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"TREATMENT CAN'T BE HARDER TO ACCESS THAN DRUGS":

Findings from a series of
community workshops about
the OPTIMA trial, OAT and
flexible models of care for
opioid use challenges in
Canada: A KT initiative



Acknowledgements

The stories we heard while engaging with folks across Canada were stories of resiliency and strength. We want to recognize the incredible people who came and shared their experiences and insights with us throughout these community workshops. Their vision for the future of opioid use disorder (OUD) care in Canada is transformative, powerful and has the potential to prevent many unjust and unnecessary drug poisoning deaths occurring in almost every community across the country. Funding for community workshops was provided in part of Health Canada's Substance Use and Addictions Program (SUAP).



Thank you to our community partner organization. Without your participation and valuable insights this work would not be possible:

Alberta Alliance Who Educate and Advocate Responsibly

ANKORS/REDUN

Manitoba Harm Reduction Network

Ontario Network of People who Use Drugs

Méta d'Âme

Direction 180



Thank you to those that helped design, coordinate and facilitate the community workshops and report:

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Land Acknowledgement

It is with deep gratitude in which we wish to acknowledge the traditional lands and territories on which this work was conducted. In the spirit of reconciliation we acknowledge that this work was conducted on the traditional lands, ancestral and unceded territories of the:

- Blackfoot Confederacy (Siksika, Kainai, Piikani), the Tsuut'ina, the Îyâxe Nakoda Nations, the Métis Nation (Region 3), and all people who make their homes in the Treaty 7 region of Southern Alberta
- Ktuanxa, the Syilx, and the Sinixt Peoples
- Mi'kmaq People
- Kanien'kehá:ka/Mohawk Nation

Background and Purpose

From 2017-2020, researchers within the Canadian Research Initiative on Substance Misuse (CRISM) launched OPTIMA - a clinical trial aimed at investigating a more flexible model of care than witnessed doses of methadone to treat prescription-type opioid use disorder (POUD). Rather than methadone, which has to be taken under close supervision at a pharmacy or clinic, this model of care was based on prescribing carry doses of buprenorphine-naloxone, known commercially as Suboxone. Participants in the study were allowed to take buprenorphine-naloxone at home as early as their first weeks of treatment. The approach proved just as effective as using methadone for reducing opioid use, without the need for close supervision. The findings indicate that offering patients flexibility in their care works just as well as supervised methods in reducing opioid use.

For information about the trial and trial findings please visit the following resources:

[OPTIMA Trial Video Abstract](#)

[Primary Outcome Infographic](#)

[Findings on fentanyl use](#)

[Findings on cravings](#)

[Findings on patient satisfaction](#)

[Findings on depression](#)

Community Workshops

After completion of the trial, a range of activities were organized to facilitate uptake of the study findings into practice (also referred to as knowledge translation). As part of this work, people with lived and living experience of substance use (PWLLE) and some of the community organizations that support them were engaged in a series of community workshops. The aim of the workshops was to discuss the community significance of the trial findings and to identify target areas to improve uptake of the findings in both community and clinical settings.

Community knowledge users have a wealth of knowledge pertaining to the needs of their community and crucial insights into substance use research and practice. In spite of this knowledge, this community is often excluded from meaningful knowledge translation (KT) activities and research findings are rarely communicated in accessible, engaging formats. Community workshops offer an opportunity to meaningfully engage community knowledge users in knowledge translation efforts and ensure that efforts to change practices are relevant and pragmatic.

Objectives

- Engage in participatory meaning making around the OPTIMA findings with community members (i.e. do these findings align with your lived/living experience and knowledge?)
- Share research findings in an accessible and engaging format.
- Define the “community significance” of the OPTIMA trial and results.
- Identify areas of further inquiry and research questions that are relevant and interesting for community members.
- Identify areas for practice change and knowledge mobilization strategies for community and clinical settings.

Description

- In-person and virtual small group sessions about the OPTIMA findings across Canada
- Brief presentation about the OPTIMA trial, followed by a facilitated discussion about the relevance of the findings for community knowledge users and how to optimize flexible models of care.
- Workshops were 1 hr in length. Food and compensation were provided.
- Hosted in partnership with community organizations and advocacy groups.

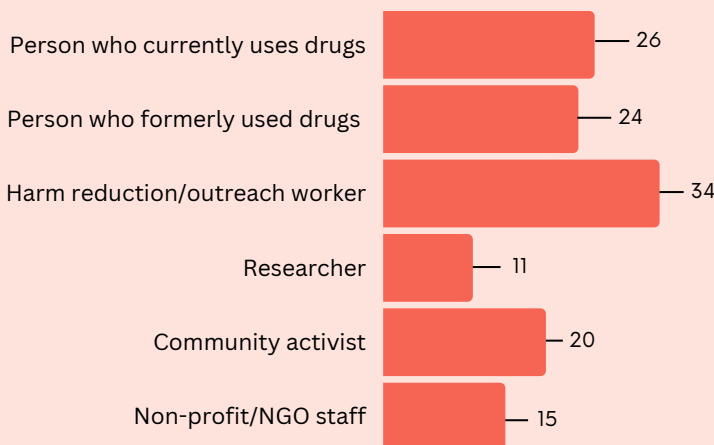
Who did we hear from?

A total of 9 community workshops were hosted across Canada with 76 participants. Sessions were held both in-person and virtually. The workshop initially scheduled in Trail, BC was unable to take place due to last minute unforeseen circumstances with participants. Part of doing meaningful knowledge translation in community settings involves flexibility, and an understanding of the complexities of everyday life. Instead, the KT team had an informal discussion with the organizing Outreach Worker about OAT and substance use models of care in Trail. Key insights from these discussions are included in this report.



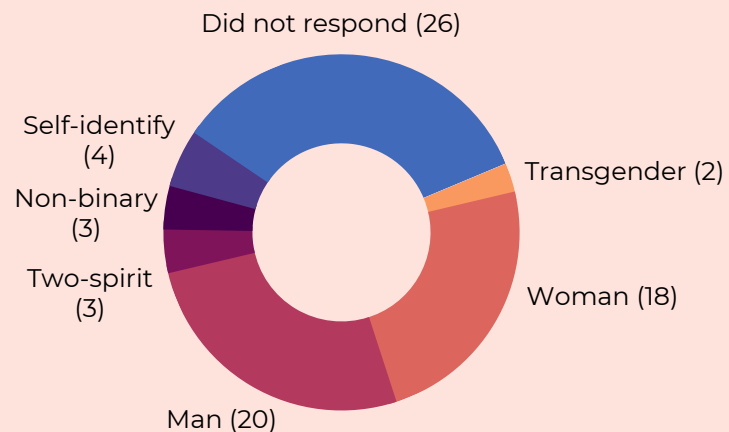
Knowledge User Profiles

Participants were recruited by community partner organizations. Many self-identified as harm reduction/outreach workers (34%).



Gender of Participants

Of those that responded, most participants identified as man (26.3%) and woman (23.7%)



How did the workshops take place?

Workshops were structured around the questions "what?" "so what?" and "now what?"



WHAT?

Involves a brief presentation on the OPTIMA findings to set the stage for discussion about the salience of the findings for community settings and flexible models of care. In order to focus the workshops on participants' thoughts and perspectives, the presentation was capped at 10 minutes and was presented using a video and printed handouts. As a result, it was not possible to present all of the OPTIMA findings including secondary analysis and ancillary studies. Instead, the presentation focused on presenting the primary outcomes.

PhD students who had experience with the trial and its results were engaged to develop and deliver this presentation. To further build their capacity conducting KT in community settings they were advised by Brandi Dawn Abele- a community member with extensive experience in creating accessible presentations. To accommodate different learning styles, information was delivered using diverse methods including: videos and print materials (handouts and infographics).



SO WHAT?

Included a group discussion around the participants' initial impressions of the research and anticipated impacts of OPTIMA findings on the community.



NOW WHAT?

Involves a continuation of the group discussion, focused around any gaps participants identified in the research findings, and any areas they would like to see investigated in the future.

Workshops were facilitated in person at community organization spaces or online over Zoom. All participants were compensated with cash or e-transfer for attending the session at a rate of \$50/hour and part thereof. Food and beverages were provided at the in-person sessions; virtual participants were given vouchers or additional cash (~\$10 per person) to purchase food. Before the session began, participants were asked to give informed consent and complete a pre-workshop evaluation survey to gather key demographic information. Facilitators took notes pertaining to key themes that emerged during the group discussions. The workshops were also audio recorded with participants consent for the purposes of note-taking and triangulation. After the session, participants were asked to complete a post-workshop evaluation survey.

How we looked at the data



Audio recordings were transcribed and anonymized following the workshops and reviewed by the Community KT Team. Transcripts and field notes from each workshop were compared and common areas of discussion, including barriers and facilitators to care, were grouped into key themes. These key themes were then defined summarized into a draft report. The draft report was reviewed by community advisors to ensure accurate interpretation of the workshop data.



What we heard

Initial thoughts/impressions of OPTIMA results

Participants were eager to share their thoughts on the OPTIMA results and flexible models of care. Discussions were free-flowing and often initiated organically directly following (or sometimes during!) the presentation. Immediate feedback about the OPTIMA trial included:




Issues related to OPTIMA's "measures of success" (e.g., reducing/stopping opioid use, and the use of urinary drug screens).



Questions about how clinical trials can better integrate clients' self-defined goals into research measures.

Many participants reflected on the OPTIMA findings in the context of their personal experiences regarding challenges with treatment for opioid use and as peer support workers, peer navigators and harm reduction educators. Discussions about OPTIMA findings extended beyond personal narratives, into the system level barriers and facilitators for opioid use care. Common themes that emerged across all workshops are summarized below.

Trust



All workshops discussions revealed that trust is an essential component of any form of OUD care. Participants who had trusting relationships with their prescribers spoke highly of the quality of care they received, and how **trust can be built out of the freedom to self-define their own goals for treatment (e.g., not just focused on sobriety)**. On the flip side- mistrust was discussed as a substantial barrier for folks when accessing and engaging in care. Specifically, when it came to take-home doses, participants shared challenges related to feeling like if they make a mistake (e.g., used illicit substances), or missed an appointment, they would lose their carries and lose the trust they had built with their prescribers.

I feel like you spend all this time building all this trust, and then you mess up once and it's gone. And you're like, Fuck this. Like, I don't even care enough to start to try it again.

Participants in all workshops across the country shared their impressions that **the state of OUD care in their communities felt extremely coercive**. In particular, urinary drug screens (UDS) and being “cut off” from their care due to punitive policies (e.g., reductions in dose due to positive UDS or missed appointments).

Participants shared how a positive UDS often resulted in them losing certain “privileges” they felt prescribers had made them “earn” (e.g., take home doses). We also heard many personal stories that highlighted how strict appointment schedules and times did not always work with the complex lives of PWUD, and how frustrating and disheartening it can be to have doses reduced or removed due to missed appointments. One participant in a rural setting shared how it was an 8 hour walk from where they live to where they access care. Another participant in the same community shared that there was limited forgiveness for people who miss appointments - **“if you don't show up two times for the clinic, you're out.”**

Another participant shared their perspectives on the impact of punitive policies as a harm reduction worker:

As a harm reduction worker, what I've seen is just the panic when it gets to day three, and someone hasn't been to the clinic. And the fear of getting knocked back to an initial dose for methadone.... And again, if there was some flexibility [it would be] about supporting people with meeting their goals and quality of life. Because like, if someone's living in an encampment, someone's living in a shelter hotel, that is like an hour travel by transit for them to get to their clinic, these things [current models of care] are just completely inaccessible.

Participants shared that constant UDS were not only burdensome, but made them feel criminalized and distrusted by their prescribers. One participant referred to prescribers as “piss goblins” because of how focused they were on urine samples. Describing care for OUD in their community the participant shared:

It operates on this principle of, 'if you jump through the hoop, then we'll give you the thing. If you give us an opioid deficient urine sample, then you get to have a thing to take home.' And I really think it's like a matter of like the coercive nature of prescribing and treating opioid use disorder or whatever the fuck you want to call it. That [flexible models of care] would be much more useful because, of course, if people have more freedom in their life, they're not sitting in a dank ass office with someone watching them take a piss. So if the process could just be more collaborative and actually improve people's quality of life instead of just like, you know, luring someone like 'I'll give you a little treat. I'll give you an extra day of the week that you don't have to come here. If you don't use for a few days and you pee in a cup'.

One participant shared how they were cut off from their OAT and subsequently experienced withdrawal because they had an overdue bill at their clinic. When reflecting on this experience and their relationship with their prescriber they shared “I have nicer drug dealers.” This theme was echoed by another participant who shared “dealers often suffer from the same traumatic events in their life, they have humanity and empathy.”

Stigma

Participants across the country shared common experiences of stigma when accessing treatment for opioid use challenges, and when navigating the medical system for other health needs. When recalling an experience in the emergency department one participant shared “They just treat you like a drug addict.” A community service provider shared that their clients were not allowed to enter the local pharmacy without accompaniment, due to fears of theft. Many participants shared that receiving carries, and being able to take their OAT at home greatly reduced their experiences of stigma- just by nature of having to interact with the medical system less vs. going to a pharmacy everyday. In addition, many participants shared a significant lack of confidentiality and privacy when going to do witnessed doses, “everyone knows what you’re lining up for.”



Intersectionality of services

When you're houseless and you're struggling, you're struggling to get your drugs. There's a lot of stuff that happens to folks- vicarious trauma day in day out. There's no easy access to anything. The more the system lets them down, the angrier they get, and the more they use. And then they think that you're [peer support workers] not trying to help them, that you're just part of that whole system that's just fuckery.

Group discussions revealed the complexities of navigating care for opioid use challenges among other services (e.g., housing, income assistance, child welfare, etc.). Many participants were “seasoned pros” of navigating care, and now used their lived experience and knowledge to help others in their community. Participants across all communities shared frustrations with the disorganization and discontinuity of services. One participant who worked as a peer navigator shared an experience of continued efforts to get their client into housing, but ultimately having the client denied because of their urinary drug screen results.

Flexible models of care

When discussing flexible models of care, many participants shared the lack of flexibility they previously and currently experienced when engaging with OUD care. The emotional, physical, and economic burden of having to go to a pharmacy everyday was a common barrier shared by all participants.

I keep hearing, 'people won't change until they want to change.' But I don't know if I really agree with that. Because when change comes with an insurmountable mountain of barriers, change seems very undesirable. Why would someone want to access supports when those supports are conditioned? Or when those supports are incredibly hard to access, and going to a pharmacist every single day and being forced to be vulnerable, not just in front of the pharmacist, but the rest of the staff and whoever else is in pharmacy is tough for anyone, let alone somebody who's already consistently being stigmatized and discriminated against. I think it's really important that we have access to all types of supports that are going to benefit the people that are accessing them. And if something isn't working, then we need to learn how to adapt to meet the needs of people accessing these services.



Many participants shared feelings of uncertainty and confusion around clinical decisions that were made about their care. A key theme that emerged was this need to be adaptive to clients' individual and unique needs, and how flexible models of care extend beyond just providing clients with take home doses. One participant shared how autonomy and choice were essential in a "flexible model," where her prescriber was flexible in meeting her needs, and designed treatment plans that would meet her where she was at:

"When I can make my own goals and have them flexible, and I can change my goals as I need to, that's the piece."

Community insights to improve care

Ideas shared on how to improve models of care to be more flexible included delivery/mobile options, and allowing peer-based roles at community organizations to play a larger role in care delivery. Group discussions revealed that adapting OAT services to include mobile and delivery options would decrease the barriers that many people face accessing care. Participants in Nova Scotia spoke about a successful mobile methadone clinic operated by Direction 180. The bus circulated in suburbs and Halifax's surrounding communities and provided a place where folks could both initiate care and regularly access their methadone without having to leave their communities. Participants spoke of the potential of mobile options to improve access to OAT for many folks, especially those who didn't have access to transportation. Many other participants in both rural and urban settings shared ideas about mobile/delivery options for care, including suggestions to situate mobile stations for OAT near transit hubs in urban centres.



Involving peers in care delivery

Another theme that emerged from group discussion was the opportunity for people with lived experience to become more involved in OUD treatment delivery. Many folks who work in roles like peer navigators, outreach, or harm reduction workers are experts at building trusting relationships with PWUD, and are often able to connect with folks that may be marginalized, stigmatized, or otherwise “fall through the cracks” of existing networks of care. One participant shared their vision for integrating outreach and virtual care: “Having basically outreach health care, or even somebody that you trust, like a peer or a harm reduction worker that can bring care [to clients]. That’s a dream of mine. I would love to be able to, like knock on a trapdoor and be like, ‘who needs to see the doctor?’ and shoot an iPad around the room. That is flexible care. And it addresses the way that we are brutalized, some of us literally physically brutalized within emergency room [and other healthcare] settings.” Another participant suggested training for peer navigators to be able to witness doses to facilitate deliveries of OAT directly to clients.

Improving guidelines and guidance for OUD care

Many participants also raised issues and concerns related to clinical guidelines that are currently practiced. Specifically how the guidelines for OAT are out of date, and do not respond to the current drug toxicity crisis, or potency of opioids circulating in communities. As one participant put it: “The problem is the doctors that are writing the guidelines are looking at other guidelines to try to justify their guidelines, and no one's willing to push the envelope and no one's willing to like, make those guidelines that are actually going to do what we need them to do, because no one else has.” The development of future guidelines would benefit greatly from the meaningful engagement of community members. KT efforts that encourage knowledge sharing between clinicians and community members should also be pursued in order for both groups to gain insight into one another's unique perspectives.

Identified Gaps

Participants were asked to identify any lingering questions or gaps they had after the brief presentation on the OPTIMA findings. This section of the group discussion greatly benefited from the presence of PhD students (GB, CM) so participants could ask questions related to OPTIMA's research methodology including the study population, study sites, and general research protocol.

Side effects


One area of concern was the lack of discussion of the negative side effects associated with the two medications (methadone and BUP/NAL). This was particularly important for participants in roles that support PWUD (e.g., peer navigators) who expressed a desire to understand the negative side effects of the medications to help them better plan and prepare their friends, family members and clients who may be initiating treatment for their opioid use “Showing some of the risks [when sharing findings with community] of buprenorphine/naloxone and other forms of OAT because it is a lot newer than methadone. Because like, there's these medications that come out, it's always changing. But it might have some more damaging effects. They're just not known yet. Because it's such a new thing.

So I like to learn more about some of the negatives that come along with medications and making sure people are educated on that as well.” It is evident that peer navigators, harm reduction workers and other frontline workers are key knowledge exchange channels for their communities. Future efforts to share research findings with community settings should consider this, and work more closely with peer-based service providers to share both the positive and negative findings of substance use research.



OUD and the criminal justice system

Many participants discussed the challenges navigating OUD care within the criminal justice system, which was not captured in the OPTIMA findings. Disruptions and cessation of OAT was common for individuals that became incarcerated - especially those being held in provincial and municipal prison systems. Even when folks were able to receive OAT in correctional facilities, they shared how there is a lack of continuity of care once discharged and limited support. Diversion of BUP/NAL in correctional facilities was also discussed as a context in which many folks initiate the use of unprescribed medications: “a good example with one of my participants would be, you know, they incarcerated on and off for, you know, the last 15 years, started using suboxone while in jail, and was released with nothing, no support, setup. Nothing done for them. And when I referred them to [opioid use disorder care] they did a urinalysis. And because he didn't have enough of anything in his system, he was essentially denied.” For folks who are not incarcerated, but may have negative encounters with law enforcement, surveillance is a significant barrier to OAT. For example, some participants in the Atlantic region shared that it is common for police to stake out pharmacies where they know individuals access care.



Areas of further inquiry

When asked about areas where research or further inquiry may be needed participants shared a variety of perspectives. Participants indicated that currently, there is a lack of opportunity for knowledge sharing and transfer. It became clear that activities like these community workshops are rare. Many shared that they would like to be involved in substance use research, and that researchers should be engaging more with community members across all stages of the research process- not just at the end when the work is done: "How many of us are actually involved in getting the findings rather than just being participants in the study? Are we participants, or are we engaged in how it [the study] was conceptualized? Where do the findings go? Do they go back to our own community?".



Care for intersecting challenges

Substance use disorders are complex, and often occur with other mental health issues. Many participants shared that there is limited integration of support for substance use with mental health care, "a lot of services won't assess your mental health until you've stopped using substances." Further research into how to best support clients with concurrent disorders is needed. Often people engaged with OAT may continue to use other types of substances. Many participants shared that they wanted to see more research being done into treatment options for other types of substance use challenges - especially stimulants.



Withdrawal Management

A major issue with current OAT programs reported across all workshops was withdrawal management. Community members were keen to see more investigations into methods to manage withdrawal symptoms. For example, many participants shared how they and their peers use cannabis for withdrawal management, however they would like to see more targeted research done in this area. There was a keen interest among peer support workers to learn more about how to support folks who may be initiating OAT and/or going through withdrawal. In particular, further investigations into more complex cases of withdrawal, due to the unregulated drug supply and presence of benzos in many street-opioids.

Geographic Considerations

Differing standards of care

The national workshops revealed vastly differing standards, options and access to care across communities. In rural communities, participants shared a lack of choice when it comes to the delivery method of their care (i.e., in person vs. virtual), long travel times to appointments, limited coordination between prescribers and pharmacies, and a lack of flexibility- with the majority of OAT (both BUP/NAL and methadone) being administered by way of witnessed doses. The discussions also revealed that there are different cultures around particular OAT medications and these cultures vary by region. In communities where BUP/NAL is being recommended as the first line of treatment, many participants felt prescribers were “pushing” this medication. In some cases, this resulted in significant resistance towards the medication as a whole. These varying cultures towards OAT medications indicate a need for more clear and collaborative decision-making between prescribers and clients around what types of medications are being recommended and why.

Summary

These workshops aimed to discover the “community significance” of the OPTIMA results. Not only did we learn more about what community knowledge users think about flexible models of care, we also gained insight into the significant barriers people are facing with the current models of care for OUD and importantly, opportunities to improve care for these communities. Participants were very passionate and engaged when talking about their experiences with OAT. Workshops provided an engaging and fun environment for folks to come together to talk about emerging research and their experiences.

This approach should be considered a standard practice for substance use research: “I am interested [in learning

about research], I want to make a change, I want things to change. I want people to have a better life.”

Discussions from the community workshops also revealed that individuals with OUD are navigating a variety of models of care, including outside of traditional medical/clinical settings. Community level care and support from other peers and community-based programs (e.g., compassion clubs, safer supply programs, community cannabis donations for withdrawal management) often act to fill the gaps of traditional OAT programs such as greater flexibility and care options. This emphasizes that traditional OAT programs need to evolve to better meet the needs of the people they are designed to serve

Opportunities for Impact

Restructure care to be centered around trust and autonomy. Establish and uphold trusting and supportive relationships with clients and provide clients with options in their care. Examples include:

- Developing client-facing tools for substance use care
- Shared decision-making tools for clients and providers
- Develop tools/capacity building initiatives to support scaling of OUD treatments across Canada (e.g., fentanyl patches, SRM, OAT, iOAT etc.).

Individualize care to people and places. Create flexible models of care for OUD that better meet people where they're at. Individualized care should be the standard of care. Examples include:

- Virtual care options
- Delivery of OAT (including peer-delivered)
- Mobile OAT stations
- Harm reduction approaches
- Integrated care

Integrate real-life experiences from both clients and clinicians working in opioid use care into clinical guidelines. This will ensure that they are pragmatic, realistic and actually meet the needs of the people they intend to serve.

Generate more evidence around withdrawal symptom management (particularly with cannabis and managing complex cases involving benzodiazepines) and treatment options for stimulant use.

Strengthen knowledge exchange between researchers and frontline workers (i.e., harm reduction workers, peer navigators etc.) to promote shared understanding of evidence and best-practices. Examples include:

- Research newsletters for frontline workers
- Client-facing tools for peer navigators

Develop guidance and frameworks for OUD care in correctional facilities, rural and remote communities, and virtual care options.

Involve more PWLLE in research to inform priority areas for investigation and potential interventions.

