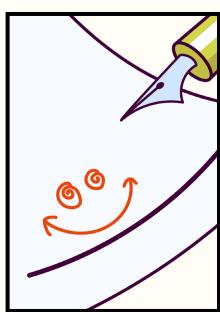
WHATWE HEARD REPORT

Improving Healthcare Provider Interactions with Young People (who may or may not use drugs)





Prepared by Get Sensible in collaboration with the Canadian Public Health Association







Dedicated to young people who use drugs and the people who support us, and in memory of those we have lost to punitive approaches to substance use, fatal drug policies, and as a result of involuntary treatment.

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We'd like to extend our deepest gratitude to all of the young people, and healthcare providers, who shared their experiences with us to inform this report and the accompanying resources. We recognize the vulnerability and sensitivity of discussing topics of both mental and physical health, substance use, trauma, stigma, and discrimination. As well as the unique experiences of young people living at notable intersections of race, gender, ability, income, housing status, and criminalization.

This work would not have been possible without the invaluable contributions from young people who participated in our surveys, roundtables, and interviews.

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PREFACE

ABOUT THE REPORT

This report presents findings from a peer-led engagement initiative focused on examining the relationship between healthcare providers and young people, aged 18-30, who use drugs in Canada. Written by young people who use drugs (YPWUD), this report aims to shed light on the challenges faced by YPWUD when accessing healthcare services and to propose strategies to foster more meaningful and supportive connections between YPWUD and healthcare providers.

This report was written with a multidisciplinary audience in mind, primarily targetting doctors and nurses but noting that this work applies to psychologists, social workers, therapists, counselors, school health workers and anyone with proximity to youth. The results of this report can be used to inform more supportive policies for young people navigating healthcare systems.

NTRODUCTION

The healthcare experiences of YPWUD in Canada have been historically marked by stigma, discrimination, marginalization, and traumatic experiences through coercive approaches in healthcare. Many young individuals with intersecting marginalized identities have found healthcare systems unwelcoming or even unsafe, which has further compounded their reluctance to seek necessary medical care. This report seeks to explore the barriers that YPWUD encounter in healthcare settings, including the impact of stigma and past trauma experienced within medical systems and offer tangible solutions and reflections directly from YPWUD.

This report provides a summary and overview of the findings from a series of outreach engagements conducted by <u>Canadian Students for Sensible</u> <u>Drug Policy</u>'s (CSSDP) <u>Get Sensible</u> project in collaboration with the Canadian Public Health Association (CPHA). Outreach was targeted to healthcare providers (HCP) and young people who use drugs (YPWUD), exploring how to foster more meaningful connections between these two groups, as part of CPHA's <u>Normalizing Conversations</u> project, funded by Health Canada's Substance Use and Addictions Program.

BACKEROUND

Between April and August 2023, the Get Sensible project partnered with CPHA to conduct a series of engagements, including a literature review, an environmental scan, surveys, and focus groups targeting HCP and YPWUD to explore the gaps in this relationship and determine best practices and guidelines.

This report uses the terms substances and drugs interchangeably. This report highlights the significance of amplifying the voices of YPWUD and their experiences with healthcare providers. This peer-led approach demonstrates the importance of engaging young people in discussions about their own health needs, and emphasizes the significance of understanding their unique perspectives and challenges within healthcare settings. By empowering YPWUD to share their experiences, Get Sensible aims to contribute valuable insights that can inform improvements in healthcare practices for this population.

OUR APPROACH

Our Best Practices and Policy Recommendations (Found on page 23) have been crafted through a synthesis of voices, data, and empathy. The foundation of this framework lies in the diverse and profound insights shared by the young people who shared their experiences, reflecting their first-hand encounters with the Canadian healthcare system. The focus group sessions and survey provided an intimate platform for these individuals to express their perspectives, stories, and concerns openly. These dialogues were not merely data collection exercises but vibrant exchanges of experiences and emotions, fostering a deep understanding of the unique challenges faced by this demographic. Their narratives served as the emotional anchor that underpinned our recommendations, reminding us of the very real and human impact of healthcare policies and practices.

The marriage of qualitative depth and quantitative breadth enriched our findings, providing a more comprehensive view of the challenges within the healthcare system. Through careful analysis and synthesis of both the focus group discussions and survey responses, patterns and recurring themes emerged, illuminating areas in need of reform and reinforcement.

Key Findings from Research

A peer-led review of the current evidence was conducted to identify barriers and facilitators to accessing healthcare for YPWUD through an intersectional lens. The following is a summary of both primary research informed by the outcomes from Get Sensible's survey and focus groups, as well as secondary, peer-reviewed research which is cited where relevant.

Barriers

Stigma and discrimination.

When youth develop motivation to seek treatment, stigma and discrimination present significant barriers. (Russell et al., 2019) The fear of stigmatization and concerns that treatment and mental health and addiction services may not meet their needs have been found to influence youth's intentions to seek help. (Gulliver et al., 2010).

Lack of supports specifically tailored to youth.

Youth who use drugs have different needs than their adult counterparts, requiring specific and tailored programming. (Winters et al., 2014).

Lack of accessible healthcare services.

The lack of services designed to accommodate the diverse healthcare needs of young people especially those who are disabled, mentally ill, or neurodivergent as co-occurring health issues was prevalent in the data. The location and hours of services offered was a factor as well. (Wisdom et al., 2011).

Youth not being taken seriously.

Youth often experience fewer negative consequences of substance use than adults as they have a shorter history of substance use, which can lead to a reduced perception of needing support, both from service providers and youth themselves feeling like their health concerns "aren't bad enough." (Winters et al., 2014).

Facilitators

Communication and trust.

Many young people reported that they were more likely to seek treatment if it was referred by a HCP, such as a doctor or nurse, indicating that they trust the care and advice of HCPs, if they get there. (Wisdom et al., 2011).

Compassion and non-judgement.

When met with compassion, young people seeking care felt safer to share information about their drug use. This allowed for the young person to receive more efficient care and granted the HCP with more information to better support their patient. (Russel et al., 2019; Turuba et al., 2022).

Support from family and friends.

Young people reported that support and encouragement from family and friends could increase their motivation to seek mental health treatment. (Radez, 2021).

Education and training.

Effective methods for delivering information to youth include social media, videos, memes, text messaging, websites, and other apps as well as location-specific, personalized, and relatable educational programs tailored to their group. (Moreland et al., 2020.

What we heard from Young People/YPWUD

Using a peer-led approach, we collected feedback from YPWUD on their experiences in navigating healthcare, focusing on interactions with healthcare providers. Information was gathered using an online survey and focus groups. The survey was shared on social media and through word of mouth, with respondents given the incentive of choosing a non-profit organization to receive a \$5 donation upon completion. Survey participants were invited to join one of two 90-minute virtual focus groups for more detailed discussions. Participants in the focus groups received a \$50 honorarium for their participation.

Measures

Engagement efforts used a mixed model approach, combining quantitative and qualitative data collection and analysis. Surveys included:

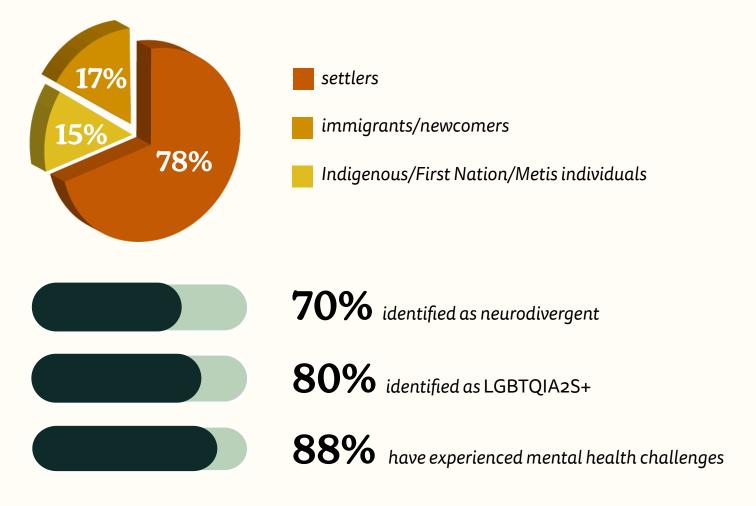
- Close-ended questions (e.g., demographic information, healthcare support accessed, experiences of disclosure, stigma)
- Rating scale questions (e.g., comfortability sharing their substance use to HCPs, confidence in their HCPs abilities to provide meaningful substance use support.)
 Some questions allowed respondents to select more than one answer.
- Open-ended questions (e.g., exploring barriers and facilitators to accessing care, personal experiences of stigma in healthcare settings, resources they would like to see for HCPs to better support YPWUD.)

The data was analyzed using a qualitative framework, allowing for an in-depth understanding of the themes and issues that emerged during the engagement process, which was then used to inform the approach to the roundtable discussions. Focus group transcripts were run through NVivo to identify key themes and recurring terms in participant quotes.

Survey Results

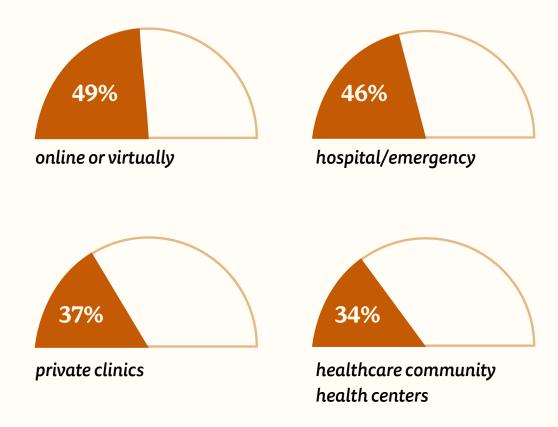
Demographics

The survey sample (n = 41) included individuals aged 18-30 (M = 24.21, SD = 2.89) from Ontario, Quebec, British Columbia, and Alberta. The majority of respondents identified themselves as settlers (78%), followed by immigrants/newcomers (17%), and Indigenous/First Nations/Metis individuals (15%). Half of the participants were post-secondary students. A significant number of respondents identified as LGBTQIA2S+ (80%), neurodivergent (70%), and have experienced mental health challenges (88%).

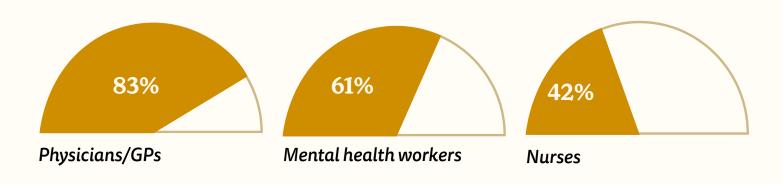


Healthcare Access and Experiences

Approximately half of young people surveyed said they access healthcare online or virtually (49%) or through the hospital/emergency (46%). Many also used community health centers (37%) and private clinics (34%).



Interactions were most common with physicians/GPs (83%), mental health workers (61%), and nurses (42%).



Despite all the participants being YPWUD, the majority (59%) have not sought out healthcare services specifically related to their substance use. 42% of participants stated that they would be unlikely to feel comfortable disclosing their substance use to a HCP. The majority (58%) had little or no confidence in healthcare providers' approach to and knowledge of youth substance use.



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would be unlikely to feel comfortable disclosing their substance use to a HCP

Barriers to Accessing Care

As shown in Figure 1 (below), YPWUD identified long wait times (73%), feeling ashamed/guilty (61%), cost/finances (59%), and co-occurring mental health conditions (56%), as the main barriers to accessing healthcare services.

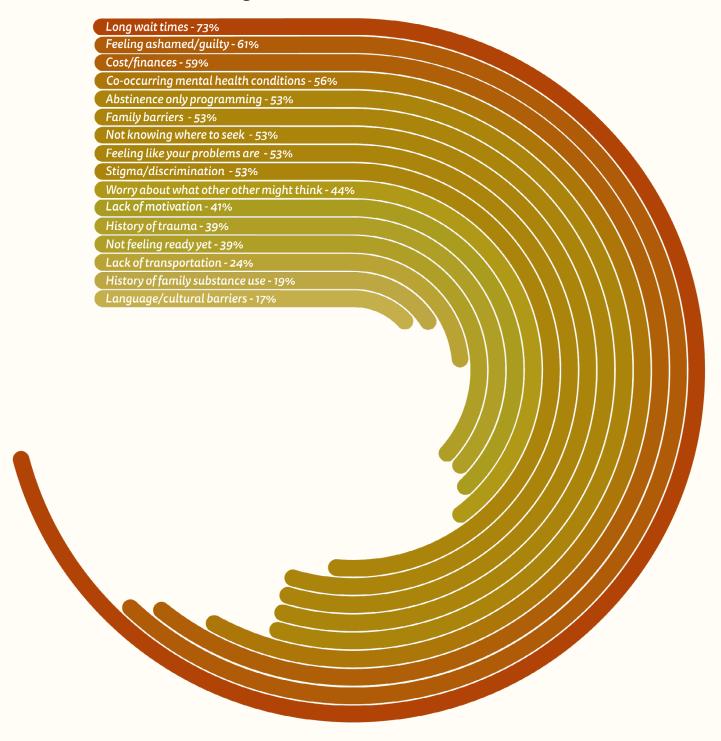


Figure 1. Most significant barriers for YPWUD to access healthcare services. Note: Respondents could provide more than one answer; total can sum to more than 100%.

Facilitators to Accessing Care

As seen in Figure 2 (below), the main facilitators to accessing healthcare services identified by YPWUD included having access to alternatives to abstinence-only programs (80%), positive relationships with treatment staff (80%), mental-health specific programming (75%), peer-support (70%) and flexibility with being late for or missing appointments (60%).

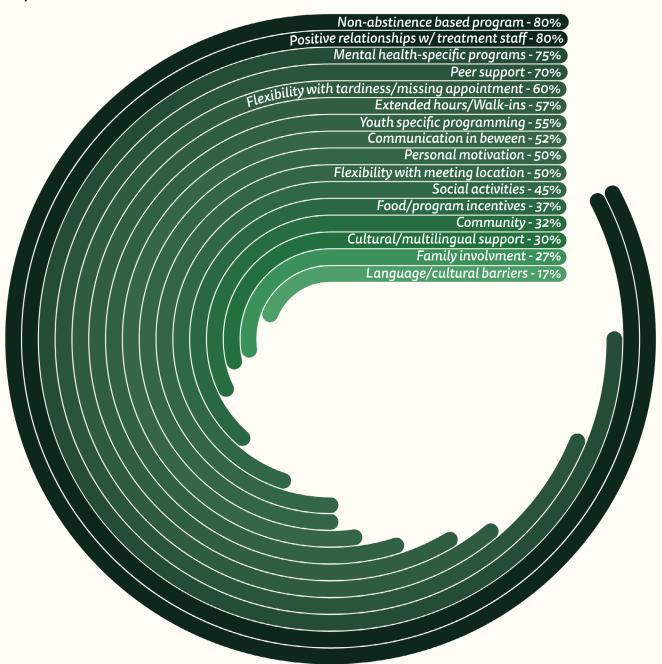
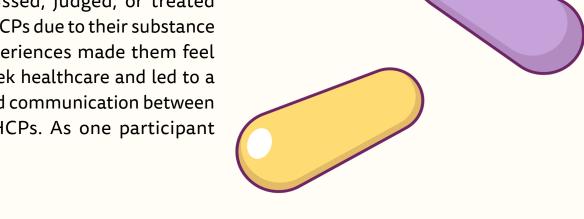


Figure 2. Most significant facilitators for YPWUD to access healthcare services. Note: Respondents could provide more than one answer; total can sum to more than 100%.

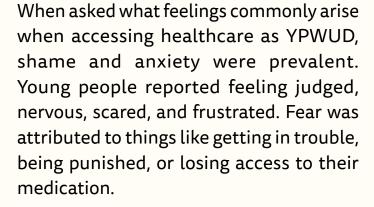
78% of YPWUD have felt stigmatized or judged by HCPs based on their substance use.

When asked about how stigma or discrimination has impacted access to healthcare, participants shared experiences of being dismissed, judged, or treated differently by HCPs due to their substance use. These experiences made them feel reluctant to seek healthcare and led to a lack of trust and communication between YPWUD and HCPs. As one participant expressed



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Stigma has made me hesitant to disclose substance use to healthcare providers.







I don't disclose my substance use to my healthcare providers unless absolutely necessary, but I wish I could without fear of repercussions." (roundtable participant) Access to medication came up repeatedly, with some respondents experiencing stigma when picking up their medication or being denied medication based on their history of drug use. Some feared losing access to medication if they disclosed their use:

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I can't ask for help, because then they'll take away my access to medications that allow me to function, like my ADHD meds or antidepressants." (roundtable participant)



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"I feel I need to hide my use, and even my knowledge of pharmacology in order to receive proper treatment. I feel like healthcare workers will see me as less worthy of treatment, or will deny me medication based on my history of substance use.» (roundtable participant)



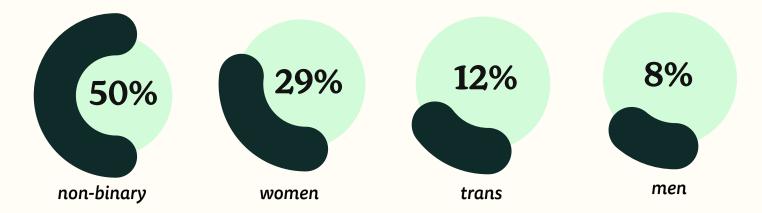
Focus Group Results

The focus group registration comprised 28 individuals who expressed interest in participation. (n = 28)

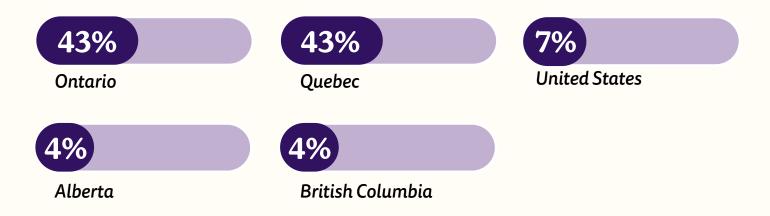
Ultimately, 10 participants actively contributed to the findings presented in this report. The data encompasses insights from both the 10 participants and the remaining 18 registrants.

All respondents were below the age of 30, predominantly falling within the 21-26 age range with the youngest registrant being 19.

In terms of gender identification, 29.2% of participants identified as women, 8.3% as men, 50% as nonbinary, and 12.5% as trans. It is important to note that participants had the option to select multiple gender identities.



Geographically, the majority of respondents were located in Ontario (42.9%) and Quebec (42.9%). A smaller percentage of participants were based in Alberta (3.6%), British Columbia (3.6%), and the United States (7.2%).



The focus groups yielded significant insights regarding YPWUD and their interactions within healthcare systems. Findings are presented as themes with supporting quotes.

Pain (38.2%) Youth spoke of their experiences with chronic pain, in some instances physical and others mental. Some participants expressed that their pain was often dismissed, or that their HCPs did not have the language to communicate about effectively about pain, or that due to differences in lived experience that their doctors could not understand their pain (eg. one youth participant discussed their experience with PCOS, and that their doctor couldn't understand because they do not have a uterus). Some participants also shared their experiences of neurodivergence, and how their doctors did not have the tools or experience to engage effectively with neurodivergent patients.

Stigma (26.8%) Similar to the survey results, the focus group findings emphasize that stigma remains a pervasive and formidable barrier for YPWUD when attempting to access healthcare. Participants shared numerous instances of feeling judged, shamed, and devalued by HCPs due to their drug use.

Harm Reduction (22.4%) Participants noted that HCPs taking an explicitly harm reduction approach or implementing harm reduction tools was a major green flag. The utilization of harm reduction language, as well as the display of harm reduction on materials such as posters and resources, within the premises of healthcare and mental health providers contributed to establishing a sense of comfort and safety for young people accessing healthcare services.

Trauma (7.8%)

Participants exhibited a deep self awareness for their experiences of trauma and the ways their experiences of trauma might influence their relationships with substances, and their substance use. They mentioned that some young people might have medical trauma, or have had traumatic experiences navigating healthcare institutions that can have long term impact on their feelings of trust and safety within healthcare systems. One participant also noted that they wished their HCPs had a deeper understanding of trauma and a curious attitude about their trauma to better tailor healthcare interventions to their unique needs and experience.

Agency (4.4%)

Youth roundtable participants also noted the ways in which their agency is doubly-denied by the nature of being youth, as well as being people who use drugs-being a youth who uses drugs creates an intersecting lack of agency or feeling a lack of respect from HCPs.

Many young individuals with a history of using drugs revealed experiencing past trauma at the hands of medical systems and HCPs. These traumatic experiences have fostered a profound mistrust of healthcare institutions, preventing some from seeking medical assistance. In some instances, these were second hand experiences of seeing how friends, family or community members had been treated by the medical system.

YPWUD, particularly those with intersecting marginalized identities, frequently encounter unwelcoming and unsupportive healthcare environments. The lack of understanding and sensitivity towards their unique needs can exacerbate feelings of vulnerability, alienation and can even cause individuals to avoid using and relying on the medical system.

Participants in the focus group were vulnerable in sharing their stories of encounters with the medical space, saying:



"Being a Black woman and kind of trying to navigate the medical space. So I'll be really honest, my experience has been more one of avoidance. I don't really think for me personally, my experiences with doctors have been neutral or like more on the positive side. But I feel like that's because I was younger and I had like my parents to advocate for me. I don't know how I would be if I had to go and advocate for myself." (roundtable participant)



And it feels like just because I use drugs now, they're not going to listen to me and only focus on my drug use. So if I want to get help, then I can only focus on one issue at a time. But healthcare is so diverse and all these things do play into each other. Still, I feel like they're not listening to me about how my issues intersect, and it's very frustrating. (roundtable participant)



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Pain is pain and no one should have to endure pain just because of their past drug use. I think consent is a huge thing, so if someone is willing and wanting to fight, this is my opinion. But reduce that pain, especially in a medical setting like they have the right to do that for themselves." (roundtable participant)

RECOMMENDATIONS

Best Practice Recommendations

These findings emphasize the importance of building trust and meaningful communication between HCPs and YPWUD. Positive encounters were often attributed to HCPs who demonstrated empathy, non-judgmental attitudes, and active listening.

Young people want care that is rooted in:

- ◆ Harm Reduction: Participants stressed the need for HCPs to possess knowledge of harm reduction practices and principles, and to understand safer drug use, alternatives to abstinence and punishment, as well as being comfortable and confident presenting these options to young patients who might be using drugs.
- Non-Judgment: Non-judgmental attitudes were reiterated as crucial for effective care. Participants emphasized the need for doctors to keep an open mind and ask questions and be willing to listen to and learn from their patients.
- ◆ Trauma-Informed Care: Recognizing the connection between trauma and substance use and called for healthcare providers to adopt a trauma-informed approach. "Understanding of the connection between trauma, mental health, and substance use," urged one participant.



- Cultural Competence: Participants underscored the value of understanding diverse backgrounds and experiences. One participant suggested HCPs receive "cultural competence training to understand diverse backgrounds".
- ◆ Peer Support Integration: Integrate peer support programs within healthcare settings, where individuals with lived experiences of drug use can engage and support young patients. Peer mentors can serve as valuable sources of information, guidance, and inspiration, fostering trust and enhancing the overall healthcare experience.
- Respect for Agency and Autonomy: Participants stressed the importance of recognizing client agency in their healthcare and treatment, including decisions around substance use. Respecting the agency and autonomy of youth in healthcare settings is crucial as it empowers them to actively participate in decisions regarding their well-being.
- ◆ **Voluntary and Patient-Centered:** Voluntary and youth-centered healthcare is essential for fostering a healthcare system that prioritizes individual needs and preferences. When healthcare is voluntary, patients have the autonomy to make informed decisions about their treatment, allowing for a more collaborative and respectful relationship between healthcare providers and patients.

Policy Recommendations

Based on our outreach, the following policy and advocacy recommendations should be implemented to improve healthcare experiences for YPWUD:

○ Comprehensive Training for Healthcare Providers: Develop and implement mandatory training programs for healthcare professionals that address the unique needs of YPWUD. This training should encompass culturally competent care, trauma-informed approaches, harm reduction strategies, and communication skills to ensure that healthcare providers can offer non-judgmental, empathetic, and effective care.

- Trauma-Informed Care Frameworks: Establish trauma-informed care frameworks within healthcare institutions to recognize and address the potential trauma experienced by YPWUD. Incorporate approaches that prioritize safety, trust, collaboration, and empowerment, creating an environment conducive to healing and recovery.
- ◇ Accessible and Non-Stigmatizing Services: Develop specialized, easily accessible healthcare services tailored to the needs of YPWUD. Implement measures to reduce stigma within healthcare settings, such as creating separate intake processes for substance-related concerns and ensuring patient confidentiality.
- ◆ Harm Reduction Strategies: Integrate harm reduction principles into healthcare policies, promoting evidence-based practices that prioritize minimizing harm and enhancing the overall well-being of YPWUD. Provide resources for safer drug use and overdose prevention, including the distribution of harm reduction supplies.
- Culturally Safe Care: Ensure healthcare institutions provide culturally competent care that considers the diverse backgrounds and identities of young people who use drugs. Develop protocols that address the intersections of race, gender, sexual orientation, disability, and other aspects of identity, promoting equitable and inclusive healthcare services.
- ◆ Youth-Centric Information and Resources: Create and disseminate ageappropriate educational materials and resources that empower young people with accurate information about drug use, its potential consequences, and available healthcare options. Utilize engaging and interactive formats to enhance understanding and awareness.
- Integrated Mental Health Support: Establish integrated mental health support services within healthcare settings to address the mental health and emotional wellbeing of YPWUD. Ensure easy access to counseling, therapy, and support groups that can help individuals manage the psychological aspects of drug use.

- ◆ Move Towards Voluntary and Non-Punitive Approaches: Advocate for policy reforms that focus on decriminalization of drug use, shifting the emphasis from punitive measures to public health approaches and moving away from models of mandatory treatment. Collaborate with community organizations, advocates, and policymakers to create a more supportive legal and policy framework for YPWUD.
- Continuous Research and Evaluation: Promote ongoing research and evaluation to better understand the evolving healthcare needs and experiences of YPWUD. Use data-driven insights to inform policy adjustments, improve interventions, and enhance the overall quality of care provided.

By implementing these policy recommendations, healthcare systems can take proactive steps to create an environment that is responsive, respectful, and supportive of the healthcare needs of YPWUD, fostering improved health outcomes and overall well-being.

Limitations and Future Directions

Throughout the execution of this project, it has been clear that youth who use drugs are not a monolith. Systems of oppression such as white supremacy, capitalism, colonialism, ageism, heterosexism and ableism are experienced differently by youth of differing backgrounds and identities, and the impacts that these intersections of identity have on their experiences within healthcare settings is highly varied. While the demographics of youth involved in this project spanned a wide range of age, sexuality, gender and ethnicity, the data collected is limited in its ability to fully reflect the realities that systems of oppression have on the healthcare outcomes of all youth who use drugs.

In order to better understand the diverse and varied experiences of youth who use drugs, future projects should focus on the ways in which the intersections of identity experienced by youth further impact their access to healthcare systems, and their health outcomes when accessing care.

CONCLUSION

The needs of young people are complex and multifaceted, regardless of whether or not they are using drugs. Each young person will have a unique relationship to the medical system, as well as a unique relationship to substances. The biggest takeaways we found in our peer-to-peer engagement with youth exploring their experiences navigating healthcare systems has been that young people experience pain, whether physical or mental, and they want their pain to be recognized. Young people are autonomous individuals with powerful insights into their own health experiences, and they want collaborative support from their healthcare providers. Young people are also hyper aware of how their identities and positioning within society may influence their treatment, and in some cases, mistreatment, by the healthcare system.

The youth engaged during this process overall just wanted their doctors to listen to them, learn alongside them, and provide a safe and non judgemental space to explore consensual treatment options.

Further Reading and Resources

<u>Best Practices Checklist for Healthcare Providers by Get Sensible</u> in collaboration with CPHA (2023)

<u>Communicating about Substance Use in Compassionate, Safe and Non-Stigmatizing Ways</u> by Public Health Agency of Canada (2019)

We encourage readers to take a look at these resources and reflect on the ways in which they may be perpetuating stigma in the language they use and how one can improve their approach when talking about drug use.

Non Stigmatizing Language Resources

The ways that healthcare providers talk about drugs and drug use can convey a lot of one's own internal and external stigma. Being mindful of one's language around substance use can allow the young person they are supporting to feel more comfortable and seen. The following table provides some language considerations to utilize when engaging in these conversations with young people.

try saying	instead of saying	because
✓ Drug use✓ Substance use	Drug abuse/Substance Misuse	Substance use occurs along a spectrum, not all drug use is problematic and framing drug use in general or addiction as drug abuse may convey a moral failing.
✓ Drugs/substances✓ Unregulated supply	★ Illicit/Illegal Drugs	Using language of criminalization conveys that you might see drug use as a criminal issue rather than a neutral public health issue creating barriers to trust/safety.

try saying	instead of saying	because
✓ Person who uses drugs✓ Person experiencing substance use disorder	× Addict(s)	While some patients may self identify as addicts, using personfirst language shows that you see the whole person and are not reducing them to their drug use.
 ✓ Substance use ✓ Substance use disorder (in some contexts) 	× Addiction	Rather than labeling someone's experience, it is important to let young patients define their own substance use to promote autonomy and self reflection.
 ✓ Drugs ✓ Substances ✓ Naming the drugs (ie. methamphetamine, cocaine, ketamine) 	× Hard/soft drugs	Reinforcing a moral hierarchy around which drugs are acceptable and which ones are not can reduce a young person's willingness to talk about escalations in use or using new/different drugs.
✓ Using/consuming drugs or substances✓ Intoxicated✓ Casual: getting high	* "Getting wasted," "tripping out." "hammered," etc.	Language like this carries certain connotations that might be potentially stigmatizing or lack relevance to the young person you are serving.
✓ Young people, youth, young adults, people.	X Kid, child, honey, sweety.	Not using patronizing or infantilizing language towards young people.

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