


Development of Best Practice Guidelines for Primary Care to Support Patients Who Use Substances

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Abstract

Introduction: People who use substances often mistrust the primary care system, impeding access. **Objectives:** To build on research clarifying how to improve patients' feelings of safety, through co-creating best practice guidelines with physicians and patient representatives. **Methods:** After obtaining Research Ethics Board approval, this qualitative study engaged 22 participants including patients, physicians, and health system partners. We held a series of workshops, co-facilitated by patients and researchers, corresponding to 3 phases of the research: (1) establishment of cultural safety processes for participants during the workshops; (2) a facilitated, collaborative world café to develop guideline content; (3) validation of best practice guidelines. An implementation plan was developed and implemented. Finally, an external peer review was conducted by McGill University. **Results:** Best practices guidelines were developed giving the patient perspective on how to enhance primary care, as follows: (1) become trauma informed; (2) consider your clinical environment; (3) build a network; (4) supply an array of resources; (5) co-create a long-term treatment plan; (6) help me to stay healthy; (7) ensure timely access to specialized medical and surgical care; (8) be an advocate; (9) ask for feedback; (10) follow up. Resources were developed and disseminated. **Conclusion:** The best practice guidelines reflect the patients' perspectives on common challenges patients have encountered, which impede their access to primary care. They support primary care physicians in providing more effective services to this challenging population of patients.

Keywords

behavioral health, hazardous drinking, patient-centeredness, practice management, primary care

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Introduction

People who use substances, including alcohol, drugs such as cannabis, cocaine, and heroin, and medications not taken as prescribed, often lack access to primary care¹ due to mistrust.^{2–4} While primary care in community health centers,⁵ street outreach,⁶ and harm reduction services,⁷ may feel safer, they can reinforce negative stereotypes, and exclude people who do not identify as drug users. Stigmatization of heavy drinkers by other drinkers, and the nuanced relationship between physicians and heavy drinkers,⁸ are often overlooked in primary care. Compared to people with other mental disorders, people with alcohol use disorder and other addictive disorders are more severely stigmatized; they are less frequently regarded as mentally ill, they are held much more responsible for their condition, they provoke more social rejection and more negative emotions, and they are at particular risk of structural discrimination.⁹

Given that harm reduction services for drug users tend to be delivered in acute settings, care appropriate for advancing the long-term health of alcohol and other drug users may be limited in primary care settings especially if such care is not integrated with other public health services that embody the harm reduction approach. Yet people who use substances are at greater risk of developing an array of chronic health problems, including cancer, cirrhosis, dementia,¹⁰ cardiovascular disease,¹¹ respiratory disorders,¹² HIV/AIDS,¹³ mental health¹⁴ and trauma related disorders.¹⁵ Health impacts are

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Table 1. Recommendations for Best Practice Guidelines on Primary Care Environment and Management.

Research cluster*	World café table questions	Recommended guideline
“Maintain my confidentiality in a welcoming and comfortable environment.” <i>waiting room environment</i> <i>confidentiality (being required to give reason for visit, staff discussing patients in waiting room)</i>	How can we create a clinic environment that is welcoming, comfortable, spacious, and non-institutional to reduce patients’ feelings of vulnerability?	Consider your physical environment welcoming, accessible, easy to understand respects confidentiality and privacy, soundproofing signs with directions, hours and FAQ
	How can we train reception staff to be more friendly, welcoming, and respectful of the privacy of patient information?	
“Be a champion for advocacy” <i>security and accessibility of services</i> <i>supports to reduce anxiety and improve perceived safety in accessing care</i> <i>bring an advocate or friend to appointments</i> <i>gender</i> <i>insurance coverage</i>	How can we make access to medical help more timely?	Build a network access to psychology, social work, dietician, harm reduction, peer support, social and cultural organizations
	What arrangements can be made to ensure care is not limited by circumstances such as race, gender, socioeconomic status, culture, income and social status, etc? How can primary care include supports such as an advocate and adequate insurance coverage?	Become trauma informed ensure all staff understand effects of trauma Be an advocate help me navigate systemic barriers Ask for feedback phone calls and gentle reminders

*Research clusters are reported in more detail in Urbanoski et al.

due to the direct toxic effects of the substances, and to the associated behavioral, social and economic consequences of addiction.¹⁶ Therefore, addressing discrimination in health care settings faced by people who use substances is imperative if their health needs are to be adequately met. Research indicates what this population needs to feel safe using primary care services.^{17,18} We developed best practice guidelines collaboratively with patients, physicians, and health system partners, to increase safety for this stigmatized and under-served population, by addressing the research question, “How can primary care providers adjust their practices to better engage and serve the needs of patients who use substances?”

Methods

Research Ethics Board approval was obtained prior to the research. All participants provided written informed consent. A total of 22 participants took part, comprising researchers n=3; trained peer research associates (patients with lived experience of substance use) n=5; physicians n=10; and health system partners (policy makers and health authority leadership) n=4. Peer research associate participants were employed to co-facilitate a series of 3 confidential, in-person workshops corresponding to 3 phases of the research: (1) establishing cultural safety for participants; (2) world café method to develop guideline content on 3 identified focus areas of need; (3) validation of draft best practice guidelines. Data were collected on flip charts in the world

café, and were transcribed verbatim. Thematic analysis¹⁹ was conducted independently by each author and then triangulated through team discussion. Consensus on the resulting best practice guidelines was reached through team meetings, and validated by member-checking with a subsample of the original participants representing the 3 participant groups (patients, physicians, and health system partners) at the final workshop (all signed release forms giving consent to use of their photographs). An implementation plan was developed.

Results

Participants discussed 3 key areas for enhancing primary care derived from the original concept mapping research⁹: primary care environment and management; interpersonal skills; medication, prescribing, and holistic healthcare. Tables 1 to 3 display the original concept mapping clusters, the questions and discussion points addressed in the world café, and the recommendations that were generated from the discussion, which formed the basis of the development of best practice guidelines.

Primary Care Environment and Management

The discussion of how the primary care environment and management could be improved drew mainly from 2 clusters in our original research⁹: “maintain my confidentiality in a welcoming and comfortable environment,” and “be a

Table 2. Recommendations for Best Practice Guidelines on Interpersonal Skills.

Research cluster*	World café table questions	Recommended guideline
“Act to prevent stigma” external stigma (being judged by others) internalized stigma (feeling embarrassed or ashamed).	How can we ensure that all patients feel treated with respect, caring, compassion, dignity, and human decency (without judgement, labeling, or stigma)?	Ask for feedback including specific questions about stigma
“Treat me right!” <i>Trusting the physician</i> <i>Being trusted by the physician</i>	How can we continue to provide access to care for challenging patients (ie, without blacklisting them)? What feedback and complaint processes could be introduced?	Become trauma informed support my healing by giving me time to discuss my history develop trust
“Do you care about me?” <i>personalized care</i> <i>rapport between physician and patient</i> <i>seeing same physician each time</i> <i>not feeling rushed</i>	How can we ensure patients are involved in decisions that affect them?	Co-create a long term treatment plan Guide me to develop a treatment plan based on my individual health needs, social circumstances, resilience and personal resources
“Acknowledge and accommodate my needs and circumstances” <i>sociodemographic circumstances</i> <i>fears of losing child custody if drug use is disclosed</i>	How can we be more respectful of family circumstances (eg, allow a patient to bring family member(s) to their appointment; safety to be honest without fear of child apprehension)?	Follow up gentle reminders to help me follow through

*Research clusters are reported in more detail in Urbanoski et al.

Table 3. Recommendations for Best Practice Guidelines on Medication and Prescribing, and Holistic Healthcare.

Research cluster*	World café table questions	Recommended guideline
“Live up to professional standards” <i>adequate treatment for pain</i> <i>appropriate medications</i> <i>being included in care planning and decision making</i>	How can we provide appropriate and adequate medication while avoiding negative medication interactions? What protocols can provide pain management for people who use drugs?	Co-create a long-term treatment plan develop a treatment plan based on individual health needs, social circumstances, resilience and personal resources support me when things do not go as planned relapses are part of the condition
“Don’t red flag me: Recognize addiction as a health issue.” <i>addiction is a legitimate health issue, not a criminal behavior</i> <i>physician knowledge (about addiction and available services and supports)</i> <i>openness to harm reduction strategies</i> <i>ability to receive ongoing physical and mental health care</i>	What mental health supports or treatment can be offered to people who use substances by or through primary care? How can we improve access to mental health treatment, even if a patient doesn’t want to stop using substances? What resources should be available through primary care to support the needs of people who use substances? How can a primary care clinic demonstrate a commitment to addiction as a health issue, rather than a criminal or moral one?	Build a network access psychology, social work, harm reduction, peer support Ensure timely access to specialized medical and surgical care recognize when medical specialist or inpatient treatment referral is required consider my substance use issues in the context of my other health needs help me to understand all of my other health conditions, medications and risks

*Research clusters are reported in more detail in Urbanoski et al.

champion for advocacy.” This discussion focused on practical steps that can be taken to create a comfortable primary care environment, welcoming, yet respectful of patients’ need for privacy and space. This included the

physical environment and the way the reception staff treated patients, respected patient confidentiality, and how the sociodemographic circumstances of patients were handled, including approaches to the consideration of the

direct and indirect costs associated with access to health services.

Interpersonal Skills

Improving interpersonal skills when working with this population was based on 4 clusters in the concept mapping research, and ran through all aspects of the research and subsequent guideline development. It ranged from the need to “act to prevent stigma,” “treat me right” (building trust), questioning “do you care about me?” to needing the physician to “acknowledge and accommodate my needs and circumstances.” While focused on how primary care physicians can better ensure patients are treated in a respectful, non-judgemental manner, staying engaged with challenging patients, the recommendation to “become trauma informed” was considered to be relevant to all guidelines.

Medications, Prescribing, and Holistic Healthcare

The medications and prescribing discussion was challenging. While some addiction protocols can be effectively managed by a primary care physician, some are too specialized to be suitable for an outpatient or primary care context, so physicians may need to access a broader network and specialized services for patients with complex medication needs and chronic pain issues. In addition, medication guidelines that physicians should follow for opioids and alcohol already exist.^{20,21}

The holistic healthcare discussion focused on primary care physicians attending to the full spectrum of healthcare needs for patients who use substances, including diet, exercise, stress management, and life skills, rather than only addressing their substance use issues. Although it was drawn from the same 2 clusters as the previous discussion on medication and prescribing, “live up to professional standards” and “don’t red flag me: recognize addiction as a health issue,” the focus of discussion was on ensuring monitoring and treatment of the whole person.

Best Practice Guidelines

The analysis reported in Tables 1 to 3 were distilled into the following 10 best practice guidelines. These were validated in the final workshop.

- (1) Become trauma informed. Understand how trauma has affected me. Allowing me enough time to discuss my history and form a trusting relationship is one of the most important things you can do to support my healing. Ensure that all of the helping staff at the office understand how trauma can affect

people and how it may impact their experiences with health care.

- (2) Consider your clinical environment. Please make your office welcoming, easy to understand and one that respects my confidentiality. Signs with directions, hours and FAQ are very helpful. Attention to privacy when discussing my concerns (eg, considering the appropriateness of discussions at the front desk and ensuring sound insulation in the examining areas) makes me feel safer.
- (3) Build a network. I don’t expect you to do it alone. Help me to access psychology, counseling, social work, dietician, rehabilitation, harm reduction, peer support, social, and cultural organizations.
- (4) Supply an array of resources. Everyone’s path is different. By having a variety of written materials and access to peer support to share, I can start to understand my health conditions and treatments.
- (5) Co-create a long-term treatment plan. Guide me to develop a long-term treatment and support plan based on my individual health needs, social circumstances and readiness to change. Discuss the use of alternative treatments, including harm reduction, in a non-judgmental way and support me when things do not go as planned. Relapses are part of the condition.
- (6) Help me to stay healthy. Ensure that I receive clear information and reminders about health maintenance screenings, vaccines and other interventions important to me. Provide me with non-judgemental information that can assist me in leading a healthy life such as fitness, nutrition, smoking cessation and stress reduction/management (eg, mindfulness).
- (7) Ensure timely access to specialized medical and surgical care. Recognize when medical specialist or inpatient treatment referral is required and have clear pathways for access to that care that considers my substance use issues in the context of my other health needs. Help me to understand all of my other health conditions, medications, and risks.
- (8) Be an advocate. Help me to navigate the complexity of my care including systematic issues preventing me from accessing support and treatment. These could include simple logistics, organizational barriers, stigma, payment or wider community and social issues.
- (9) Ask for feedback. Regularly and formally solicit feedback from me on my experience in the practice through surveys that include specific questions about stigma. In this way, you can create a learning organization.
- (10) Follow up. It may be difficult for me to follow through. I might need phone calls and gentle reminders to take action on my treatment plan.

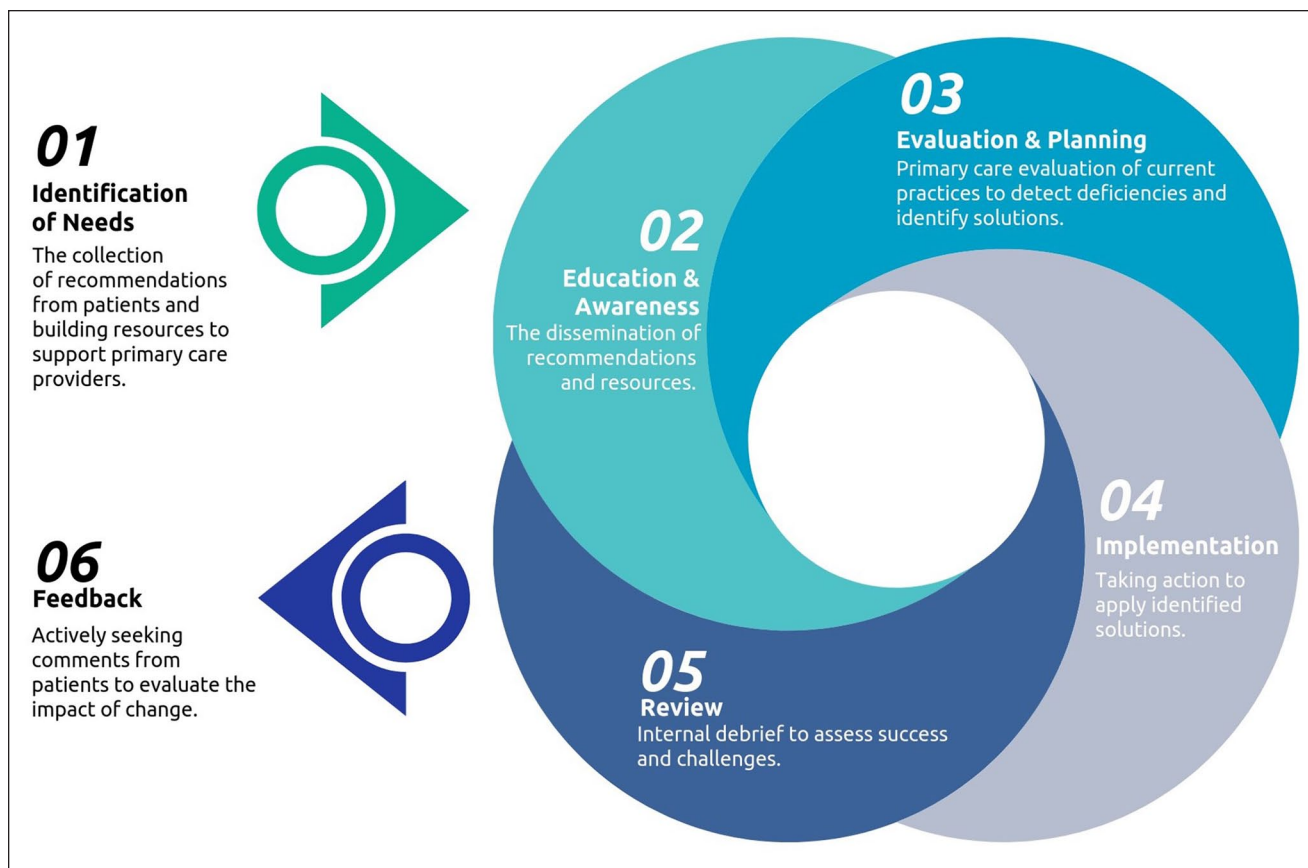


Figure 1. Implementation plan.

Implementation Plan

The implementation plan illustrated in Figure 1 was based on processes developed by other scholars.²²⁻²⁴ Systematic change in how primary care teams support individuals who use/used substances requires a phased approach.¹¹ The resources developed through this process provide best practice guidelines to physicians and health system partners, which have been disseminated through the Division of Family Practice, the Health Authority, and more widely across the province. However, individual clinics and primary care facilities will need to conduct their own implementation to effect change, including organizational learning, combined expertise, and collaboration. A strategic analysis of practices within each primary care structure is required in order to create a culture which is safe for patients who use(d) substances. Longer term evaluation and feedback will be required to fully implement new practices.

Implementation relies on shifting a number of complex systemic, cultural and operational factors, and relies on a process of continual improvement to adjust how care is provided not only to patients who have been identified as using substances, but to all patients, in a trauma informed way. Each care provider can develop their own list of feasible

implementations such as creating a patient survey, adding interdisciplinary team members to support their practice, or changing how cases are managed. However, overall the goal of implementation of the best practices is for care providers to begin looking at their practices critically, in order to reflect on how their behavior impacts a patient's experience of safety, and whether or not they feel discrimination and shame or support and inclusion.

Resource Development

The following resources were developed to communicate the best practice guidelines to primary care physicians and their teams. These reflect the patients' perspectives on common challenges to supportive primary care they have encountered, or which prevent them from accessing ongoing primary care services. Focussing on patients avoided duplication of guidelines already available to physicians which reflect providers' perspectives.²⁵

The Patient's Guide for Physicians is a 1-page summary of the 10 best practice guidelines derived from the data. It is intended to be easily read and shared with primary care providers and patients in order to invite further exploration and dialogue. This has been printed and disseminated to

physicians through the Division of Family Practice. The Primary Care Checklist assists primary care providers to incorporate the guidelines into their daily practice, and has embedded links to additional resources. It is intended to incite the development of new procedures to elevate the care of this population and serves as a focus of discussion for individual practise teams to work together to improve the full experience of care. A website (www.SupportingPatientsWhoUse.net) provides details about the project, links to the original research, and includes downloadable and printer-friendly versions of the Patient's Guide for Physicians and the Primary Care Checklist. Participants have reviewed and approved the website content.

Evaluation

An internal evaluation was completed with the participants of the initial workshop, and all indicated that the workshop was a positive experience and they would like to be involved in further events. All participants were sent copies of the resources and report for review, evaluation, and validation, and a sub-group participated in the final workshop. Their feedback has been incorporated into this report and the resources.

The guidelines were further validated through an external peer review through McGill University, which involved assessment of guideline quality using the AGREE II instrument.²⁶ This has been repeatedly shown to hold strong psychometric properties and is considered the gold standard to appraise clinical practice guidelines' quality.

Discussion

Through deliberation with both patients and primary care providers, a significant gap was identified with regards to the understanding and application of trauma informed primary care. Although resources²⁷ and training²⁸ are available, from patients' perspectives, the participation of physicians in trauma-informed practice training and the integration of these tools and guidelines are not widespread. Further research is required to advise on how clinic office staff might receive education and incorporate trauma informed practice into their office procedures. Furthermore, the emphasis on the primary care environment being comfortable, welcoming, yet respectful of patients' need for privacy and space is aligned with decades of research on the impact of set and setting on substance users' experiences,²⁹ and the positive effects of non-pharmaceutical (placebo) aspects of treatment.³⁰

As we move towards a transdisciplinary, team based approach to primary care, it was reported that a great deal of the burden falls to primary care providers to establish networks with other care providers who specialize in substance use care. There is an ongoing need for support to

both physicians and patients to streamline collaborative long-term treatment planning, referral process, follow-up procedures and how to navigate multidisciplinary and community-based services.

Systems of substance use screenings and safe dialogue should be routine in the patient-physician relationship, yet physicians and patients may be reluctant to open dialogue around substance use. When physicians lack awareness of available resources and/or effective treatment pathways, substance use behavior can be left unchecked until more serious symptoms present.

A gap remains to support cultural safety for Indigenous patients who use substances. Further collaboration with physicians and patients in Indigenous communities, and non-urban settings, is needed. In addition, further research is needed to better understand the systemic, structural, cultural, personal, and other barriers to the widespread implementation of these best practices. Limitations of the project include the small number of participants, which was necessary given the collaborative approach which emphasized safety, and the lack of available data on the outcomes of the implementation of the guidelines. It would also be helpful to illuminate some of the implementation barriers in primary care practices where these materials and supports are being used. These limitations could be addressed in future research.

Conclusion

The project provided the opportunity for respectful engagement and dialogue between people who use(d) substances, primary care physicians, and health system partners demonstrating that physicians and people who use(d) substances are able to engage in meaningful discussion, to learn from each other, and to collaborate safely in a facilitated context. The guidelines complement existing best practice guidelines focused on the medical management of addictive behavior,¹² by providing the patient perspective on how to provide supportive primary care, promoting patient-centered care for all patients.

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