

CHARTING THE PATH

**FINDINGS AND
OPPORTUNITIES
FROM THE
CONTINUING CARE
PROJECT**

NOVEMBER 2018

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mental health is health

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EXECUTIVE SUMMARY

Substance use is increasingly seen as a chronic, complex health problem that requires comprehensive, ongoing support from a variety of sources to help individuals pursue improved wellbeing and lifelong recovery.¹ Despite the growing understanding of substance use as a chronic condition, there is a sense that existing systems of treatment and care largely offer short, disconnected episodes of high-intensity treatment.^{12, 13} This is often at odds with the reality that recovery is a long-term, personal journey that takes different pathways and sources of support that help improve the person's health, social connections, and wellbeing.^{2, 11, 16} Importantly, recovery can include, but does not necessarily require abstinence from substance use.^{5, 8, 25} Substance use programming needs to offer more flexible supports that respond to lifelong needs and reinforce the person's ability to pursue their recovery goals.

THE IMPORTANCE OF CONTINUING CARE

Continuing care describes any kind of support that comes after a period of inpatient, residential, or intensive outpatient substance use treatment to maintain an individual's long-term recovery.^{10, 15, 19} It can be offered in many ways, including group counselling, individual therapy, telephone counselling, brief check-ups, self-help meetings, and recreational programming. Continuing care emphasizes the importance of longer-term support for people in recovery and can meet a person's changing needs as they experience periods of relative vulnerability and stability.²¹

The Toronto Central Local Health Integration Network (TC LHIN) indicates that roughly 32,500 adults within its boundaries experience an addiction or substance dependence. 20% of this group are estimated to need specialized assessment, case management, and treatment.¹⁸ Much of this treatment comes from the 170 agencies that provide health services funded by the TC LHIN, of which 26 focus on offering addiction and substance use services.¹⁸ However, according to information from DATIS, the system that monitors the number and types of publicly-funded substances use treatment services in Ontario, as of August 2018 TC LHIN-funded organizations were not required to account for continuing care programming and did not receive funding to offer aftercare or continuing care programming (D. Cain-Moroz, personal communication, August 27, 2018).

Since very few studies examine the cost effectiveness of the many different kinds of continuing care it is difficult to draw general conclusions from the body of literature that does exist.¹³ While one 2010 study found that some forms of continuing care are no more cost effective than other forms of treatment,⁶ others have found that specific continuing care programs can be cost effective and potentially offer cost saving ways of reducing substance use and associated harms.^{12, 13, 17}

THE CONTINUING CARE PROJECT

The Addiction Service Provider Working Group (ASPWG) enlisted the help of the Provincial System Support Program (PSSP) at the Centre for Addiction and Mental Health in the summer of 2016 to help address and improve the availability of accessible, effective, and well-coordinated continuing care for people in recovery. Together, they initiated the Continuing Care Project (CCP) to identify, adapt, and implement solutions to address issues that are shared across healthcare and social service sectors.

Between April and November 2017, diverse project stakeholders shared their perspectives about the state of continuing care in Toronto at a series of town hall meetings. These perspectives illustrated many of the challenges and opportunities that exist under a formal substance use system that relies on highly structured forms of treatment, requiring intensive organizational resourcing and individual commitment. Despite the lack of adequate or dedicated funding, project stakeholders reported that some organizations have found innovative ways to ensure their clients can access continuing care, but that these programs tend not to be connected or coordinated in any significant way.

CONTINUING CARE PROJECT CONSULTATIONS

A project Steering Committee representing a range of service providers, organizational roles, and lived experiences of accessing treatments and supports for substance use guided the PSSP team as it conducted a series of consultations. 137 service providers and people with lived experience of accessing substance use recovery supports were consulted from August to December 2017. The goals of these consultations were to:

- Understand the importance of continuing care in Toronto;
- describe important trends related to continuing care in Toronto; and,
- identify opportunities to improve continuing care in Toronto.

The perspectives of traditionally marginalized groups were sought and consultations were held with groups of men, women, First Nations, Inuit, and Métis people, people experiencing homelessness, members of the LGBTQ2 community, and representatives from Black communities. Transcripts from all consultation sessions were analyzed to draw out common themes.

CONSULTATION FINDINGS

The consultation findings have been organized into four categories, which correspond with the elements of the World Health Organization’s rights-based approach to health: availability, accessibility, acceptability, and quality.

Table 1. Summary of consultation findings

CATEGORY	SUMMARY OF FINDINGS
Availability	<p>Opportunities for service and support are limited by the availability of continuing care.</p> <p>Stable housing is a crucial foundation for any recovery journey.</p> <p>Employment opportunities and financial stability are important elements of long-term recovery planning.</p> <p>People consistently ask for advocates and system navigators who have lived experience.</p>
Accessibility	<p>Continuing care programming is offered at times that don't fit the needs of people who seek services and supports.</p> <p>Flexible continuing care can better respond to the needs of people at different stages of recovery.</p> <p>The general medicalization of substance use supports can limit holistic or culturally appropriate services and supports.</p> <p>Trauma-informed and anti-oppressive continuing care can contribute to physically and psychologically safe spaces, especially for women and lesbian, gay, bisexual, transgender, queer, two-spirit (LGBTQ2S) people.</p> <p>Costs connected to some continuing care services and supports can restrict access.</p>
Acceptability	<p>Moving between services, supports, and phases of life without useful help is stressful.</p> <p>Proper staffing is needed for high-quality continuing care.</p> <p>Staff turnover disrupts the continuity of recovery.</p> <p>Harm reduction and abstinence-based approaches to continuing care can both support recovery, depending on the individual’s specific goals.</p> <p>Data about the quality of continuing care is rarely collected or used.</p> <p>Waitlists, regardless of their length, put people at risk when they don’t have interim supports.</p> <p>The attitudes of professionals set the tone for people seeking support.</p>

Table 1. Summary of consultation findings (cont.)

CATEGORY	SUMMARY OF FINDINGS
Quality	<p>Referral processes between services and supports are inconsistent. It is hard for people to find information about where and how to access continuing care.</p> <p>Complicated, unclear, or inconsistent intake processes make the experience of accessing programming more difficult.</p> <p>People who live outside of downtown Toronto face long commute times to reach continuing care.</p> <p>Continuing care is better when it is based on strong connections, including with primary healthcare providers.</p>

OPPORTUNITIES FOR ACTION

Following a series of validation sessions to verify that the findings resonated with people who were consulted, the project Steering Committee identified opportunities for action that will form the foundation for the Continuing Care Project’s future direction.

Table 2. Opportunities for action

OPPORTUNITY	DESCRIPTION
Emphasize social connectedness and relationship building as critical components of continuing care.	Trusting relationships are the cornerstones of recovery, but opportunities for like-minded people in recovery to meet are not always available. Encouraging people to build the relationships they need to feel well and pursue their journeys of recovery will benefit both the people who need support and the people who provide it.
Use data to understand and improve the quality of continuing care.	High-quality supports and services need robust data to ensure that the people who rely on them have their needs met. A strategy for data-informed decision-making that builds on information that service providers are already using will help to strengthen the effectiveness of continuing care in Toronto.
Help people make informed choices about their well-being and recovery.	Make information about how and where to access continuing care in places and at times when people will be able to use it. Improving the availability of accurate, timely information will help individuals make better decisions about how to pursue their own recovery.

Table 2. Opportunities for action (cont.)

OPPORTUNITY	DESCRIPTION
Ensure that continuing care encourages recovery through the use of clinical, social, and economic supports and services.	Clinical and medically-based continuing care is important to recovery, but can only address a limited set of issues. Many people also need recovery supports that encourage lasting relationships, stable housing, and access to employment and income supports.
Improve the quality and availability of primary healthcare services for people who use substances.	Evidence shows that strong connections with primary healthcare providers are an important aspect of recovery. But primary healthcare providers may not be aware of the links between substance use, trauma, and recovery. Including primary healthcare providers as a source of support for individual wellness may contribute to promising models of continuing care.
Offer continuing care where people in recovery live and spend time.	Individuals who live outside Toronto have difficulty accessing substance use services and continuing care because of the concentration of services and supports in downtown Toronto. Services and supports that are mobile or otherwise connected to places where people live and spend time may help to address this challenge.
Improve discharge planning from clinical substance use services to better support recovery.	The period of uncertainty after an individual completes structured substance use treatment can be marked by fear and anxiety. Smoother transitions from clinical services to continuing care that begin before the person finishes treatment may help mitigate this uncertainty and encourage long-term success.
Improve the experience of being on a waitlist.	The uncertainty of long or unclear waitlists can cause stress and anxiety for people who want help to make changes in their lives. Waitlists offer an opportunity to provide alternate supports.
Formally include people with lived experience in continuing care.	Consultation participants said that they value receiving services and supports from people with lived experience because it lends a sense of authenticity to therapeutic relationships, a perspective which is supported by the literature. But participants also spoke about the importance of being able to draw on their own experiences to give back by offering support to others in recovery. There is potential to build on inspiring work around peer support that is already taking place.

Table 2. Opportunities for action (cont.)

OPPORTUNITY	DESCRIPTION
Advocate for the view that harm reduction and abstinence-based approaches are complementary rather than contradictory.	Different approaches to recovery will work for different people at different times in their life. Continuing care can build greater acceptance of and stronger relationships between organizations that offer harm reduction and abstinence-based programming. This will allow individuals who use substances to choose the tools and approaches that will best support their recovery journey.

The Continuing Care Project Steering Committee is moving forward to identify and develop a continuing care solution that can appropriately respond to the opportunities outlined in this document. The Steering Committee will work with other stakeholders within Toronto to determine how to best balance the needs of people seeking continuing care support with realistic opportunities for expanding those supports in meaningful and enduring ways.

For more information about the state of the Continuing Care Project, or to find out how you can get involved, please visit improvingystems.ca.

INTRODUCTION

WHAT IS CONTINUING CARE?

Continuing care is a term used to describe any kind of support that comes after a period of inpatient, residential, or intensive outpatient substance use treatment to maintain an individual's long-term recovery.^{10, 15, 19} It can be offered in a number of ways, including group counselling, individual therapy, telephone counselling, brief check-ups, self-help meetings, and recreational programming. Continuing care emphasizes the importance of longer-term support for people in recovery and of meeting a person's changing needs as they experience periods of relative vulnerability and stability.²¹

In the past, continuing care was often referred to as “aftercare,” but “continuing care” is thought to better reflect the idea that efforts to actively maintain recovery continue after formal treatment has ended and can include non-clinical supports.¹⁴

RECOVERY AND CONTINUING CARE

The concept of “recovery” and substance use is a subject of active debate and constant evolution.^{5, 8, 25} There is an increasing recognition that substance use is a chronic, complex health problem that is associated with a variety of psychological, social, environmental, and biological factors and impacts.^{8, 22} While recovery can have different meanings in different contexts, for the purposes of this report it refers to a personal journey that takes different pathways and sources of support that help improve the person's health, social connections, and wellbeing.^{8, 20, 21} Most individuals who seek to recover from substance use will have periods of relapse from their goals, participate in several episodes of formal treatment, and define their recovery in ways that have personal meaning to them.^{2, 14, 20} Importantly, recovery can include, but does not necessarily require abstinence from substance use.^{5, 8, 25}

An individual's recovery from substance use needs comprehensive, ongoing support from a variety of sources that will improve their wellbeing and ability to function throughout their lifetime.²² Despite the growing understanding of substance use as a chronic condition, existing systems of treatment and care largely offer short, disconnected episodes of high-intensity treatment.^{15, 16} By contrast, the continuing care approach encourages a flexible range of supports at different levels of intensity to encourage long-term contact and better response to an individual's journey of recovery.

WHAT IS THE CONTINUING CARE PROJECT?

The aim of the Continuing Care Project (CCP) is to expand services and supports for long-term recovery from substance use by improving continuing care in Toronto. It is led by a group of individuals who represent a range of service sectors, organizational roles, and lived experiences of accessing treatments and supports for substance use. The Provincial System Support Program at the Centre for Addiction and Mental Health (PSSP) is facilitating the project work.

The Addiction Service Provider Working Group (ASPWG) raised the issue of the lack of available and accessible continuing care supports in Toronto in the summer of 2016, during the voluntary amalgamation of two withdrawal management services. Members of the ASPWG recognized that the city's patchwork of continuing care supports and services lacked coordination and consistent resources and that better, more effective ways to adequately support people in recovery were needed. The ASPWG enlisted the help of PSSP, whose staff have experience working with diverse stakeholder groups to identify, adapt, and implement solutions to address issues that are shared across different healthcare and social service sectors.

The team held a series of four town hall meetings between April 2017 and November 2017 that set the project's tone and direction. These discussions established a common understanding of what "continuing care" means and what it can accomplish, the elements of reliable partnerships across organizations and sectors, examples of promising approaches that agencies across Toronto are using, and what a potential continuing care system might look like. For a complete list of organizations that participated in these town hall meetings, please see Appendix A.

WHAT IS THIS DOCUMENT?

This report describes the work of the Continuing Care Project from August 2017 to August 2018. During this time, the CCP Steering Committee guided the PSSP team as it conducted a series of consultations with 137 addiction sector service providers and people with lived experience of accessing substance use recovery supports. The goals of these consultations were to:

- Understand the importance of continuing care in Toronto;
- describe important trends related to continuing care in Toronto; and,
- identify opportunities to improve continuing care in Toronto.

This report outlines:

- Key considerations from the academic and grey literature around continuing care;
- the process through which the Continuing Care Project consultations were carried out;
- the findings of the Continuing Care Project consultations; and
- opportunities for future project directions based on what has been read, seen, and heard.

THE STEERING COMMITTEE

The Continuing Care Project's Steering Committee consists of 12 individuals who represent a range of service sectors, organizational roles, and lived experiences of accessing treatments and supports for substance use. For the names and affiliations of the Steering Committee members please see page 1.

Steering Committee members were selected by project stakeholders and PSSP staff through a process that considered representation from different parts of the substance use sector, connections with traditionally marginalized communities, and ability to commit to the expectations of membership. The Steering Committee is responsible for the following aspects of the Continuing Care Project, with support from the PSSP team:

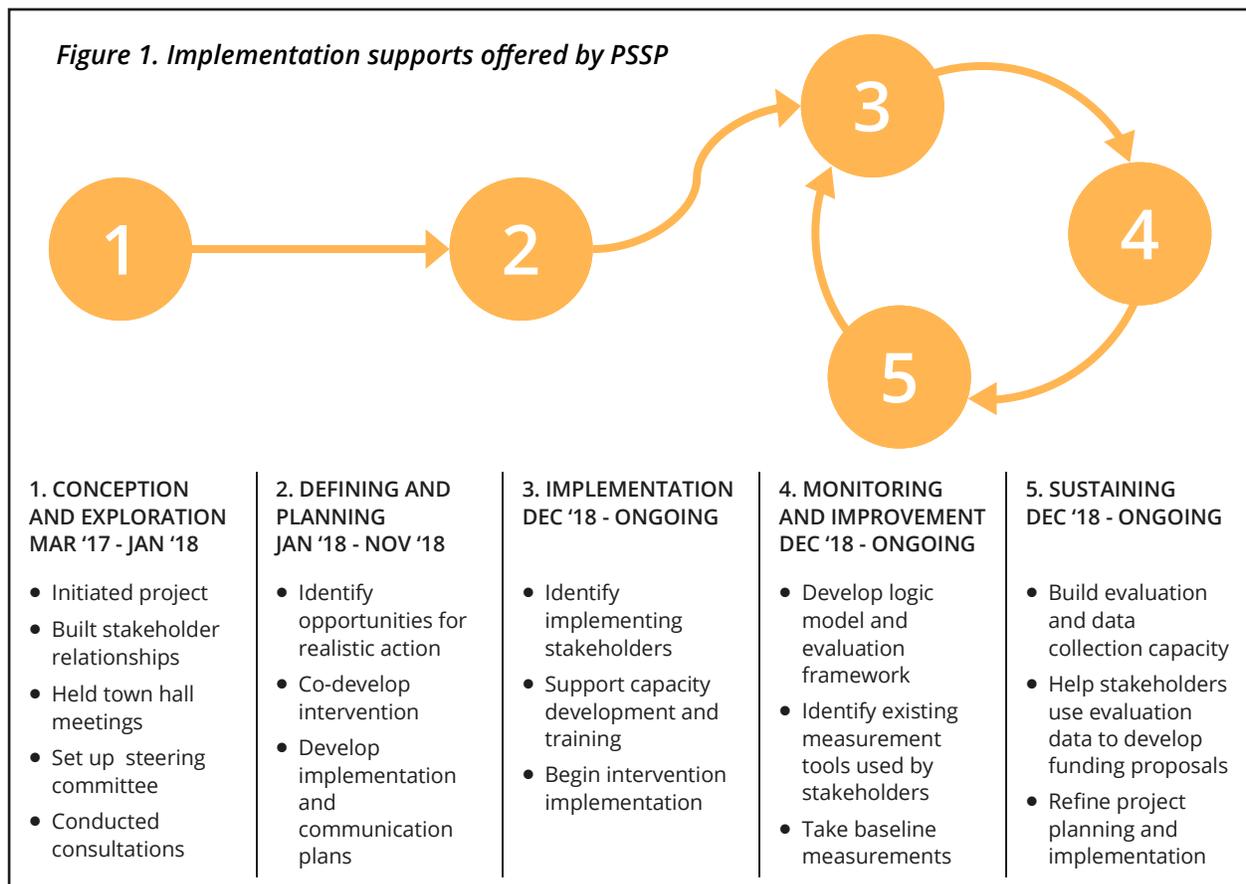
- **Decision-making:** Making decisions related to the direction of the project, including the project's focus, goals, and indicators for success.
- **Stewardship:** Making sure they consider and advocate for the views, challenges, and concerns of groups and sectors whose members have generally been denied equal access to services.
- **Evidence-informed decision-making:** Drawing on best practices and available evidence to determine the most viable, effective, and practical way of addressing continuing care needs that are identified as being a priority.
- **Implementation:** Making decisions related to planning and executing continuing care improvements, including identifying and engaging key project partners.
- **Evaluation and improvement:** Monitoring project progress and evaluating outcomes, using quality improvement processes to identify and respond to possible risks and opportunities that may impact the project's success.

- **Transparency:** Ensuring they inform and contribute to the project’s communication strategy so that partners and other stakeholders have access to relevant and useful information.
- **Financial oversight:** Monitoring the project’s budget and pursuing funding opportunities to enhance the project’s impact.
- **Project champions:** Acting as project champions by encouraging connections and alignment with related initiatives across the city.

THE PSSP TEAM

As the project’s backbone organization, PSSP staff are helping the Steering Committee and other project stakeholders as they identify, define, and implement improvements to continuing care in Toronto. PSSP staff will help them develop a project vision and strategy, build momentum to address challenges, connect with initiatives that have complimentary goals, develop measurement and evaluation practices, and highlight policy implications.

Figure 1 outlines how the PSSP team will support the Continuing Care Project.



CONTEXT

WHAT DOES THE EVIDENCE SAY ABOUT THE EFFECTIVENESS OF CONTINUING CARE?

There is no single, standardized approach for offering continuing care. Because every individual's circumstances and recovery needs are different, the programming or supports that are part of continuing care can differ from person to person. This flexibility makes it difficult to point to a clear consensus about when, how, and for whom continuing care is most effective. Despite these limitations, some systematic reviews about its effectiveness suggest a small positive impact on substance use outcomes.^{2, 15, 20} To fully understand its potential, it is important to understand how the following factors align with each other²:

- Client profile: How will the individual's personal characteristics and patterns of substance use impact the likelihood that they will benefit from different kinds of continuing care?
- Duration: What is the ideal length of time for different continuing care supports and services?
- Components: What kinds of care and support will have the most impact? How can specific types best address the needs of individuals in recovery?
- Intensity: How often should different kinds of continuing care supports be made available, and how intensive should they be?

While there is value to involving people with lived experience in the provision of continuing care supports and services²⁴, traditional, professionally-driven programming may struggle to provide safe and effective accommodation for individuals in peer or lived experience roles.²³

IMPORTANT COMPONENTS OF CONTINUING CARE

Several features appear to increase the likelihood that clients will be engaged with continuing care services and that it will be effective:

- Established connections between continuing care supports and health services, such as primary healthcare providers.⁹
- Continuing care supports are deliberately included when planning an individual's treatment and recovery journey.²⁰
- Natural supports, such as family members, are invited to participate in continuing care, when appropriate.^{3, 7}
- Continuing care supports have established connections with complementary

community supports and services.²³

- Continuing care services are offered in a way that considers the individual's ability to function, access to other recovery resources, and risk factors for relapse.²
- Continuing care includes peer-based recovery supports.²⁴
- Continuing care is offered for longer periods of time.¹⁵
- Continuing care involves active and direct attempts to bring support to individuals, through active outreach or low-burden delivery (i.e., telephone calls).¹⁵

COST EFFECTIVENESS OF CONTINUING CARE

Very few studies examine the cost effectiveness of continuing care, and it is difficult to draw general conclusions from the studies that do exist.¹³ Because continuing care is provided in many different formats, costs and impacts vary. One 2010 study found that some forms of continuing care are no more cost effective than other forms of treatment.⁶ However, other studies demonstrate significant cost effectiveness and savings associated with continuing care programming. For example, a 2008 review found that the few published studies on the subject suggest that continuing care services are generally more cost effective than single acute treatment approaches.¹⁷ A 2013 study examining the cost effectiveness of Recovery Monitor Checkups, a continuing care approach that involved quarterly monitoring and a relapse prevention protocol, was a cost effective way of reducing substance use and of reducing costs associated with use of other health care and social services, unemployment, and criminal activity.¹² Similarly, a 2016 study examining the cost effectiveness of a continuing care intervention for cocaine dependence found that a combination of telephone monitoring and counselling was a cost effective and potentially cost saving approach to reducing substance use and associated harms.¹³

HARM REDUCTION, ABSTINENCE, AND CONTINUING CARE

The longstanding tensions between abstinence-based and harm reduction philosophies of recovery emerge consistently during discussions about substance use and substance use treatment. The aim of harm reduction is to reduce the health, social, and economic harms associated with substance use, which may or may not include reducing a person's use of their substance(s) of choice.⁴ By contrast, abstinence is the complete cessation of substance use. In the strictest interpretations, this can include prescription medications.¹ The philosophies of harm reduction and abstinence are often treated as mutually exclusive, but

practical approaches based on either philosophy can be helpful, depending on the individual's needs, goals, and circumstances.¹¹ To maximize opportunities for individuals to access responsive, high-quality continuing care supports and services, it will be necessary to find creative ways to bridge the sometimes strict divide between harm reduction and abstinence philosophies.¹¹

Contemporary understandings of “recovery” are shifting to consider all aspects of a person's life and prioritize the individual as the ultimate owner of their recovery process.^{5, 8, 21} In practice, individuals in recovery who choose to abstain from substance use may find harm reduction-based continuing care supports that welcome people who are actively using to be triggering or otherwise harmful. At the same time, some individuals may find abstinence-based continuing care supports that exclude people who experience relapses or are otherwise using to be punitive or stigmatizing. Despite the shared goals of both approaches to help individuals improve their quality of life, the potential for friction (and harm) increases when people are expected to pursue a recovery path that does not fit with their recovery goals.²¹ In essence, harm reduction and abstinence both exist within a spectrum of possible approaches for pursuing recovery that relate to an individual's ability to choose, with a full understanding of the consequences of this choice.^{5, 8, 21}

CONTINUING CARE TRENDS IN TORONTO

In a 2015 report, the Toronto Central Local Health Integration Network (TC LHIN) indicated that roughly 32,500 adults within its boundaries (which covers downtown Toronto and reaches out into Scarborough, North York, and Etobicoke) experience an addiction or substance dependence. About 70% of this group has alcohol dependence, while the remaining 30% have dependence on other substances. And 20% of the 32,500 adults are estimated to require specialized assessment, case management, and treatment.¹⁸ Much of this treatment comes from the network of 170 agencies that provide health service funded by the TC LHIN, of which 26 are focused on offering addiction and substance use services. There also is a separate network of privately-funded treatment centres, community-based peer programs, and 12-step programs.¹⁸ However, according to information from DATIS, the system that monitors the number and types of publicly-funded substances use treatment services in Ontario, as of August 2018 TC LHIN-funded organizations were not required to account for continuing care programming and did not receive funding to offer aftercare or continuing care programming (D. Cain-Moroz, personal communication, August 27, 2018).

Over the course of four town hall meetings held between April and November 2017, project stakeholders were invited to share their perspectives about

continuing care supports and services in Toronto. These perspectives illustrated many of the challenges and opportunities that exist under a formal substance use service and support system that dedicates relatively few resources to continuing care. Stakeholders indicated that the current system relies on highly structured forms of substance use treatment that require intensive organizational resourcing and individual commitment. At the same time, stakeholders reported that programming and services that focus on substance use prevention or post-treatment needs (such as housing or employment supports) are rarely funded or formally supported.

Despite the lack of adequate or dedicated funding opportunities, town hall participants reported that some organizations have found innovative ways to ensure their clients can access continuing care. While specific examples vary, common elements included strong commitment to meeting the individual's needs through different kinds of partnerships, offering supports that focus on reinforcing their recovery, and ensuring that warm referrals are in place to ease transitions between different programs and organizations. Yet, participants noted that the innovative continuing care programs that do exist tend not to be connected or coordinated in any significant way. Individuals typically access these supports if they have been receiving other services from the organization, and sometimes through word of mouth. Town hall participants spoke of a growing feeling among advocates in Toronto that continuing care can play an essential role in supporting people as they pursue their recovery journeys.

CONSULTATIONS AND FINDINGS

CONSULTATION METHODS

In total, 137 individuals participated in consultations conducted by PSSP staff from August to December 2017. These included 12 focus groups with service users, five focus groups with service providers, and eight key informant interviews with service providers and policymakers.

Table 3. Consultation participant details

TYPE OF CONSULTATION	NUMBER OF PARTICIPANTS
Focus group with service users	93
Focus group with service providers	36
Key Informant Interviews	8

RECRUITMENT

In June 2017, PSSP staff began recruiting consultation participants by identifying individuals and organizations who were offering continuing care in the Greater Toronto Area (GTA), drawing on the connections of project stakeholders. They tried to ensure that the perspectives of traditionally marginalized groups were represented and consulted with groups of men, women, First Nations, Inuit, and Métis people, people experiencing homelessness, and representatives from Black communities. PSSP staff also conducted service provider focus groups, key informant interviews, and organized focus groups with service users through existing continuing care groups.

DATA COLLECTION

Facilitation guides and consent forms were developed to support the consultation sessions. Each focus group discussion or key informant interview was facilitated by two PSSP staff members. In each session, the facilitator described the purpose of the consultation, reviewed the consent and confidentiality procedures, and briefly described PSSP’s role in the project. Signed consent forms were collected and a discussion was facilitated among the participants. Each session was supported by a note-taker and was audio recorded.



DATA ANALYSIS

Audio recordings of all sessions were transcribed by a third party organization. Transcripts and subsequent analysis documents were stored on a password-protected drive, accessed only by PSSP staff members. Consistent guidelines for cleaning the transcript content (such as removing inaudible sections or comments from facilitators) and keeping participants anonymous were followed. The team then identified common themes across all consultation transcripts.

DATA VALIDATION

All findings were shared and validated by groups of service users, service providers, and members of the project's Steering Committee. Each finding was printed on a card and accompanied by an image that represented that finding's key concepts. Participants in validation sessions were then asked to prioritize the findings and develop recommendations for future action. Service user validation sessions were facilitated by a self-identified person with lived experience and a PSSP staff member.

CONSULTATION FINDINGS

The findings from the consultations have been organized into four categories, which correspond with the elements of the World Health Organization's rights-based approach to health: availability, accessibility, acceptability, and quality.

AVAILABILITY OF CONTINUING CARE

1. Opportunities for service and support are limited by the availability of continuing care.

Consultation participants spoke broadly of inadequate continuing care programming across the GTA. The few agencies that did offer continuing care were concentrated in downtown Toronto. This is further limited by the lack of supports and services in languages other than English.

"So I can understand people just giving in and going out and using because there's, like, no help. When I do leave, like I'm from [outside Toronto] and I know I'll have no help." - Service user focus group participant

2. Stable housing is a crucial foundation for any recovery journey.

A common theme that emerged was that the absence of appropriate and stable housing could undermine an individual's journey of recovery and limit the effectiveness of other continuing care supports. Participants said that lack of stable housing was a major source of anxiety for many. As a result, some felt compelled to extend their stay in residential services for fear of ending up in unsafe environments that could trigger substance use.

"Housing. Housing is ... Whoa, that's like anytime I've talked about what the biggest barrier is for women I always say it's housing right now." – Service provider interview participant

3. Employment opportunities and financial stability are important elements of long-term recovery planning.

Continuing care supports rarely included long-term planning related to employment and skill development. Participants indicated that long-term planning that included social reintegration played a key role in a person's recovery journey. But, they said few programs provided long-term employment or financial support. When it was present, financial support often focused on short-term responses to an individual's immediate needs, which increased the anxiety level for many who felt unprepared to re-integrate.

"It would be cool if there was a program specifically for people that have criminal records or addictions or things like that. Tell the employers - you know, they'll be on a six-month trial and then they're really watching you but they're going to pay part of the wages. Get people hired." - Service user focus group participant

4. People consistently ask for advocates and system navigators who have lived experience.

Data also revealed limited opportunities for people with lived experience to meaningfully participate in offering continuing care supports. Participants reported that people with lived experience can not only provide insights into the structure of continuing care supports and services, but also help support others through their journey of recovery. However, participants felt that opportunities for involvement are limited and can be tokenistic.

"I don't find that there's a lot of people that you can actually talk to that's actually been through [recovery]. There might be one out of 10 or 20 people, and it's just - it's frustrating because they know what it's like. They know - they understand when you're being triggered, or before you might even relapse they can probably

pinpoint it a lot better than I think anybody could. It's just really frustrating that we don't value people in recovery" – Service user focus group participant

ACCESSIBILITY OF CONTINUING CARE

5. Continuing care programming is offered at times that don't fit the needs of people who seek services and supports.

Participants said the few agencies that offer continuing care provide them during times that are not always appropriate for service users. This may be due to limited understanding of the populations who use these services or a lack of resources to offer services during extended hours.

"Most crisis centres are open Monday to Friday, nine to five. And a crisis does not happen Monday to Friday, nine to five. It's like two o'clock in the morning and my staff actually sometimes gets text messages at one o'clock, two o'clock in the morning and I have to tell them not to respond, right, or call 911 whatever those situations are." - Service provider focus group participant

6. Flexible continuing care can better respond to the needs of people at different stages of recovery.

Participants said that continuing care supports and services sometimes didn't have the flexibility to meet an individual's needs. They were often not tailored to specific needs related to culture, gender, or single parent families. Although it is not realistic to assume that all supports and services will provide a perfect fit for all people at all times, conversations about how to better tailor continuing care supports and services are not often happening.

"If the developing of the plan is client led, then the focus can be on how best to support the organization they are at to provide the support. Perhaps do a training of social workers or case managers especially if the organization wants to expand its mandate as well." – Service provider interview participant

7. The general medicalization of substance use supports can limit holistic or culturally appropriate services and supports.

Participants revealed that there is a need to look at the person in a holistic way, more so than just as a person with a substance use issue. For example, they said that medicalized views of substance use were often a deterrent to seeking supports and services for people from First Nations, Inuit, and Métis communities. As a result, these individuals are limited to using continuing care services and supports that do not consider their worldviews or the impacts of colonial history.

“It is super important to consider obviously First Nations, Métis and Inuit communities, yeah. And recognizing kind of like how to de-colonize some of these programs and these spaces and continuing care requires a level of cultural safety for folks that won't fit in the medical model and maybe can look at some type of hybrid mix between sort of Eurocentric western medical understandings and indigenous world views and practices. But I definitely find with a lot of our First Nations, Métis, Inuit, two-spirited community members like it's just, these places are violent and they don't honour spirit.” - Service provider interview participant

8. Trauma-informed and anti-oppressive continuing care can contribute to physically and psychologically safe spaces, especially for women and lesbian, gay, bisexual, transgender, queer, two-spirit (LGBTQ2S) people.

Participants identified trauma-focused, anti-oppressive service delivery as an important aspect of delivering continuing care supports and services. Other service delivery approaches mentioned include family-centered and strength-based approaches. They noted that environments and spaces where services are being offered should be welcoming and ensure the service user is — and feels — safe. However, participants said this was often not the case, as the spaces where continuing care were offered could be traumatizing or triggering due to their location, the way they were offered, or the language that was used. Also, these risks could be compounded for some service users as a result of how they identify themselves. For example, when accessing services, women and LGBTQ2S people (and trans people in particular) reported experiencing stigma, prejudice, and even violence.

“But [women who are using] should know that they can come back for service without condemnations or that institution will punish them, because a lot of women are punished, because they relapse, their children are removed. And that's one of the reasons why it's so difficult for them to come forward, because what they have to lose, they have their entire lives to lose, they lose their housing, they lose their children, they lose everything, so they go underground when they could've come to a place that understands.” - Service provider focus group

9. Costs connected to some continuing care services and supports can restrict access.

Affordability, or a person's ability to pay for services without financial hardship, takes into account not only the price of health services but also indirect and “opportunity costs.” These include the costs of transportation to and from facilities and of taking time away from work. Participants said that many rely on government assistance or have low income, which sometimes determines their ability to access certain services and supports. These costs also included registration fees, transportation costs, and lost wages.

"...I don't think we have enough individual counselling that's affordable to refer people to. It's not that it's none. And like you said people don't want to go very far. So unless you can find something that's relatively easy to access..." - Service user focus group participant

ACCEPTABILITY OF CONTINUING CARE

10. Moving between services, supports, and phases of life without useful help is stressful.

A common theme across consultations was fear and anxiety for people using substances about re-integration into society. This was identified as being particularly stressful because it often means transitioning from structured environments like rehabilitation centres and hospitals into unstructured community settings. A common challenge that participants mentioned is a lack of clarity about transition planning and supports available after regimented treatment. Continuing care was described as a bridge that could support ongoing recovery by making transitions easier.

"...now they're not just dealing with their addiction, "I was craving so I wanted to use," now what they're dealing with, "I had an argument with my partner and how am I going to cope?" That's what I'm noticing is they talk about real-life stuff as opposed to addiction-related things." - Service provider interview participant

11. Proper staffing is needed for high-quality continuing care.

Participants said that providing high-quality continuing care requires staff who are knowledgeable, skilled, and supported to do their work. The data revealed that a lack of adequate agency staffing was an additional barrier to providing quality continuing care. Participants noted that staff often managed large caseloads, which made it difficult for them to provide ongoing support to their clients.

"We're very limited in our time, there's too many clients, and we need more advanced support with the aftercare. That's a whole case management in itself, aftercare." - Service provider interview participant

12. Staff turnover disrupts the continuity of recovery.

Staff turnover was reported as being a problem for service users, who found the process of repeatedly sharing their story as traumatizing. Participants consistently mentioned the importance of introducing some mechanisms to provide continuity during times of staff turnover.

“... I've gone through maybe three or four [caseworkers], just in the last nine months. And the fact that they don't stay. You get support, you get used to that support, you're finally starting to gain some ground and then someone else comes in and everything gets turned around to a different direction. But yeah, you just get lost in the whole shuffle. You feel like you're starting over. “Oh man, I got to go through this again?” – Service user focus group participant

13. Harm reduction and abstinence-based approaches to continuing care can both support recovery, depending on the individual's specific goals.

Participants revealed that harm reduction and abstinence-based programs are often offered as mutually exclusive approaches rather than as useful tools that individuals can decide to pursue at different points in their recovery. The division of these approaches at times didn't respond to an individual's journey of recovery. It is therefore important to articulate what continuing care service delivery for a variety of goals and for different substances could look like.

“...our services are also very rigid by definition. We have a harm reduction centre that means you have to be a user, continuous user, to access our services. If you quit or if you are in withdrawal, no more client. What does that mean? So where shall I go then? There's no place to give me support?” - Service provider focus group participant

14. Data about the quality of continuing care is rarely collected or used.

Another theme that emerged was the difficulty in assessing the quality of continuing care because collection and analysis of useful data was often fragmented or limited. Currently, there is no consistent way of collecting information that could be used to improve continuing care services. Though participants acknowledged the value of data in ensuring that programs respond to client needs, related practices are still fairly fragmented. There is a need to have standardized data collection and measures to ensure at least minimum quality of care standards are being met and to improve the continuing care being offered.

“There's too many clients coming in and it's too overwhelming to the point where we cannot keep up with that type of continuing care. It's limited, like aftercare. We have an aftercare group, one group, for one and a half hours on Thursdays. It's not enough, it's not good enough. We don't evaluate; we're very limited in our evaluations so we don't do a lot of — when you talk about aftercare and follow-up as a continuing care model — we don't know how to follow the clients.” – Service provider interview participant

15. Waitlists, regardless of their length, put people at risk when they don't have interim supports.

Participants suggested that long wait times can be a symptom of inadequate resources (such as limited availability of services, staff, and space). While reducing waitlists to improve overall quality of care is a significant goal, it is also important to consider the risk people are put in when they have to wait for these services without any interim supports.

"... this whole notion of doing this waiting period and assessment and whatever rather than trying to get them in and ride that wave because once they're on that wave I think there's more successful outcomes if we get them into a program right away, right. If they said "I want to make a change in my life." Sometimes they're there, "I want to make a change" but there's a waiting list or there's a, they don't meet the criteria because they haven't stopped smoking marijuana for six weeks before entering into program or whatever those little things are. How to work within the system to ensure individuals get access to services" – Service provider focus group

16. The attitudes of professionals set the tone for people seeking support.

Participants said that service users accessing continuing care sometimes had to deal with poor attitudes from service providers, which included prejudice, stigma, and neglect. While prejudice and stigma were often experienced in hospitals emergency departments, neglect was reported when receiving continuing care.

"And there was a man around the corner and there was no one there. He was laying on a gurney, and a doctor came to him and gave him a big lecture saying there ... "You should have went to detox. You shouldn't have gone to the hospital. That's what rehab's for. You're an alcoholic." And this man had said how much he had drank and I could tell he felt bad already. She said, "I don't want to see you come here again," and she walked away." – Service user focus group

QUALITY OF CONTINUING CARE

17. Referral processes between services and supports are inconsistent.

Participants reported that service providers who referred service users to continuing care used inconsistent processes and often relied on personal connections or word of mouth. While this may suggest an informal network among service providers, there is a risk that individuals are being referred to programs that do not fit their individual stages of recovery. This can also overburden the few agencies that provided continuing care, which could

impact quality of care. Participants noted that while inconsistent referrals could be a symptom of limited availability of continuing care, it can also have detrimental effects on an individual's recovery.

"It's interesting because I haven't necessarily thought of when I'm referring what's continuing care and what's just treatment when it comes to people who are struggling with substance use. Generally, anything that I don't feel like I'm an expert in, which is a lot, I refer them to an organization that I know is doing good work and hope that from there on they connect them to what they need." - Service provider interview participant

18. It is hard for people to find information about where and how to access continuing care.

Access to information includes the "right to seek, receive, and impart information and ideas concerning health issues."²⁶ With regards to continuing care, participants said that information was often not readily available or it was shared in a way that is not easy to access. This was also the case for information about client rights and entitlements. Information regarding continuing care, including eligibility criteria to access them, was also difficult to navigate because it required English literacy, time, and familiarity with the current system. As a result, service providers are the default gatekeepers of this knowledge.

"So I feel like it is difficult for people to even go in and try to like spread this information because it's so foreign to them. It's there but it's foreign because it's not around. No one sees it, no one says anything, so it's almost like no one's thinking about it until that one person out of 10 says something and then there is no help. Yeah, it'd be good to maybe attack a couple of the community centres in their areas and put some stuff in there, put some type of resource in there for people who need it. Because I feel like if it's not there, then even if you need it, you're not going to go look for it, right?" - Service provider focus group participant

19. Complicated, unclear, or inconsistent intake processes limit access to programs.

Data revealed that intake processes for continuing care were often cumbersome and difficult to navigate. While they might have been designed to identify those most in need of continuing care, participants said that eligibility criteria were more excluding than inclusive.

"Or, yeah, like meeting criteria that are still in place around continuing care, like well, unless you're still at this point you can't get this. But what if you really need this, what if this is something that's actually going to make you thrive, you know. Like yes, there are things we need to survive and there are things we need to

thrive and sometimes those are the same things and they intersect a lot and there's a lot of nuance. And like, and we should not be told what it is that we need, we should be saying this sounds great for my life, I would love to have this.”
– Service user focus group participant

20. People who live outside of downtown Toronto face long commute times to reach continuing care.

Participants noted that it is difficult for people living outside of downtown Toronto to access continuing care because most programs are located downtown. Using public transit to get downtown from poorly serviced areas of the GTA can be difficult and time consuming. Participants suggested that there is a need for innovative ways to provide continuing care that better meets the needs of service users where they are.

“I think that the services are lacking and still a lot of our youth go downtown for better services, in terms of, you know, just feeling safe and so yeah. I think we need to do a lot more work around what services are provided in this area and the north, and that's something that you know, I'm starting to work with the team around and how can we inform the other services that, you know, there are black LGBTQ youth and how do we serve them, right.” – Service provider focus group participant

21. Continuing care is better when it is based on strong connections, including with primary healthcare providers.

Participants suggested that agencies need to be better connected to continuing care programs, so that they have a better understanding of what services are available. This can also help standardize reporting, pool funding, and improve monitoring processes. Participants also said that strong connections between agencies and primary care services would improve service users' quality of life and ability to pursue recovery goals.

“I'd love to see more partnerships where we could facilitate the treatment flowing into the YWCA programs for example, the programs the United Way runs, what happens under employment supports. How do we start to create some connections between those pieces that are more formal as opposed to the current informal linkages?” - Service provider interview participant

OPPORTUNITIES

HOW WERE THE OPPORTUNITIES DEVELOPED?

To verify that the analysis and interpretation of consultation findings resonated with people who were consulted at the start of the project, the PSSP project team validated the findings with three different audiences:

- People with lived experience of using continuing care (four sessions);
- Service providers (one session); and,
- Members of the project's Steering Committee (one session).

The sessions with people with lived experience were co-facilitated by trained individuals who identify as having lived experience, while the rest were facilitated by PSSP staff members. All audiences were asked to prioritize the consultation findings and suggest feasible solutions to the challenges mentioned. PSSP staff identified emerging patterns and themes, and used them to develop succinct insight statements that reflected the core meanings of the themes. In turn, the project Steering Committee used these insight statements to draw out opportunities for future action. These opportunities will form the foundation for future planning related to the Continuing Care Project.

OPPORTUNITIES FOR ACTION

1. Emphasize social connectedness and relationship building as critical components of continuing care.

Trusting relationships are the cornerstones of recovery, but opportunities for like-minded people in recovery to meet are not always available. Encouraging people to build the relationships they need to feel well and pursue their journeys of recovery will benefit both the people who need support and the people who provide it.

2. Use data to understand and improve the quality of continuing care.

High-quality supports and services need robust data to ensure that the people who rely on them have their needs met. A strategy for data-informed decision-making that builds on information that service providers are already using will help to strengthen the effectiveness of continuing care in Toronto.

3. *Help people make informed choices about their well-being and recovery.*

Make information about how and where to access continuing care available in places and at times when people will be able to use it. Improving the availability of up-to-date information will help individuals make better decisions about how to pursue their own recovery.

4. *Ensure that continuing care encourages recovery through the use of clinical, social, and economic supports and services.*

Clinical and medically-based continuing care is important to recovery, but can only address a limited set of issues. Many people also need recovery supports that encourage lasting relationships, stable housing, and access to employment and income supports.

5. *Improve the quality and availability of primary healthcare services for people who use substances.*

Evidence shows that strong connections with primary healthcare providers are an important aspect of recovery. But primary healthcare providers may not be aware of the links between substance use, trauma, and recovery. Including primary healthcare providers as a source of support for individual wellness may contribute to promising models of continuing care.

6. *Offer continuing care where people in recovery live and spend time.*

Individuals who live outside Toronto have difficulty accessing substance use services and continuing care because of the concentration of services and supports in downtown Toronto. Services and supports that are mobile or otherwise connected to places where people live and spend time may help to address this challenge.

7. *Improve discharge planning from clinical substance use services to better support recovery.*

The period of uncertainty after an individual completes structured substance use treatment can be marked by fear and anxiety. Smoother transitions from clinical services to continuing care that begin before the person finishes treatment may help mitigate this uncertainty and encourage long-term success.

8. *Improve the experience of being on a waitlist.*

The uncertainty of long or unclear waitlists can cause stress and anxiety for people who want help to make changes in their lives. Waitlists offer an opportunity to provide alternate supports.

9. *Formally include people with lived experience in continuing care.*

Consultation participants said that they value receiving services and supports from people with lived experience because it lends a sense of authenticity to therapeutic relationships, a perspective which is supported by the literature. But participants also speak about how important it is to be able to draw on their own experiences to give back by offering support to others in recovery. There is potential to build on inspiring work around peer support that is already taking place.

10. *Advocate for the view that harm reduction and abstinence-based approaches are complementary rather than contradictory.*

Different approaches to recovery will work for different people at different times in their life. Continuing care can build greater acceptance of and stronger relationships between organizations that offer harm reduction and abstinence-based programming. This will allow individuals who use substances to choose the tools and approaches that will best support their recovery journey.

NEXT STEPS

The Continuing Care Project Steering Committee is moving forward to identify and develop a continuing care solution that can appropriately respond to the opportunities outlined in this document. The Steering Committee will work with other stakeholders within Toronto to determine how to best balance the needs of people seeking continuing care support with realistic opportunities for expanding those supports in meaningful and enduring ways.

For more information about the state of the Continuing Care Project, or to find out how you can become involved, please visit improvingsystems.ca.

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APPENDICES

APPENDIX A - PARTNER ORGANIZATIONS

39 organizations and networks participated in Continuing Care Project meetings:

Addiction Service Provider Working Group
Addiction Services at St. Joseph's Health Center Toronto
Alpha House
Barbra Schlifer Commemorative Clinic
Boréal College
Breakaway Addiction Services
Centre for Addiction and Mental Health
Central Toronto Youth Services
Elizabeth Fry Society of Toronto
Entité 4
Fred Victor
Good Shepherd Non Profit Homes
Inner City Family Health Team
LOFT Community Services
Mainstay Housing
Michael Garron Hospital Withdrawal Management Services
Native Child and Family Services
Ontario Aboriginal HIV/AIDS Strategy
Reconnect Community Health Services
Regeneration Community Services
Renascent
Saint Michael's Homes
Sherbourne Health Center
Sistering
Sound Times Support Services
St. Michael's Hospital
St. Stephen's Community House
Street Haven at the Cross Roads (Addiction Services)
Street Health
The Access Point
The Jean Tweed Centre
The Salvation Army
The Works/Toronto Public Health
Toronto Western Hospital Transition House
True North Medical Services
Women's Own Withdrawal Management
YMCA of Greater Toronto

APPENDIX B - CONSULTATION STAKEHOLDERS

SERVICE USER FOCUS GROUPS (12 GROUPS, 93 PARTICIPANTS)

Women's Own Withdrawal Management Centre
6 Participants (Women)

Street Haven Addiction Services - Grant House Residential Treatment Program
10 Participants (Women)

The Jean Tweed Centre – Continuing Care Group
10 Participants (Women)

St. Michael's Homes
10 Participants (Men)

CAMH – Aboriginal Service
5 Participants

CAMH – Addiction Assessment Program
4 Participants

CAMH - Drug Treatment Court Continuing Care Group
9 Participants (Men)

CAMH – SAPACCY
5 Participants (Women)

St. Stephens Community House - TCAT Peer Program
10 Participants

Good Shepherd Ministries – DARE Program
8 Participants (Men)

Renascent – Men's Aftercare Group
8 Participants (Men)

Renascent – Men's Residential Treatment Program
8 Participants (Men)

SERVICE PROVIDER FOCUS GROUPS (5 GROUPS, 36 PARTICIPANTS)

CAFCAN (Caribbean African Canadian Social Services)
9 Participants

LGBTQ Service Providers
5 Participants

LGBTQ Service Providers (Part 2)
2 Participants

Men's Shelter Service Provider
9 Participants

Francophone Service Providers
11 Participants

KEY INFORMANT INTERVIEWS (8 INTERVIEWS)

Donna Alexander, Social Worker
CAMH Substance Abuse Program for African Canadian and Caribbean Youth (SAPACCY)

Mair Ellis, Counsellor
CAMH Rainbow Services

Dr. Yarissa Herman, Clinical Psychologist
CAMH Complex Mental Illness Program

Walter Lindstone, Social Worker
CAMH Aboriginal Service

Alex Timoteo, Resident Services Counsellor
The Redwood

Chris Pike, Social Worker
Anishnawbe Health Toronto

Andrea Tsuji, Senior Consultant, Health Performance
Toronto Central LHIN

Volletta Peters
Mainstay Housing

APPENDIX C - KEY GUIDELINES FOR CLEANING AND ORGANIZING TRANSCRIPTS

1. All transcripts should include the following information

Date of FGD/KII:	
Group:	
Participants:	
Location:	
Name of the Moderator(s):	

Feel free to copy/paste the preceding table in to your reviewed transcripts.

2. Please check the transcript to ensure it is complete.
3. Please review the transcript and anonymize all data. There should be no names of participants used. If a person is introducing themselves, please remove their name and replace with XXXX. The raw transcripts currently state the names of people who are speaking. Please replace that with Person 1, Person 2, etc. These labels can be used to identify if the same individual speaks multiple times
4. Please highlight text that is noise or should otherwise not be coded (e.g. moderators discussing weather during break etc.) in red.
5. As you are reviewing the transcripts, you will note that some sections say “unintelligible”. If you remember the context of the conversation and think this part was important, please highlight this in yellow. This way, coders can refer back to the audio recordings to transcribe these specific sections.
6. Lastly, please make sure to update the tracking chart when you have completed your review.