ENGAGEMENT WITH PHYSICIANS TO ENHANCE CULTURAL SAFETY IN PRIMARY CARE FOR PEOPLE WHO USE SUBSTANCES

Final Report
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Patient Reflection

A Preface by Dr Kenneth Kunz

Having lived life from the unique vantage points of both a consultant physician, one who provided health care, and --- at the opposite end of the spectrum --- a patient, suffering with addiction --- and someone who desperately needed health care, experience has taught me that there can be a very bleak and sometimes yawning chasm that separates these two groups of earnest and well-meaning human beings.

The perquisites of a physician: education, privilege, position, personal power, choices, and a broad base of resources, are very different from the fear, isolation, stigmatism, poverty, marginalization, and self-loathing that can pervade the life of someone struggling with substance use problems. Yet, if life is to move forward, these two very different groups must somehow, and at some point, find common ground --- must work together to build a connection and a solid bond of trust so that healing can begin.

How can this be made to happen? The answer is disarmingly simple: in an atmosphere of openness, acceptance, understanding, and a willingness to listen, share, and hear, bring these two groups --- these partners --- together in an honest, free-flowing dialogue. In this optimistic milieu, people who use substances can express, in a heartfelt way, exactly what it is that they need in terms of primary health care, and other medical needs, so that they can live life to the best of their ability and achieve their maximum potential.

This visionary workshop on Cultural Safety in Primary Care Practice, designed and facilitated by the compassionate and understanding psychologist, Dr. Elizabeth Hartney, marks a new milestone in forging that much-needed bond of trust and mutual understanding; a bond of trust that will allow people who use substances to feel safe in a primary care setting, to express their needs, and subsequently receive the best medical care possible.

Attending this remarkable workshop was an eye-opening and engaging experience --- it was marvellous to watch the connection and understanding grow between these very different yet sincere groups of people. The objectives were more than successfully met. This represents a great leap forward in addressing and relieving the burdens that beset a person who uses substances in a world that is becoming increasingly difficult to negotiate.

As both a physician and someone in recovery from substance use disorder, I hope this progressive, enlightened, and dynamic workshop, and the report and resources that have arisen out of it, will see widespread acceptance and practice in the clinical setting of our future together.
Executive Summary

This report describes the development of best practice guidelines for primary care physicians working with people who use, or have used, substances. These patients often lack trust in, and access to primary care, and while some may be further marginalized and stigmatized through segregation in safer spaces associated with substance use (MacNeil & Pauly, 2011), others may opt out of discussing substance use with their doctor (Hartney et al, 2003). As primary care physicians are providers of service and the gatekeepers of access to specialized services, it is imperative that cultural safety addresses discrimination faced by people who use substances in obtaining referrals to necessary specialized services.

The purpose of the project was to develop a plan of action to improve cultural safety for people who use substances who are seeking primary care services. There were three aims to the action plan: first, to improve cultural safety in primary care; second, to co-create mutually agreed upon best practice guidelines for primary care physicians to provide care to this population of patients; and third, to develop an implementation plan.

The objectives of the project were to develop collaborative relationships with people with lived experience of substance use, physicians, researchers and research users to enhance knowledge and further research in substance use treatment, cultural safety in primary care, and access to appropriate healthcare for people who use substances; to engage with physicians on their key concerns pertaining to lived experiences of primary care among people who use substances; to increase awareness and knowledge in understanding substance use specific cultural safety; to use findings from our research with people who use substances as the basis of knowledge for workshop discussions, and to validate the study recommendations; to develop a mutually agreed plan of action to collaboratively address improving primary care and promoting access to culturally safe healthcare for people who use substances, within and through primary care settings; and to build capacity within primary care by mentoring research trainees with academic and community experts.

Our recent research with people who use(d) substances has provided an understanding of what is needed for people who use substances to feel safe using primary care services.
(Urbanoski et al, 2018; Pauly et al, in press). The findings of this research were used as the basis for developing key questions for discussion in order to develop best practices in four key areas: primary care environment and management; interpersonal skills; medication and prescribing, and holistic healthcare. We held three days of workshops: an initial workshop to provide Peer Research Associates, who were patients who were trained to lead the workshops, to develop cultural safety within the workshop; a dialogue day with Peer Research Associates, researchers, physicians, and health systems partners, which used a world café to develop best practices; and a follow up day with Peer Research Associates, researchers, physicians, and health systems partners to validate the resources that were developed.

We developed three key resources to disseminate the best practices: a one page summary of actions that can be taken to improve supportive primary care for people who use substances; a checklist for primary care practices; and a website compiling the best practice resources for download, providing background information on the project, and providing links to community resources. This website is available at www.SupportingPatientsWhoUse.net.

The implementation plan comprised the development of the resources, dissemination through the website and through presentations, distributing online and printed resources through the Victoria Division of Family Practice, and the Patients as Partners team within the Ministry of Health, and embedding the resources on Pathways, an online resource for physicians.

Future development of the guidelines will initially focus on explicitly addressing cultural safety in Indigenous patients who use substances. Additional research is needed to better understand and address trauma-informed care and transdisciplinary primary care. Further collaboration is also needed with physician, nurse practitioner, and medical office assistant training programs and organizations who may provide related services and supports, such as Pain BC. During our review of the guidelines it was noted that there could be broader applicability to other patient groups. These additional collaborations are beyond the scope of this project and will require further funding.
1.0 Background

Primary care is often a point of entry into the health care system and is an important avenue through which patient population accesses essential health care services. People who use substances often lack access to primary care (Benjamin-Johnson, et al., 2009) as a result of lack of trust (MacNeil & Pauly, 2011; Merrill, et al., 2002; Ostertag, et al., 2006).

While trusted sources of acceptable and safe primary care include community health centres (Lightfoot et al, 2009), street outreach (Hilton, et al., 2001), and harm reduction services, such as supervised injection sites and needle distribution programs (Potier et al, 2014), the segregation of people who use substances in such settings emphasizes stigmatizing negative connotations associated with substance use, reinforces negative stereotypes, and may be alienating to people with mild to moderate substance use issues, who do not identify as drug users, and may be left without any safe access to primary care. Hartney et al.’s (2003) previous research with untreated heavy drinkers indicated both the stigmatization of drinkers by other drinkers, and the nuanced relationship between physicians and heavy drinkers in effectively promoting change in the population. It was noted that researchers and clinicians often neglect this large sub-population of people who use substances, who stand to benefit greatly from effective, culturally safe primary care.

Harm reduction services can serve as key points of access to primary care; but are often hampered by a lack of integration between these services, and other public health services as well as more intensive substance use care or treatment. Harm reduction services typically have limited capacity to provide primary care in the absence of such integration. There may be a greater emphasis on acute healthcare needs, and therefore less attention paid to long term wellness, and referrals to specialized services within the broader health system. People who use substances are at greater risk of developing an array of chronic health problems, due to the health consequences of alcohol and drug use including cancer, diabetes, respiratory disorders, liver disease, and HIV/AIDS. Furthermore, mental health problems and trauma related disorders are higher among people who use substances; thus, enhancing services for this population will improve mental health care for people with concurrent disorders.
As primary care physicians are both service providers and the gatekeepers of access to specialized services, it is imperative that cultural safety addresses discrimination faced by people who use substances in obtaining necessary services. We have recently conducted research with people who use(d) substances, which has provided an understanding of what is needed for people who use substances to feel safe using primary care services (Urbanoski et al, 2018; Pauly et al, in press).

In light of these concerns, the research team decided that further collaboration between patients, physicians, and health system partners was needed to develop best practice guidelines and to increase cultural safety for this stigmatized population.

2.0 Project Purpose, Aims, and Objectives

The purpose of the project was to develop a plan of action to improve cultural safety for people who use substances who are seeking primary care services.

The project had the following aims:

- **To improve cultural safety in primary care** We aimed to improve cultural safety in primary care for people who use substances, to enable people within this patient group to be able to access appropriate primary care services which meet their complex healthcare needs. Access to primary care will be enabled by delivering primary care services in a manner which is respectful, preserves the dignity of these patients, and provides equity in service provision to people who use substances. Part of the purpose of bringing together people with lived experience of substance use who are working in a leadership capacity within the workshop, with primary care physicians, addiction medicine specialists, and health policy makers, was to expose service providers and policy makers to this group of patients outside of the stereotypical context in which they are often viewed.

- **To develop best practices for primary care** We aimed to develop mutually agreed upon guidelines for primary care physicians in providing care to this population of patients to improve their competence and confidence in their ability to meet the primary care needs of these patients. Our previous research with the Victoria Division of Family
Practice shows that this group of physicians lack knowledge on how to provide care for this patient population, and often hold negative attitudes toward people who use substances. This can lead to discrimination in service provision, and patients being given sub-standard care, or even being turned away from care. Yet there is a moral imperative that such practices not continue, and physicians recognize their need to develop competencies in this area.

- **To develop an implementation plan** We aimed to develop an implementation plan for applying our research findings to improving cultural safety for people who use substances who are seeking primary care services. This is a commitment to system change, beyond the valuable dialogue that occurred in the workshop. Representatives from the Ministry of Health primary care policy area, and from the Ministry of Mental Health and Addictions were invited to participate, and have the ability to take the action plan to the broader system level, and bring about more wide-ranging and sustainable change across the health system.

By conducting meaningful engagement with the key system partners around primary care for people who use substances, the project had six key objectives. The specific objectives were:

1. To develop and foster meaningful, collaborative and sustainable relationships with people with lived experience of substance use, physicians, researchers and research users to enhance knowledge and further research in substance use treatment, cultural safety in primary care, and access to appropriate healthcare for people who use substances.
2. To meaningfully engage with physicians on their key concerns pertaining to lived experiences of primary care among people who use substances, and to develop some preliminary guidelines for intervention, recognizing both physicians’ concerns and evidence on how to promote cultural safety.
3. To increase awareness and knowledge in understanding substance use with a specific focus on cultural safety.
4. To integrate findings from our concept mapping with people who use substances with survey data from the Victoria Divisions of Family Practice, to be used as the basis of knowledge for workshop discussions, and to validate the study recommendations.

5. To develop a mutually agreed plan of action to collaboratively address improving primary care and promoting access to culturally safe healthcare for people who use substances, within and through primary care settings.

6. To build capacity within primary care by mentoring research trainees with academic and community experts with the goal to develop skills and competencies to conduct further research in the area of improving health leadership in order to promote appropriate healthcare for people who use substances.

3.0 Methodology

3.1 Role of Patients (Peer Research Associates)

The workshop was co-facilitated by a team of patients, who were employed as Peer Research Associates (Peer RAs). The first day of the workshop brought together this team of Peer RAs with the researchers to develop processes for engagement with physicians and health system partners, including addressing and supporting each other through any emotional triggers that might occur during the process of discussing care for people who use substances. This created cohesion and mutual support among team members, as well as developing a strategy for supporting other participants on the second day of the workshop. On the second day of the workshop, when Peer RAs were joined by physicians and health system partners, Peer RAs took a lead role in facilitating the world café and sharing their experiences through a patient panel.

This approach ensured that mutual respect was established between patients, researchers, physicians, and health system partners throughout the workshop, and that all participants felt supported throughout the process. By privileging the voices of patients, we ensured that the focus was on the expertise and lived experiences of people who use(d) substances, with physicians and health system partners contributing their professional perspectives to co-create guidelines.
In the follow up workshop, a smaller group of Peer RAs, physicians, and health system partners re-convened to validate the resources that had been developed from the initial workshop. Again, we established mutual respect and collaboration between participants, whether patients, physicians, or health system partners.

3.2 World Café

A world café approach was used to stimulate discussion and gather input from participants. The original eight concepts identified in the original research (Urbanoski, 2018) was used as the basis for four areas of discussion and dialogue around how primary care can be improved: primary care environment and management; interpersonal skills; medication and prescribing; and holistic healthcare. Key issues brought forward by patients in the original research were used to develop questions for discussion at the four world café tables, which specifically addressed ways to ensure that people who use substances feel safe using primary care services.

3.3 Development and Validation of Best Practices

The discussion from the world café, which brought together the perspectives of patients, physicians, and health system partners, was transcribed and was used to develop several resources for physicians: a Patient’s Guide for Physicians; a Primary Care Checklist, and a website providing details of the project and downloadable and printable versions of both resources. Draft versions were provided to patients, physicians, and health system partners, and were discussed at a follow up workshop. In addition, detailed feedback was provided by representatives of the Victoria Division of Family Practice, and the Ministry of Health.

4.0 Best Practice Guidelines Development and Implementation

4.1 Key Considerations

4.1.1 Relationships are Paramount

While the original research that the guidelines were based on included reports of negative experiences of primary care, patients in the workshop predominantly described experiences of highly effective care which had been instrumental in their recovery. The central message from patients was that the relationship with their primary care provider was crucial to
feeling supported. Conveying a sense of collaboration and shared responsibility to the patient profoundly affected their own commitment to their treatment and recovery process.

4.1.2 Language Considerations

Translating the words of the original patients into language that physicians could relate to and respond to was a key consideration of the workshop, and it was essential for physicians as well as patients to be part of this process. It was also important to neutralize any implications of blame towards physicians that could be inferred from the language in the concept mapping, recognizing that physicians are working in a system that is not always patient-centred, creates time pressures, and may be vicariously traumatizing to physicians themselves.

In addition, certain concepts that have been part of the discourse of the project to date, or which were raised in the discussion, were identified as problematic during the feedback process.

Cultural Safety

The concept of cultural safety was a foundational part of our original project. However, using this concept in relation to people who used substances was challenging, because cultural safety was originally developed in relation to Indigenous peoples, and is widely recognized as specific to them. Colleagues working in the field of cultural safety for Indigenous peoples were initially excited to hear of our work, believing it to be specific to Indigenous peoples, then disengaged when we explained that our work focused on people who used substances. This raised concerns for us that using the term cultural safety might be confusing or perceived as misleading to the wider community and the healthcare system; that it might be a form of cultural appropriation, or that it has the potential to further compound stigma for either or both of these marginalized, stigmatized groups through conflation. To avoid further misunderstandings, the term “cultural safety” was replaced with the term “supportive primary care.” It is also noted that there is a gap in terms of cultural safety resources for Indigenous patients who use substances.
Recovery Capital

Recovery capital was a term that was used in an earlier draft of the best practice guidelines. However, follow up feedback indicated that this concept may not be helpful for physicians. While the reasoning for this was unclear, and workshop participants (including physicians) felt the term would be helpful in best practices, it was decided that the using the term might stimulate debate on issues that were not the principal concern of this project, so it was replaced with resilience, readiness to change and personal resources.

4.1.3 Format of Guidelines

Dealing with the issues of stigma and marginalization in clinical settings does not easily lend itself to a formal guideline development approach. Primary care settings vary widely and the social, cultural, and administrative circumstances in BC may not be reflected in published research in this field.

In British Columbia, there is a rigorous process for the development, adoption and dissemination of practice guidelines for physicians. Published guidelines have focused on clinical topics where specific approaches for diagnosis and management can be recommended based on a synthesis of published evidence and professional judgment. These include the comprehensive Opioid Use Disorder - Diagnosis and Management in Primary Care (BCCSU & Ministry of Health, 2017). Additionally, there are excellent detailed guides for physicians such as the Recovery-Oriented Mental Health and Addiction Care in the Patient’s Medical Home (College of Family Physicians of Canada, 2018).

In light of these considerations, we needed to develop guidelines in a format that did not duplicate the excellent medical advice provided by existing guidelines, but complemented it with the patient perspective. Therefore, we developed the Patient’s Guide for Physicians (Appendix A). Furthermore, we recognized that with the current development of primary care networks, primary care practices could benefit from a checklist to review and plan the enhancement of their services to better support people who use substances. However, patients and families have few mechanisms to provide feedback and input, particularly if they are disenfranchised. Additionally, the daily urgent demands on primary care teams leave little time
and opportunity for consideration of the important but less immediately pressing issue of developing approaches to minimizing barriers to care. To address these needs, we developed the Physician’s Checklist (Appendix B). This version of the checklist was designed to help primary care providers to focus in on priorities that might have the fastest yet most impactful effects on patients who use substances. Finally, we developed a website, that contained information about the project, provided the resources for download and links to additional tools to support further practice development. This can be accessed at: www.SupportingPatientsWhoUse.net

4.2 Key Areas for Enhancing Primary Care for People Who Use(d) Substances

Patients, physicians, and health system partners explored four key areas for enhancing primary care: primary care environment and management; interpersonal skills; medication and prescribing; and holistic healthcare. These four areas were derived from the original concept mapping research (Urbanoski et al, 2018). Tables 1 to 4 display the original clusters identified within the concept mapping, the discussion points and table questions addressed in the world café, and the recommendations that were generated from the dialogue and discussion, which formed the basis of the development of best practices for primary care.

4.2.1 Primary Care Environment and Management

The discussion of how the primary care environment and management could be improved drew mainly from two clusters in our original research (Urbanoski et al, 2018): “maintain my confidentiality in a welcoming and comfortable environment,” and “be a 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. As well as the physical environment, it included the way the reception staff treated patients and respected patient confidentiality, and how the sociodemographic circumstances of patients were handled.
Table 1. Recommendations for best practice guidelines on primary care environment and management

| World Café Table 1 Discussion Topic: Primary care environment and management |
|---|---|---|
| **Developed collaboratively by patient, physician, and health system partners** | **Research Cluster** | **World Café Table Questions** | **Recommended Guideline** |
| “Maintain my confidentiality in a welcoming and comfortable environment.” | “Maintain my confidentiality in a welcoming and comfortable environment.” | 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 |
| - waiting room environment | - waiting room environment | | - welcoming, accessible, easy to understand |
| - confidentiality (being required to give reason for visit, staff discussing patient in waiting room) | - confidentiality (being required to give reason for visit, staff discussing patient in waiting room) | | - respects confidentiality and privacy, soundproofing |
| “Be a champion for advocacy” | “Be a champion for advocacy” | How can we train reception staff to be more friendly, welcoming, and respectful of the privacy of patient information? | - signs with directions, hours and FAQ |
| - security and accessibility of services | - security and accessibility of services | | Build a network |
| - supports to reduce anxiety and improve perceived safety in accessing care | - supports to reduce anxiety and improve perceived safety in accessing care | 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? | - access to psychology, social work, dietician, harm reduction, peer support, social and cultural organizations |
| - bring an advocate or friend to appointments | - bring an advocate or friend to appointments | | Become trauma informed |
| - choice of physician by gender | - choice of physician by gender | How can primary care include supports such as an advocate and adequate insurance coverage? | - ensure all staff understand effects of trauma |
| - insurance coverage | - insurance coverage | | Be an advocate |
| - treatment options when insurance coverage is a problem | - treatment options when insurance coverage is a problem | | - help me navigate systemic barriers |
| 1 Research clusters are reported in more detail in Urbanoski et al (2018) | 2 Full guidelines in appendix A | | Ask for feedback |

- phone calls and gentle reminders
4.2.2 Interpersonal Skills

The discussion of how primary care physicians can improve their interpersonal skills when working with people who use substances was based on four clusters in the concept mapping research and was a thread that 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 there was a dedicated discussion 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.

Table 2. Recommendations for best practice guidelines on interpersonal skills

<table>
<thead>
<tr>
<th>Research Cluster ¹</th>
<th>World Café Table Questions</th>
<th>Recommended Guideline ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Act to prevent stigma”</td>
<td>How can we ensure that all patients feel treated with respect, caring, compassion, dignity, and human decency (without judgement, labelling, or stigma)?</td>
<td>Become trauma informed - support my healing by giving me time to discuss my history - develop trust</td>
</tr>
<tr>
<td>- external stigma (being judged by others)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- internalized stigma (feeling embarrassed or ashamed).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Treat me right!”</td>
<td>How can we continue to provide access to care for challenging patients (i.e. without blacklisting them)? What feedback and complaint processes could be introduced?</td>
<td>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</td>
</tr>
<tr>
<td>- Trusting the physician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Being trusted by the physician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Do you care about me?”</td>
<td>How can we ensure patients are involved in decisions that affect them?</td>
<td>Ask for feedback - including specific questions about stigma</td>
</tr>
<tr>
<td>- personalized care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- rapport between physician and patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- seeing same physician each time</td>
<td></td>
<td></td>
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<tr>
<td>- not feeling rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How can we be more respectful of family circumstances (e.g. allow a patient to bring family</td>
<td>Follow up - gentle reminders to help me follow through</td>
<td></td>
</tr>
</tbody>
</table>
“Acknowledge and accommodate my needs and circumstances”
- sociodemographic circumstances
- fears of losing child custody if drug use is disclosed

<table>
<thead>
<tr>
<th>“Live up to professional standards”</th>
<th>World Café Table Questions</th>
<th>Recommended Guideline (^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- adequate treatment for pain</td>
<td>How can we provide appropriate and adequate medication while avoiding negative medication interactions?</td>
<td>Co-create a long-term treatment plan</td>
</tr>
<tr>
<td>- appropriate medications</td>
<td>What protocols can provide pain management for people who use drugs?</td>
<td>- develop a treatment plan based on individual health needs, social circumstances, resilience and personal resources</td>
</tr>
<tr>
<td>- being included in care planning and decision making</td>
<td>What mental health supports or treatment can be offered to people who use substances by or through primary care?</td>
<td>- support me when things do not go as planned</td>
</tr>
<tr>
<td>“Don’t red flag me: Recognize addiction as a health issue.”</td>
<td></td>
<td>- relapses are part of the condition</td>
</tr>
</tbody>
</table>

Table 3. Recommendations for best practice guidelines on medication and prescribing

1 Research clusters are reported in more detail in Urbanoski et al (2018)
2 Full guidelines in appendix A

4.2.3 Medications and Prescribing

The discussion on medications and prescribing was one of the most challenging. While there are protocols that can be effectively managed by a primary care physician, some of these are too specialized to be suitable for an outpatient or primary care context. In addition, we recognize that there are already medication guidelines that physicians should follow. Ultimately, primary care physicians may need to access a broader network and specialized services for patients with complex medication needs and chronic pain issues.
addiction is a legitimate health issue, not a criminal behaviour
- physician knowledge (about addiction and available services and supports)
- openness to harm reduction strategies
- ability to receive ongoing physical and mental health 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?

- 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

1 Research clusters are reported in more detail in Urbanoski et al (2018)
2 Full guidelines in appendix A

4.2.4 Holistic Healthcare

The holistic healthcare discussion focused on primary care physicians paying attention to the full spectrum of healthcare needs for patients who use substances, rather than only addressing their substance use issues. Although it was drawn from the same two 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.

Table 4. Recommendations for best practice guidelines on holistic healthcare

<table>
<thead>
<tr>
<th>World Café Table 4 Discussion Topic: Holistic healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developed collaboratively by patient, physician, and health system partners</td>
</tr>
<tr>
<td>Research Cluster ¹</td>
</tr>
<tr>
<td>“Live up to professional standards.”</td>
</tr>
<tr>
<td>- professional competency in substance use and addiction</td>
</tr>
<tr>
<td>- pain management and medication</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

¹ Research clusters are reported in more detail in Urbanoski et al (2018)
² Full guidelines in appendix A
- patient involvement in care planning

“Don’t red flag me: Recognize addiction as a health issue.”

- addiction is a legitimate health issue, not a criminal behaviour

- physician knowledge (about addiction and available services and supports)

- ability to receive ongoing physical and mental health care

| the patient get to the root of their underlying problems? |
| How can we improve collaboration between providers, to avoid medication interactions? |
| How can we ensure we meet all of the primary care needs of people who use substances (such as routine medical screening, referrals for specialist treatment etc)? |
| How can we routinely ensure follow up and continuity of care? |

- health maintenance screenings, vaccines etc.
- information on healthy lifestyles

Ensure timely access to specialized medical and surgical care

- recognize when specialist referrals are required
- consider my substance use issues and other health needs
- help me to understand all health conditions, medications and risks

Follow up

- phone calls and reminders to follow through on actions

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1 Research clusters are reported in more detail in Urbanoski et al (2018)

2 Full guidelines in appendix A
5.0 Implementation Plan

The implementation plan was based on processes developed by Lassi et al (2014) and Tucker, Nembhard, & Edmondson (2007), and is illustrated in figure 1. In order to create systematic change in how primary care teams support individuals who use/used substances, a phased approach is required (Lassi et al, 2014). The resources we have developed through this process provide best practice guidelines to physicians and health system partners, and through their dissemination, through the Victoria Division of Family Practice, the Vancouver Island Health Authority (Island Health), and more widely across the province. However, individual clinics and primary care facilities will be required to carry out in depth implementation for it to be successful.

Organizational learning, combined expertise and collaboration are required in order to effect change (Tucker et al, 2003). As the above diagram describes, 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 actualize and adopt new practices as the new normal.

5.1 Resource Development

Based on patient voices, the following resources have been developed, to communicate the best practice recommendations to primary care physicians and their teams:

- A Patient’s Guide for Physicians (Appendix A)
- A Primary Care Checklist (Appendix B)
- A website detailing the project and resources: www.SupportingPatientsWhoUse.net

These resources reflect the patients’ perspectives on common challenges to supportive primary care they have encountered, or which prevent them from accessing ongoing primary care services.

5.1.1 Patient’s Guide for Physicians

This is a one-page introduction to the wider project, workshops, and resources developed. It is intended to be easily read and shared with primary care providers and patients in order to invite further exploration and dialogue.

5.1.2 Primary Care Checklist

With embedded links to additional resources and expanded recommendations, this is a complete guide to assist primary care providers to incorporate supportive primary care for people who use/used substances into their daily practice. It is intended to incite the development of new procedures to elevate the care of this population by supporting primary care providers.

5.1.3 Website

The website is an online space which includes downloadable and printer-friendly versions of the Patient’s Guide for Physicians and the Primary Care Checklist. It also provides details of the background of the project and links to the original research. The photographs included are not models, but are the real participants engaging in workshops and in the
community. All signed release forms to indicate their consent and have reviewed and approved the website content.

5.2 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. Due to budgetary constraints, it was not possible to pay all patient and physician participants to participate in the half day follow up workshop, however, all participants were sent copies of the resources and report for review, evaluation, and validation. Their feedback has been incorporated into this report and the resources.

An external peer review of the best practice development was conducted through a team of three trained, experienced reviewers at McGill University. The reviewers used The Appraisal of Guidelines for Research and Evaluation-II (AGREE-II) instrument (AGREECollaboration, 2003; Brouwers, Kerkvliet, Spithoff, & the AGREE Next Steps Consortium, 2016) to assess the quality of the guideline. This instrument has been repeatedly shown to hold strong psychometric properties and is considered the gold standard to appraise clinical practice guidelines’ quality. Specifically, it examines how the guideline was developed by looking at 6 domains: scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and transparency. In addition, a consensus score was calculated, using intraclass correlation coefficients and deemed to be excellent, with ICC=0.87, indicating agreement across appraisers for all the individual items.

The results of the review were as follows:

Domain 1, scope and purpose, received a scaled domain score of 85%. The objectives and health related questions addressed in the guideline were outlined well.

Domain 2, stakeholder involvement, received a scaled domain score of 80%. The preferences of the target population and of the target users were clearly described.

Domain 3, rigour of development, our recommendations were adequately tied to the data gathered from the previous study of patients’ preferences (Urbanoski et al, 2018).
The reviewers recommended providing a procedure for updating the guideline.

Domain 4, clarity of presentation, received a score of 70%. However, after further discussing the items comprised in this domain during the consensus meeting, it was concluded that the guideline should receive almost full points for items within this domain.

Domain 5, applicability, and domain 6, editorial independence, received scores of 28% and 17% respectively. While the tools and advice to facilitate the uptake of the guideline were provided, the reviewers recommended adding a discussion to describe in more detail the potential facilitators and barriers to implementation and suggested discussing the need for resources to implement the guideline and developing a procedure to monitor the use of the guideline.

For all domains, the reviewers recommended providing more detailed information. These recommendations will be followed prior to publication of the guidelines.

5.3 Dissemination

The patient’s guide and checklist will be printed and distributed in print and online to primary care physicians through the Victoria Division of Family Practice.

This report is open access published through the Royal Roads University online repository. In addition, the resources we developed are available for unlimited free download from the website. We will also write up the development of the best practice guidelines for publication, once we have the results of the external peer review from McGill University.

The project will be presented at the Ministry of Health Research Rounds, and the Royal Roads University Roads to Research, and copies of the resources will be provided to the Primary Care Branch, Ministry of Health, Patients as Partners, Ministry of Health, the BC Centre on Substance Use and the Ministry of Mental Health and Addictions. In addition, this project will be presented to community organizations who service individuals who use substances. Further opportunities for presentations are being explored.

A centralized online resource for physicians across British Columbia, Pathways is the preferred method of disseminating information to physicians. Pathways is administered jointly by Doctors of BC, the Ministry of Health, individual health authorities and divisions of family
practice across the province. Preliminary discussions with ministry personnel and divisions of family practice indicated further dissemination of the Patient’s Guide and the Checklist for Physicians could be possible through Pathways. These resources will be submitted and revised in accordance with the standards provided.

5.4 Recommendations for Future Research and Resource Development

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 resources and training are available, the participation and integration of these tools and guidelines are not widespread. Additional investigation is required to advise on how clinic office staff might receive education and support incorporate trauma informed practice into their office procedures.

As British Columbia moves towards a transdisciplinary, team based approach to primary care, it was reported that a great deal of burden was placed on primary care providers to establish linkages and networks between other care providers who specialize in the care of individuals who use substances. 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.

Reluctance on the part of physicians and patients exists in opening dialogue around substance use. A lack of awareness on the part of physicians with regards to available resources and/or effective treatment pathways can result in substance use behaviour being left unchecked until more serious symptoms present. There is a need to establish systems where substance use screenings and safe dialogue become routine in the patient-physician relationship.

As discussed previously, there is currently confusion in the application of the term “cultural safety” to the broad population of people who use substances. However, it is clear that there is a gap in resources to support cultural safety for Indigenous patients who use substances. We are planning further collaboration with physicians and patients in Indigenous communities to develop cultural safety resources to address this need.
In the follow up workshop, it was noted that patients might benefit from a similar guide to the Patient’s Guide for Physicians, from the physician’s perspective. This would provide advice to patients on how to get the most out of their relationship with their primary care physician, and would help the patient to understand some of the processes involved in primary care, which could help to ease this process with greater understanding. Further funding would be required to develop this resource.

6.0 Conclusions

The project provided the opportunity for respectful engagement and dialogue between people who use(d) substances, primary care physicians, and health system partners. Physicians and patients unanimously reported that the experience was both personally fulfilling, and professionally informative. Many requested to be invited to future events. This demonstrates that, contrary to common opinion, physicians and people who use(d) substances are able to engage in meaningful discussion, to learn from each other, and to collaborate.

The guidelines we have developed compliment existing best practice guidelines focused on the medical management of addictive behaviour, by providing the patient perspective on how to effectively provide care. With the relationship being paramount to patients’ feelings of safety and trust, these guidelines are just as essential as those that are medically oriented, for providing patients with primary care services, and thereby access to the broader health system and services.

Publication and dissemination of these guidelines more broadly is anticipated to support changes in the culture of primary care, specifically, to reduce stigma and improve the well-being of people who use(d) substances. In addition, the actions reflect patient-centred care and good practice for all patients, and therefore most of the recommendations are not limited to those who are known to use or have used substances. For many people, substance use is a private issue that is not freely disclosed, even to a physician, so implanting these actions with all patients ensures that those who have not disclosed substance use also receive supportive primary care.
References


Appendix A: Patient’s Guide for Physicians

SUPPORTIVE PRIMARY CARE FOR PATIENTS WHO USE SUBSTANCES
A Patient’s Guide for Physicians

These suggested actions are informed by a research funded by the Canadian Institutes of Health Research (CIHR) and the Michael Smith Foundation for Health Research, focused on reducing stigma and building cultural safety in primary care for people who use, or have used substances. They are based on the outputs of focus groups and workshops involving BC patients, physicians, and health system partners. The intention is to share the experiences of patients in order to encourage ongoing dialogue about issues that may be difficult to discuss in day-to-day encounters, particularly in times of crisis and relapse. This is a compilation of patients’ voices that can assist in the planning of primary care for those with substance use and encourage the examination of structural issues in the context of the wider community. For further information please go to www.supportingpatientswhouse.net

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, accessible, 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 (for example 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, counselling, social work, rehabilitation, dietician, 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 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 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 and mental health concerns 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.

WWW.SUPPORTINGPATIENTSWHOUSE.NET
Appendix B: Primary Care Checklist

SUPPORTIVE PRIMARY CARE FOR PATIENTS WHO USE SUBSTANCES

Guidance from Patients:
A Checklist for Primary Care

For more information go to: www.supportingpatientswhouse.net
WHY IS THIS NEEDED?

This checklist is based on best practices which were developed from the findings of a series of focus groups with people who use substances, funded by the Canadian Institutes of Health Research(1) and workshops involving patients, physicians, and health system partners in BC, funded by the Michael Smith Foundation for Health Research. (2) The best practices are available in a companion document, Supportive Primary Care for People Who Use Substances: A Patient’s Guide for Physicians. In addition, physicians can access relevant clinical guidelines (3) focused on diagnosis and medical management, based on a rigorous process, including synthesis of published evidence and professional judgement. Relevant clinical guidelines that physicians should follow in tandem with this checklist include:

- Problem Drinking – Screening, Assessment, Brief Intervention, Withdrawal Management
- Opioid Use Disorder – Diagnosis and Management in Primary Care
- Mental Health Problems – Anxiety, Depression, Cognitive Impairment, Eating Disorders
- Withdrawal Management (Biopsychosocial/spiritual)

The checklist is a tool for primary care practices to review their current adherence to the best practices, and to plan for future developments. It is intended to share the experiences of patients in a constructive way and to encourage ongoing dialogue about issues that may be difficult to discuss in day to day encounters, particularly in times of crisis or relapse when the barriers faced by people who use substances may be particularly difficult to address. Many of the issues raised have solutions outside of the individual primary care provider’s control. This compilation of patients’ voices can also assist in the planning of primary care for those who use substances, and encourage the examination of structural issues, such as primary care practice organization in the context of the wider community, and the impact of funding policies on the implementation of better quality care. A detailed guide for primary care teams is also available to support practices in their work with this population, Recovery-Oriented Mental Health and Addiction Care in the Patient’s Medical Home. (4)

2 Hartney, E. (2018). Engagement with Physicians to Enhance Cultural Safety in Primary Care for People Who Use Substances: Final report. Victoria, Canada: Centre for Health Leadership and Research, Royal Roads University, DOI: 10.25566/1R-9748
3 BC Guidelines.ca
4 College of Family Physicians of Canada (2018). Recovery-Oriented Mental Health and Addiction Care in the Patient’s Medical Home
THE CHECKLIST

The following examples are provided to support a practice in the self-assessment of their services in the context of expressed patient needs. It is understood that with the wide array of practice settings some of the suggestions may not apply and it is hoped that in those cases the practice consider the need and develop ways to address it that fit with their circumstances.

Provide a welcoming and safe place/way for me to access care with understanding and kind staff.

**THE OFFICE**

- Is it well signed, with clear directions for incoming patients?
- Does it provide a sufficient waiting area for patients and families?
- Does the office environment protect confidentiality needs with private areas for intake and adequate sound insulation between offices.
- Can patients access care on the weekends or evenings?

**STAFF**

- Do all staff understand the importance of a supportive and kind demeanor.
- Are all staff trained in trauma informed care?
- Are there options for maintaining confidentiality in the waiting room?
- Do patients have the option to write down the reason for their visit or to have a private discussion?
- Are staff provided with clear expectations/scripts regarding communications with patients?
  - “How would you like to be addressed?”
  - “How can I help you?”
  - “Do you understand how this referral/lab test/follow up visit is to be arranged?”
- Do performance evaluations include a discussion of patients’ experiences?
Do patients have access to the necessary supporting information?
- Clear and up to date information about office hours, wait times, emergency information, after hours etc.
- Specific guidance about options for care if it cannot be provided at the practice site when requested.
- Local transit information/parking
- Practice description, staff role, processes etc.
- Intake processes/forms that include questions for patients regarding preferences.
- Translation supports services/materials

Does the care team have the opportunity to debrief/learn from difficult office experiences?

Do staff have access and support to participate in continuing education and training?

Do all staff understand the importance and concepts of trauma informed care?

Does the team receive support to understand the patient needs around cultural safety?

Does the team optimize their use of telephone for follow-ups?

Does the team regularly solicit feedback surrounding safety and stigma through surveys or other anonymous methods?

Does the team regularly review supporting educational materials such as those provided by the Canadian College of Family Practice:
- Mental Health
- Physician Patient Relations
- Physician Online Communication Guidelines
- Addiction and Substance Use
  www.cfpca.ca/ProjectAssets/Templates/Resource.aspx?id=2062&type=4105&terms=guidelines
- Aboriginal Health
Please treat me as a whole person.

MY CARE

- Please understand how trauma may have affected me.
- Please take a full social and family history as part of intake processes and initial assessments.
- Please make sure we have enough time to discuss all of my needs and develop a trusting relationship.
- Allow me to choose between various substance use treatment options, based on best current medical knowledge and my history, preferences and other conditions.
- Understand and consider the importance of my other health conditions, medications and risks.
  - Do you have access to Pharmasave and use it whenever new medications are introduced?
- Help me to access specialists when they are required.
  - Do you have lists, contact information, wait times etc. for formal referral addiction specialists in the area?
  - Can you provide me with detailed referral information?
  - Do you use Rapid Access to Consultative Expertise (RACE) for telephone advice? www.raceconnect.ca
- Can you please help me to access to psychology, social work, dietician, harm reduction services, peer support, social and cultural organizations?
  - Do you have contact lists and establish working relationships with these providers?
  - Do you communicate and share information as permitted and appropriate with these providers?
- Can you please ensure that I receive all of the recommended health maintenance interventions including screening?
  - Do you use tools within the EMR to flag when health maintenance interventions are required?
  - Can you please provide me with information to assist me in living a healthy life? (smoking cessation, fitness, nutrition etc.) www.preventioninhand.com/Home
Can you please pay special attention to health issues that may be masked or made difficult to treat, caused, or made worse by substance use?

- Can you modify screenings or follow-ups to address the higher risk associated with my current or past substance use? (e.g., Liver function testing in alcohol use, closer monitoring of diabetes)
- Can you specifically request guidance in necessary ongoing follow-up when requesting specialists’ consults?
- Can you treat acute and chronic pain in the context of helping me manage all of my health conditions, including substance use?
- Can you help me seek pain specialist consultation early in the condition and suggest peer support, self-management and other community resources?
- Help me to review all medications.
- Do you access and use available resources such as:
  a) Safe prescribing practices for addictive medications and management of substance use disorders in primary care: A pocket reference for family physicians.  
  www.cfpc.ca/uploadedFiles/Directories/Committees_List/2017-04-03%20PCP%20pocket%20guide.pdf  
  b) 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain  
  www.cfpc.ca/2017_canadian_guidelineopioids_chronic_non_cancer_pain/  
  c) Chronic Pain Program Committee -resources  
  www.cfpc.ca/ProjectAssets/Templates/Series.aspx?id=4238&terms=guidelines

Do you access and use available guidelines for the care of substance use disorders including pharmacological and non-pharmacological options? These include:

- CAMH Primary Care Addiction Toolkit  
  www.porticnetwork.ca/tools/toolkits/pcat
- Opioid Use Disorder: Diagnosis and Management  
  www.bccsu.ca/care-guidance-publications
- Addiction Medicine Program Committee -resources  
  www.cfpc.ca/ProjectAssets/Templates/Series.aspx?id=4233&terms=guidelines
- 2017 Canadian Opioid Prescribing Guideline – Summary of Recommendations  
  https://www.cfpc.ca/uploadedFiles/CPD/Opioid%20poster_CFP_ENG.pdf
- Mentoring, Education, and Clinical Tools for Addiction: Primary Care-Hospital Integration (META:PHI) is a collaborative project to create new care pathways for addiction  
  www.womenscollegehospital.ca/programs-and-services/METAPHI
- Canada’s Low Risk Alcohol Drinking Guidelines  
- Alcohol Screening, Brief Intervention & Referral (SBIR) - Helping patients reduce alcohol-related risks  
  www.sbir-dih.ca/
- Communities of Practice in the Patient’s Medical Home  
  www.patientsmedicalhome.ca/resources/best-advice-guides/communities-practice-patients-medical-home/
- Buprenorphine/Naloxone for Opioid Dependence: Clinical Practice Guidelines  
Please help me access all of the available resources including written materials, self-management tools and peer support. It is useful for me to fully understand my condition and all available treatments. Some examples could include:

- Addiction: An Information guide
- Moving Beyond Stigma
- Straight Talk: Fentanyl
- Substance Use: Issues to Consider in the LGBTQ Community
  www.camh.ca/en/health-info/guides-publications/substance-use

Please help me develop a shared, long-term treatment plan that we all agree to. It would be incredibly helpful if you could:

- Draw on all of the above resources to help co-develop a treatment plan based on my individual health needs and social circumstances.
- Ask me if I want to involve family members and friends to assist me. Ask these support people how they are doing and if they need any resources and help to support them in their role.
- Provide me with a copy of the plan to review and keep.
- With my permission, share the plan with other providers involved in my care.
- If you think it is helpful, create written agreements or contracts to assist our ongoing relationship.
- Consider my ongoing education as part of the plan and have access to materials or people to assist me.
- Check in with me regularly to see how the plan is working.
- Help me explore alternative treatments in a non-judgmental way to help find a path that is safe for me.
- Support me when things do not go as planned. Relapses are part of my conditions. Please don’t take them personally or as a comment on the care you provide me.
Be an advocate and support me in advocating for myself.

- My care is complex. I need support to navigate the existing systems and structures to ensure that am receiving the right care and treatment.

- Help me to ensure my entire care team has the right information. These include Medical Office Assistants groups, Divisions of Family Practice, Regional Health Authorities, professional organizations, FNHA, EMR providers, patient advocacy organizations. Encourage the development and dissemination of materials and promote communication mechanisms to help everyone to learn and grow.

- Please consider how systematic issues might affect the delivery of my care and how difficult this might be for me to manage on my own. I have a lot going on.
  - Can you help me to foresee and navigate any organizational barriers that might add complexity or challenges? This is especially troublesome when coordinating multiple providers.
  - Can you help me to understand and navigate payment issues?
  - How do issues such as location, transportation, housing, stigma etc. impact my ability to change?
  - How can individuals with lived experience provide continual feedback to improve services and structures?

- Please understand the entire care team is essential to create a welcoming and therapeutic environment.

- Please help everyone on the care team is supported with ongoing training and education.