Guidance for Healthcare Professionals When Caring for People Who Use Drugs: A Perspective from Persons Who Use Drugs. A Scoping Review

A Thesis Submitted to the Committee on Graduate Studies in Partial Fulfillment of the Requirements for the Degree of Master of Science in Nursing

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Abstract

Guidance for Healthcare Professionals When Caring for People Who Use Drugs: A Perspective from Persons Who Use Drugs: A Scoping Review

Authored by Julia Brandsma

Individuals who use drugs face stigma in healthcare, leading to poor health outcomes and limited treatment access. This scoping review aims to provide healthcare professionals with key evidence needed for delivering acceptable care from the perspective of those who use drugs. A Lived Experience Advisory Panel determined what contributions represented the perspective of people who use drugs. Over 22,000 grey and white literature articles were screened, resulting in 14 relevant articles. Participant quotes illustrate five emerging themes: Being someone who matters, I trust that the people taking care of me trust me, I'm happy that you listened… I clearly have knowledge in this area, You don't know unless you've been there… We can tell you and Help me access services and resources—the importance of listening weaves through each theme. The findings have significant implications for healthcare professionals, aiding them and decision-makers provide more acceptable care for people who use drugs.

Keywords: people who use drugs, PWUD, substance use, patient perspective, patient voice, patient preference, patient satisfaction

Preface

This dissertation is an original, unpublished, intellectual product by J. Brandsma. I am the sole author of this thesis. As my thesis supervisor, Dr. Kirsten Woodend was a second reviewer for data screening, extraction and theming. My thesis supervisor and the thesis advisory committee guided the process and aided in reviewing the document below.

This submission is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public. I further authorize Trent University to reproduce this thesis by photocopying or by other means, in total or part, at the request of other institutions or individuals for scholarly research.

Table 1

Thesis Advisory Committee

Role	**Name**
Thesis Supervisor	Dr. Kirsten Woodend RN, MSc, PhD, FCNEI Professor Emeritus, Nursing, Trent University
Thesis Advisory Committee	Dr. Catherine Thibeault Professor Emerita, Trent University
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I respectfully acknowledge that I am on the treaty and traditional territory of the Michi Saagiig Anishinaabeg. I offer my gratitude to the First Peoples for their care for and teachings about our earth and our relations. May this work honour those teachings.

The thesis portion of this Master of Science in Nursing journey has been equally trying and rewarding. To help keep me engaged, my thesis supervisor often said, “Think about how much you are learning!” She is right. I have learned so much through the process, and I could not have done it without the support of some key people.

Dr. Kirsten Woodend, an Emeritus Professor at Trent University, has been my thesis supervisor and secondary reviewer through many articles. Thank you so much for your knowledge and expertise, primarily for your curious mind and heart for learning. Dr. Catherine Thibeault, an Emeritus Professor at Trent University, was the other member of the supervisory committee. Thank you so much for your thought-provoking questions and attention to detail. I appreciate both of you delving into each draft and encouraging me to expand my thinking.

An incredibly diverse thesis advisory committee supported me, each bringing exceptional skills and knowledge. This group shared so much from their life experience and vocational expertise. Thank you for keeping me focused and for your gentle instruction and encouragement.

Searching through databases requires knowledge of what resembles a new language. Thank you, Amy Faulkner and Ellen Olsen Lynch, Public Health and Trent University librarians, for your patience and support.

To the Lived Experience Advisory Panel, affiliated with the Peterborough Drug Strategy, thank you for your vulnerability and expertise. Your input was invaluable to me and the research process. The wisdom you shared during the consultation has stayed with me throughout this undertaking. It was an honour to sit with you and learn. Thank you.

Thank you to my partner and my children; you are my heart. I love my life with you. Let us continue to be curious, try new things, and remember to recognize “how much we are learning!”

To any graduate student reading this thesis submission, the information you are researching is valuable. Keep going; you can do it!

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My master-level education has been personally funded and supported by some education funds and scholarships, such as the Registered Nurses Association of Ontario (RNAO), Nurse Education Initiative (NEI), Workplace Education Reimbursement and the Joyce Shack Memorial Bursary through the Registered Nurses Foundation of Ontario (RNFOO). As part of the research for this thesis, I consulted the Lived Experience Advisory Panel. The consultation fee was covered jointly by the generous contributions of Peterborough Public Health (PPH) and the Trent Fleming School of Nursing (TFSON) Graduate Student Research Implementation and Mobilization Grant.

None of the funding organizations had input into the research design, data collection, analysis, interpretation, report writing, or product outcomes. The attached content is solely the responsibility of the author.

Conflicts of Interest

The author reports no real or perceived vested interests related to this article that could be construed as a conflict of interest.

Authors and Affiliations

This document was solely authored by Julia Brandsma, a student at Trent University in the Master of Science in Nursing Program with a focus on Professional Practice Leadership. The author resides in Peterborough, Ontario, and is a full-time public health nurse at Peterborough Public Health.

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Table 2

Glossary of Terms

Term	Definition
Equity Deserving Population	Equity-deserving populations are communities that experience significant collective barriers to equal access, opportunities, and resources due to disadvantage and discrimination (Queens University, 2017). Synonyms are equity-denied, equity-seeking (University of British Columbia, n.d.), marginalized, oppressed, underrepresented, or underserved populations (Government of Canada, October 2024). No one term captures the harms, barriers, or violence experienced by these communities. This thesis will use the term equity-deserving population.
Harm Reduction	"Harm reduction refers to policies, programs and practices that aim to minimize the negative health, social and legal impacts associated with drug use, drug policies and drug laws. Harm reduction is grounded in justice and human rights. It focuses on positive change and on working with people without judgement, coercion, discrimination, or requiring that people stop using drugs as a precondition of support" (Harm Reduction International, n.d. p. 1).
Healthcare Professional	In this research paper, healthcare professionals or practitioners are staff who work in the healthcare system, including hospitals, community and public health.
Healthcare Setting	Settings that provide healthcare. Healthcare settings included in this research were hospitals, community, and public health. Healthcare sites that treat only substance use disorders or sites that only provide harm reduction strategies were not included.
Healthcare System	A healthcare system is a combination of people, organizations, and institutions that interact, collaborate, and allocate resources to promote health and treat health concerns. Healthcare structure is the interplay that allows it to function.
Intersectionality	"Intersectionality considers how systems such as racism, classism, sexism, homophobia and other forms of discrimination overlap and interact with one another to advantage some and disadvantage others at an individual

	and social-structural level" (National Collaborating Centre for Determinants of Health, 2022, p. 2)
People Who Use Drugs (PWUD)	People who use drugs are residents, patients and clients who use drugs, whether for recreational, medicinal, or other purposes (Ophelia, n.d.). In this research, people who use drugs are residents, patients, and clients who have a history or present usage of street or illegal drug use or people who misuse prescription drugs.
Social Determinants of Health	The social determinants of health are non-medical factors influencing health outcomes (World Health Organization, 2024). Some social determinants of health include income, employment, education, gender, culture, and race.
Stigma	"Stigma is negative attitudes, beliefs or behaviours about or towards a group of people because of their situation in life. It includes discrimination, prejudice, judgment and stereotypes, which can isolate people who use drugs" (Health Canada, 2022).
Trauma-Informed	Trauma-informed is understanding that many persons who access health and social services have had experiences of trauma in their lives (RNAO, 2014)
Trauma-Informed Approach	A trauma-informed approach ensures that persons are not further traumatized while accessing care. It uses principles such as safety, trustworthiness and transparency, peer support, collaboration, empowerment, voice and choice, and cultural, historical and gender issues. (RNAO, 2014)

Table 3

Glossary of Abbreviations

Abbreviation	Definition
BPG	Best Practice Guidelines
LEAP	Lived Experience Advisory Panel
NHRC	National Harm Reduction Coalition
NEI	Nurse Education Initiative
PDS	Peterborough Drug Strategy
PHU	Public Health Unit
PWUD	In this document, *people who use drugs* will be used chiefly instead of PWUD (Pivovarova & Steine, 2019). There will be exceptions when using a table to conserve space or directly in a quote format.
RNAO	Registered Nurses Association of Ontario
RNFOO	Registered Nurses Foundation of Ontario
TFSON	Trent Fleming School of Nursing

Guidance for Healthcare Professionals When Caring for People Who Use Drugs: A Perspective from Persons Who Use Drugs: A Scoping Review

From 2019 to 2020, in Ontario, there was a 60% rise in the death count associated with the toxicity in the supply of illicit drugs (Gomes et al., 2021), and there has been a steady increase in opioid-related harms for more than a decade (Government of Canada, 2023; Public Health Ontario, 2023). In 2023, the national death rate associated with opioid harms was 21.1 per 100,000. This equates to 8480 lives lost (Government of Canada, 2023). In Ontario, in 2023, the death rate associated with opioid harm was 17.2 per 100,000 (Government of Canada, 2023; Public Health Ontario, 2023). The situation locally in Peterborough City and County is even more alarming. The local health unit's death rates exceeded the National and Ontario death rates at 34.3 per 100,000 (Public Health Ontario, 2023). In the last 12 months, 73 people have died from opioid-related harms; this equates to one person dying every 5 days in the local geographical area (Peterborough Public Health, September 2024). It is essential to recognize that the opioid poisoning crisis is a complex issue that is more complicated than an individual's choice to use drugs. Drug use is enmeshed in a web of intersecting issues, many of which are often beyond the control of the individual. These intersectionalities are evident in the social determinants of health. Income, social support, childhood experiences, pain, gender, race and inequality have significant impacts on the lives of people who use drugs (Government of Canada, 2024). This crisis is having a tragic impact on people

who use drugs, their families, and communities across the country. It is an international, federal, provincial and local concern that only continues to worsen.

Healthcare System is Part of the Problem

Within this healthcare crisis, people who use drugs, whether for recreational, medicinal, or other purposes, face incredible stigma within healthcare settings, and as a result, they are not getting the support and care they need. In this document, I will refer to this equity-deserving community as *people who use drugs*.

People who use drugs state that healthcare workers see them as a 'drug user' first and neglect to see them as a person (Brondani et al., 2017). Even those recovering from substance use disorders have reported that they lose their identity to these labels (Brondani et al., 2017). People who use drugs have shared stories of being stereotyped as unworthy, labelled as different, and spoken to in demeaning language. They report being excluded from decision-making and receiving little empathy from healthcare workers. People who use drugs have stated that they are targets of discrimination and unfair treatment and feel powerless when interacting with healthcare systems (Brondani et al., 2017; Tam, 2019; The Canadian Centre on Substance Use and Addiction, 2019). Adverse health outcomes associated with stigma toward people who use drugs resulted in increased risks of poorer physical health, quality of life and psychological outcomes, limited uptake of opioid agonist therapy and poorer outcomes for substance use disorder treatment (Tam, 2019). Stigma discourages people from seeking help, decreases the quality of and access to health care and

distorts policy that influences healthcare (Canadian Centre on Substance Use and Addiction, 2019). Carusone et al. (2019) reported that stigma in the healthcare system resulted in participants experiencing inadequate pain control, poor withdrawal management, and an increased likelihood of patients discharge against medical advice. Reasons for leaving against medical advice included stigma or discrimination from hospital staff, hospital restrictions, not being allowed to leave intermittently, and uncontrolled pain or cravings (Simon et al., 2020). Patients whose pain was not well managed tended to self-medicate (Mueller et al., 2021), exacerbating the cycle of drug use.

These adverse outcomes are often the result of negative beliefs and judgements from healthcare professionals towards people who use drugs. These judgments also impact willingness to seek treatment. As Friedman et al. explained, stigma in the healthcare system is “a fundamental driver of negative health outcomes” (2022, p.38); this is true for people who use drugs. A member of the Lived Experience Advisory Panel (personal communication, June 21, 2024) also highlighted that healthcare professionals work in an environment where they are often overworked and under-resourced, suggesting that many factors influence the care that healthcare professionals provide.

Although the environment in which healthcare professionals work is challenging, poor treatment of people who use(d) drugs is embedded in the healthcare system at the individual up to the system level (Tam, 2019). In a report on inclusivity in the healthcare systems, Dr. Theresa Tam, Canada’s Chief Public Health Officer (2019), highlights the effect of stigma. She urges public

health to be a powerful leading sector to ensure equitable treatment of vulnerable populations. The report highlighted people who use illicit drugs as a group that often faces maltreatment in healthcare. Two main themes were highlighted in Tam's report (2019) and echoed in the Action Framework for Building an Inclusive Health System (Public Health Agency of Canada, 2019). The reports affirmed that healthcare professionals have a vital role in helping reduce stigma, and efforts to ensure that people who use drugs are receiving acceptable, equitable care must be in conjunction with meaningful engagement with people with lived and living experiences.

Need to Include the Expertise of People Who Use Drugs

The Canadian Drug and Substance Use Strategy (Government of Canada, 2023b) addresses the escalating opioid crisis. It is an evidence-based, comprehensive, and compassionate drug and substance use strategy. The strategy indicates that healthcare settings and providers must adopt compassion and equity within their organizations, with collaboration as the fourth guiding principle.

Collaboration is also a guiding principle of the Canadian Association of People Who Use Drugs (CAPUD). Their vision is to "empower people who currently use drugs deemed illegal to survive and thrive, with their human rights respected and their voices heard" (CAPUD, 2022, para. 1). In the report *Hear Us, See Us, Respect Us* (CAPUD, 2022), CAPUD outlines the importance of using the expertise of people who use drugs in decision making in healthcare and outlines examples of where that strategy has been successful. The report also

identifies a myriad of ways that people who use drugs should lead the design, development, and implementation of policies, procedures, protocols, and practices at all organizational and governmental levels.

The National Harm Reduction Coalition (NHRC), advocates and allies for people who use drugs, has a rallying call of “Nothing About Us Without Us” (NHRC, 2021, p.1). This slogan was first used in the disability rights movement. When adopted by harm reduction activists, it acknowledges a connection to the HIV/AIDS and disabilities movements (C. King, personal communication, November 19, 2024). Engagement of equity-deserving groups is a widely accepted and espoused principle. It is also widely established that engagement and efforts to achieve equity for people who use drugs benefit the people involved as well as the processes (Pauly, 2008; Newfoundland Government, 2017).

Merging Evidence and Engagement

Healthcare settings and practitioners have a role to play in reducing the adverse health outcomes associated with stigma related to the opioid poisoning crisis (Public Health Agency of Canada, 2019; Tam, 2019). It is also apparent, through the *Hear Us, See Us, Respect Us* Report (CAPUD, 2022), that people who use drugs want to be engaged when it comes to healthcare treatment and program decisions. Tam (2019) urges a reduction of stigma in healthcare settings. Healthcare settings require evidence and practical instruction on how to provide acceptable and equitable care to people who use drugs. Considering both the need for evidence and the importance of ensuring that the evidence

includes the perspectives of people who use drugs, an interesting research question is presented.

Research Question: Guidance When Caring for People who use Drugs

The question that guides this research is: What do healthcare professionals need to know about how people who use drugs want to be treated to provide acceptable care for people who use drugs?

Healthcare professionals are defined as all staff who work in the healthcare system, including hospitals, community health centers, and public health departments.

People who use drugs is an umbrella term that describes people who use drugs for recreational, medicinal, or other purposes. In this research, people who use drugs are residents, patients, and clients who have a history or present usage of street or illegal drug use or people who misuse prescription drugs. Some researchers use the acronym PWUD for people who use drugs. I will refrain from using the acronym and write out the term *people who use drugs* to promote the use of destigmatizing, person-centred language (Pivovarova & Steine, 2019). Using this person-first terminology, I hope to keep the person central to the discussion (Kameg, 2019), humanizing individuals rather than defining them by their drug use (Ophelia, n.d.).

People who use drugs is a general term, and people from that community highlighted that there are many different groups captured within that term, such as people who inhale drugs, people who inject drugs, people who use illicit drugs or people who misuse prescription drugs. People who use drugs are individuals,

and research needs to reflect the nuances of each person's circumstance (Lived Experience Advisory Panel, personal communication, June 21, 2024). The general term *people who use drugs* will be used to be consistent with how it appears in literature.

Acceptable care does not refer to evidence-based assessments or treatment plans but care that is respectful of the culture and priorities of people who use drugs (UNICEF, 2019). People who use drugs must define what is acceptable care is for them.

What Makes this Question Unique?

There is substantial literature highlighting the presence of stigma, inequity and associated poor health outcomes for people who use drugs. There are also efforts to offer solutions to these deep-rooted problems. Unfortunately, few researchers have asked people who use drugs their perspectives, missing out on the expert evidence from this group. Furthermore, when researchers consult people who use drugs, the research questions emphasize the issues within healthcare, not what could make healthcare better and acceptable for people who use drugs. The research question for this thesis focuses on what people who use drugs recommend to healthcare professionals, thus providing direction for healthcare professionals on how to provide acceptable care for people who use drugs.

Improving healthcare practices that affect people who use drugs by including their lived and living experiential knowledge can support a decrease in harms associated with opioid use and reduce barriers caused by stigma, inequality or

barriers to access. Centering the voice of people who use drugs to contribute their lived experience and share their understanding of the situation and their personal expertise will inform the direction needed to help improve healthcare for this population.

Engaging with people who use substances is an important part of healthcare professionals' practice. The Registered Nurses Association of Ontario (RNAO) has Best Practices Guidelines (BPG), one of which is entitled Engaging People who Use Substances (RNAO, 2015). Within the BPG, evidence-based recommendations support healthcare organizations in engaging with people who use substances. Substances include alcohol and tobacco, and the BPG also names people who use drugs as one equity-deserving group. This BPG was authored in 2015 and is due to be renewed. The RNAO also has several e-learning modules on addiction and mental health, including Engaging Clients Who Use Substances (n.d.). The e-learning modules have three goals for healthcare professionals: to examine their attitudes and beliefs, better understand substance use, and gain knowledge about treatment. It is unclear whether people who use drugs influence the content of the learning material.

Public Health Ontario and COM-CAP recently completed a *Rapid Review: Evidence for Strategies that Address Substance-Use Related Stigma (2024),* synthesizing 36 studies on strategies to reduce stigma. Key findings highlighted that training or skill-based programs that included contact with people who use drugs demonstrated effectiveness. These outcomes did not focus on healthcare as a setting and did not come from the perspective of people who use drugs.

There was a comment on the importance of including the voices of people who use drugs as a potential for further research.

One of the principles of harm reduction outlined by the National Harm Reduction Coalition (NHRC) is to “ensure that [People Who Use Drugs] and those with a history of drug use routinely have a real voice in the creation of programs and policies designed to serve them” (NHRC, 2020, principle five). Given that the current evidence predominantly reflects healthcare professionals’ perspectives and primarily addresses barriers, it is essential to explore how healthcare practices can be modified through a solution-focused approach that prioritizes the perspective of people who use drugs. By integrating their lived and living experiential knowledge and focusing on facilitators, we can enhance healthcare delivery, improve health outcomes for people who use drugs and reduce harms associated with opioid use. This scoping review aims to address some of these existing limitations.

Methods

To provide healthcare professionals with a summary of current evidence-based information on providing acceptable care for people who use drugs, I will use a scoping review research format. Scoping reviews summarize knowledge by incorporating various evidence sources (Peters et al., 2023) to provide an overview of available research to inform practice, programs, and policy (Arskey & O'Malley, 2005). Due to the focus on evidence found only in peer-reviewed literature, a systematic review was ruled out. Including only peer-reviewed literature results would not include the breadth of expertise captured in important reports and discussions expressing the thoughts and feelings of those with lived and living experiences.

A realist synthesis approach identifies the benefits and barriers to implementation (Raycroft-Malone et al., 2012). In the early stages of research question development, this approach was considered, as it could focus on the benefits and barriers of implementing procedures to engage people who use drugs. This research focuses on summarizing the findings of various evidence types; therefore, a scoping review is more fitting to the research question.

Many methodological structures were assessed in forming the format of this scoping review (Colquhoun, 2016; Lima et al., 2017; Peters et al., 2023; Tricco et al., 2024; University of Toronto Libraries, 2023). Arskey and O'Malley's (2005) 5-Stage Methodological Framework is used to explain the methods used for this scoping review. The five stages include identifying the research question, identifying relevant studies, selecting the study, charting the data, collating,

summarizing, and reporting the results. Levac et al. (2010) added a sixth optional stage to the Arskey and O'Malley (2005) methodological framework; the 6th stage is consultation.

Consultations

Consultation appears in every stage of this scoping review, providing opportunities for stakeholders to provide insight into the process. The Canadian Centre on Substance Use and Addiction's (CCSA) *Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends* (2021) were integral in shaping the action items and process for consultation. The thesis advisory committee, including the thesis supervisor, and the Lived Experience Advisory Panel, were the two groups that provided the most insight into developing the research process. These two groups represent several different sectors, academia, people who work in healthcare, advocates and allies of people who use drugs and people with lived/living experience of drug use.

Thesis Advisory Committee

I have worked with a thesis advisory committee with unique qualities, expertise, identities, abilities, and lived experiences. The thesis advisory committee supported all study phases: question development, research planning, screening, data analysis and conclusions. The thesis advisory committee comprises people with a wide range of expertise, from academic to clinical practice to persons with lived experience of drug use to community allies and advocates. Their expertise has influenced process development and challenged

personal biases. It has been a privilege to have their advice throughout this research process.

Lived Experience Advisory Panel

A group of people with lived and living experience of drug use, called the Lived Experience Advisory Panel, was consulted to gain valuable insight into the research process and define aspects of the inclusion/exclusion criteria. In this scoping review, evidence that supports healthcare practitioners when caring for people who use drugs was synthesized. Because of the importance of listening to people who use drugs, only evidence that included the perspective of people who use drugs was included. Consulting with the Lived Experience Advisory Panel ensured that the voices of people who use drugs were considered the expert opinions in the evidence used. People who use drugs are the primary stakeholders for research done about them. People who use drugs have expert knowledge of what works best for their community and, from a human rights perspective, should have input into research that affects them (Canadian HIV/Aids Legal Network, 2005; CCSA, 2021). The criteria developed by the Lived Experience Advisory Panel influenced the screening process, ensuring that healthcare providers get information on how to care for people who use drugs from the perspective of people who use drugs. Further details on the consultative process are captured in Appendix M.

During meetings with the thesis advisory committee and the Lived Experience Advisory Panel, I intentionally created opportunities for dialogue and

appreciated, recognized and incorporated their feedback into the research process.

Search Strategy

After developing the thesis question, stakeholder groups were consulted, and relevant studies were collected to answer the question: What do healthcare professionals need to know to provide acceptable care for people who use drugs? The public health librarian, through the Shared Library Services Partnership, and the librarian at Trent supported the development of a search strategy. They reviewed it using the Peer Review Electronic Search Strategy (PRESS) tool (Canada's Drug and Health Technology Agency, 2015). Articles were found using specific key terms and search locations.

Key Terms and Search Locations

The key terms are important to establish an advanced search, and Boolean operators such as AND, OR, and NOT were used as necessary. The PICO tool (Health Evidence, 2021) was used as a guide to generate preliminary key terms from the research question.

The search strategies outline synonyms, descriptors, and combinations of the keywords more fully. See the search strategies in Appendix A, B, C, D, and E. The search strategies use four search locations: peer-reviewed literature searches, grey literature searches, mining-specific journals and organizational websites, and a hand search.

Peer-Reviewed Literature Search. The search strategy included many health, social science, and social work databases, including Medline (OVID),

CINAHL (EBSCO), PsycINFO (ProQuest), Social Work Abstracts (EBSCO), Social Services Abstracts (ProQuest), Sociological Abstracts (ProQuest), and the Web of Science (core collection). In total, 17588 articles were retrieved. Duplicates were removed, and 9711 articles were uploaded to Covidence™ for screening. Covidence™ is an evidence synthesis program used in this research's screening, review and data extraction phases. This review management software program allows multiple reviewers to participate in each phase of the process.

Grey Literature Search. It is also important in a scoping review to search for unpublished studies, the grey literature. Grey literature includes research, government reports, dissertations, theses, community agency reports, and guidance documents. Books and book chapters were excluded. An advanced Google™ search using Google™ and Google Scholar™ was also done. Details on the specific search strategy appear in Appendix F. In the thesis proposal, I suggested that only the first 50 results from each Google™ search would be reviewed. The librarians suggested screening the first 100 results from each Google™ search was the best practice (Briscoe et al., 2023). Therefore, the original suggestion was augmented, and the first 100 results from each Google search were reviewed. Eleven searches were performed, 1,100 articles were reviewed, and 21 were uploaded to Covidence™ for screening and review.

Mining Specific Organizations and Websites. A targeted search of evidence-based websites and websites of organizations that espoused to be allies of people who use drugs was conducted to ensure a variety of evidence was included in this scoping review. A list of these websites was developed through the research process and amended by the librarians, the Lived Experience Advisory Panel, and thesis committee members. In the end, twenty-seven websites were searched, 3,617 articles or pages reviewed, 62 articles of interest recorded, and 20 articles uploaded to Covidence™ for full-text review. See Appendix G for a list of websites.

Hand-searching. Many articles that went to a full-text review were mined to see if there was relevant evidence in their reference lists. Polling the thesis advisory committee and the Lived Experience Advisory Panel also yielded relevant evidence to include. Polling experts in the field and conducting a manual search of reference lists identified additional relevant evidence to include in the screening process.

The evidence was collected and sorted in Mendeley™ or Zotero™, then uploaded to Covidence™ for review. Mendeley™ and Zotero™ are reference management software with a sorting function that can help remove duplicates. Twenty-five articles were uploaded to Covidence™, where multiple reviewers participated in the scoping review screening steps.

Study Selection

Dr. Tam's report, *Addressing Stigma: Towards a More Inclusive Health System* (2019), was a call to action to healthcare to address stigma within its

organizations. Using that as a goal post, the search was focused on evidence published after Dr. Tam's report, from January 2019 to May 2024. After gathering all the evidence, specific inclusion and exclusion screening criteria were used to narrow down the library of evidence.

The inclusion and exclusion criteria were used at two screening levels. Level one involved reviewing the titles and abstracts. Articles that passed that screening level went on to the second screening level, a full-text review. Screening at each level was done by two independent reviewers: myself and the thesis supervisor. Disagreements were remedied through discussions. There was a plan to use a third-party reviewer if consensus was not reached, but it was unnecessary.

Inclusion and Exclusion Criteria

The inclusion criteria consisted of evidence published between January 2019 and December 2024. Qualitative and quantitative articles were included. Evidence was not limited to peer-reviewed journals but included experience reports, literature reviews, systematic reviews, scoping reviews, guidelines, booklets, protocols, expert opinions, theses, and dissertations. Evidence was limited to the articles written in English, with research subjects being adults aged 18 and older and focused on research where the findings included facilitators to improve healthcare practices and was from the perspective of people who use drugs.

The Lived Experience Advisory Panel defined which articles would be considered to be from the perspective of people who use drugs. The Lived

Experience Advisory Panel (LEAP, personal communication, June 21, 2024) determined that for an article to be considered as coming from the perspective of people who used drugs and therefore included as evidence in this scoping review, one or more of the three primary criteria items (see Figure 1) had to be met.

Figure 1

Definition of Perspective of People Who Use Drugs for Inclusion Criteria

1. Evidence is authored by a person who uses drugs or has a history of drug use.
2. The voices of people who use drugs are collected as part of the research; for example, qualitative research or an evaluation done with people who use drugs. (i.e. Interviews or focus groups of people who use drugs).
    - There needs to be equal or majority representation of people who use drugs voices in the research to be considered the perspective of people who use drugs.
3. People who use drugs are consulted in creating the evidence.
    - It is vital that people who use drugs need to have lived or living experience of drug use. Friends and family of people who use drugs can also be included.
    - If a group of diverse people are consulted in a report or article, there needs to be an equal or majority representation of people who use drugs (i.e., if nurses and patients are consulted, there need to be more patients who use drugs than nurses).
    - The article should show that the input gathered in the consultation of people who use drugs was incorporated into the evidence results.

During the consultation with this equity-deserving population, I recognized my biases and power imbalances, provided a culturally safe environment, ensured adequate compensation for expertise, and adhered to trauma-informed practices. Further details from this consultation are found in Appendix M. Incorporating the perspective of people who use drugs is central to this discourse. Using the inclusion criteria from the Lived Experience Advisory Panel ensured that the

articles in this scoping review represented the perspective of people who use drugs.

Data Extraction

A data extraction template was developed based on the Joanna Briggs Institute Manual for Evidence Synthesis (Peters et al., 2020). The researcher and the secondary reviewer tested and revised the resulting extraction template. The two reviewers then extrapolated the information listed in Table 4 from each of the articles included in the final analysis.

Table 4

Categories for Extrapolating Data

Categories	Sub-Categories
Study Demographics	• Covidence™ study number • DOI address • Title of article • Lead author contact details • Country in which the study was conducted • Date of publication • Study funding sources • Possible conflicts of interest for study authors
Characteristics of included studies	• Aim of study • Study Design • Start and end date of data collection period • Healthcare setting details
Participants	• Population description • Methods of Collection • Total number of participants who were PWUD • Total number of other research participants (not PWUD) • Gender • Race • Age
Recommendations from PWUD for HCP	• Open text box • Places for notes in each section

Critical Appraisal of Evidence

A scoping review differs from a systematic review in that a critical appraisal of evidence is not usually undertaken when conducting a scoping review (Plante, 2024). In this study, I was guided by the perspective of the Lived Experience Advisory Panel. I used their inclusion criteria to determine whether the evidence would constitute having the perspective of people who use drugs. A critical appraisal tool was not necessary.

Data Analysis

The role of the scoping review is to provide an overview of all the available evidence on a topic. A scoping review is not an assessment of the certainty of those results. The data extracted from the evidence was analyzed by locating themes, coding concepts and grouping ideas of evidence. The *Consolidated Criteria for Reporting Qualitative Research* (Tong et al., 2007) and the six-step approach to using thematic analysis (Braun & Clarke, 2006) were used to guide the thematic analysis of the data. The six steps are familiarization with the data, coding, searching for themes, reviewing themes, naming and defining themes, and writing up the results. These steps are outlined in detail in Appendix H.

To stay as close to the perspective of people who use drugs as possible, an inductive approach to the thematic analysis was used. An inductive approach strongly links the themes to the extrapolated data (Patton,1990); it differs from a deductive approach in which predetermined themes are used (Jones, n.d.). A semantic approach identifies the explicit and surface meanings, whereas a latent approach conceptualizes underlying assumptions in the data (Braun & Clarke,

2006). This scoping review uses a semantic approach to present the findings to reflect the voices of people who use drugs found in the evidence.

Ethical Considerations

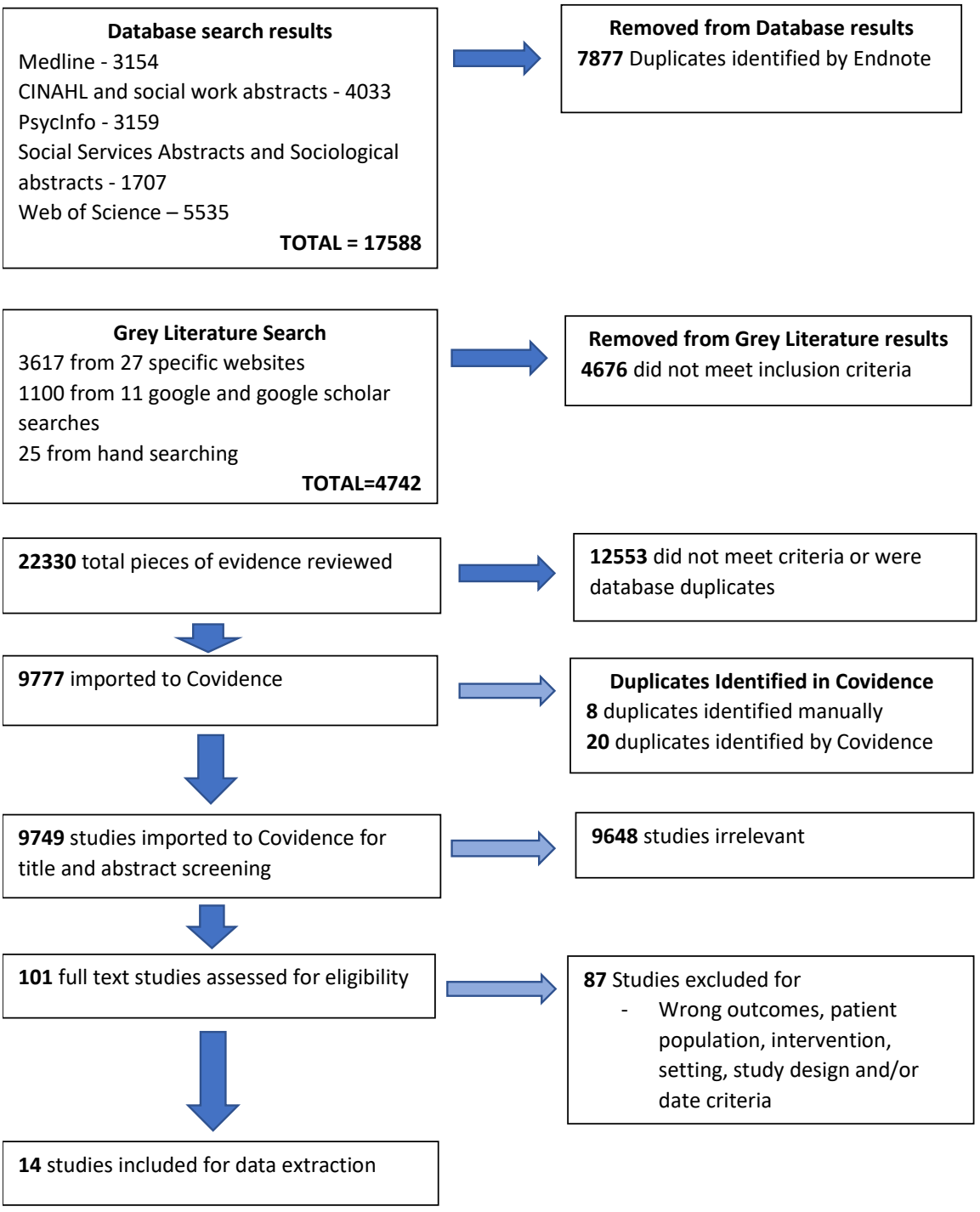
New data was not gathered in this scoping review; evidence from previously collected and synthesized sources is utilized. It remains essential that the perspectives of those with lived and living experiences be represented in the evidence. The researcher consulted with the Lived Experience Advisory Panel to inform parts of the inclusion criteria, specifically which evidence would include the perspective of people who use drugs. The Tri- Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2) is the Canadian guidance policy on ethically conducting research (Canadian Institutes of Health Research et al., 2022). The TCPS2 distinguishes between the planning phase of research, where consulting with the community is an integral part of planning and the data collection phase, where participants are asked to answer a specific research question. The preliminary planning activities, such as consulting the Lived Experience Advisory Panel and the thesis advisory committee, did not need to undergo Research Ethics Board (REB) approval (Canadian Institutes of Health Research et al., 2022, p. 188-189). Although REB approval was not necessary, people who use drugs must be approached with respect and recognition of their lived realities (Wallace et al., 2020).

Results

The initial search for this research project resulted in 17,588 articles from the database search and 4,742 from grey literature searches. After removing duplicates, 9,777 titles and abstracts were screened, leaving 101 articles for full-text review. Articles were excluded due to the incorrect patient population, healthcare setting, date criteria and study design. Figure 2 (PRISMA, 2024) outlines the screening process. Fourteen articles fulfilled the eligibility criteria for final analysis. Two reviewers extracted and summarized articles using thematic analysis to accommodate distinct characteristics within the qualitative findings.

Figure 2

Evidence Screening process displayed in a PRISMA-ScR



Characteristics of Included Evidence

The 14 articles reviewed represented various settings, countries of origin, study designs, and populations. All evidence was published between 2020 and 2024. Table 5 and Appendix J display the study articles used for data extraction.

Table 5

Cross Study Display Articles Used for Data Extraction

Title	Healthcare Setting	Country	Date	Study Design	PWUD	Not PWUD
Building Healthcare Provider Relationships for Patient-Centered Care: A Qualitative Study of the Experiences of People Receiving Injectable Opioid Agonist Treatment (Marchant et al.)	Primary Care	Canada	2020	Qualitative research	30	0
Care Experiences of Persons with Perinatal Opioid Use: A Qualitative Study (Blair et al.)	Hospital - Perinatal	United States	2021	Qualitative research	11	0
Defining Culturally Safe Primary Care for People Who Use Substances: A Participatory Concept Mapping Study (Urbanoski et al.)	Primary Care	Canada	2020	Participatory action research	75*	0
Examining the Primary Care Experience of Patients with Opioid Use Disorder: A Qualitative Study (Incze et al.)	Primary Care	United States	2023	Qualitative research	14	0
Experiences of Patients at High Risk of Opioid Overdose Accessing Emergency Department and Behavioural Health Interventions: A Qualitative Analysis in an Urban Emergency Department (Collins et al.)	Emergency Department	United States	2023	Qualitative research	19	0

Healthcare Encounters of Pregnant and Postpartum Women with Substance Use Disorders (Renbarger et al.)	Hospital - Perinatal	United States	2020	Meta-synthesis of published qualitative studies	Patient reported data 19 -100%	0
Healthcare Seeking Among Swedish Patients in Opioid Substitution Treatment. A Mixed Methods Study on Barriers and Facilitators (Troberg et al.)	Healthcare General	Sweden	2022	Quantitative survey and Qualitative research	survey-210 interview -11	0
How do People who use Drugs Experience Treatment? A Qualitative Analysis of Views About Opioid Substitution Treatment in Primary Care (iCARE Study) (Alves et al.)	Primary care	UK	2021	Qualitative research	24	0
“It's Like A Partnership": Exploring the Primary Care Experiences and Patient-Defined Goals of People Who Use Drugs (Dunham et al.)	Primary care	United States	2024	Qualitative research	17	0
Nursing and Healthcare Preferences Among Opioid and Stimulant Using Black Sexual Minority Men: An Exploratory Study (Dangerfield et al.)	Healthcare General	United States	2021	Qualitative research	30	0
Patient and Provider Perspectives on Processes of Engagement in Outpatient Treatment for Opioid Use Disorder: A Scoping Review (Austin et al.)	Multiple Settings	US 60%, Canada 13%, Ukraine, UK, China, Vietnam Tanzani SA)	2024	Scoping review	+Patient reported data 19 studies 63%	Provider reported data 4 -13% Both patient- and provider reported data 7 - 23%
Perspectives and Recommendations from Hospitalized Patients with Substance Use Disorders: A Qualitative Study (Balmuth et al.)	Hospital – Medical + Surgical	United States	2024	Qualitative research	15	0

Qualitative Exploration of Emergency Department Care Experiences Among People With Opioid Use Disorder (Galarneau et al.)	Emergency Department	Canada	2023	Qualitative research	19	0
Understanding healthcare engagement for people who inject drugs (Heidari et al.)	Outpatient care	United States	2024	Qualitative research	24	0

*Note: *75 unique people in three different focus groups. +30 studies total in the scoping review. PWUD= People who use drugs*

Study Settings

Studies were set in a variety of healthcare environments, including primary care (n=5), hospitals (n=5), and outpatient services (n=1). One scoping review included literature from multiple settings. Two reported studies were not focused on a particular setting but referred to healthcare in general (n=2).

Studies Country of Origin

Studies were conducted in the United States (n=8), Canada (n=3), Sweden (n=1) and the UK (n=1). The scoping review article (n=1) included evidence from multiple countries (USA, Canada, Ukraine, Vietnam, Tanzania, South America and China).

Research Design

Most articles are classified as qualitative research (n=10); the others included were a scoping review (n=1), mixed methods (n=1), qualitative meta-summary (n=1) and participatory action research (n=1). Within the 10 qualitative research articles, 203 people who use drugs participated in semi-structured interviews. The mixed methods study included quantitative surveys (210 participants) and qualitative interviews (n=11 participants). The qualitative meta-summary reviewed 19 patient-reported studies. The participatory action research

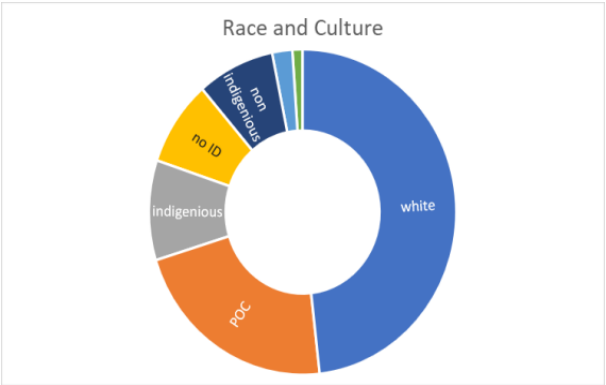
study did concept mapping with three focus groups comprising 75 unique participants. All study participants were people who use drugs. The scoping review article included data extracted from 30 studies. Nineteen of those studies included patient-reported data, four were provider-reported data, and seven were patient and provider-reported data. The perspective of people who use drugs was the predominant voice in each article included in the final analysis. In the qualitative studies, the sample size was between 11 and 75, and the age of participants was between 18 and 63 at the time of research.

Study Population

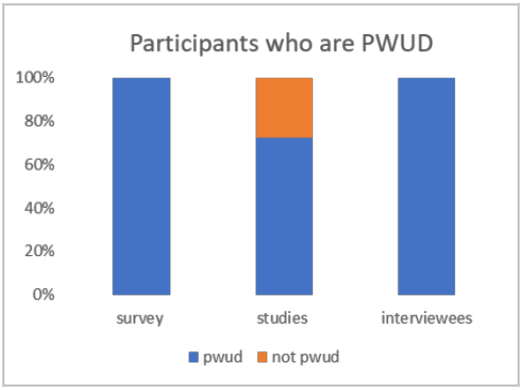
Across the 14 articles, 486 participants identified their gender; 323 identified as male (66.5%), 162 as female 33.3%, and one person (0.2%) did not identify their gender. Where race was recorded, participants identified as the following: white (n=136), person of colour (n=62), Hispanic (n=6), Asian (n=3) and 24 participants did not identify their race. Three Canadian studies captured whether participants were Indigenous (n=28), and one study had Indigeneity as the focus population, with the rest categorized as non-Indigenous (n=23).

Figure 3

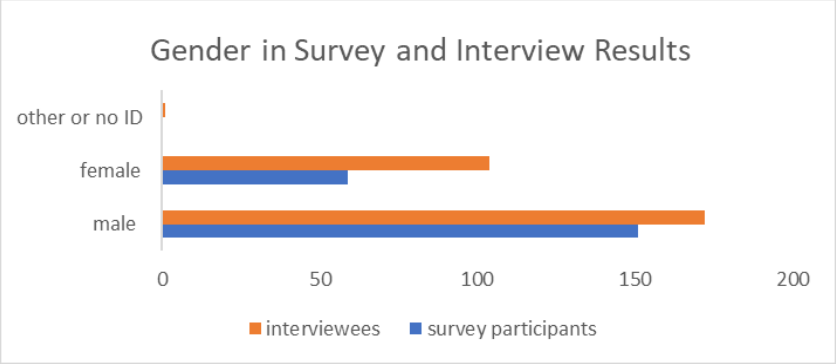
Scoping Review Demographics



Note: POC =Person of Colour



Note: PWUD = People who use Drugs



Note: No ID= participant chose not to identify themselves as a specific gender

Thematic Analysis

The thesis supervisor and I used an inductive approach for theme creation and a semantic approach to analyze the explicit content of the data without hypothesizing any underlying meaning behind it. This thematic analysis included interview data (direct quotes) published in the articles and author-identified themes. We extrapolated and themed concrete actions and direct perspectives from people who use drugs. The data was coded and themed by two people to reduce the bias that could come from one perspective.

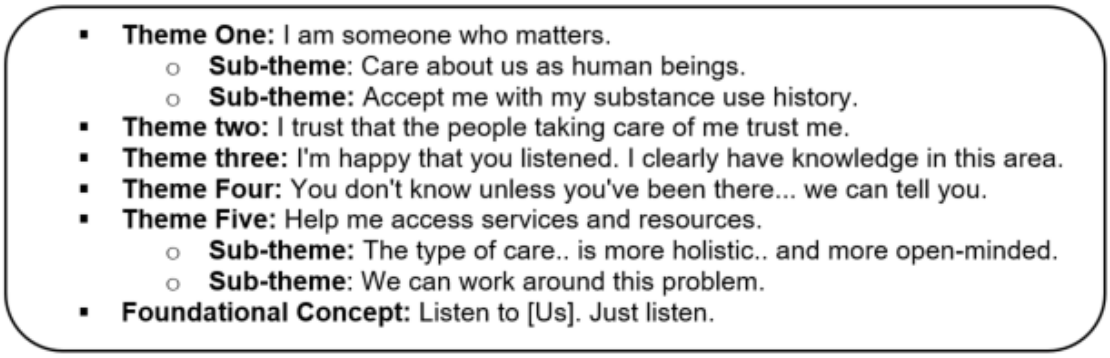
Thematic analysis is not a linear approach to the data but rather a recursive process (Braun & Clarke, 2006). I included a formulaic approach to

coding by observing Domain 3, Analysis and Findings, in the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) (Tong et al., 2007). However, the process remained iterative (Braun & Clarke, 2013).

Two people independently coded and themed the extracted data. The two reviewers met regularly to construct meaning from the data collaboratively. During these conversations, there was considerable overlap between how the two reviewers understood and grouped the data. The theme titles are participant quotes that summarize the codes included in the theme (Figure 4).

Figure 4

Themes Created from Extracted Data



In most studies, participants identified listening as a fundamental concept. Listening includes the act of listening by the healthcare provider and feeling listened to from the participant's perspective. Listening is not captured as a theme; instead, it is an integral concept woven throughout the themes. One participant described listening as transformative: "It’s the people that actually took their time to hear what I was saying that made the biggest difference in my life” (Galarneau et al., 2023, p. 5). Listening is foundational to caring for people

who use drugs. The concept of listening is integrated into each theme's description.

Theme One: I am Someone Who Matters

Participants identified the importance of being treated with compassion, kindness, and caring when interacting with healthcare professionals. They also highlighted the importance of feeling accepted and safe. Being someone who matters is the first theme, which comprises two overlapping subthemes: *Care about us as human beings* and *Accept me with my substance use history*.

Care About Us as Human Beings. Participants identified that this experience of caring about us humans was reflected in received compassion and kindness. They also identified respect, dignity, transparency, validation, genuine interactions, being valued, and being treated fairly as attributes of being treated like a human. These concepts appeared in 10 of the 14 articles. One participant from a primary care setting highlighted the importance of feeling cared for by their healthcare providers, "I mean, you guys show that you actually care about us as human beings and care about our well-being and help us succeed, rather than just push us in and out of the door" (Incze et al., 2023, p. 6).

Keywords used to describe *care about us as human beings* differ between healthcare settings. Examples from primary care settings focused on respect and being treated like a valued, unique person. Participants from the general healthcare studies stated the importance of transparency and being genuine. Participants in hospital settings focused more on respect and being treated as important as others. Respect and being treated equally to others overlap with

concepts in the next sub-theme, concepts of acceptance, safety and feeling free from judgment.

Accept Me with My Substance Use History. Participants wanted to be accepted and feel free from being judged. These anti-stigma concepts appeared in 13 out of 14 articles. Participants wanted healthcare providers to share views that addiction is a legitimate health issue, not criminal behaviour and use non-stigmatizing language with a non-demeaning tone. Other vital concepts included feeling safe and receiving unbiased, professional, impartial and judgment-free treatment. A hospital-based, perinatal patient who uses drugs described a positive experience with healthcare professionals; "They make you feel like you are doing the right thing; that you've not done something bad. That you've done the right thing; that it's okay to ask for help" (Blair et al., 2021, p. 326). A participant on a medical-/surgical unit highlighted the importance of acceptance: "They don't treat you any different here. If you're an addict here, they do everything they can to make you comfortable" (Balmuth et al., 2024, p. 2090). Another participant described a positive relationship with the primary care provider: "Really like that whole sort of shame-based way of thinking of things isn't there, so you really feel safe asking for what you need" (Marchard et al., 2020, p.4). In a study which used a participatory approach (Urbanoski et al., 2020, p.6-7), participants responded to the statement, "I would feel safe going to the doctor if…". Some of the 73 synthesized study findings highlight the need to feel accepted and free from judgment when connecting with a healthcare professional:

I would feel safe going to the doctor if…

- I knew that I wouldn't be judged or labelled
- I wasn't embarrassed, ashamed, or thought they would be disappointed in me
- I knew they would respect boundaries and didn't talk down to me
- They are professional and impartial and don't act surprised when I tell them things
- I knew that I wouldn't be treated badly or lectured about my drug use
- I wasn't blacklisted, red-flagged, or refused care
- I knew that addiction would be treated like any other health problem
- I know I wouldn't be in trouble with the law or treated like a criminal
- They are accepting of drug use so that I could speak openly about it.

Participants from the primary care studies connected feelings of safety and not being judged with the importance of relationships and trust, which is reflected in theme two. Participant thoughts about being treated like someone who matters, being a patient or person first and desiring an experience free of judgment were present across all healthcare settings.

Listen to [Us]. Just Listen. To facilitate an approach in healthcare where people feel they matter, it is crucial to listen to the patient and listen to ourselves as healthcare professionals. Participants identified wanting to be treated like humans, and listening to understand someone is part of that. One participant from a primary care study summarized this concept well:

> Listen to them. Just listen. And just encourage them. They can get better. Because a lot of people don't do that. They just, "Well, you're using, and you want to go kill yourself, just go kill yourself." But if they got somebody that's positive in their corner, it's a big difference. (Heidari et al., 2024 p.246)

Participants also identified wanting access to healthcare that is accepting of their substance use history. To create a judgment-free environment, participants

identified that it is important to listen to language and tone when speaking to people who use drugs. As healthcare professionals promoting acceptance and safety, taking time to listen and evaluate biases is essential.

For participants, the theme of *Being Someone Who Matters* included the concepts of caring, being treated like a human, acceptance, and safety. Listening was highlighted as a tool to help achieve these concepts.

Theme Two: I Trust That the People Taking Care of Me Trust Me

Theme one contained the concepts of caring and acceptance. These were focused on how people who use drugs would like to be treated by healthcare professionals. Theme two is about the two-way relationship between the patient and the healthcare provider. The connection with the healthcare professional was one of the most critical aspects of treatment identified by participants and appeared in all 14 articles. Participants stated that patient-provider relationships were positively associated with the duration of time spent together, developing a connection of trust, understanding the participant's personal life, having a family or friend-like feel, and functioning in a strength-based approach.

Participants identified that the patient-provider relationship is built on meaningful, ongoing, positive experiences established over time. This continuity of care allows patients and providers to know and understand each other. Having the same healthcare provider spares patients from sharing their medical history repeatedly, making patients feel at ease during the healthcare experience. Extended time with the same healthcare provider is associated with building a patient-provider relationship.

Building a relationship allows time to establish trust between patients and providers. Participants identified that having trust was positively associated with feeling safe. One participant from a primary care setting related how difficult it is to establish trusting relationships: “a lot of us have huge trust issues…so it takes time to get to know somebody, to trust them to be around you while you’re doing this private thing” (Marchand et al., 2020, p.3). Another hospital-based participant describes the connection between forming a relationship and building trust: “The better they get to know me, the better the trust.” (Balmuth et al., 2024, p.9). This participant relates the depth of a trusting relationship with a primary care provider: “He knows the bad. He knows the good. He knows me, and I just feel like he helps” (Incze et al., 2023, p.404). The title of this theme, “I trust that the people taking care of me trust me” (Balmuth et al., 2024, p.2090), shows how trust is a collaborative aspect of the patient-provider relationship.

Participants shared that healthcare providers needed to see them as more than people who use drugs; they also needed to understand their personal lives. One participant appreciated that her primary care provider was a social connection; “She asks me how’s my family. I go, ‘They’re doing good.’… never have nobody to talk to like that since my mother passed away” (Dunham et al., 2024, p.1686). Establishing strong relationships built on trust requires getting to know each other on a personal level. The trusting relationships participants described had depth to them and grew over time. A participant from a study exploring general healthcare settings described the depth of the relationship in this way, “I would like a nurse to genuinely want to – genuinely want to know you

and really care for you… But just getting to know you, understand you, watch you, feel you, get into you…Encourage you, embrace you". (Dangerfield et al., 2021, p. e33). Some participants even compared their relationships with healthcare providers as being like family or friends. One participant described positive connections in the primary care setting: "It's like one big family here, and when you come, you all get treated like that. So, it's very welcoming" (Alves et al., 2021, p.5). Participants desired that the patient-provider relationship have a personal aspect to it.

People who use drugs want a healthcare provider who believes in them and provides success-focused care. The following three quotes from participants exemplify the importance of healthcare providers knowing, connecting and believing in their patients. The first participant was from a primary care setting: "I feel like I let them down, but they're still there for me, and they still back me up" (Dunham et al., 2024, p.1684). The second participant was from a general healthcare setting; "They are so proud of me, I know they are. The way that I have dealt with everything. The doctor even told me that I'd done very well for myself. Sometimes you just need to hear that" (Troberg et al., 2022, p. 9). Lastly, from a participant on a medical/surgical floor; "Dr. X was the first person in my lifetime … to sit across from me and look me in my eyes and tell me that she believed in me… That meant a lot to me" (Balmuth et al., 2024, p.9). Participants appreciated healthcare providers who used a strength-based approach and celebrated patient successes.

Description of patient-provider relationships differed between healthcare settings. Participants from primary care settings emphasized developing trusting connections. Those from the emergency department highlighted the need to connect personally with their healthcare practitioners. One participant from the emergency department described it as; “She was funny, she was down to earth. You know, she talked on my level – she didn’t talk doctor. And, [she] just felt like a friend, you know? Like a friend conversing with each other" (Collins et al., 2023, p.4-5). Participants from primary care, emergency department, hospital and general healthcare settings affirmed the importance of asking questions and listening to understand someone's situation.

Listen to [Us]. Just Listen. A patient-provider relationship built on trust is an important concept identified by people who use drugs in the research. To build trust, asking questions and listening to the answers creates understanding. In a study done in multiple settings, a participant describes the importance of active listening;

> To me, it's more like a friend because she probes until she can find out what's going on with you and try to help you because people have crisis, and just by looking, you can't tell what's going on with a person, sometimes you have to dig a little deeper (Heidari et al., 2024, p.245)

For participants, the theme *I trust that the people taking care of me trust me* was about the patient-provider connection, with trust being an integral part. Time spent together, connecting personally and using a strength-based approach

also added to the patient-provider relationship. Participants identified that asking questions and listening to the response was foundational to building trust and a positive patient-provider relationship.

Theme Three: I'm Happy That You Listened… I Clearly Have Knowledge in This Area

Participants drew attention to the heterogeneous ways in which people use substances; supporting people who use drugs requires individualized care. People who use drugs must be partners in their care, and that can happen by having open conversations about drug use, discussing clinical decisions together and tailoring treatment to their individual needs to support their healthcare goals.

Healthcare professionals who took the time to ask questions and have an open conversation about drug use had a meaningful impact on participants. One participant commented on the significance of a primary care professional taking time to listen: "He's always asking questions, working with me through stuff. So, I feel like when I am there, he's invested in what's going on with me" (Incze et al., 2023, p.6). Another participant from an emergency department articulated the benefit of having open conversations before offering advice and how this influenced possible health outcomes:

> At least get to know the person first before you ask them questions like that. Like talk to them for a second and then ask that question. Don't come off like, 'Are you going to a detox?' That's not going to make me want to get sober (Collins et al., 2023, p. 5).

Participants valued open conversations and being asked questions, which improved understanding and allowed patients to have input in treatment decisions.

Discussing clinical decisions with their healthcare provider allowed participants to have agency over their health. Participants appreciated being taken seriously and having the expertise of their health and lived experience recognized. People who use drugs want to engage in shared decision-making and are “grateful when doctors are willing to engage with [them]” (Galarneau et al., 2023, p.5). One participant said engagement “looks like a conversation” (Dangerfield et al., 2021, p. e33). Discussing options allowed Participants to feel more involved in their care and increased the likelihood of treatment uptake and follow-through.

Participants expressed the value of tailoring treatment to an individual’s needs and goals. One participant appreciated that primary care providers “look at what you need and what direction you want, and how you want to do it” (Alves et al., 2021, p.3). To ensure the treatment fits into their lives and is in line with the patient's needs, another participant recommended that healthcare providers get to know their patients and “figure out someone’s lifestyle first” (Dangerfield et al., 2021 p.e34). A participant from an emergency department talked about the importance of being provided choices to tailor treatment to patient goals; “It’s good to have options. Yeah, and I found having the options that I felt like…. my opinion matters” (Galarneau et al., 2023, p.6). Participants identified having options and tailoring care to individuals' needs as a valuable aspect of treatment.

People who use drugs want to be partners in their care by having a voice in planning their treatment goals and health outcomes. One participant from the emergency department described the significance of being part of care planning; “They allowed me to feel like [I] was part of my own care and understand what was going on with my body and what we were doing to fix it” (Galarneau et al., 2023, p.6). Being a partner in care meant that the concerns of people who use drugs were being taken seriously. Participants also stressed that healthcare professionals need to focus on the person’s reason for seeking healthcare and not on their drug use or history of drug use. Participants from all healthcare settings demonstrated the need for people who use drugs to be partners in care.

Listen to [Us]. Just Listen. Participants asserted that they are experts in their own lives and health. They expressed the importance of being listened to as a partner in their care. One participant from the medical/surgical floor speaks of how listening to their expertise is essential;

> I’m happy that you listened, and you took my opinion into account. Because I clearly have knowledge in this area … Listening to what I’m telling you is going on in my body is important to me. I know that I trust that the people who are taking care of me trust me. (Balmuth et al., 2024, p.6)

Having open conversations about their experiences can have meaningful impacts on people who use drugs. Listening and collaborating in clinical decisions gives people agency over their lives. People who use drugs want to be

partners in their care by having open conversations about drug use, discussing clinical options and tailoring treatment plans to support their healthcare goals.

Theme Four: You Don't Know Unless You've Been There… We Can Tell You

All the articles included in this scoping review included evidence that participants wanted their healthcare practitioners to have current knowledge of drug use support and treatment and be well-versed in trauma-informed and harm-reduction practices. Other characteristics of this contextual competency were vocational experience, understanding pain relief in relation to drug use, and recognizing expertise in the lived experience of people who use drugs. When those characteristics were lacking, people who used drugs encouraged healthcare professionals to listen to those with lived experience as a first step to learning.

Both people who use drugs and healthcare professionals value current and evidence-based information. Participants identified that people who use drugs would find it "much easier if healthcare personnel would have experience and knowledge of drug use" (Toberg et al., 2022, p.9). Harm-reduction approaches, trauma-informed practices, and culturally inclusive care are essential healthcare strategies for people who use drugs.

Participants communicated that a healthcare professional's comfort with drug use medications, triggers, and relapse prevention fostered confidence in their ability to support people who use drugs. A clinician with years of experience helped a participant "feel reassured because he was obviously very capable.

He'd obviously been doing this for years" (Alves et al., 2021, p.5). Knowledge of appropriate dosing around pain control was also a prominent part of this theme. People who use drugs would like their description of pain seen as credible and legitimate. One participant appreciated having their pain controlled in a judgement-free way; "If … I called and needed pain medication, I got it, no questions asked. There was none of that, 'are you drug seeking right now?'" (Balmuth et al., 2024, p.2090).

In hospital and emergency department settings, participants discussed the benefits of having someone with expertise in the form of lived experience as part of the care team. One emergency department participant said they would "rather talk to somebody who's been through it than somebody who doesn't know anything about it except what they learned in school or whatever" (Collins et al., 2023, p.6). Participants proposed using peer groups for primary care or peer workers in emergency departments or hospital inpatient units to enable a peer support model.

Participants also recognized that some healthcare professionals do not yet have the knowledge or experience described above. People who use drugs encourage healthcare professionals to listen to those with lived experience as a first step to learning. The lived experience of drug use is an expertise that cannot be taught. One participant recommended that healthcare professionals "should do a little class under the bridge somewhere. Exactly, where they can see what it's like. Not all of us want to be here" (Collins et al., 2023, p.7). Listening to patients' expertise can be an essential educational resource for healthcare

providers. Listening to one patient's experience can enhance understanding and improve care for patients with similar experiences.

Listen to [Us]. Just Listen. To garner experience in caring for people who use drugs, participants encouraged healthcare professionals to listen and learn. In the scoping review article on perspectives on engagement, participants reported that sharing stories of lived experiences broke down barriers within the patient-provider relationship. Collins et al. (2023) expanded on this, stating that listening to patient expertise is an essential educational resource for healthcare providers. Extending this concept to the systems level, those with lived experience of drug use should have an active role in training healthcare professionals. Listening and learning from people who use drugs can improve care and understanding for present and future interactions.

Participants encourage healthcare professionals to have current knowledge of drug use supports, pain relief strategies, trauma-informed practices and harm-reduction options. One participant from the emergency department emphasized the importance of recognizing the expertise of those with lived experience: "You don't know unless you've been there. You can see it, and we can tell you as much as we can" (Galarneau et al., 2023, p.7). Listening and learning from people who use drugs should be part of healthcare professionals' practice and training.

Theme Five: Help Me Access Services and Resources

Themes one through four are primarily about professional practice. In contrast, theme five is about creating an integrated and accessible care

structure. Participants identified the need for resources and referrals that reflect holistic services. They also identified areas where the healthcare structure could be adapted to remove barriers to accessing care. This theme is divided into two sub-themes: open-minded, holistic care and flexible healthcare structure.

Subtheme One: The Type of Care… is More Holistic… and More Open Minded. Non-medical factors influence a person's health outcomes. The cohesiveness of healthcare support also influences health outcomes. Participants identified the need for a holistic approach to health care. Holistic care was defined as ancillary supports, consistent, centralized care, cohesive services, and referrals to other services, specifically mental health services.

Participants identified that people who use drugs accessing the healthcare system have a variety of psychosocial concerns and need ancillary support. They disclosed at times needing support with transportation, food, spiritual issues and more, all of which contributed to receiving holistic care. One participant from a hospital setting appreciated receiving support from the hospital with personal needs,

> They would help you out, you know, and they even worked with me because they knew about my ride situation…. sometimes the coordinators would give us these [food] vouchers. So yeah, that helped a whole lot. Like we would get like four apiece and that would buy us for a week. (Blair et al., 2021, p.325)

Holistic care also includes consistent, centralized care, cohesive services and referrals to alternate resources.

Fragmentation within the healthcare system can be restored by offering consistent and centralized care. Participants from primary care settings appreciated having one trusted healthcare provider for all their health-related concerns. Another participant addressed the benefits of having a collaborating team approach in primary care;

> I just feel like whatever issues are going on they're all working together to help me do better with my diabetes and the addiction itself. So, it's nice to have them even when I'm not there, they're talking to each other how to solve issues or get stuff done (Incze et al., 2023, p.5).

The benefits of cohesive, direct-service healthcare models where patients could access multiple services in one place were highlighted in several studies. One participant from a primary care study described that drug use

> causes a lot of medical problems. So, you always have backfires in one or the other, so it makes it really helpful that you can come [attend to generalized health concerns and drug use] issues at the same time. So that you can come and get both sorted (Alves et al., 2021, p.5).

Coordinated care was recommended when a cohesive direct service model was not possible.

Participants discussed the importance of accessing services and resources offered by community agencies. Many discussed the benefits of referrals to resources supporting their psychosocial or personal needs. A

participant appreciated that the emergency department gave “you the resources you need to get whatever it is you need to get, whether it’s out of a bad home into a good home, whatever” (Collins et al., 2023, p.6). Participants articulated that referrals or navigation to other services needed to be step-by-step or more hands-on to eliminate barriers to accessing those resources. There was an emphasis on connecting to mental health resources. Due to the intersectionality of drug use and mental health issues, participants suggested that having these supports in one location or care providers closely collaborating would make services more accessible.

Primary and general healthcare participants commented on the benefits of continuity of care and having a centralized place to access services. Participants further described how flexible support and clinic policies improved their primary care experience. In addition, participants in the emergency department and hospital setting highlighted psychosocial referrals to other services as essential. Integrating treatment with mental health services was important for people who use drugs across all healthcare settings.

Offering holistic care that incorporated referrals to psychosocial supports and mental health services was determined as vital. Participants also highlighted the importance of centralized care and cohesive services when offering holistic care.

Subtheme Two: We Can Work Around This Problem. Participants identified many barriers for people who use drugs when accessing healthcare. Collaborating to create a flexible healthcare structure makes removing barriers and accessing services easier. Modifying appointment structures, making accommodations to reduce anxieties, and creating opportunities to collect patient feedback all help make healthcare more accessible to people who use drugs.

Modifying appointment structure in format, length, and time of day influences whether patients can attend appointments. Participants appreciated having a choice of appointment format: in-person, via telephone, or walk-in. Accommodations in appointment format can remove barriers to access, as one primary care participant explained;

> Prior to coming into treatment, I was homeless. I didn't have a car. And my mom would drive me to my appointments sometimes, but if my mom and I had a falling out, I didn't have a way to get to the appointment. And he [PCP] would do – and I had called once to cancel the appointment, and it was like, "No, you don't need to. We'll just do telehealth. We can work around this problem" (Incze et al., 2023, p.5).

The length of appointments was also a barrier. Participants related that the brevity of primary care appointments hindered meaningful relationships with healthcare providers. Allowing longer appointment times, provided time to listen to patient concerns. For healthcare settings not open 24 hours a day, participants appreciated the option to book appointments outside regular business hours and

stated that using flexible approaches to care removes barriers to accessing treatment.

Participants highlighted small accommodations to reduce anxiety in accessing healthcare. Examples include online booking, not having to wait long for appointments, and patient-provider contact between appointments; these made a difference in treatment outcomes. One participant in a study about general healthcare stated that the additional communication of check-ins and reminders between appointments was a beneficial part of the therapeutic care plan:

> I can just either call them or they just check up and say, “Hey, how’s it going? Do you need a little checkup?” Or, “Is there anything wrong? Do you need [anything]?” Because I guess besides being a doctor, also being kind of therapeutic a little bit in a way to making them feel as though they’re not alone. So yeah [because] it’s tough out here… But knowing the fact that you got somebody to rely on (Dangerfield et al., 2021, p.e34-e35).

To ensure people who use drugs can access services, healthcare providers need to ask and understand their patient’s needs to provide appropriate accommodations for care.

To create a flexible and accessible healthcare system, it is essential to have open feedback between patients and healthcare professionals. There is often an imbalance of power between healthcare professionals and patients, with

healthcare providers holding more power regarding decision-making. Participants disclosed their feelings of stigmatization and desire to be included in decision-making. Participants appreciated it when healthcare providers were open to feedback, which created a sense of accountability in the relationship; “I felt that we were accountable to each other” (Urbanoski et al., 2020, p.7). Participants introduced the importance of a system that fosters feedback to ensure patient and provider accountability.

Listen to [Us]. Just Listen. When providing accommodations to care for patients, a one-size-fits-all approach is ineffective. People who use drugs have complex and intersecting issues that often do not fit within the healthcare structures that are currently in place. It is, therefore, important for healthcare providers to listen and create opportunities to modify structures to accommodate patient needs. Healthcare professionals can listen to feedback on how to modify the healthcare structure to make it accessible for people who use drugs.

There are many barriers for people who use drugs when accessing healthcare. Collaborating to modify appointment structure, making accommodations and creating opportunities to collect patient feedback makes removing barriers and accessing services easier. Including the input from people who use drugs supports the creation of a flexible healthcare structure.

Summary of Findings

During the thematic analysis, an effort was made to represent the voices of people who used drugs by summarizing the findings from the 14 final articles that met the inclusion criteria. Five themes emerged from the evidence

encapsulated in participant quotes: *I am someone who matters, I trust that the people taking care of me trust me, I'm happy that you listened… I clearly have knowledge in this area, You don't know unless you've been there … we can tell you* and *Help me access services and resources.* The foundational concept of listening, *Listen to [Us]. Just listen*. was integrated throughout the themes.

The insights gathered from people who use drugs, expressed through these themes, address the research question: What do healthcare professionals need to know about how people who use drugs want to be treated to provide acceptable care for people who use drugs? Two key takeaways from the findings are that individuals who use drugs desire to be understood and to be active collaborators in their care. Listening was the intervention that was most frequently identified to help achieve this. When healthcare providers take time to listen to their client's needs, people who use drugs experience a greater sense of autonomy and empowerment regarding their treatment plan. Furthermore, effective listening fosters understanding, strengthens the patient-provider relationship, and creates avenues for learning.

The evidence was predominantly focused on the patient-provider level; however, participants also identified that people who use drugs want to be understood and engaged as collaborators in their care at the structural level. They seek opportunities to provide input on accommodations that could eliminate barriers, making the healthcare structure more flexible and accessible.

Discussion

Stigmatizing behaviour among health professionals, adverse healthcare experiences (Mental Health Commission of Canada, 2020), and inequitable policy and healthcare structures impede the quality of healthcare for people who use drugs. The participants offered solution-focused recommendations for enhancing the acceptability and accessibility of healthcare for this equity-deserving group. The findings from this study advance the current knowledge about what healthcare professionals need to know to provide acceptable care for people who use drugs. What distinguishes this research is that the evidence is from the perspective of people who use drugs.

The key takeaway from the findings of this scoping review is that people who use drugs seek to be understood and wish to collaborate in their care. This was evident in the five themes that emerged. The results strongly align with previous studies, affirming the relevance of all five identified themes. Although aspects of the five themes have been explored in earlier studies, less emphasis was placed on the importance of listening, highlighting a distinctive element of these findings. In this section, I will examine the themes in relation to existing literature and their implications for practice. Attention will then be given to how the themes align as a whole. Additionally, the study's limitations will be discussed, and opportunities for future research will be proposed.

Theme One: Being Someone Who Matters

Participants described the need to *be someone who matters* as being cared for, being treated like a human, feeling free from judgement and being

accepted with their substance use history. Healthcare extends beyond treating illnesses; it also encompasses the critical aspect of delivering *quality patient care.* Quality care is said to have a positive effect on health outcomes. It benefits the patient recovery experience and helps patients feel more comfortable in hospital settings (Carrington College, 2013). The findings from this scoping review emphasize the importance of caring and providing acceptable care for people who use drugs, as well as offering more profound insights into what constitutes *quality care* for this equity-deserving population.

Theme Two: I Trust that the People Taking Care of Me Trust Me

The benefits of a positive patient-provider connection are highlighted in this scoping review and supported by other research (CATIE, 2024; Mental Health Commission of Canada, 2023; Wenger et al., 2024). A trust-based patient-provider relationship benefits both parties involved. When people positively view their relationship with their healthcare provider, healthcare engagement increases (Heidari et al., 2024). Providers can most effectively support patients' needs by understanding their unique experiences with their health conditions (Heidari et al., 2024). The use of trauma-informed approaches (Wenger et al., 2024), the implementation of harm-reduction practices and the importance of building trust (Guta et al., 2022; Messinger & Suzuki, 2022) is consistently emphasized in the literature.

Theme Three: I'm Happy that You Listened... I Clearly Have Knowledge in this Area

Patient-centred care is emphasized throughout the literature and is a widely recognized, evidence-based approach (Henderson et al., 2024; Marchand et al., 2019). Similar concepts surfaced in the themes; I'm *happy that you listened… I clearly have knowledge in the area* and *I trust that people who take care of me trust me.* The results of this scoping review emphasize that people who use drugs want their unique needs to be central to care decisions, and they wish to be active partners in developing their care plans. The Centre for Addiction and Mental Health (CAMH, n.d.) echoes this, stating that people who use drugs want to be actively involved in their care.

People who use drugs seek recognition for their expertise and desire to be engaged during their healthcare experience, which emerged from the findings of this scoping review. The key takeaways described in the summary of the findings were that people who use drugs want to be understood and contribute to their healthcare experiences. Authentic engagement with people who use drugs in decision-making and at all stages of research planning, development, and analysis has been demonstrated to be significant (COM-CAP & PHO, 2024; Livingston, 2021; Mental Health Commission of Canada, 2020; Wallace et al., 2021). Healthcare practices should incorporate meaningful and respectful engagement with people who use drugs, ensuring that their input and priorities are reflected in programs, policies, and protocols. It is essential to prioritize the perspective of people who use drugs in decisions made about them.

Theme Four: You Don't Know Unless You've Been There… We Can Tell You

Participants expressed the importance of healthcare providers having current knowledge of drug use support and treatment. When this knowledge was lacking, people who used drugs encouraged healthcare professionals to listen to those with lived experience as a first step to learning. This is reinforced in a rapid review titled *Evidence for Strategies that Address Substance-Use Related Stigma* (COM-CAP & PHO, 2024). Training and education for healthcare professionals, which incorporates motivational interviewing and contact with individuals with lived experience of substance use, as effective in developing competence when caring for people who use drugs (COM- CAP & PHO, 2024).

Theme Four highlighted the benefits of learning from people who use drugs, thus recognizing the need to redistribute power toward the patient. Power differentials perpetuate stigmatizing processes and policies and devalue the expertise of people with lived and living experience (Mental Health Commission of Canada, 2023). The Mental Health Commission of Canada (2023) has a comprehensive strategy for addressing structural stigma, which demonstrates the need for power redistribution in healthcare by fostering the inclusion and participation of people who use drugs. Other ways to redistribute power on the patient level include emphasizing trust and safety, offering choices through connection and collaboration, and building on people's strengths (Community Resilience Coalition of Guelph and Wellington, n.d.). This was evident in the results of this scoping review in relation to the importance of building trust in a

collaborative, patient-centred relationship with healthcare professionals. At the structural level, participants in this scoping review stressed the importance of being involved in decision-making, educating healthcare staff, hiring people with lived experience and allowing people who use drugs to be in positions of trust and authority.

Theme Five: Help Me Access Services and Resources

The Mental Health Commission of Canada (2020) suggests that fragmented care is one element that compromises access to healthcare for people who use drugs. An element of their comprehensive strategy is strengthening care coordination, specifically around mental health and substance use services. This parallels the findings from participants that there is a need to promote consistent, centralized, or coordinated care, specifically around mental health and substance use concerns. The association between mental health issues and substance use concerns is found in other research and underscores the importance of collaborative care (CATIE, 2024; Jaiteh et al., 2019; Jeffries et al., n.d.).

Substance use is a complex issue with intersecting challenges. Participants identified that many patients who use drugs also need support with psychosocial concerns such as housing, food security, or income. Extensive research exists on the influence of social determinants on health outcomes (Government of Canada, 2024). Although other social determinants of health, such as food security, income and employment, are complexly connected to substance use, housing has been identified as the most significant psychosocial

concern for some people who use drugs (Bardwell et al., 2020; Ezell et al., 2021; Wenger et al., 2024). Participants articulated that referrals or navigation to other services needed to be step-by-step or more hands-on to eliminate barriers to accessing those resources. By integrating referrals to housing support and other psychosocial concerns into healthcare practices, healthcare support can be more comprehensive.

Structural stigma in healthcare occurs when policies and practices produce inequitable access to healthcare for people who use drugs (Henderson et al., 2024; Ontario Drug Policy Research Network, 2024; Tam, 2019). Methods for measuring structural stigma towards individuals who use drugs, along with examples of potential measures, are discussed in other research (Livingston, 2021; Mental Health Commission of Canada, 2020 & 2023; van der Sterren et al., 2023). Some of these measures include establishing feedback avenues using quality-of-care indicators (Knaak et al., 2015 & 2017) so people who use drugs can provide input into their healthcare experience.

Understanding the perspective of people who use drugs regarding healthcare structures and policy was a gap in the evidence found in this scoping review. Participants identified the need for healthcare structures to be flexible to remove possible barriers. However, the scoping review yielded no insights into how people who use drugs should participate in policy and program structure development. Participants in this scoping review advocated for an avenue to offer feedback regarding their healthcare experiences to establish a sense of accountability between provider and patient. Studies included in this review

primarily focused on the quality of healthcare services, suggesting that study participants were not given the opportunity to comment on necessary policy or structure changes. This may be an opportunity for future research.

Listen to [Us]. Just Listen

Research indicates that individuals who use drugs often feel that healthcare providers do not adequately listen to them, leading to feelings of disrespect and belittlement (Recovery Research Institution, n.d.; Tam, 2019). While a lack of listening has been identified as a significant issue, the concept of listening as a potential intervention has not been extensively addressed in the literature. Although it is implied in broader concepts such as collaboration, engagement, and the development of positive relationships, it remains underrepresented in existing studies. In contrast, participants in this scoping review emphasized that listening is fundamental to delivering acceptable care. People who use drugs propose solutions to the challenges faced by their community, yet they often feel that decision-makers do not seek or consider their insights (Touesnard et al., 2021). Evidence gathered from participants reinforces that listening can enhance feelings of value, strengthen connections between patients and providers, promote patient-centred care, impart experiential knowledge, foster an integrated healthcare system, and support solutions for challenges encountered by this equity-deserving community. This highlights the significance of this distinctive finding.

General Approaches or Specialized Care

The findings from this scoping review are consistent with current health strategies that could benefit all patients. However, individuals who use drugs continue to experience discrimination, leading to adverse health outcomes. Participants have suggested strategies for caring for people who use drugs, and we will also discuss the professional responsibilities involved.

Practices for all Patients

Approaches such as patient-centred care and therapeutic relationships are evidence-based healthcare practices. These strategies benefit all patients by promoting better outcomes, higher patient engagement, and increased satisfaction. (DeAngelis, 2019; Welkin, 2020). Trauma-informed practices acknowledge the effects of trauma on health, emphasizing the necessity for healthcare professionals to understand a patient's life circumstances to provide acceptable care. Trauma-informed care includes safety, trust, transparency, peer support, collaboration, a focus on strengths, and recognizing biases. (Trauma-Informed Care Implementation Resource Centre, 2024). Harm reduction practices focus on positive change by engaging with individuals in a judgement-free, non-coercion and non-discriminatory manner (Harm Reduction International, n.d.). The aim of harm reduction interventions is to mitigate the risks of adverse health-associated behaviours without expecting patients to terminate the behaviour. The principles of harm reduction include humanism, individualism, autonomy, incrementalism and accountability (Hawk et al., 2017). Concepts such as patient-centred care, therapeutic relationships, harm reduction

approaches and trauma-informed practice have value for all patients. These approaches are particularly valuable to people who use drugs. However, it is important not to conclude that general evidence-based approaches that support all patients are sufficient to provide acceptable care for people who use drugs.

Even with these approaches and practices available, people who use drugs are still facing twice the amount of stigma and discrimination as the general population. In a Canadian national survey, over 25% of Canadians reported experiencing at least one form of discrimination in their lifetime (Godley, 2018). In another Canadian national survey, 50% of individuals who use(d) substances report experiencing stigma or discrimination during the time they were using substances (McQuaid et al., 2017; Public Health Agency of Canada, 2019). Stigma within the healthcare system is a significant factor contributing to adverse health outcomes (Friedman et al., 2022). Stigmatization in healthcare leads to decreased utilization of health and social services, inferior quality of care, concealment of substance use disorders, job loss, limited access to leadership positions, an increased risk of homelessness, and contributes to opioid-related deaths (COM-CAP & Public Health Ontario, 2024). It is clear that current healthcare practices are failing this equity-deserving population.

The definition of equity is to allocate resources and opportunities to individuals of varying circumstances in order to achieve equal outcomes. Health equity is attained when individuals have a fair chance to reach their maximum health potential (Public Health Ontario, 2024). The participants from this scoping review identified ways that healthcare professionals can create opportunities for

people who use drugs to reach their maximum health potential. In the findings from theme one, *Being Someone Who Matters,* participants identified the importance of having healthcare interactions that are unbiased, accepting, and free from judgment. In theme two, participants described their relationship with their healthcare professionals as therapeutic but also personal, based on trust and connection, comparing it to being treated like family. In theme three, participants wanted to be more than the central subject of care decisions but actively contributing partners in their care, where their expertise is recognized. One of the key takeaways from the findings is that people who use drugs want to be understood.

Participants in this scoping review also identified barriers to accessing healthcare which are impeding equitable care. In theme five, participants identified the need to modify the current healthcare structures by providing accommodations to access service, extra support with referrals and consistent, centralized, or coordinated care, specifically around mental health and substance use concerns. Participants valued healthcare professionals who demonstrated contextual competencies and utilized evidence-based practices in substance use care. In the findings from theme four, participants highlighted that individuals who use drugs want to support education for healthcare professionals. The other key takeaway in the findings was that people who use drugs want to be active contributors to their care, both at the individual relationship level and at the structural level. Healthcare professionals have a vital role in making this happen.

Professional Responsibility

The College of Nurses of Ontario (CNO) is the regulatory body that ensures that nurses practice safely, competently and ethically. The CNO's practice standard that outlines a nurse's Code of Conduct (CNO, 2024) has several principles, which address respecting the client's dignity, practicing cultural humility, providing competent care, and acting in the client's best interest. The CNO also has a diversity, equity and inclusion (DEI) strategy to ensure nurses address barriers to equity and implement equitable and transparent policies, practices and processes (CNO,2024b). The findings from this scoping review are reflective of these practice standards and highlight how these principles can be applied when working with people who use drugs.

As a nurse, I have a professional obligation to adhere to these practice standards. Providing acceptable care to people who use drugs is part of my professional responsibilities. The correlation between the guidance documents and the research findings creates an avenue to integrate the findings into practice. Implementing the findings can be practical and attainable.

It is evident that healthcare practices need to change. There are benefits to adopting general approaches such as patient-centred care, therapeutic relationships, trauma-informed practices, and harm reduction interventions. However, the findings from this scoping review offer specific insights into providing acceptable care for people who use drugs. Healthcare professionals have a vital role to play. Efforts to ensure that people who use drugs are

receiving acceptable, equitable care must be in conjunction with meaningful engagement with people with lived and living experiences.

Strengths and Limitations

While this scoping review employed accepted methodologies, it is important to acknowledge its limitations. The limitations and strengths to be discussed include the involvement of people who use drugs, the breadth of the search strategy, healthcare as the research setting, and power differentials.

Involvement of People Who Use Drugs

Engaging people who use drugs contributes meaningful perspectives that enrich the findings of the scoping review (Wojcik, 2021). A strength of this research is the consultation with people who use drugs in the process of developing the research project. The Lived Experience Advisory Panel defined the criterion for determining whether the literature included in this review was from the perspective of people who use drugs. These inclusion criteria impacted the research outcomes.

A limitation of this review is that people who used drugs were not included in all stages of the research process. People who use drugs could have collaborated during question development, data extraction, coding, theming and interpreting the findings. People who use drugs are a marginalized community which is often denied equitable involvement in research opportunities. When working with an equity-deserving population, such as people who use drugs, it is important to ensure that a trauma-informed approach is being used. It may also be necessary to consult a research ethics board. However, these additional steps

should not limit their participation in research. Having a person(s) with lived or living experience involved in the research enhances the legitimacy of the results.

In addition to having the Lived Experience Advisory Panel involved in the planning stages of this research, I was also able to have a person with lived or living experience peer-review this thesis submission. Their feedback offered valuable insight into the findings and this research.

Breadth of Search Strategy

The search strategies employed resulted in a large volume of literature. A decision was made to have an inclusive search strategy instead of a specific search strategy to ensure comprehensive results. Extra time was spent to thoroughly screen search options to mitigate the risk of being saturated with too much evidence, thus experiencing screening fatigue. Limits added to the search strategy, such as English language, age of participants and years of publication, may have contributed to missing articles. Search terms were developed in consultation with two research librarians, resulting in expansive search results. However, this does not guarantee that all relevant articles were included in this research process.

Research Conducted Within Healthcare Settings

The research in this scoping review was conducted mainly in healthcare settings. People who use drugs disclose not accessing healthcare due to stigma, power imbalance, or adverse history. It is unclear if the power differential associated with conducting the research in a healthcare setting influenced participants' answers. Interestingly, the findings from Urbanoski et al.'s (2020)

study, which was conducted in a peer-run community organization, do reflect findings from articles that were conducted in a healthcare setting. When conducting research with this equity deserving group, it is crucial for researchers to engage in Trauma and Violence Informed practices when determining the research setting.

Bias and Power Differentials

Personal bias and power influence the research findings and need to be recognized. My life experience as a person who has not used drugs and my position as a nurse means there is a power differential that may have influenced the extraction and interpretation of data.

My life experience does not include the use of illicit or illegal drugs as a way to cope with daily living. Although there is an attempt to keep the voices and perspectives of people who use drugs as the focal point of this research, all qualitative research contains the reflections of the researcher's standpoint. Recognizing the researchers within the process and acknowledging the influence of the researchers' experiences in interpreting meaning follows Braun & Clarkes' (2013) description of *reflexive thematic analysis*. Reflective thematic analysis acknowledges the theoretical underpinnings and the researcher's role in constructing meaning (Braun & Clarke, 2013). Although I did take precautions to manage the risk of personal judgment influencing results, it is impossible to remove it from research. I kept a journal to reflect on the process of research and the moral and ethical questions I encountered. During my supervisory meetings and thesis advisory meetings, I shared areas of struggle, recognized my personal

bias and was challenged by different perspectives. To have the actual perspective of people who use drugs reflected, people who use drugs need to be included in every stage of research (COM-CAP & Public Health Ontario,2024), especially authorship.

I work in the healthcare system as a registered nurse, and I have witnessed the stigma faced by people who use drugs. I am on a journey to recognize my personal biases. Being a healthcare provider can be seen as a limitation, as I hold a position of power in the healthcare system. However, I also see being a healthcare provider as a strength, as I am committed to obtaining evidence-based results I can implement into my practice.

Considerations when Applying Findings

It is important to exercise caution when applying the findings of this scoping review. This review did not differentiate between rural and urban settings, nor did it consider the specific substances used or the methods of drug administration. As a result, the findings may not accurately represent the experiences of individuals from particular drug-use communities. Compared to the entirety of the community, this scoping review represents a limited number of people who use drugs.

The findings from this scoping review are a compilation of individual experiences to provide an overview of a specific topic. Consequently, the findings may not be universally applicable. This scoping review is one source of evidence; it is the responsibility of the reader and decision-makers to engage people with

lived experience to ascertain when findings are relevant to a particular healthcare setting and how to implement these findings effectively.

Implications of Findings

The findings from this scoping review demonstrate what healthcare professionals need to know about how people who use drugs want to be treated to provide acceptable care for people who use drugs. Several key implications emerge based on this study's findings and current research. The implementation of key implications must be approached as a collaborative effort, involving active collaboration from individuals who use drugs. These implications encompass the preparation for healthcare providers, practice considerations, and research implications. Additionally, considerations for implementation and potential future research will also be discussed.

Preparation of Healthcare Providers

The findings from this scoping review have implications for healthcare providers. Personal reflection and education support professional development and enhance the quality of care provided to patients. Personal reflection is a crucial intervention for healthcare providers to engage in continuous learning, as identified in the literature, these scoping review findings, and as a quality assurance expectation. Participants identified three avenues for educational implications: learning to understand, contextual competencies that would improve practice and training opportunities that include interactions with people who use drugs.

Personal Reflection

It is essential to consider the role of healthcare professionals in escalating or abating stigma in the healthcare system. As part of a comprehensive strategy,

Dr. Tam (2019) encourages healthcare professionals to understand and address implicit and conscious biases and negative assumptions. Personal reflection is a crucial intervention for recognizing stigmatizing beliefs and practices (Tam, 2019). Participants in this scoping review encouraged healthcare professionals to reflect on personal bias, power imbalance and discrimination in the healthcare system (Marchand et al., 2020; Urbanoski et al., 2020). A key takeaway from the findings is that people who use drugs want to be understood. To combat negative assumptions, participants urged nurses to be open-minded when assessing the patient's history, lifestyle and motivation for drug use (Balmuth et al., 2024; Dangerfield et al., 2021; Marchand et al., 2020). Participants also highlighted the importance of nurses listening and asking more questions to better understand patients' perspectives (Urbanoski et al., 2020). Listening emerged as a fundamental concept in the findings and is an effective practice connected to personal reflection to help dismantle biases.

Registered nurses in Ontario must reflect on the CNO's Code of Conduct principles as part of their yearly quality assurance exercise (CNO, n.d). Implementing the findings from this research offers nurses the chance to reflect on their practice and apply the principles in the CNO's Code of Conduct while caring for individuals who use drugs. Many healthcare professionals must participate in personal reflection as a component of the expectations set forth by their governing bodies. This practice supports professional development and enhances the quality of care provided to patients.

Education Implications

People who use drugs state that they benefit from trained and knowledgeable healthcare professionals. This was outlined in theme four: *You don't know unless you've been there… we can tell you.* To enhance training and knowledge acquisition, participants identified three avenues for effective learning: learning to understand, contextual competencies that would improve practice and training opportunities that include interactions with people who use drugs.

Learning to Understand. In the results, two key takeaways summarized all five themes: People who use drugs want to be understood and be collaborators in their care. There is an opportunity to implement these findings by connecting with clients and asking them questions to understand them more (Urbanoski et al., 2020). To expand their knowledge, healthcare professionals could ask questions regarding patients' experiences and opinions and listen to their expertise about their health and lives (Alves et al., 2021; Austin et al., 2024; Dangerfield et al., 2024; Incze et al., 2023; Marchand et al., 2020; Troberg et al., 2022; Urbanoski et al., 2020). The foundational concept, *Listen to [Us]. Just Listen*. is a practical intervention for healthcare professionals when learning to understand.

Contextual Competencies to Improve Practice. Within the findings, the participants outlined some areas of learning that would benefit healthcare practitioners when caring for people who use drugs. Participants felt that healthcare providers should be proficient in trauma-informed approaches, harm reduction practices and pain management strategies (Alves et al., 2021; Balmuth

et al., 2024; Dangerfield et al., 2021; Urbanoski et al., 2020). Participants also felt that healthcare professionals should understand the connection between substance use and mental health concerns as a first step to providing consistent, centralized, collaborative care. (Urbanoski et al., 2020). In addition, participants encouraged healthcare professionals to gather a comprehensive education about substance use, services and care, including learning from those with lived and living experience (Austin et al., 2024; Collins et al., 2023; Dangerfield et al., 2021; Toberg et al., 2022; Urbanoski et al., 2020).

Training for Healthcare Providers. Research findings were related to training for new and seasoned healthcare professionals. Participants from this scoping review emphasized the importance of incorporating connections with individuals with lived experience of substance use during formal or informal training programs (Collins et al., 2023; COM-CAP & PHO, 2024). This immersive training was effective in developing healthcare professionals' contextual competence (COM-CAP & PHO, 2024). The key takeaway from this scoping review is that people who use drugs want to be understood, and they aspire to be active collaborators. When engaging with people who use drugs to provide training for healthcare staff, it is crucial to apply trauma-informed approaches and ensure that they are adequately compensated for their time and expertise (Alberta Health Services, 2018; Canadian AIDS Society, 2015; Greer et al., 2017).

Solution-focused recommendations from the perspective of individuals who use drugs to enhance healthcare professionals' learning are summarized in

Appendix K. The aim of these recommendations is to make healthcare more accessible and acceptable for this population. They can be utilized to improve existing practices and inform the development of new healthcare structures. To assist healthcare professionals in implementing the findings from this research, participants highlighted three key areas for learning: learning to understand, contextual competencies that would improve practice and training opportunities that include interactions with people who use drugs.

For healthcare professionals to feel prepared to provide acceptable care for people who use drugs, they must engage in personal reflection and educational opportunities. Participants in this scoping review encouraged healthcare professionals to implement these findings by recognizing personal biases, challenging negative assumptions, learning to understand, bolstering contextual competencies, and learning from people with lived experiences.

Practice Implications

Ferlie and Shortell (2001) identified a four-level model of the healthcare system. When developing recommendations to improve healthcare quality for people who use drugs, it is vital to consider practice implications at all four levels: the patient level, the care team level, the organization or infrastructure level, and the larger system environment or policy level.

The recommendations generated by the research participants in this scoping review were mainly at the patient level. Findings from themes one, two, and three highlight the importance of the interactions between healthcare professionals and their clients. When healthcare professionals take time to treat someone with

respect and understand their substance use history, it helps patients feel cared for and accepted. Establishing a trusting patient-provider connection and partnering with people who use drugs in their care are patient-level interventions that can be implemented.

As highlighted in theme five, implementing research findings at the care team level involves delivering holistic and connected care. Participants encouraged healthcare professionals to deliver holistic care by fostering strong connections between substance use services and mental health supports (Blair et al., 2021; Dangerfield et al., 2021; Galarneau et al., 2023; Heidari et al., 2024; Marchand et al., 2020; Urbanoski et al., 2020). When making connections to other services, participants felt that the healthcare team could provide additional support during the referral process (Collins et al., 2023; Dunham et al., 2024) and offer cohesive healthcare through consistent, centralized service or coordinated care whenever possible (Dunham et al., 2024; Marchand et al., 2020).

Due to the intersecting complexities and inequities faced by people who use drugs, there are many opportunities to provide accommodations in healthcare at the organizational level. Research participants from this scoping review said they would like to be asked about and allowed accommodations to make healthcare more accessible (Urbanoski et al., 2020). The results from the fifth theme identified that collaborating to modify appointment structure in format, length, and time of day and making accommodations removes barriers to accessing healthcare and could improve health accessibility and acceptability.

As highlighted in the discussion section, there was limited input from the research participants in this study around advocating for change at the environmental or policy level. The use of *Patient Advisory Councils* is one example of an opportunity for patients to share their insights and recommendations regarding strategic health policy priorities and healthcare operations that influence the quality of care and healthcare experience (Government of Ontario, 2021). These councils must have appropriate representation of equity-deserving groups and ensure that participants receive adequate training and compensation (Robinson & Gogolishvili, 2022). The participants from two studies in this scoping review also recommended hiring diverse staff that reflect the community's culture, race, gender, and lived experience, which would influence the healthcare environment (Dangerfield et al., 2021; Urbanoski et al., 2020). Participants from this scoping review had limited opportunity to comment on system, environment or policy-level implementations.

At all four of Ferlie and Shortell's (2001) identified levels, people who use drugs identified wanting to be active collaborators in making the healthcare system more acceptable for them. Creating opportunities for patients who use drugs to provide feedback at the personal, healthcare team, organizational, or policy levels is one way of achieving this goal (Austin et al., 2024; Urbanoski et al., 2020).

Implications for Research

It is evident from the results of this scoping review that when given the opportunity, people who use drugs provide insightful and practical perspectives. Participants identified that people who use drugs want to be involved in research as research partners, involved in the planning, implementing, and disseminating research, mainly when research influences their healthcare experience. When direct involvement is not feasible, researchers should prioritize the perspectives of people who use drugs when conducting research which is about them.

When implementing the findings outlined above, involving individuals who use drugs in evaluating current practices, adopting new practices, and establishing measures to hold practitioners accountable for changes is essential. Appendix K includes suggestions derived from the perspective of people who use drugs reflected in this study, organized into the five themes identified in the findings. Appendix L provides additional resources to support the implementation of the findings in this scoping review.

The results of this scoping review underscore the importance of healthcare professionals understanding how individuals who use drugs prefer to be treated in order to deliver acceptable care. These implications encompass the preparation of healthcare providers, applications to practice, and research implications.

Considerations for Implementation

Acknowledging the complex intersecting issues that people who use drugs need to manage is essential. Suggesting that a small amount of kindness will

solve their healthcare concerns would be insulting. Focusing on how people who use drugs want to be treated when accessing healthcare is one part of breaking down systematic barriers and providing equitable healthcare.

This topic extends beyond the scope of this research. Nonetheless, it is important to acknowledge that changing healthcare practices and structures in an underfunded system based on paternalism (Mental Health Commission of Canada, 2020) and stigma (Tam, 2019) will be complicated. Funding for mental health and substance use issues is not adequate to meet the burden that these concerns place on our communities (Mental Health Commission of Canada, 2020). Underfunding services relative to disease burden creates a significant barrier to providing acceptable care. Lack of funding also impedes efforts to change healthcare practices and structure. Recognizing the intersectionality of drug use and colonization (The Public Health Agency of Canada, 2024), as well as the relationship between drug use and race, and the connectedness of drug use and the social determinants of health highlights the multifaceted nature of this issue. This complexity will make it hard to implement the findings. However, the challenges associated with implementing findings should not be used as excuses for not undertaking this necessary work.

Participants indicated they wanted to be understood and be collaborators in their healthcare. Depending on where healthcare professionals or organizations are in their journey to achieving this goal, there are several guidance documents to support organizations on how to foster engagement and sustainable dialogues between people who use drugs, policymakers and

healthcare providers (Canadian HIV/ AIDS Legal Network, 2005; CATIE, 2021; CDPC & CAPUD, 2021; Greer et al., 2017; Watson et al., 2024). Additional resources to support the implementation of the findings are included in Appendix K and L to accompany the results found in this scoping review. It is important to include people who use drugs in any implementation plans.

Areas for Future Research

To date, efforts to minimize stigma and eliminate barriers have not yielded the changes that people who use drugs desire. The aim of this scoping review was to uncover the information necessary for health professionals to provide acceptable care to people who use drugs using evidence from the perspective of people who use drugs. During the screening process, it was challenging to find research that was from the perspective of people who use drugs, was conducted in healthcare settings, and incorporated findings which focused on facilitators or solution-focused findings. There is clear evidence of the benefits of collaborating with people who use drugs when the research is about them (Canadian Drug Policy Coalition and the Canadian Association of People who Use Drugs, 2021; Canadian HIV/AIDS Legal Network, 2005). To my knowledge, this is the first scoping review that prioritizes the voices of people who use drugs, focuses on healthcare settings and has a solution-based emphasis. This highlights the need for more research with these foci.

In the current political climate, harm reduction services are being eliminated, and they are underfunded or are functioning as temporary pilot projects. These services are essential and should remain available. Due to the lack of funding,

support for people who use drugs is integrated into other healthcare settings. Research that focuses on people who use drugs interacting with healthcare settings such as hospitals, primary care and emergency departments is needed.

In an attempt to adopt an intersectional lens, future researchers could consider overlapping factors like gender, concurrent illnesses, race (COM-CAP & PHO, 2024) and age. Researching the perspectives of youth who use drugs or focusing on only people who inject drugs could highlight the specific needs of subgroups. The Lived Experience Advisory Panel advised that there will be different perspectives from different groups of people who use drugs (personal communication, June 21, 2024), which requires more focused research efforts. A First Nation population may also be a subgroup with specific needs. Working with Indigenous communities would require Indigenous-led partnerships and community data ownership models, all guided by that community's ways of knowing.

Expanding research beyond what healthcare professionals need to know and focusing on structure and policy in healthcare was identified as a gap in this scoping review. This gap presents a research opportunity that allows people who use drugs to contribute their insights on policy and systemic changes in healthcare environments. Future research questions could also include measuring stigma in healthcare, how to improve feedback systems among people who use drugs beyond evaluation forms and how to engage people who use drugs effectively. There are many opportunities for people who use drugs to advise, conduct and participate in future research.

Conclusion

There is a substantial body of literature highlighting the presence of stigma, inequity and poor health outcomes for people who use drugs in healthcare settings. While there are efforts to offer solutions to these deeply-rooted problems, few researchers ask people who use drugs their opinions. As a result, we are missing the expert evidence from this group. The findings from this scoping review demonstrate what healthcare professionals need to know about how people who use drugs want to be treated. To my knowledge, this is the first scoping review that focuses on the voices of people who use drugs, is solution-based, and is done regarding healthcare settings. Focusing on the perspective of people who use drugs adds a diverse perspective that is not prioritized in the academic conversation.

The participants in this scoping review provided evidence summarized into themes and subthemes. Quotes from the participants were used to depict each theme and sub-theme.

Theme One: Being someone who matters
- **Sub-theme One A**: Care about us as human beings
- **Sub-theme One B:** Accept me with my substance use history

Theme two: I trust that the people taking care of me trust me.
Theme three: I'm happy that you listened... I clearly have knowledge in this area.
Theme Four: You don't know unless you've been there... we can tell you
Theme Five: Help me access services and resources
- **Sub-theme Five A**: The type of care... is more holistic... and more open-minded
- **Sub-theme Five B:** We can work around this problem

Foundational Concept: Listen to [Us]. Just listen

Listening was a vital component of each theme. If implemented, the recommendations from this scoping review could support healthcare

professionals and decision-makers in providing acceptable care for people who use drugs.

As a healthcare professional, I will advocate for the findings from this scoping review to supplement efforts to provide equitable treatment and acceptable care within my organization. The findings have important implications for healthcare professionals in personal reflection, education, practice, and research. Implementing these findings is one part of decreasing barriers to access, promoting equitable treatment, and providing acceptable care to people who use drugs.

The opioid poisoning crisis is a multifaceted and continually expanding challenge. Individuals who use drugs face a range of complex, intersecting issues. It is crucial to involve those most affected by these issues in the development and execution of any implementation plans. Engaging people who use drugs and leveraging their unique insights is a vital component in addressing this pressing problem.

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Appendix A

Medline (OVID) Search Strategy

(Extracted May 25, 2024)

Line	Formula	Results
11	limit 10 to (English language and yr="2019 -Current")	3,154
10	8 and 9	9,459
9	1 or 2 or 3 or 4	346,005
8	5 or 6 or 7	473,119
7	Patient Preference/	*
6	Patient Satisfaction/ or Patient-Centered Care/	*
5	((patient* or client* or "service user*" or "people who use drugs" or pwud or "people with lived experience" or pwle or peer or community) adj2 (perspective* or evaluat* or research or engag* or collaborat* or preference* or participa* or centered or centered or partner* or voice* or unvoiced or involv* or consult* or opinion* or oriented or "provider relationship" or satisfaction)).ti,ab,kf.	*
4	illicit drugs/ or designer drugs/	*
3	((drug* or substance*) adj2 (use* or abuse* or illicit or misuse or depend* or addict* or street* or overdose* or disorder* or poisoning or poisoned or problem or recreational or designer)).ti,ab,kf.	*
2	Drug Users/	*
1	substance-related disorders/ or drug misuse/ or prescription drug misuse/ or drug overdose/ or opiate overdose/ or prescription drug overuse/ or narcotic-related disorders/ or opioid-related disorders/ or substance abuse, intravenous/ or substance abuse, oral/ or substance withdrawal syndrome/ or opioid epidemic/	*

Note. * indicates instances where the program did not display all results on a rerun of the formula

Appendix B

CINAHL and Social Work Abstract (EBSCO) Search Strategy

(Extracted, May 25, 2024)

Line	Formula	Results
S9	(S1 OR S5) AND (S2 OR S3 OR S4) Narrow by Language: - English	4,033
S8	(S1 OR S5) AND (S2 OR S3 OR S4) Limiters - Publication Date: 20190101-20241231	4,129
S7	(S1 OR S5) AND (S2 OR S3 OR S4)	11,211
S6	S1 OR S5	344,367
S5	(MH "Patient Preference") OR (MH "Patient Satisfaction") OR (MH "Personal Satisfaction") OR (MH "Patient Centered Care")	116,019
S4	(MH "Designer Drugs") OR (MH "Recreational Drug Use") OR (MH "Street Drugs+")	7,112
S3	((drug* or substance*) adj2 (use* or abuse* or illicit or misuse or (MH "Substance Abusers") OR (MH "Street Drugs") OR (MH "Drugs, Non-Prescription") OR (MH "Recreational Drug Use") OR (MH "Substance Abuse Detection") OR (MH "Substance Dependence") OR (MH "Substance Abuse, Intravenous") OR (MH "Substance Abuse+") OR (MH "Overdose+") OR (MH " Opioid Epidemic")	106,170
S2	((drug* or substance*) N2 (use* or abuse* or illicit or misuse or depend* or addict* or street* or overdose* or disorder* or poisoning or poisoned or problem or recreational or designer))	Display
S1	((patient* or client* or service user* or "people who use drugs" or pwud or "people with lived experience" or pwle or peer or community) N2 (perspective* or evaluat* or research or engag* or collaborat* or preference* or participa* or centered or centered or partner* or voice* or unvoiced or involv* or consult* or opinion* or involv* or oriented or provider relationship))	280,128

Appendix C

PsycINFO Database (ProQuest) Search Strategy

(Extracted May 28, 2024)

Line	Formula	Results
1	((((noft(drug*) OR noft(substance*)) NEAR/2 (noft(use*) OR noft(abuse*) OR noft(illicit) OR noft(misuse) OR noft(depend*) OR noft(addict*) OR noft(street*) OR noft(overdose*) OR noft(disorder*) OR noft(poisoning) OR noft(poisoned) OR noft(problem) OR noft(recreational) OR noft(designer))) OR (MAINSUBJECT.EXACT("Drug Abuse") OR MAINSUBJECT.EXACT("Substance Related and Addictive Disorders") OR MAINSUBJECT.EXACT("Drug Dependency") OR MAINSUBJECT.EXACT("Substance Use Disorder")) OR (MAINSUBJECT.EXACT("Drug Dependency") OR MAINSUBJECT.EXACT("Drug Abuse") OR MAINSUBJECT.EXACT("Drug Usage Attitudes") OR MAINSUBJECT.EXACT("Illegal Drug Distribution") OR MAINSUBJECT.EXACT("Drug Overdoses") OR MAINSUBJECT.EXACT("Drug Usage") OR MAINSUBJECT.EXACT("Drug Addiction") OR MAINSUBJECT.EXACT("Addiction (Attitudes Toward)") OR MAINSUBJECT.EXACT("Substance Abuse and Addiction Measures") OR MAINSUBJECT.EXACT("Substance Use Prevention") OR MAINSUBJECT.EXACT("Prescription Drug Misuse") OR MAINSUBJECT.EXACT("Designer Drugs") OR MAINSUBJECT.EXACT("Opioid Epidemic") OR MAINSUBJECT.EXACT("Substance Use Disorder") OR MAINSUBJECT.EXACT("Drug Withdrawal"))) AND (((noft(patient*) OR noft(client*) OR (noft("service user") OR noft("service users")) OR noft("people who use drugs") OR noft(pwud) OR noft("people with lived experience") OR noft(pwle) OR noft(peer) OR noft(community)) NEAR/2 (noft(perspective*) OR noft(evaluat*) OR noft(research) OR noft(engag*) OR noft(collaborat*) OR noft(preference*) OR noft(participa*) OR noft(centered) OR noft(centered) OR noft(partner*) OR noft(voice*) OR noft(unvoiced) OR noft(involv*) OR noft(consult*) OR noft(opinion*) OR noft(involv*) OR noft(oriented) OR noft("provider relationship") OR noft(satisfaction))) OR ((MAINSUBJECT.EXACT("Client Satisfaction") OR MAINSUBJECT.EXACT.EXPLODE("Client Satisfaction")) OR (MAINSUBJECT.EXACT("Participation") OR MAINSUBJECT.EXACT("Involvement") OR MAINSUBJECT.EXACT("Client Rights") OR MAINSUBJECT.EXACT("Client Participation")) OR MAINSUBJECT.EXACT("Patient Centered Care")))) AND (la.exact("ENG") AND stype.exact(("Scholarly Journals" OR "Dissertations & Theses") NOT "Books") AND pd(20190101-20241231))	3,159

Note: Final formula as saved in the program. The program did not display all results on rerun.

Appendix D

Social Services and Sociological Abstracts (ProQuest) Search Strategy

(Extracted May 28, 2024)

Line	Final Formula as it is Saved in Program	Results
1	((((noft(drug*) OR noft(substance*)) NEAR/2 (noft(use*) OR noft(abuse*) OR noft(illicit) OR noft(misuse) OR noft(depend*) OR noft(addict*) OR noft(street*) OR noft(overdose*) OR noft(disorder*) OR noft(poisoning) OR noft(poisoned) OR noft(problem) OR noft(recreational) OR noft(designer))) OR (MAINSUBJECT.EXACT("Drug Abuse") OR MAINSUBJECT.EXACT("Substance Related and Addictive Disorders") OR MAINSUBJECT.EXACT("Drug Dependency") OR MAINSUBJECT.EXACT("Substance Use Disorder")) OR (MAINSUBJECT.EXACT("Drug Dependency") OR MAINSUBJECT.EXACT("Drug Abuse") OR MAINSUBJECT.EXACT("Drug Usage Attitudes") OR MAINSUBJECT.EXACT("Illegal Drug Distribution") OR MAINSUBJECT.EXACT("Drug Overdoses") OR MAINSUBJECT.EXACT("Drug Usage") OR MAINSUBJECT.EXACT("Drug Addiction") OR MAINSUBJECT.EXACT("Addiction (Attitudes Toward)") OR MAINSUBJECT.EXACT("Substance Abuse and Addiction Measures") OR MAINSUBJECT.EXACT("Substance Use Prevention") OR MAINSUBJECT.EXACT("Opiates") OR MAINSUBJECT.EXACT("Prescription Drug Misuse") OR MAINSUBJECT.EXACT("Designer Drugs") OR MAINSUBJECT.EXACT("Opioid Epidemic") OR MAINSUBJECT.EXACT("Substance Use Disorder") OR MAINSUBJECT.EXACT("Drug Withdrawal"))) AND (((noft(patient*) OR noft(client*) OR (noft("service user") OR noft("service users")) OR noft("people who use drugs") OR noft(pwud) OR noft("people with lived experience") OR noft(pwle) OR noft(peer) OR noft(community)) NEAR/2 (noft(perspective*) OR noft(evaluat*) OR noft(research) OR noft(engag*) OR noft(collaborat*) OR noft(preference*) OR noft(participa*) OR noft(centered) OR noft(centered) OR noft(partner*) OR noft(voice*) OR noft(unvoiced) OR noft(involv*) OR noft(consult*) OR noft(opinion*) OR noft(involv*) OR noft(oriented) OR noft("provider relationship") OR noft(satisfaction))) OR (MAINSUBJECT.EXACT("Client satisfaction") AND MAINSUBJECT.EXACT("Patients rights")))) AND (stype.exact(("Scholarly Journals" OR "Dissertations & Theses" OR "Conference Papers & Proceedings" OR "Magazines" OR "Reports" OR "Other Sources" OR "Trade Journals" OR "Working Papers") NOT "Books") AND la.exact("ENG") AND pd(20190101-20241231))	1,707

Note: *Final formula as saved in the program. The program did not display all results when rerun.*

Appendix E

Web of Science Search Strategy

(Extracted May 29, 2024)

Line	Formula	Results
5	#1 AND #4 and English (Languages) and Letter or Book Chapters or News Item or Reprint or Meeting Abstract (Exclude – Document Types)	5,535
4	#2 OR #3	592,265
3	TS=((patient* or client* or "service user*" or "people who use drugs" or "pwud" or "people with lived experience" or "pwle" or peer* or community) NEAR/2 (perspective* or evaluate* or research or engage* or collaborat* or preference* or participa* or centred or centered or partner* or voice* or unvoiced or involv* or consult* or opinion* or oriented or "provider relationship*" or satisfaction))	591,393
2	TS="patient attitude*"	1,518
1	TS=((drug* or substance*) NEAR/2 (use* or abuse* or illicit or misuse or depend* or addict* or street* or overdose* or disorder* or poisoning or poisoned or problem* or recreational or designer*))	401,879

Appendix F

Google™ and Google Scholar™ Searches

(Extracted July 31, 2024)

# of p. viewed	Search Formula	Findings
First 100	drug|substance+use|abuse|illicit|misuse|dependent|addict|street|overdose|disorder|poisoning|problem|recreational|designer+perspective|evaluate|research|engage|collaborate|preference|participate|participation|centred|centered|partner|voice|unvoiced|involve|consult|opinion	Added three websites to the website search
100	drug|substance+use|abuse|illicit|misuse|dependent|addict|street|overdose|disorder|poisoning|problem|recreational|designer+perspective|evaluate|research|engage|collaborate|preference|participate|participation|centred|centered|partner|voice|unvoiced|involve|consult|opinion filter .ca	nothing
100	substance+use+patient+perspective|preference|center|centered|opinion|participation|satisfaction	5 articles to look at closer
100	substance use patient perspective canada	3 articles to look at closer
100	drug use canada health preference|voice|consult|opinion|evaluation|perspective	Nothing that fit
100	substance use canada health preference|voice|consult|opinion|evaluation|perspective	1 article to look at closer
100	substance use canada health preference|voice|consult|opinion|evaluation|perspective filter 2020 – sorted by relevance	5 articles to look at closer
100	substance+use+patient+perspective|preference|center|centered|opinion|participation|satisfaction filter Since 2020	2 articles to look at closer
100	substance use patient perspective Canada Filter since 2020	7 articles to look at closer
100	drug use canada health preference|voice|consult|opinion|evaluation|perspective	Nothing that fit
100	substance use canada health preference|voice|consult|opinion|evaluation|perspective	Nothing new
1,100	TOTALS	21 articles included in screening

Appendix G

Websites Searched for Evidence

(Extracted July 24 – 30, 2024)

#	Organization	Link	Pieces of Evidence/Articles
		Municipal Level Websites	
77	Vancouver Area Network of Drug Users *(non-gov)*	https://vandu.org/	Screened 77 titles- 2 found Wednesday, July 24, 2024
55	Drug User Advocacy League *(non-gov)*	https://dualottawa.wordpress.com/	Screened 55 articles – 0 found Wednesday, July 24, 2024
		Provincial Level Websites	
227	Public Health Ontario *(gov)*	https://www.publichealthontario.ca/	Search term: Substance use disorder Screened 183 articles – 8 found on July 24, 2024 Search term: People who use drugs Screened 43 articles – 1 found
37	Toward the Heart *(gov)*	https://towardtheheart.com/	Screened 37 articles - 0 found on July 24, 2024
359	Ontario Drug Policy Research Network *(gov funded)*	https://odprn.ca/	Screened 275 entries – 3 found On July 24, 2024 Screened 84 - 1 found On July 24, 2024
69	Ontario Harm Reduction Network *(gov funded)*	https://ohrn.org/	Screened 69 before reached out of date range -2 found On July 24, 2024
		National Level Websites	
341	CATIE *(non-gov)*	https://www.catie.ca/	Search term: PWUD Screened 9 entries– 2 found Search term: substance use disorder Screened 112 entries – 2 found Search term: Healthcare and people who use drugs Screened – 77 – 4 found Search term: Health and pwud Screened 143 – 7 found On July 26, 2024

#	Organization	Link	Pieces of Evidence/Articles
22	National Collaborating Center for Determinants of Health *(gov)*	https://nccdh.ca/	Search term: Substance use disorder Screened – 1 Search term: Opioid Screened - 7 Search term: People who use drugs Screened- 6 Search term: Drug Screened -8 2 entries looked further at On July 26, 2024
48	Canadian Association of People who use drugs *(non-gov)*	https://www.capud.ca/	Screened full resource list Screened 48 – 1 found On July 26, 2024
299	Health Canada Substance Use and Addiction *(gov)*	https://www.canada.ca/en/health-canada/services/substance-use.html	Search term: Substance use and healthcare Screened – 13 Search term: Drugs and health Screened – 278 Search term: Opioid and healthcare Screened -8 0 entries looked further at On July 26, 2024
953	Canadian Centre on Substance Use and Addiction *(non-gov)*	https://www.ccsa.ca/	Looked at the resources list Screened 953 – 9 found On July 26, 2024
56	Canadian Drug Policy Coalition *(non-gov)*	https://drugpolicy.ca/	Searched sites Screened 8 Search term: hospital Screened - 21 Search Term: healthcare Screened – 27 0 entries looked further at On July 26, 2024
70	National Safer Supply Community of Practice *(gov and non-gov alliance)*	https://www.substanceusehealth.ca/	Screen 70 – 0 found On July 30, 2024

#	Organization	Link	Pieces of Evidence/Articles
104	Canadian Substance Use Resource and Knowledge Exchange Centre *(gov funded)*	https://substanceuse.ca/	Opioids heading Screened 4 sites Search Term: “people who use drugs” 928- looked at first 100 – 4 found On July 30 Search term: Substance use disorder Screened 14 – found 1 Search term: People who use drugs Screened 35- found 1 Search term: Healthcare Screened 81 – found 2 Search term: Opioid Screened 41 – found 0 On July 28, 2024
171	Canadian Public Health Association *(gov)*	https://www.cpha.ca/	
	Websites from the Lived Experience Advisory Panel		
20	Keeping the 6	https://keepingsix.org/	Screened 20 web pages- found 0 On July 28, 2024
37	Drug Policy Alliance	https://drugpolicy.org/	Screened 37 articles – found 1 On July 28, 2024
69	Drug User’s Liberation Front	https://www.dulf.ca/	Screened 69 – found 2 On July 28, 2024
87	Tweak Easy Peterborough	Facebook page	Called Tweak Easy E – Yaagwaamzijig Screened a year's worth of posts Screened 87- found 0 On July 28, 2024
0	Nogojiwanong Drug Users Network Meeting		Could not find it on Instagram, Facebook or X, but is advertised on Tweak Easy E site. On July 30, 2024
20	KT6 Peterborough	Found on Instagram	July 30 – KT6 crew – 20 posts. Mostly about the community resources and KT6 helping to clean up
	Websites Found Through Hand Searching		
216	Center for Addiction and Mental Health	The Centre for Addiction and Mental Health | CAMH	Search term: Substance use disorder and health Screened– 100 results – organized by date present - June 2021

#	Organization	Link	Pieces of Evidence/Articles
	Center for Addiction and Mental Health, continued		Search term: PWUD Screened– 1 Search term: “people who use drug” Screened-15 Search term: Opioid Screened first 100 present to Sept 2021 Found 4 entries On July 30, 2024
7	Oasis Advisory - Ottawa	Oasis Program at SHCHC (sandyhillchc.on.ca)	Looked through website 7 pages Found 0 On July 28, 2024
57	International Association of People Who Use Drugs	Home - (inpud.net)	Under Key publications, Screened– 19, found 1 Under Position statements, Screened -8, found 0 Under Resources, Screened- 30, found 1 On July 28, 2024
	Found with Google™ and Google Scholar™ Searches		
13	Harm Reduction Nurses Association	Home | HRNA/AIIRM (hrna-aiirm.ca)	Screened 13 position statements On July 28, 2024
203	Canadian Institute for Substance Use Research	Home - University of Victoria (uvic.ca)	Screened 203 https://www.uvic.ca/research/centres/cisur/assets/docs/colab/colab-substance-use-monitoring-framework-overview.pdf– found 1 On July 31, 2024
0	Canadian Research Initiative in Substance Misuse	Home - CRISM	July 31, 2024 Have guidelines for healthcare professionals – not PWUD voice Also have PWLE – National working group
3617	**Total Screened Articles out of 27 websites**		Found 62 articles of interest – upon further reading 20 were exported to Covidence for full text review.

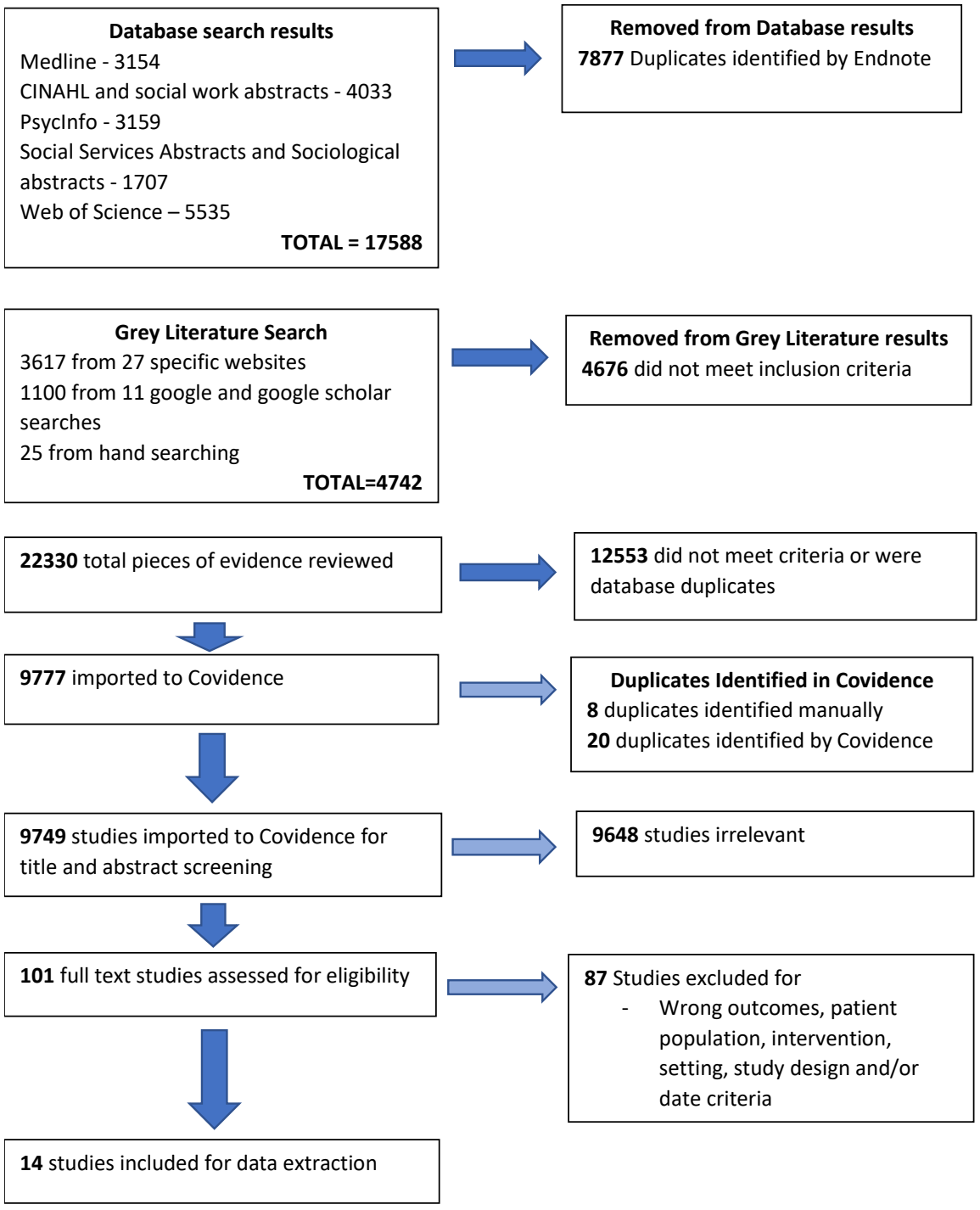
Appendix H

Using Thematic Analysis in Psychology, by Braun, V. and Clarke, V. (2006)

Step	Description
1	*Familiarisation with the data:* The researcher must become intimately familiar with the data by reading and re-reading it.
2	*Coding*: Involves generating succinct labels for important items in the data related to the research question. The researcher then collates all their codes and relevant data.
3	*Searching for themes*: The researcher constructs themes by highlighting coherent and meaningful patterns in the data relevant to the research question. The researcher then collates all the relevant coded data into the appropriate theme.
4	*Reviewing themes*: Checking that the themes are reflected in both the coded extracts and the full data set. It may be necessary to modify or edit themes at this stage.
5	*Defining and naming themes*: After writing a detailed analysis of each theme, the researcher must construct a reflective, concise and informative name or title.
6	*Writing up*: The researcher must weave together the analytic narrative and data extracts to tell the reader a coherent and persuasive summary of the data.

Appendix I

Evidence Screening process displayed in a PRISMA-ScR



Appendix J

Cross Study Display of Articles Used for Data Extraction

Title	Healthcare Setting	Country	Date	Study Design	PWUD	Not PWUD
Building Healthcare Provider Relationships for Patient-Centered Care: A Qualitative Study of the Experiences Of People Receiving Injectable Opioid Agonist Treatment (Marchant et al.)	Primary Care	Canada	2020	Qualitative research	30	0
Care Experiences of Persons with Perinatal Opioid Use: A Qualitative Study (Blair et al.)	Hospital - Perinatal	United States	2021	Qualitative research	11	0
Defining Culturally Safe Primary Care for People Who Use Substances: A Participatory Concept Mapping Study (Urbanoski et al.)	Primary Care	Canada	2020	Participatory research approach	75*	0
Examining the Primary Care Experience of Patients with Opioid Use Disorder: A Qualitative Study (Incze et al.)	Primary Care	United States	2023	Qualitative research	14	0
Experiences of Patients at High Risk of Opioid Overdose Accessing Emergency Department and Behavioural Health Interventions: A Qualitative Analysis in an Urban Emergency Department (Collins et al.)	Emergency Department	United States	2023	Qualitative research	19	0
Healthcare Encounters of Pregnant and Postpartum Women with Substance Use Disorders (Renbarger et al.)	Hospital - Perinatal	United States	2020	Meta-synthesis of published qualitative studies	Patient-reported data 19 studies 100%	0
Healthcare Seeking Among Swedish Patients in Opioid Substitution Treatment. A Mixed Methods Study on Barriers and Facilitators (Troberg et al.)	Healthcare General	Sweden	2022	Quantitative survey and Qualitative research	survey-210 interviews -11	0

How do People who use Drugs Experience Treatment? A Qualitative Analysis of Views About Opioid Substitution Treatment in Primary Care (iCARE Study) (Alves et al.)	Primary care	UK	2021	Qualitative research	24	0
“It's Like A Partnership": Exploring the Primary Care Experiences and Patient-Defined Goals of People Who Use Drugs (Dunham et al.)	Primary care	United States	2024	Qualitative research	17	0
Nursing and Healthcare Preferences Among Opioid and Stimulant Using Black Sexual Minority Men: An Exploratory Study (Dangerfield et al.)	Healthcare General	United States	2021	Qualitative research	30	0
Patient and Provider Perspectives on Processes of Engagement in Outpatient Treatment for Opioid Use Disorder: A Scoping Review (Austin et al.)	Multiple Settings	multiple countries (60% US, Canada 13%, Ukraine, UK, China, Vietnam, Tanzania, SA)	2024	Scoping review	+Patient-reported data 19 studies 63%	+Provider-reported data- 4 - 13% Both patient- and provider-reported data- 7 - 23%
Perspectives and Recommendations from Hospitalized Patients with Substance Use Disorders: A Qualitative Study (Balmuth et al.)	Hospital – Medical + Surgical	United States	2024	Qualitative research	15	0
Qualitative Exploration of Emergency Department Care Experiences Among People With Opioid Use Disorder (Galarneau et al.)	Emergency Department	Canada	2023	Qualitative research	19	0
Understanding healthcare engagement for people who inject drugs (Heidari et al.)	Outpatient care	United States	2024	Qualitative research	24	0

*Note: *75 unique people in three different focus groups. +30 studies total in the scoping review.*
PWUD= People who use drugs

Appendix K

Suggestions from the Perspective of People Who Use Drugs Organized by Theme

The characteristics that interfere with the quality of healthcare for people who use drugs include stigmatizing behaviour among healthcare professionals, adverse healthcare experiences (Mental Health Commission of Canada, 2020) and inequitable policy and healthcare structures. The participants offered solution-based advice on how to make healthcare more acceptable for this group. Data extrapolated from the perspective of people who use drugs is captured below, grouped by the five themes identified from the research findings. In conjunction with the findings from this scoping review, these suggestions can be used to improve existing and inform new healthcare practices and structures.

Theme One: Being Someone Who Matters

This theme included concepts like caring, respect, kindness, transparency, acceptance, and feeling free from judgment. To translate that into practice, people who use drugs felt that healthcare professionals could try some of the advice below.

- Being a positive supporter of the patient (Heidari et al., 2024).
- Being transparent about treatment expectations and changes (Austin et al., 2024).
- Treat people who use drugs the same as your other patients (Balmuth et al., 2024; Balmuth et al., 2024; Blair et al., 2021).
- Communicate respectfully with empathy and consideration (Renbarger et al., 2020).
- Offer comprehensive, unbiased information (Austin et al., 2024).
- Provide an open, judgement-free and accepting presence (Heidari et al., 2024, Blair et al., 2021).
- Recognize the power imbalance and discrimination in the healthcare system (Marchand et al., 2020; Urbanoski et al., 2020).

- Express Genuine care for overall health and well-being as a person (Dangerfield et al., 2021; Incze et al., 2023).
- Be kind and willing to listen (Alves et al., 2021).
- Invite and share stories about patients' lived experiences (Austin et al., 2024).

Theme Two: I Trust that the Person Taking Care of Me Trust Me

Every article mentioned the importance of a good relationship between patients and healthcare providers, no matter what healthcare setting the research was done in. Guidance on how to establish an advantageous patient-provider connection is described below.

- Look at them and make eye contact (Urbanoski et al., 2020).
- Ask them more questions in an attempt to understand (Urbanoski et al., 2020).
- Be personable, ask personal questions (Urbanoski et al., 2020), and share personal stories (Blair et al., 2021).
- Provide transparent and supportive treatment expectations (Austin et al., 2024).
- Facilitate positive and friendly interactions with all healthcare staff (Marchand et al., 2020).
- Celebrate achievements in care (Austin et al., 2024).
- Be open-minded and have a respectful communication style (Marchand et al., 2020)
- To establish a trusting relationship, healthcare providers must trust their patients (Balmuth et al., 2024).
- Establish rapport and open communication (Heidari et al., 2024).
- Where possible, establish continuity of care (Dunham et al., 2024).

Theme Three: I'm Happy that You Listened…I Clearly have Knowledge in this Area

Pulling directly from the research, below are examples for healthcare providers on how to enable people who use drugs to be partners in their own care.

- Focus on the reason that patients are seeking healthcare (Heidari et al., 2024; Troberg et al., 2022).
- Ask questions, and try to understand patient opinions (Incze et al., 2023; Marchand et al., 2020; Troberg et al., 2022).

- Incremental goal setting based on patient goals, not abstinence (Austin et al., 2024; Dunham et al., 2024; Renbarger et al., 2020).
- Provide options and supportive advice tailored to patient's needs (Dunham et al., 2024; Galarneau et al., 2023).
- Recognize that patients have expertise in their own health and lives (Dangerfield et al., 2024; Urbanoski et al., 2020).
- Consult with patients and get consent before making decisions about patient care (Urbanoski et al., 2020).
- Focus on how patients can be/have been successful in treatment (Austin et al., 2024).

Theme Four: You Don't Know Unless You've Been There… We Can Tell You

This theme showed the importance of healthcare providers being knowledgeable about drug use support and treatment. Below is guidance on where to start when gathering knowledge.

- Gather a comprehensive education about substance use, services and care, including learning from those with lived experience (Austin et al., 2024; Collins et al., 2023; Dangerfield et al., 2021; Toberg et al., 2022; Urbanoski et al., 2020).
- Hire diverse staff that are reflective of the community's culture, race, gender, and lived experience (Dangerfield et al., 2021; Urbanoski et al., 2020).
- Create a safe, trauma-informed, non-triggering environment (Dangerfield et al., 2021, Urbanoski et al., 2020).
- Take time to assess history, lifestyle and motivation for drug use (Balmuth et al., 2024; Dangerfield et al., 2021).
- Clearly describe treatment options, expectations and consequences in a direct and supportive way (Austin et al., 2024; Galarneau et al., 2023; Renbarger et al., 2020).
- Understand the connection between addiction and mental health (Urbanoski et al., 2020).
- Engage in harm reduction practices (Urbanoski et al., 2020).

Theme Five: Help Me Access Services and Resources

Theme five is divided into two subthemes: providing open-minded, holistic care and solving problems with a flexible healthcare structure. Holistic care is

characterized by supporting personal needs, providing cohesive services, and having access to other services and resources.

Working around a problem by, modifying appointment structure, making accommodations to reduce anxieties, and creating opportunities to collect patient feedback help facilitate a flexible healthcare structure. Below is some guidance from people who use drugs on how to provide holistic and flexible care, which makes it easier to remove barriers and access services.

Sub-theme: The Type of Care… is More Holistic… and More Open Minded

- Connect drug use services and mental health services (Dangerfield et al., 2021; Heidari et al., 2024; Urbanoski et al., 2020).
- Provide holistic care (Blair et al., 2021; Galarneau et al., 2023; Marchand et al., 2020; Urbanoski et al., 2020).
- Recognize logistical challenges to treatment plans like transportation, housing, food insecurity, and income (Blair et al., 2021; Renbarger et al., 2020).
- Provide cohesive healthcare through multiple direct services or coordinated care (Marchand et al., 2020).
- Provide extra support when making referrals (Collins et al., 2023; Dunham et al., 2024).

Sub-theme: We Can Work Around This Problem

- Provide flexible appointment options, such as walk-in, telephone, or in-person (Austin et al., 2024; Urbanoski et al., 2020; Incze et al., 2023).
- Allow for accommodations for patients to reduce anxiety; ask patients what these accommodations could be (Urbanoski et al., 2020).
- Schedule extra appointment time to ensure patients can communicate their complex concerns (Austin et al., 2024; Dunham et al., 2024; Urbanoski et al., 2020; Marchand et al., 2020).
- Offer extra support when booking appointments, sending reminders, doing check-ins and connecting to other agencies or services (Austin et al., 2024; Collins et al., 2023; Dangerfield et al., 2021; Renbarger et al., 2020).
- Offer services outside standard operating hours (Galarneau et al., 2023).
- Create opportunities for patients to provide feedback (Austin et al., 2024; Urbanoski et al., 2020).

Appendix L

Supporting Healthcare to Provide Acceptable Care to People Who Use Drugs

Additional Resources

This scoping review gives healthcare professionals the evidence necessary to provide acceptable care to people who use drugs. It also ensures that the evidence provided comes from the perspective of people who use drugs. The results from this scoping review are only part of the necessary solutions. It is important to include people who use drugs in any implementation plans. Depending on where healthcare professionals or organizations are in their journey to provide acceptable care for people who use drugs, here are some supporting resources for implementation to accompany the results found in this scoping review.

Resource Title	Date of publication Author	Level of PWUD involvement in development
People who use drugs were consulted in the development of resource		
Dismantling structural stigma in healthcare. An implementation guide to making real change for and with people living with mental health problems or illnesses and/or substance use concerns	2023 Mental Health Commission of Canada	Some Substance use service agencies contributed to the guide.
Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends	2021 Canadian Centre on Substance Use and Addiction	Document review but LLEAFF working group
Hear Us, See Us, Respect Us: Respecting the Expertise of People Who Use Drugs	2021 Canadian Association of People who use Drugs & Canadian Drug Policy Coalition	Authored by a PWUD advocacy group.

Engaging People Who Use Drugs (PWUD) to Build Organizational Capacity	2020 Ontario Harm Reduction Network	Webinar with PWUD guest speakers
Hospital Care: Experiences of People Who Use Drugs: Town Hall Meeting Summary	2024 Ontario Drug Policy Research Network	Lived Experience Advisory Group advised on Town Hall meeting objectives.
Guidance for Healthcare Professional When Caring for People who use Drugs: A Perspective from Persons who use Drugs	2025 Brandsma, J Trent University	Lived Experience Advisory Panel Consulted during research planning
No mention of collaborating with people who use drugs		
Evidence for Strategies that Address Substance-Use-Related Stigma	2024 COM-CAP & Public Health Ontario	There is no mention of collaboration or consultation with PWUD
Structural Stigma in Healthcare Context for People with Mental Health and Substance Use Issues A Literature Review	2020 Livingston et al. Mental Health Commission of Canada	There is no mention of collaboration or consultation with PWUD
Collaborative Care for Mental Health and Substance Use Issues in Primary Healthcare: Overview of Reviews and Narrative Summaries	n.d. Jeffries et al. Mental Health Commission of Canada	There is no mention of collaboration or consultation with PWUD
Behavioural Competencies for Canada's Substance Use and Mental Health Workforce V.3	2023 Canadian Centre of Substance Use and Addiction	There is no mention of collaboration or consultation with PWUD
RNAO: Mental Health and Substance Use: Learning Resources	n.d. Registered Nurses Association of Canada	There is no mention of collaboration or consultation with PWUD

*Note: PWUD stands for people who use drugs

Appendix M

Summary of Consultation with Lived Experience Advisory Panel

The Canadian Centre on Substance Use and Addiction's (CCSA) *Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends* (2021) were integral in shaping the action items and process for consultation. The Lived Experience Advisory Panel provided incredible insight into developing the research process.

When consulting with an equity-deserving community, such as people who use drugs, some important aspects need to be considered: choose a group that can best achieve your consultation goals, reflect on and plan for ethical considerations, define concrete asks for the group, create a trauma-informed agenda and activities, and determine how consultants' voices will be incorporated into evidence.

People Involved in the Consultation

In the local community, there are various groups of people who use drugs who will consult with agencies. After consulting with a member of the thesis advisory committee who has interacted with various groups (C. King, personal communication, March 6, 2024), it was decided to approach the Lived Experience Advisory Panel. The Lived Experience Advisory Panel is connected to the Peterborough Drug Strategy (PDS) alliance. They are comprised of a group of local people who have a history or current involvement with drug use. This group was developed specifically so that community agencies would have a group of people who use drugs with whom to consult. The current group

coordinator reiterated that the Lived Experience Advisory Panel has worked together for years and has received training to help support themselves and each other when consulting with community agencies. Team building was part of the group design to provide a safe environment for consultants to share. The current coordinator also provided me with some ethical considerations to reflect on (Keitel, personal communication, March 26, 2024) when consulting with this marginalized community.

Ethical Considerations

Reflecting on my personal bias, power imbalance, cultural safety, and adequate compensation will help provide a safe environment for consulting with the Lived Experience Advisory Panel and improve the research process. Tannenbaum et al. (2019) state that incorporating Equity, Diversity and Inclusion themes into the research process promotes research excellence by making it more relevant to society as a whole, ethically sound, rigorous, reproducible, and useful.

Recognize Bias and Power Imbalance

During the introduction and consultation, I attempted to be transparent by identifying my biases and possible power imbalances (CCSA, 2021). I recognized the privilege of consulting with them and thanked them for sharing their expertise. I identified myself and my different roles: I work in healthcare, am a student and a researcher, and work for the government. I recognize personal bias and unearned privilege coming from not having lived or living experience of drug use and power imbalance from being a healthcare professional. The Lived

Experience Advisory Panel needed to understand how much I appreciated their expertise during the consultation and how that expertise reflected gaps in my knowledge. I fortified the fact that the research would be better with their input. I took time to recognize that the process, consultation, and language would be imperfect, but I was open to hearing feedback to improve it. I also recognized that the problem with stigma in healthcare is vast, and the scope of this research and consultation was small compared. The small scope of this research did limit the input that the group wanted to provide, particularly on their personal experiences in healthcare. The group was gracious in accepting this limitation and knowledgeable about the information provided regarding the inclusion/exclusion criteria.

Cultural Safety

Adding to the safety built into the supportive structure of the People with Lived Experience Advisory Panel, I was guided by the group coordinator to ensure that trauma-informed care was provided during the consultation. The coordinator also acted as a trusted support person who was present to assist group members who needed additional emotional support. I provided snacks to ensure everyone was not hungry during the consultation. I was cognizant of meeting time and place to ensure people could come and people were not exposed for participating (CCSA, 2021). I attempted to keep the group's time, duration and meeting place familiar. I used directional signs connecting them to the Peterborough Drug Strategy, not the Lived Experience Advisory Panel, as proposed by the coordinator. After completing this scoping review, I will inform

the group how their input was used in the research. It is also essential that group participants are adequately compensated for their time.

Adequate Compensation

It was ethically crucial that people on this panel be adequately compensated for their time (Alberta Health Services, 2018; Canadian AIDS Society, 2015; Greer et al., 2017). The expertise available through this group is valuable, and the engagement process is beneficial regardless of the outcome (Canadian HIV/AIDS Legal Network, 2005; Pauly, 2008; Newfoundland Government, 2017). Each group member was compensated for five hours of their time, as outlined by the group's expectations. The five hours were broken down into two hours for the meeting, two hours before and one hour after, to accommodate varying learning styles. This gave group members time to prepare and think about the request. It also gave group members time to manage triggering emotions associated with the topic. Members were paid between $30.00 - $35.00 per hour. Peterborough Drug Strategy previously determined where on the pay scale members would be. Payment of participants happened through the group coordinator, an employee of the Peterborough Drug Strategy. Funds for this consultation were procured through the generous support of Trent Fleming School of Nursing and Peterborough Public Health.

Concrete Asks

To avoid tokenism, concrete questions were developed (CCSA, 2021), and their input was directly used in the inclusion/exclusion criteria of evidence. The goals of the consultation were communicated and delivered a month and

again, a week before the meeting day. The local Lived Experience Advisory Panel was asked three things: to define the criteria of whether this evidence supports the perspective of people who use drugs, to share evidence to include in the scoping review and to define how they would like to be recognized in this document for their contributions.

Define Criteria of Perspective of People who Use Drugs. To help the group come up with the criteria to define whether the evidence supported the perspective of people who use drugs, a variety of activities were used. Different examples of literature were provided, and the group dissected the examples to develop a set of criteria on which the group could agree. The group looked at examples of qualitative literature, literature that stated that there was consultation with people who used drugs and various websites to determine what defines if the evidence reflects the perspective of people who use drugs.

Evidence to add. I also asked the Lived Experience Advisory Panel if they had examples of literature or evidence to add to the scoping review. These were collected at the consultation or were filtered through the coordinator by email.

Acknowledged in the Research. The Lived Experience Advisory Panel's contribution to the research process was significant. I asked the group how they would like to be recognized for their contribution.

Trauma-Informed Agenda

There are emotional risks when consulting groups that may have experienced trauma. Some people may have even experienced trauma due to

the healthcare system, which is closely associated with the research question. Several things were considered in an attempt not to retraumatize the Lived Experience Advisory Panel members. As an outside researcher, I consulted with the group coordinator to ensure the agenda was appropriate before the meeting. I provided access to all available information (CCSA, 2021) a week before the meeting. I maintained confidentiality (CCSA, 2021) by communicating through the coordinator and having discreet signage that maintained group privacy.

Trauma-informed care practices were used by recognizing the role that trauma has on people's emotions and interactions. It was essential to have someone not part of the consultation to support individuals if needed. The coordinator was available at the meeting to provide a stable, consistent and known staff person (CCSA, 2021) to be available for group members. Notes were taken on sizeable flipchart-style paper during the meeting to capture their voices. This was done to be transparent so they could see what was written and ensure it was appropriately captured. Although I came to the meeting with suggestions, it was openly verbalized that my ideas could be wrong, and I desired that the group challenge them. There was an attempt to give the group as much power over decisions as possible. Once a concept was defined, it was double-checked with the group to ensure clarity.

The group consulted on the research process, not providing primary data or personal experiences. One client stated that they found it challenging not to share her personal life experience and drug use journey during the exercises (LEAP, personal communication, June 21, 2024). I also found this hard, as I felt I

was only accessing their academic knowledge and not their heartfelt life experiences. Due to the constraints of the Tri- Council Policy Statement Ethical Conduct for Research Involving Humans, I could not include this part of what they wanted to share as part of my research. I reflected that even though the meeting expectations were clear, it was challenging to provide trauma-informed care due to the unequal power relations (Shimmin et al., 2017) at that moment. I was not meeting the group where they were (CCSA, 2021), as I was limiting their ability to share. I followed up with the coordinator at the end of the session, shared my thoughts and asked them to reach out to that participant.

It is part of the group's expectations that I share how their input was used, providing a respectful ending to the engagement (CCSA, 2021). I will share this thesis document with the group so they can see that their input was central to this research.

Findings Incorporated as Evidence

The insights provided during the consultation were valuable and used as a central aspect of this research. Although the Lived Experience Advisory Panel appreciated being involved in the research process design stage, they reiterated that people who use drugs should be involved in every part of research design, implementation, and analysis of the research or outcomes involved them (LEAP, personal communication, June 21, 2024). People who use drugs can do more than tell their stories but provide “expert perspectives and insights throughout the project’ or research process (CCSA, 2021; Healthcare Excellence Canada, n.d.). The Lived Experience Advisory Panel also advised that academic peer-reviewed

articles about people who use drugs should have at least one person with lived experience review the article as well.

Besides people who use drugs being involved at every level, other areas were essential to the Lived Experience Advisory Panel but were not often reflected in research. A safe space needed to be provided for research.

> The consultation needs to be done in a safe and trusting environment, where the person being consulted is feeling safe there to share their experiences in that room or that space. This could also mean excluding certain groups from that discussion table." "We need to know that there is at least equal or above representation. As soon as it's below, our voices get drowned out (LEAP members, personal communication, June 21, 2024).

The Lived Experience Advisory Panel also considered it essential that the research results were presented in an accessible way. If the research content concerns people who use drugs, then the language and recommendations need to be written so they can understand (LEAP, personal communication, June 21, 2024).

The Lived Experience Advisory Panel provided excellent insights, specifically on the criteria for perspectives of people who use drugs. This added to the evidence for the scoping review and identified how they would like to be recognized.

Define Criteria of Perspective of People who Use Drugs

The Lived Experience Advisory Panel deemed that an article written from the perspective of people who used drugs could be considered and included as evidence in this scoping review if one or more of the three major criteria items below are evident.

Criteria for Perspective of People Who Use Drugs Inclusion Criteria

1. Evidence is authored by a person who uses drugs or has a history of drug use.
2. Research design collects the voice of people who use drugs; as an example, qualitative Research or evaluation is done with people who use drugs. (ie. Interviews or focus groups of people who use drugs).
    - There needs to be equal or majority representation of people who use drugs voices in the research to be considered the perspective of people who use drugs.
3. People who use drugs are consulted to create the evidence.
    - It is important that those people who use drugs need to have lived or living experience of drug use. Friends and family of people who use drugs can also be included.
    - If a group of diverse people are consulted in a report or article, there needs to be an equal or majority representation of people who use drugs (i.e., if nurses and patients are consulted, there need to be more patients who use drugs than nurses).
    - The article should show that the input gathered in the consultation of people who use drugs was incorporated into the evidence results.

Evidence to add

The Lived Experience Advisory Panel shared examples of literature or evidence to add to the scoping review with the coordinator via email or at the consultation meeting.

Acknowledged in the Research

At the time of the consultation, the Lived Experience Advisory Panel wanted to be acknowledged not as individuals but as the Lived Experience Advisory Panel affiliated with the Peterborough Drugs Strategy.

The insight gathered from the Lived Experience Advisory Panel was integral in developing the inclusion/exclusion criteria for this scoping review. Their expertise influenced every article included in this study for data extraction and thematic analysis.

Summary

When consulting with this equity-deserving community, the researcher reflected on ethical considerations, created a trauma-informed agenda and ensured that their input was incorporated into practice.