IT system to provide reports for quality performance and evaluation of programs and providers.

- Clients and clinicians both spoke about data collection as a burden on service providers, particularly contracted agencies. Over-emphasis on metrics takes resources away from client care and can result in an incentive to only serve less complex clients because they, “bring the numbers up.” Both groups emphasized that any metrics captured should be meaningful and data collection should be made more efficient by creating standardized templates across health authorities.

F3. Develop infrastructure for continuous quality improvement and implementation.

F4. Develop research agreements with academic programs that can cost effectively contribute to monitoring and evaluation and research.

- Clients and families both mentioned that families and people with lived experience should be involved in developing and delivering research.
- Families recommended that VCH and PHC research what is working in other jurisdictions.

G. Leveraging Resources and Collaboration

G1. Collaborate with partners internal and external to the Health Authorities in order to maximize resources and efficiency.

- Family members felt that the health system needed to collaborate with them as partners in the system of care, not just consult with them as stakeholders.

H. Stakeholder engagement

H1. Encourage patients and their families, community partners and care providers to participate in planning and decision making.

- Clients suggested that employers be included as a stakeholder in the substance use system of care and that employers needed education in order to support employees and prevent job loss.
- Families encouraged VCH and PHC to ensure that future engagement efforts were multilingual and culturally appropriate.