

STATS ON THE STREETS:

Understanding harms and the lives of people who use drugs

A REPORT BY

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BACKGROUND

In response to increased numbers of substance-related deaths and other harms, the Public Health Agency of Canada began surveillance of overdoses and deaths involving opioids and/or stimulants in 2016 (1). In working with federal, provincial, and territorial partners across the country, monitoring other substance use-related harms (SRH) and outcomes has been considered essential in understanding how best to respond to the public health crisis (1). Although standardized indicators do not exist across provinces, general indicators include: pattern of use (e.g., drug combinations, use settings), length of use (e.g., substances used over long term), mode of use (e.g., injection, smoking, equipment and supplies used), acute health effects (e.g., overdoses), chronic health effects (e.g., blood-borne infections), and social determinants (e.g., impacts on social, work, legal, and financial aspects) (2-4).

In Ontario, SRH reporting varies across municipalities. For instance, Hamilton Public Health Services in collaboration with Hamilton Paramedic Services, Health Sciences, St. Joseph's Healthcare, and community partners, have created a quick and responsive opioid-related information platform for the public (5). This platform provides local opioid information such as opioid overdoses, naloxone distribution, emergency department visits and hospitalizations, and more (5).

People who use drugs (PWUD) and supporting frontline workers have expressed the need for better engagement of their community in the development of responses to the current drug toxicity and overdose crisis in Canada. Several suggestions have been made to improve data collection for surveillance, early warning systems, and to communicate local data and information (e.g., alerts) in Ontario, such as strengthening provincial coordination and technical assistance (1). In addition, other areas proposed for support to Ontario overdose response plans included real-time provincial data collection systems involving information from community partners (1).

There has been limited engagement of PWUD in the development of provincial and local SRH strategies in Ontario. As a result, there have been gaps in selecting indicators for monitoring SRH that are most meaningful to PWUD and how this information could be used to respond more effectively to local needs (6).

The current lack of engagement leads to continued systemic harm and oppression of PWUD, which often isolates people from services and leaves them with unmet needs. In the field, staff at public health units and drug strategy coordinators have identified gaps in meaningful engagement with PWUD in their work to monitor and effectively respond to SRH. Additionally, experts have indicated the importance of these relationships in informing work to address harms through evidence-based practices.

From an equitable and non-stigmatizing perspective, data and information reported and shared should include the knowledge and experiences of community members and

community-based agencies at the forefront of the overdose response (1). Placing community action and engagement at the center of SRH strategies would require the deliberate involvement of community members as a priority strategy for prevention and harm reduction efforts (7-10). The goal of the project was to meaningfully bring together PWUD to co-design strategies and frameworks that could support increased access to SRH information in the community to reduce harms within the current system. Following the ethos of “Nothing About Us Without Us,” the Ontario Network of People who Use Drugs (ONPUD) co-led this project alongside Public Health Ontario (PHO) and Healthcare Human Factors (HHF). This project was funded by the Public Health Agency of Canada (PHAC).

METHODS

We used the findings from a scoping review completed in the first stage of this project to inform this stage of the project. The scoping review focused on current engagement practices with PWUD in monitoring SRH, and was submitted as a manuscript to a peer-reviewed journal for publication.

Following the literature review, this report focuses on the next phase of the project that was conducted in two parts. The first part focused on storytelling through in-depth interviews with a variety of partners, including PWUD to glean insights into people’s goals, values, and lived experiences. These insights informed the second part consisting of three virtual co-design workshops, led by ONPUD, and attended by PWUD and service providers, to uncover strategies and tools that will allow for meaningful and sustainable engagement with PWUD.

Part 1: Interviews (Immersion and Discovery)

Five members of the project team conducted a series of interviews with individuals involved in harm reduction, community health, public health, policy, and community members. Team members reached a consensus to interview 10-15 service providers and community members each. We define service providers as representatives from organizations engaged in harm reduction, public health, substance use policy or programming. Ultimately, 27 individuals (17 service providers and 10 community members) agreed to participate in this study and were interviewed.

The interviews were conducted between December 3, 2022, and February 8, 2023, on Zoom and in-person. Three team members from ONPUD conducted semi-structured interviews with community members. We focused the discussion with community members on understanding what is important to PWUD in accessing and learning about SRH, their goals for a dissemination system, who they trust with information about SRH, their experiences sharing information about drug overdoses, and what they want service providers to know.

In addition, two team members from Healthcare Human Factors (HHF) conducted semi-structured interviews with service providers. These discussions centered around their understanding of how information about drug overdoses and adverse drug reactions are currently gathered and shared, what works well and what does not in the current system, organizational roles, standards of the system including the process, timeline, and actions taken based on this data, how information is shared and to whom, and how information reaches the community.

We used an interview guide adapted for both service providers and community members (found in Appendices 1 and 2), and interviews were audio recorded or hand-written for transcription and analysis. The 27 transcripts were individually assessed by team members from HHF, and ultimately informed the content for the workshops series.

Part 2: Workshops (Explore and Co-Design)

During the consent process in part 1, individuals who participated in interviews were asked if they would like to be re-contacted for participation in a three-part workshop series. Participants who indicated 'yes' were re-contacted, and a total of two service providers and 14 community members participated across all three workshops. The workshops lasted two hours each, and were held on February 22nd, March 7th, and March 22nd, 2023 through Zoom. Facilitators included members from ONPUD, HHF and PHO.

Topics covered in the workshop series included: types of information that could be part of an information sharing platform; priority features to include or exclude; how a platform like this could be impactful; concerns or challenges that could arise with this tool; strategies for safety; and building awareness about the tool. At the beginning of each workshop, facilitators went through the consent process, discussed ground rules, and presented the agenda. Participants were placed in breakout rooms with moderators to encourage focused discussions, and findings were shared back to the group before the end of each workshop. In workshops 2 and 3, there was a shareback of the findings from the previous workshops to ensure that the discussion insights were accurately captured. Workshop agendas and activities can be found in Appendix 3.

To support the discussions held in these workshops, we also introduced relevant platforms that we prepared as an inspiration scan, to encourage dialogue around key features and tools that would support increased access to and sharing of SRH information by PWUD (see Appendix 4).

Our project received approval from the Ethics Review Board at Public Health Ontario, including the consent process and materials. All team members followed the approved processes. We provided an Information Letter and Consent Form to all interview participants for their review. Additionally, we verbally discussed the contents of these documents with participants prior to conducting the interviews, while implied consent was discussed with participants in the workshops.

RESULTS

Interviews with People Who Use Drugs

PARTICIPANT CHARACTERISTICS

The community members engaged in our interviews represent a sample of 10 people who generally live in urban areas in Southern Ontario. Most of the demographic information of the participants were not collected to protect the anonymity of the participants. However, the contents of the interviews helped us to gather additional information about our sample.

Geographic locations and contexts from which participants responded ranged in nature. Some were located in and around the Greater Toronto Area where services for people who use substances are more plentiful, while others were located in urban-suburban communities in London, Hamilton, Guelph, Simcoe and St. Thomas where harm reduction and substance use services are more sparse. These varying perspectives allowed for a diverse series of insights, even among a small sample. The structural experiences of participants ranged widely, with some having access to secure housing, health and social services, and digital technology, and others who were experiencing housing insecurity or were unhoused and navigating varying housing support services such as shelters.

TRUSTED INFORMATION SOURCES

When asking PWUD what information sources were trusted and consistently accessed, all shared that the most trusted sources were other PWUD. Reasons for this ranged, but surrounded the close-knit and trust-based drug culture and community that has developed over decades in response to the stigma, isolation, and criminalization that PWUD face. Participants shared how members of the community consistently care for each other and have developed comprehensive strategies to keep each other safe despite inadequate systems and structural harm imposed on them. Participants shared that they trusted other PWUD because of 1) first-hand knowledge and expertise in the area of substance use and 2) understanding of the unique needs and harms faced by PWUD. As one participant shared:

*“I only trust those who use, because they actually know what drugs are like”
(CM-01).*

There were mixed opinions about whether drug sellers (often called “drug dealers”) were a trusted source of information. Although many people who sell drugs are also PWUD, participants shared that they were cautious about gaining information on safety, purity, and impact of substances if the person was motivated to just “try to sell you their drugs” as they may not be entirely truthful. Others shared that they trusted knowledge from people who sell

drugs because they may have a lot of information from contacts and interactions with PWUD, and their knowledge about the source of drugs.

We heard that harm reduction workers are another group of service providers that PWUD trust with information regarding SRH. These individuals were described to 1) be knowledgeable on community-specific overdose events, 2) have strong connections with community members; and 3) have access to, and aim to disseminate information in a timely and appropriate manner.

ACCESS TO SERVICES AND EXISTING ALERTS

Many participants outlined major gaps in the use of existing information sharing strategies and the design of harm reduction and substance use services in communities. As shared by participants, the current rules and policies within harm reduction spaces deter groups of people from using services, limiting accuracy and reach of information. When discussing services relating to drug checking, participants shared that results are often shared in a slow manner which is unhelpful for individuals who need/want to use substances in the current moment. In addition, drug checking services were described to not be uniformly available. As a result of the gaps that exist among drug checking services, no interview participants had ever used a drug checking service.

More broadly, participants shared that existing drug alerts do not provide them with up-to-date information. Individuals described that by the time these alerts reach the community, the specific batches of drugs that they refer to are no longer in circulation. When community members view these alerts, they often lack sufficient detail to be helpful and don't use wording that is clear. Information that was often missing in existing drug alerts, which was described to be particularly important for people who use drugs, included the location/area where the substance was purchased, a description of the drug (including colour, taste, shape, texture, smell, effect), and accurate images. As a result, participants shared that they often relied on their community to meet their needs for staying up to date on current supply conditions and SRH.

As shared by participants, their engagement in 'drug testing' consists of asking people who have used the current supply what they have experienced and what the outcomes were. Drawing on informal connections to learn necessary information was described to have many strengths. These strengths include an efficient response and dissemination times, the ability to share knowledge on the drug supply and broader harm reduction strategies, the opportunity to build connections within the community/ reduce isolation, and finally the creation of safe and appropriate places where people who use drugs can do so in the presence of those who are trained to respond to an overdose event.

Participants explained that they often shared information with peers and community members through word of mouth including:

- / Which substances they used

- / How to identify these substances (the look, smell, taste, packaging, etc.)
- / Whether they liked or disliked using the substance
- / The experiential details of how they felt during use (positive, negative and neutral)
- / If anyone within the community had experienced a previous overdose event as a result of this supply and what the details were surrounding the event

Information was disseminated using a variety of strategies including word of mouth in person, by phone or text, using social media such as Facebook posts, or communicating with external stakeholders such as harm reduction workers and occasionally police officers.

Although participants primarily disseminated and gained information using these grassroots measures, a variety of limitations were also discussed. Information access was limited for certain groups, including for those who were less connected to their respective communities because they were newer to substance use; those concerned about stigma and criminalization, or individuals who resided in smaller communities. In addition, participants expressed that due to the lack of information available to them, PWUD may not know the most effective harm reduction techniques, which can lead to accidental harm.

WHAT INFORMATION SHARING SHOULD LOOK LIKE

“Warnings don’t make me feel safe [...] but would make me more cautious and flag what the supply looks like” (CM-03).

When asked what an effective information system for substance use-related harms would be, people who use drugs shared that it must:

1. Be accessible
2. Include language that is easy to understand
3. Be anonymous and confidential
4. Include characteristics of contact with the substance: information such as the general location (purchase, consumption, reaction), mode of use (smoking, injecting), and characteristics of the substance (colour, taste, smell, and how the substance reacts when being prepared for use)

A particularly relevant consideration shared by PWUD in ensuring engagement in such a system is trust. Participants explained that trust can be built by:

- / Ensuring information comes from other PWUD
- / Emphasizing when information is coming from a person who is a more experienced drug user rather than a less experienced or first time user, or from a person who is well-known in their community

- / Creating equitable access to information through harm reduction workers and organizations
- / Using terms and language that people who use drugs would use to describe circumstances

Interviews with Service Providers

We spoke with 17 service providers from various organizations involved in harm reduction, community health, public health, and public policy sectors. We spoke with representatives from each of these sectors from locations across Ontario, Canada including Toronto, London, the Simcoe-Muskoka Region, Ottawa, and Thunder Bay.

CURRENT INFORMATION DISSEMINATION SOURCES

Stakeholders shared a variety of information sources that they currently engage with or are aware of to disseminate information on SRH. An overview of these sources can be seen in Table 1.

Table 1: Overview of Information Sources Used by Service Providers

Information Sources	Service Provider Discussion
Emergency Medical Services, Police, and Hospital Data	Service providers rely primarily on this data source. They feel that it is helpful that this data is structured and formatted conveniently and is readily available to them. However, they noted that the information from these institutions is incomplete because many SRH incidents go unreported to institutions.
People Who Use Drugs	Service providers who work closely with PWUD rely heavily on what the community tells them about SRH incidents. They often share this information within their organization, but have no outlet for reporting it to other institutions or sharing it more broadly across the province.
Toronto Drug Checking	Service providers shared that drug checking data is helpful in understanding the composition of the current drug supply. However, the stakeholder reports contain aggregate data and there are gaps in the data because the drug checking service only tests a small subset of the drugs in circulation.

Drug Alerts

Some service providers liked that drug alerts aim to avoid alarm fatigue by using thresholds to limit how frequently people are notified. Others felt that alert thresholds cause critical information to be withheld from the public for too long, especially in areas with small populations.

Coroner's Reports

Service providers turn to these reports to understand the number of fatal overdoses and what substances were involved. However, this source is too slow to help inform real time harm reduction actions.

When discussing the available information sources, service providers shared three main challenges including data gaps, timeliness of reporting, and language used (e.g., inaccessible language for community members). They shared that currently, there are no clear data sources that provide information about individuals who are experiencing non-fatal harms, creating major gaps in knowledge for communities and service providers. Finally, participants described that not all PWUD have access or feel safe engaging with and reporting harms to harm reduction services, creating gaps in knowledge about the impacts of different supplies on varying communities.

INFORMATION SHARING WITH THE SUBSTANCE USE COMMUNITY

Front-line workers discussed that information about drug reactions and overdoses is often voluntarily reported to them by PWUD when they are distributing harm reduction supplies or providing substance use-based support. These service providers often gain and disseminate information surrounding the colour of substances, the substance type, and location of overdose events or adverse reactions. For some organizations, there are unique individuals who work in an outreach capacity who share this information back out to members of the community in person, using social media posts, posts on public health websites, bulletin boards, and using flyers. Stakeholders shared that the dissemination of this information is strictly related to the existing relationships and trust built by harm reduction workers with the community.

Although interpersonal relationships with the community can be leveraged to help spread information, there remains challenges in sharing drug information and resources to people who use alone, those who have no access to harm reduction supplies (such as those living in correctional facilities), and people transitioning out of shelters or treatment facilities. The majority of overdoses occur in these contexts for PWUD; however, they are often isolated from these in-person methods of information sharing due to fear of stigma or criminalization and thus cannot benefit from the information shared by organizations and other community members.

INFORMATION SHARING WITH OTHER HARM REDUCTION ORGANIZATIONS

Service providers voiced that information about adverse drug reactions and overdoses they receive from the community are often shared among other staff members within the organization; however, there remains no coordinated effort to share information relating to substance use-related harms between agencies. Often, this is as a result of limited pathways to report this information between organizations (e.g., at the local, provincial, or national level). Service providers shared that the main cross-agency information dissemination was between supervised consumption sites and the city, when reporting overdose events.

“We don’t share the overdose info with other organizations- no one is asking us for this data” (SH-06).

WHAT INFORMATION SHARING SHOULD LOOK LIKE

Stakeholders who were interviewed shared varying perspectives on what information would be helpful in knowing about SRH. An overview of different perspectives is below.

Harm Reduction Based Organizations Would Like Information Surrounding:

- / Number of overdoses and the location of each
- / Colour, substance, and amount of substance
- / Preventive harm reduction information

Community Health and Clinical Organizations Would Like Information Surrounding:

- / Drug composition, highlighting the emergence of new substances
- / Explanations of new substances found including safety information
- / Addiction and withdrawal information for each drug

In light of sharing what information would be most helpful in learning, service providers also shared key considerations and concerns regarding the dissemination of this information. Some service providers are concerned that sharing information about drug related harms may increase stigma toward PWUD from people outside their community. On the other hand, others felt that talking openly about drugs will reduce stigma by increasing understanding of the community through education and openness. Some shared concerns that releasing alerts before a certain threshold of incidents have been reached could lead to over alerting and alert fatigue. In a similar regard, participants shared fears that warnings might not be helpful because it is very challenging to create alerts fast enough to keep up with the rapidly changing drug supply. Finally, service providers discussed how broader structural/systemic issues and discrimination around substance use will continue to create challenges for PWUD,

specifically that they will continue to lack alternative choices even if they have information about the toxic drug supply.

Despite the stated concerns, most participants expressed interest in having access to data reported by PWUD. Some service providers want to use this information to directly benefit the community through:

- / Knowing when and where to increase harm reduction services
- / Knowing which tools and resources are most needed by the community
- / Improving harm reduction information and communication strategies

Other service providers who do not work directly with the community also expressed an interest in this type of information, which they believe can indirectly benefit PWUD through:

- / Advocacy for policy change (e.g. safer supply and decriminalization)
- / Reducing stigma around drug use through open public dialogue
- / Understanding drug trends and better understanding of the current drug supply which could inform clinical care

Workshop 1: What Information PWUD Wish to Access and Share

Based on the perspectives gathered from the interviews, there was a clear gap between the information currently provided by formal sources, such as drug alerts, and the types of information that are important for PWUD to share with others in the community. For PWUD, conversations extended beyond the sole focus of SRH often seen in current drug reporting systems, to include sharing of other topics that are closely intertwined with their experience using drugs. These interim findings broadened our scope of exploration during the workshop series to start uncovering what an information sharing platform designed and used by PWUD might look like.

CORE VALUES

PWUD shared a series of values that a SRH information sharing platform should follow. These values are highlighted in Table 2.

Table 2: Overview of Core Values a Substance Use-Related Harm Information Sharing System Must Have

Core Values	Description of Values
Fitting within drug culture	Focuses on the real priorities of the community and uses wording, drug names, and phrasing of questions that are meaningful to PWUD.
Protects the community	This tool should strive to support anonymity and to help community members to stay safe.
Is extremely timely	Information needs to get to the community as fast as possible. It quickly loses its value as time goes on and could become completely useless in 1-2 weeks.
Contains the most useful details	Information and alerts about drugs often don't have enough detail to be helpful. Practical descriptions, things you can taste/smell/see/feel and information about neighbourhoods are very important.
Is easy to access and navigate	Because people have different levels of access to technology and the internet, there should be more than one way to get information in and out of this tool. Information should be easy to filter to the types of drug you use and the areas you buy and use in.

TOPICS TO SHARE

Along with the values above, participants also shared the types of information they want greater access to in order to stay safe. PWUD wanted to share their experiences and personal perspectives on the local drug supply, harm reduction strategies, and other services that impact their daily lives.

For PWUD, sharing information about the local drug supply included telling others about bad drug experiences, good experiences, and everything in-between. Context of use was also an important factor to consider since people can have different reactions to the same drug. The information requested by PWUD is highlighted in Table 3.

Table 3: List of Information PWUD Want to Share About

Type of Information	Detailed Information Requested
Drug experiences	<ul style="list-style-type: none"> / Street name of the drug / Photo of the drug / Description - Colour, smell, taste, texture, changes to the drug when being prepared for use / Amount used / Location/area purchased / Effects of the drug / Duration of drug onset / Duration of drug effects / Additional context <ul style="list-style-type: none"> o E.g. Other drugs taken / Information source <ul style="list-style-type: none"> o E.g. Firsthand account or word of mouth / Personal info - Experience and tolerance with this drug
Service experiences (E.g. Shelters, treatment programs, harm reduction kit pickup locations)	<ul style="list-style-type: none"> / Name of service and the location / What service it offers / What the experience was like
Harm reduction resources	<ul style="list-style-type: none"> / Where to get single-use equipment / How to use this equipment / How to prepare and use drugs / How to respond to individuals in crisis / How to deal with overdoses

Participants discussed that sharing information about the current drug market would give PWUD a better understanding of what options are available, allowing them the autonomy to seek out desired experiences and services while avoiding unwanted experiences. In addition, PWUD shared that learning about other people’s experiences would give them peace of mind because it allows them to anticipate what reactions they may have themselves and compare their experiences with others.

PWUD envisioned these real-time drug reports significantly improving the timeliness and dissemination of information to the community, leading to a better understanding of when to take extra precautions. In addition, sharing life saving strategies through reporting on the signs and symptoms of specific overdoses can help inform what harm reduction methods are effective in responding to similar overdoses. These details will also help people more accurately identify what someone might have taken in the case of an overdose.

OPPORTUNITIES FOR SERVICE PROVIDERS

Service providers shared that they want to understand the needs of the community to prioritize how to better support PWUD. These participants explained that they want to understand what comprises local drug supply to better respond to the needs of the communities they serve. This information will allow service providers to understand how best to respond to adverse reactions, overdoses, and withdrawal, determine which harm reduction supplies to procure and have on hand, and to assess which neighbourhoods and regional areas need to be prioritized for service delivery.

Additionally, accurate and timely knowledge of the state of the current supply will allow service providers to provide more appropriate support to clients, including making more informed and helpful referrals, and determine how best to collaborate with members of the community and external agencies to fill gaps left by existing services. Finally, service providers shared that gaining comprehensive knowledge of the drug supply and harms caused will allow for increased opportunity to support the movement for substance use decriminalization, to add to evidence for initiatives such as safer supply, and to better advocate for substance use support for individuals who are incarcerated and people returning to the community after being institutionalized (e.g., hospital, residential treatment).

Workshop 2: Impacts and Risks of an Information Sharing Platform

When reflecting on how an information sharing tool might impact their daily lives as well as those in the community, participants identified some potential risks that might arise from having a tool like this, alongside mitigation strategies that can be implemented to promote safety.

POTENTIAL CONCERNS

The primary concern people held was the risk of identification. Due to the social stigma and criminalization surrounding the use of drugs in the current system, people were concerned that a tool like this could be used to track their use and could harm people's relationships with others, or could put their livelihoods, custody of children, or personal safety at risk. Fear of identification strongly impacted how openly people would share information on this platform and could significantly reduce the quality of the information or uptake of use in the community.

Participants also voiced a concern for the intentional misuse of this tool which may cause further harms to the community. For PWUD to benefit from this tool, it is important that they can rely on the information within it. Although subjectivity is acceptable and even desirable in this case, there were concerns about the intentional sharing of misinformation, particularly by people without the best interest of the community in mind. There were also concerns that the information shared on this platform could be potentially triggering for some people due to range of serious topics that could be shared, such as overdose, mental health, suicide, sexual assault, sexism, or racism. Additionally, there is a risk that PWUD could be maliciously targeted through anonymous comments.

STRATEGIES FOR SAFETY

Possible ways to promote safety were discussed by participants in response to some of the potential concerns raised about this tool. The primary strategy proposed was implementing moderation of the information on the platform by PWUD to protect against unintentional or malicious identification of community members. Moderation would also help protect against anything else that could violate community guidelines or harm the community (e.g. hate speech, threats, etc.).

Community guidelines suggested by participants include:

- / No sharing of real names, nicknames, descriptions, or photos of PWUD
- / No sharing of any information outing a drug seller's identity or their location
- / No homophobia, xenophobia, racism, etc.
- / No violence or threats

Participants want to be able to respond to submissions through comments, up/down voting, and flagging content that is incorrect or inappropriate for review by moderators. These actions will allow information to be updated and corrected over time while still reaching the community rapidly. People would also like to know what information or users may be more trustworthy. Important or frequent contributors could have “verified” or “endorsed” accounts.

In the case that anyone uses the free text fields on the platform for unintended purposes like attempting to promote the sale of drugs, participants had mixed opinions about whether or not this text should be removed. Some participants felt that trading this kind of information could help them to stay safe, by giving them access to more options when seeking alternative supply, especially when navigating unfamiliar areas. Others felt that this kind of information should be removed to avoid outing drug sellers, revealing locations of drug use, or increasing police scrutiny within the platform or in particular neighbourhoods.

Another strategy proposed was implementing controlled access of the information sharing platform to protect against misuse of the tool. Some participants brought up the idea that a sharing tool may not be appropriate for everyone to access and there should be a vetting process in place, along with potential age restrictions, invitation-only, or regional access.

However, other participants raised concerns that this could further exclude groups in the community, such as youth who already face limited access to harm-reduction resources due to their age.

Workshop 3: How to Promote Awareness and Support Accessibility

Given the range of experiences and resources PWUD have access to throughout the province, it was important to consider how this tool might be shared among the various communities. Participants brainstormed ways to build awareness and interest in an information sharing tool for people who use drugs, and how people with different levels of access to technology and internet connection could access this platform.

BUILDING AWARENESS

As PWUD are already using informal communication pathways to share some of the information that this tool hopes to capture, leveraging existing relationships will be most effective for building awareness. The services and programs used by the community of PWUD should be used to spread the word about this tool and to provide training on how to use it. Peers and outreach workers that have trusted relationships with PWUD can also play an integral part in building trust and awareness. Participants noted that areas of outreach should focus on places that PWUD typically frequent.

Areas of outreach include but are not limited to:

- / Supervised consumption sites
- / Shelters
- / Treatment programs including abstinence-based programs
- / Hospitals and community health centres
- / Jails
- / Cultural centres
- / Community centres
- / Raves, concerts, and sporting events
- / Beaches
- / Encampments
- / Libraries
- / Convenience stores

Meeting people where they are at requires utilizing various modes of communication to ensure widespread reach. Both print and digital media can be effective if placed in locations that PWUD frequent; however, participants indicated a preference for in-person communication so that they can vet the information source and ask additional questions.

Participants also indicated that it is important to know who the promotional messaging is coming from. Knowing that the tool is built by and for the community will increase trust and encourage PWUD to engage in the tool. In addition to transparency, another factor impacting the acceptability of the tool is knowing what safety practices and policies are in place to keep the community safe.

SUPPORTING ACCESSIBILITY

One population that was frequently prioritized by community members is people who are isolated by societal stigma from others who use drugs and from existing support systems. This includes but is not limited to: people who use alone, people living in rural or smaller communities, people who are incarcerated, and people in transition out of shelter services. In order to protect these populations from being harmed by marginalization, there is a need to develop targeted outreach strategies. Potential methods of outreach to these groups include: building intentional relationships with the leaders in their communities, mobilizing outreach teams, and utilizing other community spaces (e.g. libraries, community centres, etc.) to provide access to the tool.

Recognizing that not all PWUD will have equal access to technology, there is also a need to ensure that there are multiple ways to report and receive information from this tool, without accessing the web interface directly. Potential solutions include providing ways to interact with the tool through: verbal communication with support staff, a telephone hotline, paper reporting forms, printouts of the information found on the tool, and designated shared technology resource hubs in the community to access the tool.

In order for harm reduction workers and other community allies to support information sharing among people without technology access, it is critical to identify workers with strong relationships within the community, direct funding toward these roles to make information sharing support a part of their work responsibilities, to provide them with training to effectively use info sharing as a harm reduction tactic, and to develop resources and workflows that support them in effectively gathering and disseminating information. In order to build capacity for this work, support for information sharing activities needs to become a priority at a policy level within public health agencies and health policy bodies.

NEXT STEPS

To disseminate these findings broadly our team will be developing an implementation guide (using plain language) to share with stakeholders and participants. This guide will highlight the recommendations made by PWUD throughout this project into tangible resources that can be implemented by PWUD, peer workers, and ally organizations to guide the use of information sharing as a harm reduction tool. Additionally, the guide will include strategies for

implementing this tool, potential ways to develop services to address accessibility needs, as well as strategies to adapt this tool to different communities across the province.

Future steps to move this project beyond the current scope includes seeking funding to design and build a prototype of the information sharing platform and run a pilot. Evaluation findings from the pilot will help determine the effectiveness, challenges and reach of the proposed platform and guide steps for further iterations. These next steps will build towards the launching of information sharing platforms that are aligned with the community needs through close collaboration and continued partnership with PWUD.

REFLEXIVE NOTE

In the collaborative journey of this project involving ONPUD, PHO, and HHF, we recognized the rich perspectives, backgrounds, disciplines, lived experiences, and expertise that our team members brought to the table. This inclusive team included individuals who use(d) drugs, harm reduction workers, community leaders, public health service providers, and designers, all united by a shared goal to advance the knowledge of current provincial SRH information sharing and reporting.

While every member of our team played a pivotal role in moving the project forward, it is essential to acknowledge the influence of organizational standards of practice on the project's scope and methodologies (e.g., research ethics, privacy). These standards, inherent to the operational norms of our organizations, undoubtedly left their imprint on the project's structure and the final outcomes.

For transparency, it is important to outline the role distribution within our project. The data analysis and report writing predominantly involved PHO and HHF representatives, whereas ONPUD focused primarily on community member engagement and report review, and HHF took the lead in engaging service providers. The foundation of this project rested on a rapid review that collected and analyzed various data sources. However, it's important to consider potential gaps in data collection and interpretation, which shaped our chosen methodology.

It is also important to recognize that our project was guided by traditional organizational and academic regulations, which, although necessary in some contexts, may have limited the scope of our conversations, led to certain data points being considered insignificant, and influenced the methods used for data collection. These constraints are worth noting as they offer insight into the context within which our work was undertaken and the potential areas for further exploration and development (e.g., reducing barriers) in the future.

LIMITATIONS

1. There were limitations to the recruitment and attendance of PWUD in the interviews and workshops due to the ongoing impacts of poverty, stigma, and criminalization. During the community interviews, we reached out to people where they are at, meeting them in-person and in safe environments. However, there were additional challenges during the virtual workshops where people in rural/remote areas or without access to technology could not join. It can also be hard on community members to meet organizational timelines.
2. Another limitation to this project is the lack of representation of IBPOC (Indigenous, Black, People of Color) people who use drugs in the recruitment process. This limited engagement potentially affects the generalizability of the findings, and the report's ability to address the unique experiences and needs of these specific populations. Therefore the recommendations discussed in this report may not be transferable and effective across all communities and populations.
3. In addition, one limitation of our approach was the intention to engage service providers in the focus group sessions, which ultimately included 1-2 representatives. We had initially planned to involve service providers to ensure a more comprehensive discussion with community members regarding priority information. However, due to scheduling challenges, we were unable to secure their participation as extensively as we had hoped. This limitation hindered the depth of insights we could have gathered from service providers, potentially impacting the overall completeness of our findings from this perspective.
4. The budgetary constraints in our research project limited our ability to conduct a more extensive sampling of participants (e.g., service providers and community members). This choice may have resulted in a limited diversity of perspectives and experiences being represented in our project. A more comprehensive and varied set of interviews would have provided a broader understanding of the issues at hand.

CONCLUSION

These findings underscore the need for information sharing among communities of PWUD to support individuals as they navigate the toxic drug supply and substance use services around them. By engaging with PWUD as project leaders and knowledge holders, we have come to understand that information sharing within and between communities of PWUD is a core component of harm reduction. To maximize the effectiveness of information sharing, PWUD require the ability to freely, openly, and honestly share information about their experiences navigating the world of substance use without the risk of stigmatization or criminalization. Specific interventions will need to be further evaluated to understand potential benefits and mitigate unintended harms.

ACKNOWLEDGEMENTS

Thank you to all the people who so openly shared their knowledge, expertise, experiences and their goals for future tools and services. Your participation in this work despite ongoing competing priorities and challenges is deeply appreciated.

We recognize the limitations placed on participation by rural communities due to the virtual nature of the workshops. Organizations looking to further engage with PWUD must consider the potential barriers their research process may cause PWUD and take steps to meet the community where they are at.

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APPENDICES

Appendix 1: Community Member Interview Guide

INTRODUCTION

Thank you _____ for agreeing to speak with me. My name is _____ and I'm leading this interview on behalf of the project team. We were referred to you by the Ontario Network of People who Use Drugs. Our goal is to find ways for people to access or share information about overdoses in the community, so that we can make the community safer.

This interview will last 30-60 minutes, and we can be flexible with timing. Please take a break at any time if you need one. It's OK if emotions arise. This is a non-judgemental space. There are no wrong answers. You can answer "nothing" or "nobody". All answers are valid. Our goal is simply to learn from your experiences.

We will be discussing drug poisoning or overdose. Is it ok to proceed?

Before we begin, do you have any questions for me?

THEMES

Getting to Know You

Tell me a little bit about yourself.

Trust and Interactions

Where do you go when you need to feel safe (e.g., from overdose)?

Who is your most trusted source for information about the safety of drugs?

Do you ever go to anyone to have your drug supply checked?

Does anyone ever provide you with warnings or other information about your drug supply?

- / Where did those warnings come from?
- / Was the information useful? Why or why not?
- / What did you do as a result of those warnings?
- / Did those warnings help you to feel safer?

SHARING INFORMATION

How do you typically communicate with others?

- / Face-to-face, phone, text, email, other?

How do you communicate with others around drug use trends, incidents, bad reactions, poisonings, and overdoses?

- / How do you receive that information?
- / How do you share it with others?

- / Do you ever report it to any organizations or other professionals?

The last time you needed to find out or share/report information, how did you do it? Who was involved? What did you experience?

- How did the experience feel?
- What might have made the experience better for you?
 - Probes: who, how, when, what, why?

WHAT THEY WANT STAKEHOLDERS TO KNOW

If you were speaking to a person designing a new system to share information or drug alerts, what would you want to tell them?

What would you want them to know about how community members share information to keep themselves or others safe?

How would you want to be involved in the process of creating a system to share alerts?

Appendix 2: Stakeholder Interview Guide

INTRODUCTION

Thank you _____ for agreeing to speak with me. My name is _____ and I'm leading this interview on behalf of Public Health Ontario and the Ontario Network of People who Use Drugs (ONPUD) who connected us with you. Our goals are to learn about the work that you do, what success looks like for this project, and your perspectives on the strengths and weaknesses of current community engagement and data collection strategies. I have some questions to ask you if that is ok with you.

THEMES

Getting to Know You

Could you tell me a bit about yourself and your role at _____?

In this role, what are your primary responsibilities?

- / What settings do you work in?
- / Are there any priority populations you work with?
- / How are people who use drugs involved in your work/your organization?

What are your goals for the next year?

Project Goals and Risks

The goal of this project is to co-design tools and techniques that will allow programs and policy makers to more rapidly collect, share and use meaningful data and information around substance-related harms (SRH) (e.g., cluster of overdoses, unexpected reactions to drugs) with PWUD. To accomplish this, we will also be interviewing PWUD and leading a series of co-design workshops.

- / Could you please share with me your understanding of how information about drug overdoses and adverse drug reactions are currently gathered and shared?
 - What works well in the current system?
 - What does not?

Front Line Questions

- / What is your/your organization's role in this system?
 - What is the process for getting SRH information?
 - What are your sources of information?
 - Do you receive any reports from the community?
 - How is it validated?
 - How is this information shared and to whom?
 - How does the information reach the community?
 - How long does it take for an alert to go out?
 - Are there any challenges you face around gathering and sharing this information?
- / How does SRH data inform your work?
 - What do you want to learn from this data?
 - What actions do you take based on this data?
 - How does this information benefit PWUD?
- / Are there any existing strategies or tools outside of this province that you know of that you think we should take inspiration from?
- / What key challenges would you like to see us tackle or address through this project?
- / Are there risks or things you think we should be mindful of as we proceed with this project?

Non-Front Line Questions

- / Tell me a bit about what your organization does
 - What are your streams of work?
 - Does your work impact drug policy? How?
 - How are people who use drugs involved in your work/your organization?
- / Could you tell me a bit about yourself and your role at _____?

- / Does your organization rely on information about SRH for any reason?
- / What are your sources of information?
 - o Do you receive any reports from the community?
 - o How is it validated?
- / What do you do with this info or population level data within your org?
- / Are there any challenges you face around gathering and sharing SRH related information?
- / Is there any information/data that you wish you had access to that is challenging to gather elsewhere?
- / If there was a system where PWUD could report every time they used tainted drugs or had an overdose or close call would that information be of value to you or your org? Why or why not?
 - o If you could access that kind of information what would you want to do with it?
 - o What would the downstream effects be (if it's easy for you to foresee that...)?

GUIDING DISCOVERY

Are there other people you think we should talk to as we proceed?

Are there particular programs or policies you think we should know about or learn about to ensure we bring the best ideas together?

Appendix 3: Workshop Agendas

Workshop One Agenda

Introductions

- / Explanation of what we're doing
 - o We are imagining an info sharing platform for PWUD and their allies (harm reduction workers, etc.)
 - o To share information that PWUD find valuable in helping them to stay safe and reduce harms
- / Goals for the day
- / To understand what kinds of information PWUD wish they could access more easily
- / To understand what kinds of information PWUD wish they could share with each others (friends, allies, other communities, or organizations)
- / To understand what information stakeholders may want access to and how that access will directly benefit PWUD
- / Why is this project so important?
 - o What barriers have stopped these conversations in the past?
 - o What do we hope the impacts will be?
 - o Why now?

Activity 1: Finding Inspiration

- / What kind of tool are we thinking about building? Let's look at examples of crowd-sourced information platforms to help brainstorm what this tool could look like.
- / Show examples of analogous platforms
 - Waze - driving navigation with crowd-sourced warnings and info
 - Yelp - food reviews
 - Bad Date - review on bad encounters
 - StreetRx - drug purchase prices
 - St. John's Ambulance drug alerts - map of national drug alerts
- / Discussion
 - How do you feel about these tools?
(What about our system should be similar/different?)
 - If something like this existed for PWUD to access the information they want, what features from these examples do you think would be helpful?
 - Layout
 - Navigation
 - Content
 - Information sources

Different Types of Information

- / Activity Introduction
 - As we think about building an information sharing platform, we want to get a better understanding of what information is currently being shared and why it's important to you.
 - Presenting the features:
 - Read the cards to the participants
 - Here are types of info that could be a part of the tool
 - Drugs that have been found to contain other unexpected drugs
 - Drugs that have been found to contain other toxic substances (not drugs)
 - Information about how many people have encountered a tainted drug
 - Information about how many overdoses have happened in an area
 - Harm reduction supply pickup
 - Safe harm reduction supply disposal (needles, etc,)
 - Information about support services for people who use substances
 - Supervised consumption sites

- Drug checking services
- Local OAT therapies
- Local withdrawal management centres
- Substance related therapy (group therapy etc.?)
- Housing related? Shelters? Do people want this info?
- Social work or any other support services?

Breakout Rooms: Activity 2

- / Self-Introductions
- / Review the Feature Cards
 - Facilitator to go over each of the feature cards, context, and prompts.
 - Ask the group if there are any questions about the feature cards? Are there any other pieces of info or features the group would want to add?
- / Solo brainstorm
 - Think about what details or extra information you would like to know about each of the features presented. Start with the ones you think are most important in case we run out of time.
 - For PWUD
 - What do you want to know about this topic?
 - Why is it important to you?
 - For stakeholders
 - What do you want to know about this topic?
 - How does your access to this information directly benefit PWUD?
- / Group shareback in breakout room (~5mins)
 - Each person shares, facilitator notes down main themes
 - Is there anything you want to add to this list?

Activity 3 Introduction

- / Activity Introduction
 - Prioritizing the features:
 - Which features do you want to include/exclude and why?

Breakout Rooms: Activity 3

- / Solo work time
 - Sort them from most wanted to most unwanted (or just write down your ranking on a paper if the technology is tough) 2-3 mins
 - Consider what features you want included and not included (are there any things you want to leave out of this system)

- Write down at least one post-it for each one that explains your reason for why it is where it is (Why do you want or not want it? Why is it more important than X and less important than Y?)
- / Group shareback in breakout
 - Some example questions:
 - Tell us about something unexpected you learned or heard?
 - Tell us about your top 3 things?

Group Discussion

- / Is there anything unexpected you learned from the shareback?
- / Facilitator to share some learnings/discussion points from the group

Closing Remarks

- / Thank participants for their engagement + outline next steps
- / Pass to Pam or other leaders to close the workshop

Workshop Two Agenda

Introductions

- / Review purpose of this project
 - We are imagining an info sharing platform for PWUD and their allies (harm reduction workers, etc.)
 - To share information that PWUD find valuable in helping them to stay safe and reduce harms
- / Goals for the day
 - Quickly review what we heard last time, discuss how a tool for sharing info might work, and hear your thoughts and feedback
 - Learn more about how a platform that shares this kind of information might change or improve your life
 - Talk about anything that worries you about a tool like this, any risks or safety concerns you might have for yourself or others

Workshop One Shareback

- / What we heard from community members so far
- / What we heard from stakeholders so far
- / Discussion: How do you feel about what we shared?
- / Does it resonate with you?
- / Is there anything that stands out to you most?

- / Is there anything you add/change/take away?

Activity Introduction - Understanding Impact

- / We want to understand how a platform like this could impact your life
- / If you had access to an info resource like the one we have discussed:
 - When would you open up a tool like this and what would it help you to decide?
 - How would having access to this kind of information change your behaviour?
 - How else might this impact your daily routine?
 - How might it impact the daily routines of others in your community?
 - Think about both good and bad impacts

Breakout Rooms: Part 1

- / Positive solo brainstorm (~5mins)
 - Take some time to write down all of the good impacts this tool would have on your life and the lives of people around you
- / Round table discussion (~20mins)
 - Facilitator to ask each group member to share their responses
 - Notetaker to share Miro board and write down the ideas on Miro for the rest of the participants to see

Breakout Rooms: Part 2

- / Negative solo brainstorm (~5mins)
 - Take some time to write down all of the concerns you have about a tool like this
 - What are the risks for someone who is reporting
 - What are the risks for someone who is viewing or using the info
 - For each concern you have:
 - How could we reduce those risks to keep people who use this tool safe
- / Round table discussion (~20mins)
 - Facilitator to ask each group member to share their responses
 - Notetaker to share Miro board and write down the ideas on Miro for the rest of the participants to see

Shareback + Closing

- / Facilitator/group representative to share some learnings/discussion points from the group
- / Thank participants for their engagement + outline next steps
- / Pass to ONPUD or Pam to close the workshop

Workshop Three Agenda

Project Overview

- / Review purpose of this project
 - We are imagining an info sharing platform for PWUD and their allies (harm reduction workers, etc.)
 - To share information that PWUD find valuable in helping them to stay safe and reduce harms

- / Goals for the day
 - Discuss how to build awareness and interest in an information sharing tool for people who use drugs
 - Brainstorm how people with different levels of access to technology and internet can access the platform
 - Share ideas about what information (if anything) should not be shared or should be moderated on this tool

Workshop Two Shareback

- / What we heard from the second workshop: positive impacts, concerns, strategies for safety
- / Discussion
- / Is there anything you want to highlight?
- / Is there anything that you would like to clarify/change?

Breakout Activity - Awareness and Promotion

- / What is the best way for us to build awareness about this tool for the people who need it most?
 - Is there anyone who is a very high priority for outreach?
 - What message is most important for them to hear?
 - What is the content?
 - How should we get that message out to them?
 - Brainstorm different channels of communication
 - What information do they need to start using the tool?

Breakout Activity - Accessibility of Information

- / Is there anything we can do to help get information to people who don't use or don't have access to the internet?

- How could they learn about this tool?
- How could they still contribute info to the tool?
- How could they get info from the tool without using it?
- What are some accessibility concerns?

Breakout Activity - Rules & Moderation

- / Is there any information that doesn't belong, or shouldn't be allowed on this platform?
 - What doesn't fit within the scope?
 - What are the community guidelines?
 - What should be removed if it's posted?
 - Who can be moderators?

Group Shareback

- / Facilitator/group representative to share some learnings/discussion points from the group

Closing

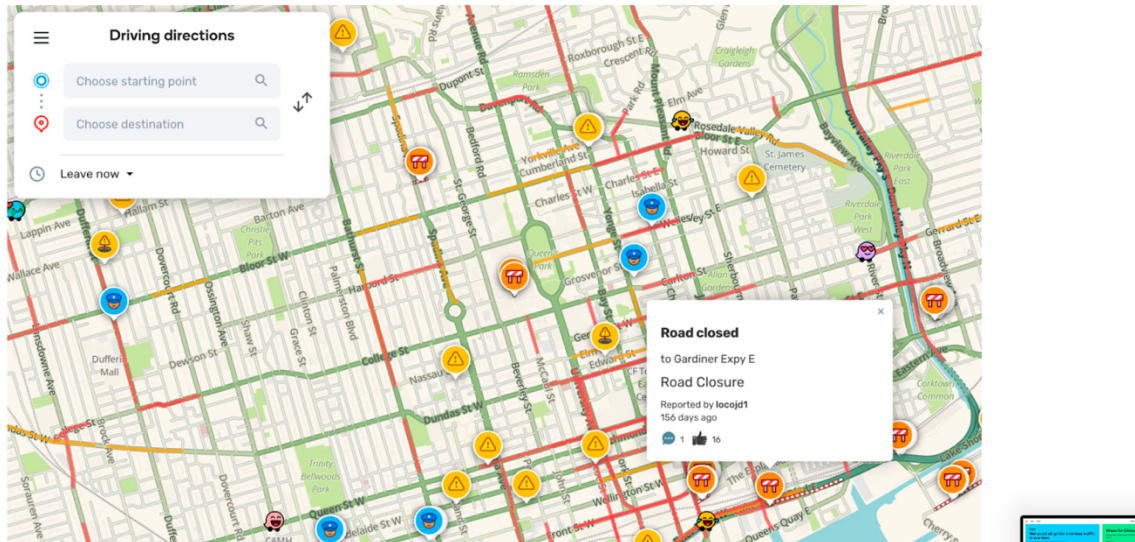
- / Thank participants for their engagement
- / Next steps

Appendix 4: Parallel Market Scan

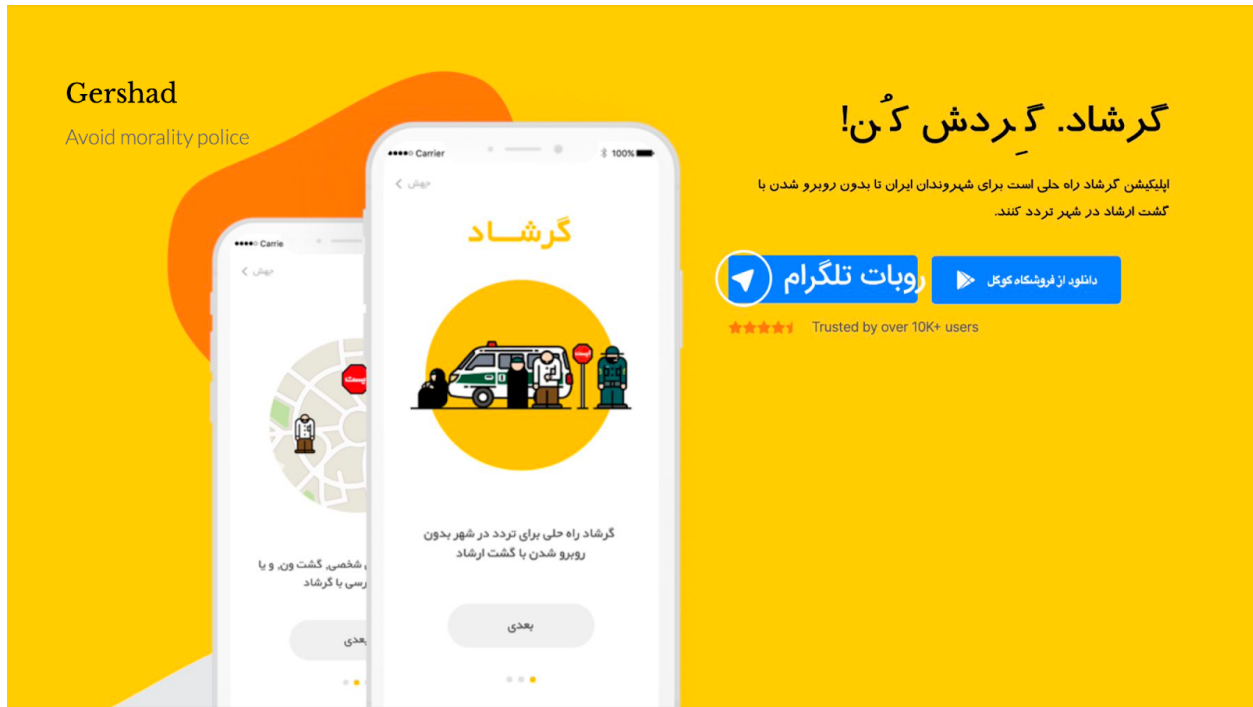
The following products highlight how information sharing is commonly used by other communities to help community members to: avoid undesirable experiences and identify experiences they desire.

Waze

Crowd-sourced wayfinder



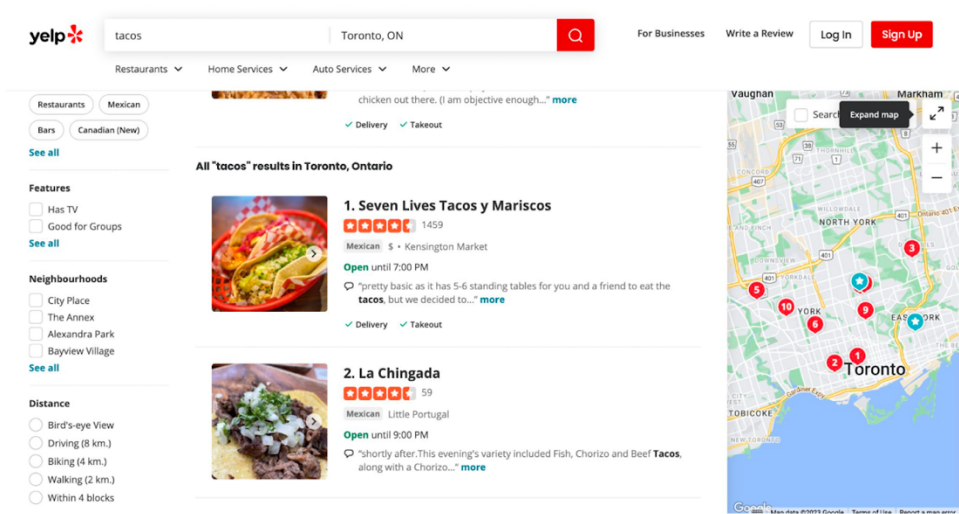
For example, Waze allows communities of drivers to access information about hazards and inconveniences such as: traffic, potholes, road closures, or construction. It crowdsources and highlights police activity and equipment to help users to avoid unexpected encounters. It also shares authorship data, the age of reports, and community votes to help users to gauge the trustworthiness and usefulness of each report.



Gershad is a tool that was created to help people in Iran to avoid unexpected encounters with morality police who enforce state mandated dress-codes. It crowdsources sightings of police, checkpoints, and equipment. The tool emphasizes timeliness as a number one priority by making all entries start to fade if they are not confirmed again within 6 hours. The reported locations disappear completely after 24 hours without being confirmed. This ensures that users can always trust the data they are viewing to be valuable and up-to-date.

Yelp

Food reviews by restaurant goers



Yelp is a tool that helps people who are seeking food to see what is locally available and to navigate metrics and qualitative reviews of other people's experiences. The information can be easily filtered to apply to styles of food, particular neighbourhoods to ensure that the user can see information that applies to the experience they are seeking. This tool also reminds us that avoiding negative experiences is also about seeking experiences that you see as positive. Information about harm is only half of the equation as people seek to reduce substance related harms.

StreetRx

Letting other people know how much you paid for your drugs

The screenshot shows the StreetRx website interface. At the top, it says "streetRx latest street prices for illicit and prescription drugs" and "Choose country: Canada". There are navigation links for "Latest Prices" and "PAST MONTH", along with "Register" and "Log In" buttons.

On the left, there is a search bar with the text "See what others paid" and a search button. Below it, a map of Canada is displayed with several orange dots indicating drug transactions. A green box asks "Did you get a good deal?" with a note "Submissions are anonymous". Below this, there are input fields for "Name of drug", "Formulation", and "Price per unit (e.g., pill, vial)".

On the right, there is a list of drug transactions with columns for price, date, drug name, location, and a rating of five stars. The list includes:

- \$10 Percocet, 5mg/325mg pill, Regina, Saskatchewan (Feb 16 2023)
- \$8 lorazepam tablet (generic Ativan), 2mg pill, Ottawa, Ontario (Feb 16 2023)
- \$8 lorazepam tablet (generic Ativan), 2mg pill, Ottawa, Ontario (Feb 16 2023)
- \$100 cocaine powder, 1g powder, Vancouver, British Columbia (Feb 16 2023)
- \$10 Vyvanse, 10mg pill, Ottawa, Ontario (Feb 16 2023)
- \$5 Biphentin, 60mg pill, Winnipeg MB, Manitoba (Feb 16 2023)
- \$5 clonazepam, 0.5mg pill, Saskatchewan (Feb 15 2023)
- \$10 Oxycodone tablet by Pro Doc Limitee, 5mg pill, Ontario (Feb 15 2023)
- \$10 Oxycodone tablet by Pro Doc Limitee, 5mg pill, Ontario (Feb 15 2023)
- \$10 morphine tablet, 10mg pill, Ontario (Feb 15 2023)
- \$70 crack cocaine, 1oz rock/crystal, Ontario (Feb 12 2023)
- \$10 Dexedrine, 5mg pill, Ontario (Feb 12 2023)

At the bottom right, there is an "About StreetRx" section with the text: "Inspired by the principles of crowdsourcing, StreetRx is a one-of-a-kind program that identifies and tracks the street value of prescription and illicit drugs. StreetRx gathers user-submitted data to map the street price of a variety of drugs across the country."

StreetRx is a tool that allows people who want to know about the current prices of drugs across the country to seek out the most recent data about what people have paid for a substance that was purchased informally from drug sellers in the community. Users rate whether the price paid was high or low compared to their experience.

Bad Date Report

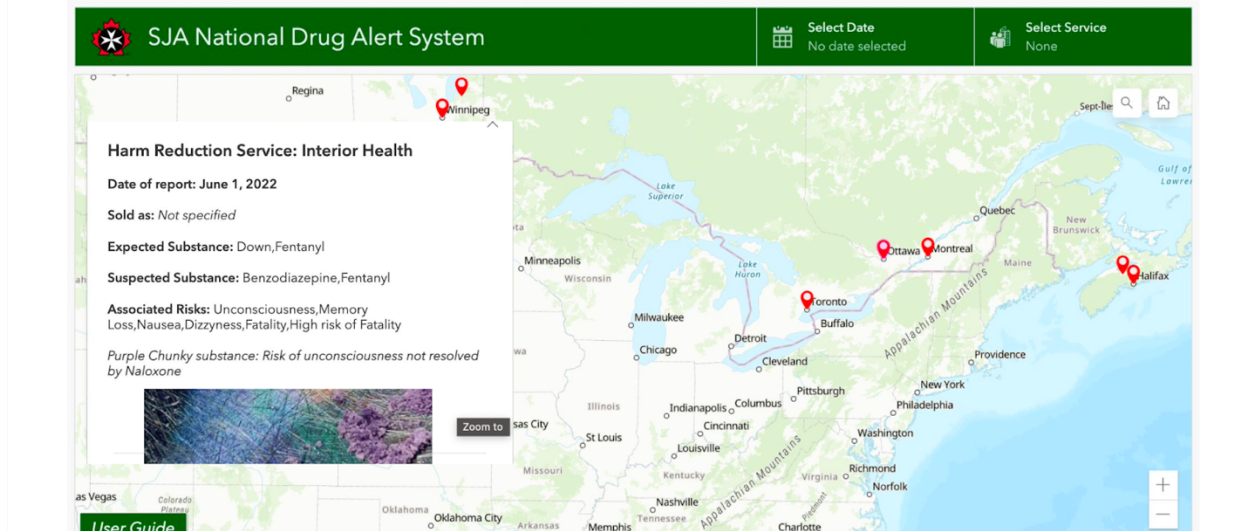
Letting other sex workers know if you had a bad date

Time and Date of Incident * <input type="text"/> <small>am/pm & mm/dd/yyyy</small>	Name <input type="text"/> <small>First Name</small>	<input type="text"/> <small>Last Name</small>
Location of Incident * <input type="text"/> <small>Address/landmarks</small>	Age <input type="text"/>	
Picked Up by * <input type="text" value="Foot"/>	Hair Colour/Type <input type="text"/> <small>Eg: Blonde/ crew cut</small>	
How was date arranged? * <small>Street/Parlour/online</small> <input type="text"/>	Height/Weight/Build <input type="text"/> <small>E.g. 6ft/200lbs/muscular</small>	
Location picked up <input type="text"/> <small>Address/landmarks</small>	Tattoos & Scars <input type="text"/> <small>Distinguishing marks: what & where</small>	
DESCRIPTION OF VEHICLE <hr/>	Nationality <input type="text"/> <small>Accent/Known nationality</small>	
Colour	Smells <input type="text"/> <small>Cologne? Substances?</small>	

The Bad Date Report is a tool used by sex workers to warn other sex workers about negative experiences they have had with people seeking their services. Access to the tool is protected to avoid manipulation of the data by people who are customers rather than service providers. The tool gathers a wide range of experiential and sensory information that would be helpful to other sex workers in identifying risky clients. The tool is also designed by and for sex workers to share information that matters most to members of the community rather than information that might matter to an institution.

National Drug Alert System

Shared drug alerts from across Canada



The St. John's Ambulance National drug alert system shares information about types of substances that have been identified in municipalities across Canada as having unexpected and undesired effects on people who used them. The system takes great care to verify information before making a post and to not double post information if similar events happen repeatedly in a city. Information can only be entered by people who work for vetted institutions and drug checking services.