



# Engaging Individuals with Lived Experience

## A Framework

Version 3.2

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# 1 Introduction

For those who have had experiences with opioid use, this journey has given them insights, wisdom and skills that can only be found within the lived experience and yet are crucial to those who are developing, implementing and operating programs and services designed for this demographic. Whether an individual who has used opioids to the families and friends who support those who use and even lose those loved ones, these experiences are necessary to ensure that supports and services meet their needs, speak to them in a way that engages and builds community and rapport. This document has been developed to include the supports for all involved, best practices in engagement and tools to support success.

Patients, their families, and other individuals with lived experience have important insights, and innovative ideas to share through opportunities for engagement. They bring their unique perspectives, gained throughout their journeys, of having or not having, accessed and navigated health services and related supports. Engaging individuals, who have a lived experience as a recipient of care with a particular condition, such as Opioid Use Disorder, informs an understanding of the impact of the condition on their day to day lives, and what matters most to them in their interactions with health care providers.

The framework outlined here is designed to support leaders, physicians, health care providers and teams to create the necessary conditions, readiness, and supports to respectfully and meaningfully engage patients, families and other individuals with lived experience to inform initiatives and/or projects at the provincial, zone and PCN level (See Figure 1). Though translatable to other contexts the focus here is specific to the *Primary Health Care Opioid Response Initiative (PHC ORI)*. Development of this framework reflects phase one of the engagement process. Phase II: Implementation involves the development of tools and resources to build capacity and capability at each of the 3 levels identified as a foundational enabler toward ensuring positive and informative experiences for both the individuals leading the engagement process and those individuals who are being engaged. Levels 4 and 5, as illustrated in Figure 1, are beyond the scope of this document, however many of the guiding principles outlined for engagement at levels 1 through 3 can still be applied.

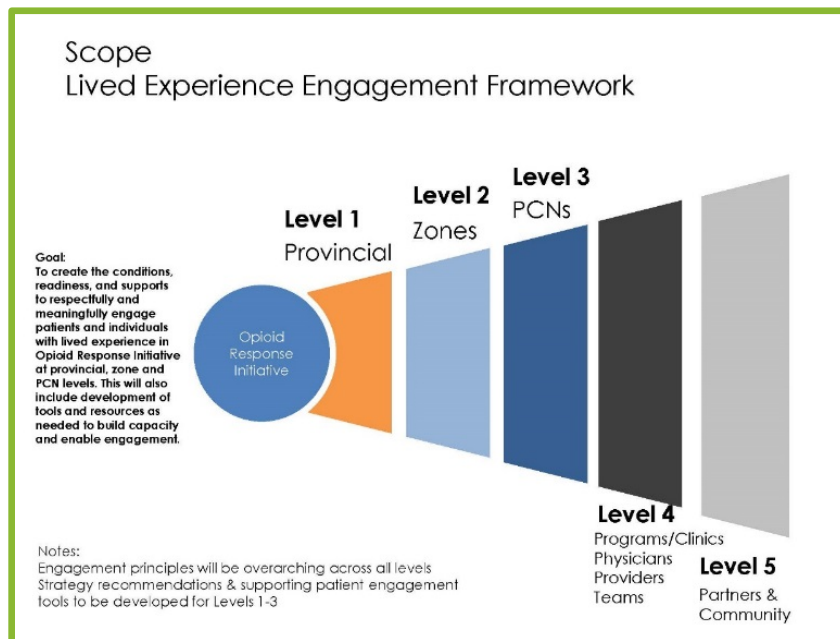


Figure 1

Included in this document are recommended principles, and overview of a framework including various levels, and phases for engaging individuals with lived experience to share their unique experiences. Engagement also allows for individuals with lived experience to partner on the planning, design, and development of activities toward addressing the opioid crisis within the context of the PHC Opioid Response Initiative and elsewhere.

Ideally planning and implementation of activities are tailored to the needs of patients, clients, and families including individuals with lived experience. What better way to learn what their needs are than to engage, ask the questions, listen to their stories, and leverage their insights and suggestions to improve service delivery. Teams who enter into an engagement process then have the opportunity to incorporate the knowledge and insights brought forward into program design and decision making contributing to a system that is more responsive to the preferences, values and needs of individuals and families.

## 2 Development Process

This framework and related principles were developed through an accelerated process including the following components:

- Review of the evidence, including best and promising practices, for engaging patients, families and individuals with lived experience that may include populations not traditionally engaged in health services planning;
- Rapid review and leveraging the multiple public and patient engagement frameworks that support engagement work in Alberta and beyond;
- Identification of guiding principles;
- An engagement checklist;
- A roadmap for engagement work;
- A glossary of terms to ground common understanding;
- Scenarios to assist with addressing potential lived experience partners; and
- Targeted informal consultations with key informants from a community agency perspective, medical/clinician leaders, family members and individuals with lived experience was obtained to inform this document's rapid development.

## 3 Purpose

*"Involving patients and families in understanding and designing improvements to care processes leads to different insights and better results than providers working on their own."*

Canadian Foundation for Healthcare

This document, and the framework it illustrates, have been developed in partnership with the Engagement and Patient Experience program within Alberta Health Services and the Patient Engagement Working Group of the PHC Opioid Response Initiative. It reflects a commitment to ensuring that individuals with lived experience are engaged in the planning, design, build, and implementation of activities intended to best support individuals using opioids in a proactive, and patient-centered way free of judgement and bias. There has been a tendency to

be overly reliant on subject matter experts, evidence and best practices of "expert" clinicians. However, it is now well acknowledged that this approach when combined with 'best practices' in the engagement of patient and families, often results in better outcomes. Ideal solutions are those co-designed in partnership with patients, their families and other individuals with 'lived' experience.

This framework is intended to provide guidance, considerations and recommendations to teams, zones, sites, programs and clinics to support meaningful and respectful engagement practices, focused on settings within primary health care and answers to questions such as those below.

- How can we best support you on your journey when you walk through our door?
- How can we ensure a safe and welcoming environment for all who enter?
- What matters most to you when you here / are reaching out for support for you or your loved one through opioid use?
- How can we guide you through using your personal story to build community and improve our processes?

## 4 Background

Tackling the opioid crisis in Alberta will require new approaches and an immediate response of the entire health system to change its trajectory. The engagement and response of primary care physicians, their teams and Primary Care Networks (PCNs) in Alberta will be essential in defining new primary health care approaches to address the crisis and the systemic issues that contribute to the crisis.

The Alberta College of Family Physicians (ACFP), Alberta Medical Association (AMA) and Alberta Health Services (AHS), together with Alberta Health (AH) are aligned to lead this essential work to focus the primary care response. The primary care response will include:

- **Urgent Opioid Response** - addressing the urgent needs of those in crisis through the distribution of naloxone kits and the provision of Opioid Agonist Therapy (OAT) within primary care settings
- **Enhanced Provider Decision Support, Knowledge Translation and Education** - ensuring basic knowledge and competencies to support patients with addiction, mental health and pain issues, and changing current practice within primary care clinics and PCNs to better care for individuals using opioids
- **Enhanced Opioid Related Service Delivery through PCN Zone Committee Engagement, Planning and Implementation** – developing new integrated service delivery models coordinated with partners including Alberta Health Services (AHS), AHS zone Addiction and Mental Health services, community services, and others.

Engaging those with lived experience is critical to the primary care opioid response.

Engagement of Patients and Families in the healthcare system has been shown to have educational benefits for both the patients and the system members and improved processes and communication (<http://insite.albertahealthservices.ca/assets/pe/tms-pe-patient-engagement-resource-kit.pdf>). AHS has committed to both the Patient First Proclamation and Patient First Strategy, inclusive of patients and families being recognized as an integral part of their health care team as well as critical members to be involved in planning, implementation and evaluation of existing and future care services, policies, procedures and hiring. The involvement of patients in all areas of health care align with Accreditation Canada's inclusion of client-centered services as a key quality dimension.

The unique dimensions of engaging individuals with lived experience in an advisory capacity brings to the table those impacted by the crisis in a number of different ways, some have experienced it first hand, supported someone through Opioid Dependency or lost a loved one. These authentic and raw experiences offer a unique perspective that only those who have been there can speak to. This first-hand experience and perspective offer potential solutions and opportunities that may not otherwise come to light.

## 5 Principles

The process for engaging individuals with lived experience within the context of opioid use is somewhat unique. It requires, on the part of health care providers or other team members, an understanding of the potential sensitivities and vulnerabilities present for the individuals and/or groups being engaged. Regardless of who is engaged it is likely that they have either directly or indirectly been impacted by loss; death of a loved one, loss of livelihood, loss of respect, loss of trust, and in many cases they have experienced stigma from health care providers and others in positions of power.

It is critical that site and agency response requirements and policies are clear, understood, and discussed before engagement activities take place. It is also essential to ensure there is a respectful opportunity for an individual and/or groups with lived experience to have the opportunity to decline participation at any time in the process. It can also be beneficial to identify alternate sites and various ways in which engagement can take place to accommodate as much as possible the needs, and requests of individuals to ensure they feel comfortable, and safe participating.

The following principles are intended to guide health care providers, teams, programs, and project planners as they move forward on engagement related activities.

### EQUITY AND RESPECT

- Individuals with lived experience related to opioid use, hold their own expert perspective. The history of connection with all aspects of opioid use, and related use of the health care system offer insight and perspective
- An understanding that this is about “us” as a community, not “them” as individuals with lived experience
- Know your team’s biases with regard to opioid use, grief, loss and support through understanding and growing
- All attempts will be made to ensure safety for Individuals with lived experience. This may mean adaptation for opioid use during a meeting (possibly host the meeting at a safe use site), adjustments for literacy or any other barriers to not understanding documentation. Documentation will be kept to a minimum so as to prevent it becoming a barrier but still meets any ethics requirements as determined by all parties (AHS, community agencies etc.) (Refer to Risks & Mitigation Strategies)
- Individuals with lived experience, regardless of the experience, is one of vulnerability. Appropriate supports, clear guidelines, responsive care and equitable relationship balances will be developed before engaging by the team
- A culture shift is critical to the success of this strategy. The support of leadership, the encouragement and opportunity for individuals with lived experience engagement and the unique requirement of each site will be developed and made available to all
- Awareness that engaging a single individual for input can put them at risk and make them feel vulnerable. Engaging a larger group allows for equity in numbers, safety to speak and respects the voices at the table
- Working with individuals with lived experience of opioid use brings a unique relationship into play, any clinical members engaging must also be supported in being vulnerable, offered an environment of safety to step outside of previous relational boundaries and offered clear and concise guidelines at a local or zone level

- Clinical members may be at risk of vicarious trauma or grief and loss in the event of a lived experience individual's death. Individuals experiencing their own vulnerability due to the emotional risks may have prior awareness, where they feel safe, to access support and resources to heal as needed. More than administration of Naloxone is imperative, this is about compassion and empathy.
- Duty of care in the professional workplace environment differs from engaging with individuals with lived experiences. There will be clarity with regard to the differences between the responsibilities in role and the responsibilities as a lived experience practitioner.
- Those individuals with lived experience should end the engagement with a richer understanding of themselves, their personal journey, their options, and most importantly hope.

### **BUILDING RESILIENCY AND HOPE WHILE ENGAGING**

- Ensure your culture shifts include the opportunity to build capacity in those with lived experience
- Have conversations with individuals with lived experience partner if you have relationship and trust in place and they are open to such conversations
- Reducing stigma will enhance individual sense of belonging
- Be willing to take this journey with them, knowing it could potentially be emotional and vulnerable for all parties
- Allow the other person to identify what matters to them
- If they are not interested in this area of relationship, you can still instill positives, identify strengths and support increased self-worth through the engagement
- Those individuals with lived experience should reach the end of the engagement with a richer understanding of themselves, their personal journey, their options, and most importantly hope.
- Be aware of the potential for re-traumatization and/or disappointment

### **SUPPORT FOR THE CLINICAL AND NON-CLINICAL TEAM MEMBERS**

- Site specific training for staff in engaging the lived experience, providing support for them and also ensuring support and safety for staff members must be explored and engaged to ensure success
- Duty of care in the professional workplace environment differs from engaging with individuals with lived experiences. There will be clarity with regard to the differences between the responsibilities in role and the responsibilities as a lived experience practitioner.

### **SHIFTING CULTURE**

- The involved organization(s) and all team members will journey together through preparatory work before engaging, ensuring that the entire team, space and culture has shifted to one of vulnerability, transparency and willingness to engage.
- A culture shift is critical to the success. The support of leadership, the encouragement and opportunity for individuals with lived experience engagement and the unique requirement of each site will be developed and made available to all
- Authentic identification of biases, existing stigma, assumptions and intolerances
- Engagement and willingness to learn from community partners, other teams, internal wisdom on your team



## TRANSPARENCY, PURPOSE AND LEARNING

- Those individuals with lived experience will be encouraged to:
  - Feel safe enough to speak up, set their own boundaries and goals for engagement
  - Set goals for what they would like to see once engagement is complete (referrals, support, developed documentation, future engagement etc.)
  - Safety and risk discussions
- Any agency expectations will be shared with the lived experience members. For example:
  - If someone uses on site, do they want intervention
  - If a lived experience individual brought their child with them, what will responses be if they become unable
  - Is the environment a safe place to meet for all
  - Any recording; written, audio or video will be clearly announced to all
- Transparency and discussion with regard to any power differentials, with agreed upon outcomes *before any discussions begin*. Any potential risks (policies that must be followed) will be discussed

## DURATION AND RESPECTFUL ENDING OF ENGAGEMENT

- Disengagement is a natural ending or a premature ending of the engagement. Endings to the engagement are conversations that should occur before engagement is agreed upon or begins. If reasons arise during engagement that either party wishes to disengage, supportive conversation will occur.
- It is critical that ongoing discussions occur regarding the ending of this commitment, potential for triggers, supports offered and referrals. This is potentially a high risk activity for those with lived experience and the levels of support required may vary throughout the engagement itself
- Clarity with regard to the proposed length of engagement, commitment expectations, type of engagement (focus group, one to one, digital storytelling, presentation, working group membership) and other considerations will be discussed by all parties
- If this is a lengthy or ongoing consultation, transportation or other supportive conversations will occur openly
- Closure or ending of the engagement relationship will be discussed. Understanding that the potential for a sense of loss, a need to stay in a connected relationship due to the work done together and trust built, a sense of “what now” on the part of the volunteer with the lived experience will be openly discussed and supports reviewed
- One party may find it critical with withdraw from the process or someone with a lived experience may not make appointments. Clarity, support, trust and safety are critical for an equal and transparent relationship and the ability to dissolve the relationship must also be clear, supportive, trusting and safe
- Discussion about future projects and interest will be reviewed. Consent for referrals will be garnered if required

## CULTURE OF CELEBRATION

- As conversations are held with all parties involved, conversations for moments of celebration are critical
- Celebrating successful engagement for all parties builds relationship and trust
- Community grows when there is celebration of unity and understanding

### INDIVIDUALS WITH LIVED EXPERIENCE

- A story told, healing because of it
- Belonging, recognizing personal skills and sharing, being part of community
- Using a lived experience as a skill
- Learning new engagement, advisory and collaboration skills
- Helping to change a community through experiences
- Working with a system to improve it

### THOSE ENGAGING WITH INDIVIDUALS WITH LIVED EXPERIENCE

- Capturing the wisdom that was shared to change a culture
- Identification of culture shifts
- Being involved in engaging vulnerable individuals in a positive and powerful way

## 6 Framework

This framework is based on and adapted from a multi-dimensional model for patient and family engagement in health and healthcare developed by Carmen et al, 2013 (Figure 2). This model is linked to a public participation spectrum (International Association for Public Participation – IAP2) that frames a continuum of engagement across five levels identified as; inform, consult, involve, collaborate, and empower.

As outlined in red in the figure below, this framework supports a desire to engage individuals with lived experience (i.e. patients/families/others) at the organizational design and governance level, by consulting and involving individuals to inform provincial, zone and PCN Opioid Response Initiatives in primary care settings.

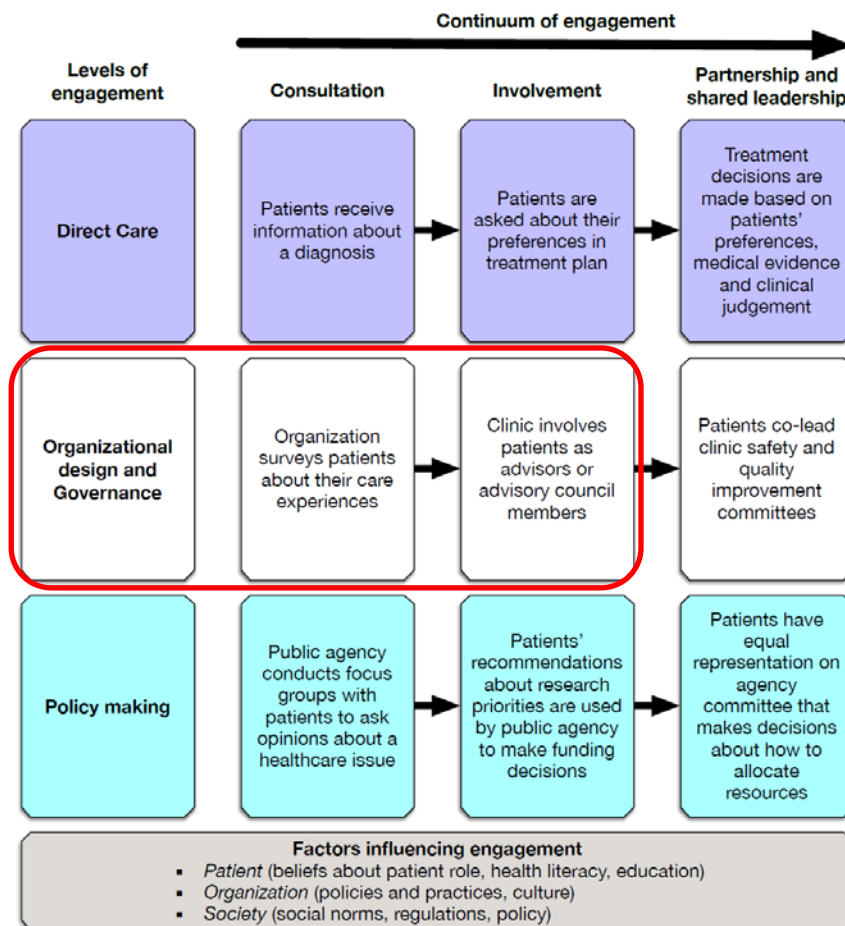


Figure 2: Carmen, et al. 2013

### 6.1 Processes

The capacity to meaningfully engage individuals with lived experience toward informing improvements and a cultural change must be built across all groups – health system leaders; physicians/staff/teams; and patients/families/lived experience individuals.

Building engagement-capable environments draws on three core processes (Figure 3):

1. **Ensuring leadership support and strategic focus:** Leaders at all levels will need to empower clinicians and teams to work in different ways with individuals with lived experience. They will need to champion and set an expectation and accountability for both engaging individuals in the work and create the conditions to take action.
2. **Engaging staff to involve patients:** Clinicians/teams/planners must value the input of individuals with lived experience and recognize the usefulness of their views and experiences.
3. **Enlisting and preparing the individuals and groups to be engaged such as patients, families, and/or individuals with lived experience:** Effective engagement requires the recruitment, on-boarding, preparation, orientation, and appropriate supports.

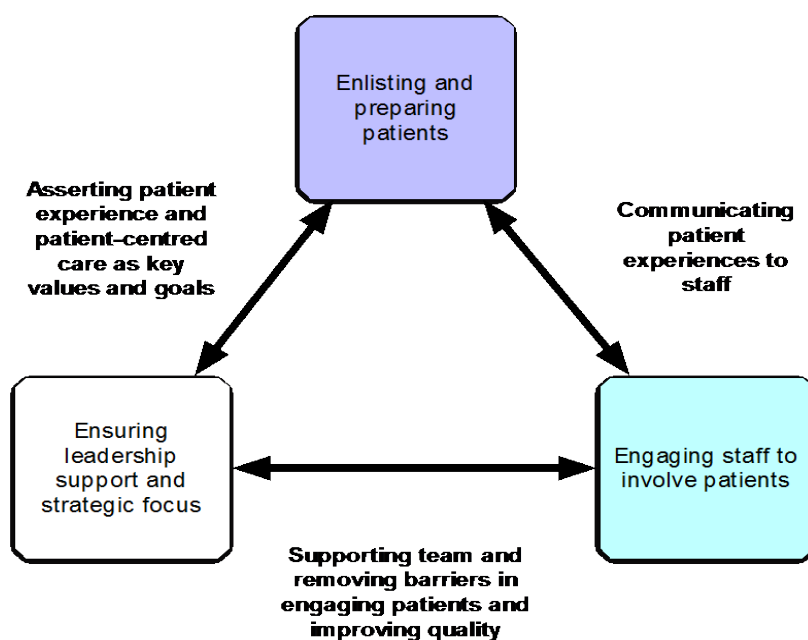


Figure 3: Baker & Denis. 2011

Each process will have supporting tools and orientation to build engagement-capable environments at provincial, zone and PCN levels of activity. Co-designing sustainable solutions will be achieved through clinicians, staff and teams working together with individuals with lived experiences.

## 6.2 Populations for Consideration

As groups prepare to engage individuals, they are encouraged to seek diverse perspectives, including but not limited to the following:

- [People Who Use Drugs](#) (Nothing About us Without us, CAPUD is raising the voice of people who use(d) drugs throughout the policy making process through every level of government)
- Patient advisory groups – e.g. AHS Provincial Patient & Family Advisory Group; Calgary-zone 3. Addictions & Mental Health Client Advisory; SCN Patient Engagement Reference Group; others
- Individuals using prescription opioids
- Individuals using illicit sources of opioids
- Families living within and impacted by opioid use (parents, spouses, children)
- Families facing loss due to opioid use
- Individuals chronically using prescribed opioids
- Individuals experiencing acute or chronic pain

- Recreational / non-medical use of opioids
- Well at-risk
- Veterans and other populations of individuals with PTSD
- Expecting mothers using opioids
- Caregivers, parents and/or health care providers for newborns born with dependency to opioids
- Patients within a family practice clinic or Primary Care Network (PCN)
- Indigenous populations & communities
- Vulnerable and/or complex high needs populations
- Multiple co-morbidities and/or chronic disease
- Individuals experiencing homelessness, vulnerably housed

### 6.3 Engagement Methods

There are numerous methods for gaining the voice of patients and individuals. Each method has its purpose, limitations and advantages contingent upon the scope of the initiative, population to engage, resources and type of input needed.

Types of Engagement Activities to consider include:

- Focus group
- Phone call
- In-person individual meeting
- Audio, video or written recording
- Patient Shadowing, Patient Journey Mapping, Empathy Mapping
- Collaboration with community agencies
- Interactive blogging with teams and those with lived experience
- Educational presentation
- On-going membership on a committee or initiative working group
- Council or advisory

## 7 A Roadmap for Engaging Individuals with Lived Experience

The purpose of this roadmap is to guide engagement with individuals with lived experience. It outlines steps that allow for the unique development of your engagement and guidance on considerations **before** actual engagement activities until the engagement has been completed. Using this roadmap as a guide, plan your own ensuring that each area's work and goals have been developed based on your unique initiative and engagement opportunity. Consider that often you may not know what your opportunities are until you have those with lived experience actually assist you with looking into this.

Note: Roadmap is displayed on the next page. Printable document (size 11" X 17") is attached below.



Engaging Lived  
Experience Roadmap.

# A Roadmap for Engaging Individuals with Lived Experience

AREAS TO ADDRESS	PHASE 1: READINESS & LEADERSHIP SUPPORT	PHASE 2: PLANNING THE ENGAGEMENT & PREPARING THE TEAM	PHASE 3: RECRUITMENT, ON-BOARDING & ORIENTATION	PHASE 4: ENGAGEMENT ACTIVITIES	PHASE 5: EVALUATION OF ENGAGEMENT	PHASE 6: REPORT BACK & RESPECTFUL ENDINGS
Site/Leadership Readiness	<ul style="list-style-type: none"> <li>Why are we engaging?</li> <li>What are your expectations and hopes?</li> <li>Have we consulted with the right supports?</li> <li>What will you do with the input?</li> <li>Are your goals clear?</li> </ul>	<ul style="list-style-type: none"> <li>Preparation, education, skill building within the team</li> <li>What type of engagement is best for the situation</li> <li>Do you have infrastructure in place prior to engagement commencing?</li> </ul>	<ul style="list-style-type: none"> <li>Where will you recruit or seek the voice of lived experience from?</li> <li>How will diversity of voices be included?</li> <li>Are you aware of engagement &amp; community resources to assist and partner with you?</li> <li>Who will develop and provide orientation?</li> </ul>	<ul style="list-style-type: none"> <li>The engagement has clear beginning, ending, and goals</li> <li>How will you minimize risk and potential harm?</li> <li>Are the team members involved committed to this process in a respectful and caring manner?</li> </ul>	<ul style="list-style-type: none"> <li>What are the evaluative pieces of this engagement?</li> <li>How will outcomes of the evaluation be measured?</li> <li>How will outcomes be shared with the individuals who were engaged?</li> </ul>	<ul style="list-style-type: none"> <li>Those conducting the engagement have a plan to communicate back how input was used, actioned and decisions impacted as a result</li> <li>What if one party wishes to end the engagement?</li> </ul>
Lived Experience Engagement	<ul style="list-style-type: none"> <li>What support do we need, or have we offered supports before we engage (community, friend)</li> <li>Are there unique needs you have to enable participation</li> <li>Who are your resources and supports</li> <li>What are your goals for engaging</li> <li>How can this opportunity enhance your life and your community</li> <li>Do you feel safe in this environment and trust the team to be respectful</li> <li>Are you able to share openly regardless of what your story holds</li> </ul>	<ul style="list-style-type: none"> <li>You feel comfortable with the spaces and readiness of the group you are meeting with</li> <li>You feel heard and your needs before engaging have been met</li> <li>What type of engagement are you comfortable with</li> <li>Who would you like to have come with you</li> <li>Do you feel comfortable with the team you are consulting with, if not what do you need?</li> <li>Are you prepared for what this engagement may include (emotion, vulnerability etc.)</li> </ul>	<ul style="list-style-type: none"> <li>You have been approached in a respectful manner clearly outlining what the group is looking for</li> <li>You have had opportunity to review and seek support before signing any documentation</li> <li>You are clear on your role and reason for engaging</li> <li>You feel prepared to engage</li> <li>I know who to call with questions</li> <li>I know expenses and barriers to engage will be removed</li> </ul>	<ul style="list-style-type: none"> <li>You are invited into the engagement in a meaningful way</li> <li>You feel respected, cared for, involved</li> <li>You are clear on your role</li> </ul>	<ul style="list-style-type: none"> <li>You know your feedback on the engagement process is welcomed and will be listened to</li> <li>You know how your input was used or why it was not</li> </ul>	<ul style="list-style-type: none"> <li>How will you ensure you are well and ready to end the engagement</li> <li>Do you feel safe to end the engagement at any time (future engagement, community referral etc.)</li> <li>You are aware that your role was critical and created change</li> <li>You know the outcomes and next steps</li> <li>You felt respected and cared for</li> <li>You know how your input and experience impacted changes</li> <li>You are clear when the engagement has concluded</li> </ul>
Changing Practice Culture	<ul style="list-style-type: none"> <li>Do we need consultation with specialists on changing culture</li> <li>Has the team developed trust among themselves to take on this journey</li> <li>Clear communication channels and responsibilities established</li> <li>Is empathy authentic</li> <li>The difference between engaging lived experience because it is the right thing to do and that is where the wisdom lives vs. tokenism</li> <li>Are supports in place for team debrief, processing and caring</li> </ul>	<ul style="list-style-type: none"> <li>Have your team members developed relationship, rapport and trust (this is a time component)</li> <li>Training is complete and the team has addressed barriers, concerns, biases, fears and feels supported and ready to engage</li> <li>Are you familiar with protocols for each unique type of engagement</li> </ul>	<ul style="list-style-type: none"> <li>Leadership supports the direction of engagement</li> <li>Orientation for all is complete and a sense of understanding the importance of engagement now exists</li> </ul>	<ul style="list-style-type: none"> <li>Awareness of the importance of ongoing support for all involved has been addressed</li> <li>Capacity is built within the team to support future engagement activities</li> <li>If the reasons why either party is engaging change, a pause and re-evaluation will occur</li> </ul>	<ul style="list-style-type: none"> <li>The team has a debrief process in place</li> <li>All parties identify what worked and what needs to change or grow</li> <li>Engagement was purposeful and positive</li> </ul>	<ul style="list-style-type: none"> <li>A culture of mutual trust and respect has been developed</li> <li>Teaching what ending needs to look like may need to occur for all parties</li> <li>Next steps will be set if engagement activities will continue or take new directions</li> </ul>
Special Considerations	<ul style="list-style-type: none"> <li>What type of engagement is best (video, teleconference, audio, 1:1, written etc.)</li> <li>Has a conversation occurred about space (will a child be present, will there be active use, is lived experience person still grieving a loss?)</li> <li>Who will be designated as the 'liaison' or contact and support person throughout the process</li> <li>If the reasons why either party is engaging change, a pause and re-evaluation will occur</li> <li>Awareness and respect of hopes and expectations for all parties is critical to success</li> </ul>	<ul style="list-style-type: none"> <li>Have you consulted where the individual with lived experience is most comfortable? YOU CAN COME TO THEM...meet in a space of their choosing, keeping safety for all in mind (will lived experience person be under the influence, etc.)</li> <li>Are there adaptations needed to your space to be welcoming and safe for everyone</li> <li>Are there resources available for all parties if required (team may need further support in learning to work with those in active addiction, lived experience individual may wish to move from addiction to treatment)</li> </ul>	<ul style="list-style-type: none"> <li>Recruitment is about building relationship, this is a time commitment by all</li> <li>Orientation is ideally held face to face to build relationship and trust; conducted by leaders/facilitators leading the initiative</li> <li>This is where the risk of tokenism vs authentic engagement can become blurred</li> </ul>	<ul style="list-style-type: none"> <li>During engagement is the most vulnerable time for those with lived experience; this has been planned for and mitigated</li> <li>Processes are in place to support applying the learning's from the engagement processes</li> </ul>	<ul style="list-style-type: none"> <li>Do all parties understand the risks, expectations and goals of the other and how to open conversation up if these change</li> </ul>	<ul style="list-style-type: none"> <li>A disengagement plan is in place that is positive</li> <li>There is no failure, but rather this is a journey</li> <li>How to reconnect if an abrupt ending occurs</li> <li>Referrals for on-going support made if requested</li> <li>At no time should an engaged lived experience individual feel "dropped" or suddenly alone. Clear support is critical.</li> </ul>
Tools & Resources to support	<ul style="list-style-type: none"> <li>The Voice of Patients and Families: A Getting Started Guide <a href="http://www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-voice-patient-families-guide.pdf">www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-voice-patient-families-guide.pdf</a></li> <li>Engagement Readiness Checklist <a href="http://insite.albertahealthservices.ca/assets/pe/tms-pe-readiness-checklist-for-partnering-with-patient-and-family-advisors.pdf">http://insite.albertahealthservices.ca/assets/pe/tms-pe-readiness-checklist-for-partnering-with-patient-and-family-advisors.pdf</a></li> <li>Empathy Mapping <a href="https://www.albertahealthservices.ca/assets/info/hp/cdm/if-hp-cdm-empathy-mapping-summary.pdf">https://www.albertahealthservices.ca/assets/info/hp/cdm/if-hp-cdm-empathy-mapping-summary.pdf</a></li> <li>Seek support in your zone through AHS Engagement &amp; Patient Experience zone-based consultants as well as local Patient/Family Advisors</li> </ul>	<ul style="list-style-type: none"> <li>AHS online learning modules: Patient Engagement 101 (Available Spring 2018)</li> <li>Meaningful Engagement Module 1: Roles &amp; Responsibilities of Patient Advisors; Module 2: Roles and Responsibilities of Staff; Module 3: Creating Meaningful Engagement</li> <li>AHS EPE Patient Engagement Guidebook- <a href="https://www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-guidebook-for-engaging-patient-family-advisors.pdf">https://www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-guidebook-for-engaging-patient-family-advisors.pdf</a></li> </ul>	<ul style="list-style-type: none"> <li>AHS Patient and Family Engagement toolkit <a href="http://insite.albertahealthservices.ca/assets/pe/tms-pe-patient-engagement-resource-kit.pdf">http://insite.albertahealthservices.ca/assets/pe/tms-pe-patient-engagement-resource-kit.pdf</a></li> <li>AHS Patient and Family Advisor Resources- <a href="https://www.albertahealthservices.ca/info/Page15876.aspx">https://www.albertahealthservices.ca/info/Page15876.aspx</a></li> <li>How to Involve People Who Use Drugs <a href="http://towardtheheart.com/assets/uploads/151614422666vjis05U2QP2Pu4p56pp6f05c0mObC2L.pdf">http://towardtheheart.com/assets/uploads/151614422666vjis05U2QP2Pu4p56pp6f05c0mObC2L.pdf</a></li> </ul>	<ul style="list-style-type: none"> <li>Ways to include the voice of patients and families <a href="http://insite.albertahealthservices.ca/17294.asp">http://insite.albertahealthservices.ca/17294.asp</a></li> <li>Existing AHS Engagement &amp; Patient Experience toolkits can be leveraged and customized as needed for PHC Contact: <a href="mailto:patient.engagement@ahs.ca">patient.engagement@ahs.ca</a></li> <li>Seek support in your zone through AHS Engagement &amp; Patient Experience zone-based consultants as well as local Patient/Family Advisors</li> </ul>	<ul style="list-style-type: none"> <li>(coming soon Spring 2018) Evaluation Tool for Patient Engagement in SCIs</li> <li>Contact: <a href="mailto:patient.engagement@ahs.ca">patient.engagement@ahs.ca</a></li> <li><a href="https://www.cfhi-fcss.ca/sf-docs/default-source/patient-engagement/awesome_workbook-fraser-health.pdf">https://www.cfhi-fcss.ca/sf-docs/default-source/patient-engagement/awesome_workbook-fraser-health.pdf</a></li> <li><a href="http://insite.albertahealthservices.ca/assets/pe/tms-pe-the-value-of-engaging-patients-and-families.pdf">http://insite.albertahealthservices.ca/assets/pe/tms-pe-the-value-of-engaging-patients-and-families.pdf</a></li> </ul>	<ul style="list-style-type: none"> <li>AHS EPE Patient Engagement Guidebook <a href="https://www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-guidebook-for-engaging-patient-family-advisors.pdf">https://www.albertahealthservices.ca/assets/info/pt/pe/if-pt-pe-guidebook-for-engaging-patient-family-advisors.pdf</a></li> </ul>

## 8 Risks and Mitigation Strategies: Preparing for Challenging Situations

As with any engagement activity preparation and planning presents the opportunity, through reflection, to identify potential challenges and risks that may arise. Doing so allows for identifying steps to proactively plan for, prevent and/or mitigate such difficulties from arising creating beneficial experiences for both the individuals and groups being engaged and those taking on the engagement. There are also potential risks with engaging those who have experienced first-hand the opioid crisis and these will be explored, identified and mitigated over time through the expertise that only a lived experience can offer. This is a journey of vulnerability for all involved, understanding, supporting and sharing will build trust.

The following table outlines some of the potential risks that may arise when engaging individuals with lived experience related to opioid use and/or dependency. Health care providers, teams and programs are encouraged to inquire about any relevant risks and mitigation strategies, policies and procedures within their area / organization.

Identified Risk	Impact (Low/Medium/High)	Recommended Mitigation Strategy
An individual experiences significant distress during an engagement session	Medium	Identify relevant and appropriate local resources that individuals can be referred to. Where possible identify / confirm potential opportunities for a 'warm handoff' to the identified service. Ensure that anyone conducting an engagement activity or session is aware of the resources and how they can be accessed (e.g. Is a physician referral required)
During an engagement session an individual self-identifies a desire to seek treatment or follow-up with a local service	Medium	Ensure local and accessible resources have been identified ahead of time, include specialty services for Opioid Dependency Treatment and/or chronic pain (see PHC ORI Toolkit service inventory listing) and that staff are familiar with the services identified and how they can be accessed
Confusion or miscommunication of engagement opportunities in ORI initiatives	Medium	Risk assessments and local environmental scans of current engagement activities should developed at local and zone levels  Open channels of communication with local agencies, zone working groups & provincial groups on engagement activities
Awareness that the engaged relationship can move fluidly from therapeutic to community member engagement as determined by those with lived experience	Medium	Clear ethical guidelines between a therapeutic relationship and lived experience volunteer engagement  Review of any required clinical ethics guidelines &/or AHS Volunteer Policy separating patient care and volunteer advisor engagement (AHS vs non-AHS policies)

Identified Risk	Impact (Low/Medium/High)	Recommended Mitigation Strategy
<p>During an engagement session an individual arrives high or decides to use an illicit substance</p>	<p>Low</p>	<p>It is strongly recommended that all staff conducting engagement activities or sessions have a Naloxone kit on hand and training in administration (See PHC ORI toolkit resource)</p> <p>Staff who are engaging know appropriate processes &amp; procedures to respond if necessary (e.g. 911, referral to primary care provider....)</p> <p>Appropriate procedures shall be initiated in emergency situations where an illicit substance overdose is suspected</p> <p>Follow specific documentary requirements in the event of Naloxone administration (Emergency Intervention Record). Each site will have to assess the requirements for adherence to AHS standards or ensure development and compliance of their own documents, inclusive of transfer of care</p> <p>Access Safe Consumption Site materials and education to reduce harm associated with illicit substance use and provide access to supports and referrals for patients to address their substance use, should they wish to (refer also to the change from engagement to care)</p> <p>A review of potential barriers and risks (an overdose during a meeting, and clear guidelines were set for no resuscitation or naloxone is requested in the event of an OD), literacy, too many documents and too bureaucratic a process, financial remuneration (cash without conditions, therefore without judgement)</p>
<p>After an engagement session has ended it is noted that an illicit substance is left behind by one of the individuals who attended</p>	<p>Low</p>	<p>There are often organization specific policies and procedures in place outlining steps to take in such instances. Consider identifying your organizations expectations for response in such situations.</p> <p>If not an AHS site, development of appropriate protocols to guide staff and inform the lived experience individuals are critical to ensuring knowledge of appropriate processes</p> <p>Confirm if Local Police, EMS or Fire Service will pick up any substances left behind and documentation of such is critical</p>



## 9 Appendix I – Readiness Checklist: Engaging Individuals with Lived Experience

This checklist has been developed in alignment with the *Patient and Family Centered Care* model and Alberta Health Service's *Patient First Strategy*. This checklist is intended to support decision making in regard to when and how patients, their families and individuals with lived experience are best engaged to ensure positive experiences for the individuals engaged, staff, health care providers, and project teams maximizing the potential for benefits to health care system.

### THE DECISION TO ENGAGE: a checklist

Prior to reviewing the checklist ensure some degree of pre-work and reflection has occurred to identify the desired outcome or intention for the engagement, purpose, scope and how the engagement activities will be used to inform system and practice level improvements.

- ✦ Problem or issue (target area) to be addressed has been, at least in a cursory way, defined including identification of individuals or particular populations who can further an understanding of the issues and inform potential solutions
- ✦ Potential biases, beliefs and assumptions have been discussed and explored within the project team to minimize potential for unintended influence or negative impact (stigmatizing experiences) on the individuals being engaged
- ✦ Degree of expertise of members of the project team, in regard to engagement with patients, families, and individuals with lived experience, has been assessed, gaps identified, and a plan developed that builds on team strengths and identifies opportunities for improvement including building capacity.
- ✦ Initial ideas have been generated regarding who; individuals, groups, areas of care etc., to reach out to
- ✦ Project team members who will be involved, including the lead, for the engagement work have been identified including roles and expectations
- ✦ Leadership at various levels has been engaged and provided endorsement for the engagement activities and work to occur. Inclusive of resourcing, budget, staff time, and intended follow-up including intent to inform growth of team, organization, and provision of care
- ✦ A risk assessment and mitigation plan has been conducted
- ✦ Engagement activities and work is aligned with the organization, zone, PCN, program and clinic strategic direction
- ✦ A rationale for the engagement including valued and tangible outcomes has been identified
- ✦ An appropriate site, space, schedule and time for the engagement activities taking place has been identified
- ✦ Any needed training or pre-work for individuals involved on the project team has taken place
- ✦ A plan for closing-off engagement activities with those being engaged has been prepared and socialized across the project team, including evaluation needs, debriefing, and how the information and insights gained will be used to inform or make improvements
- ✦ Required documentation including consent forms have been identified and are in place
- ✦ Principles to guide engagement related activities, such as those listed in this document, have been identified and socialized across the project team. Others considerations include empathic or active listening, potential for vicarious trauma and need for supports for project team members in addition to the supports for the individuals being engaged
- ✦ Resources for follow-up support and/or referral for both staff (project team) and individuals or groups being engaged have been identified

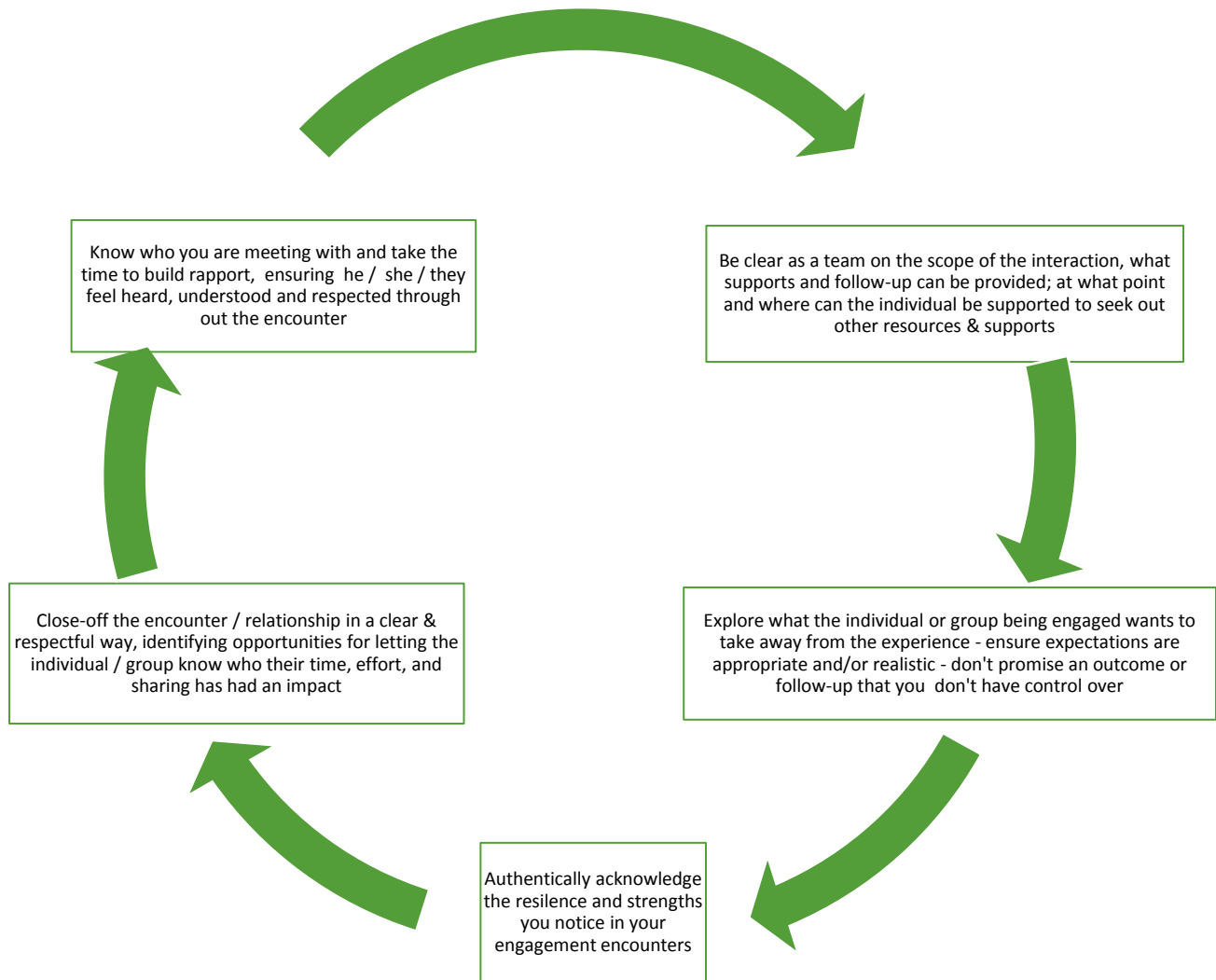
**CREATING VALUE FOR PATIENTS, FAMILIES AND INDIVIDUALS WITH LIVED EXPERIENCE**

Prior to initiating engagement activities, it is important to consider the value of participating in the engagement activities for the individuals and groups that are being engaged. Consider the following:

- ✦ What are the outcomes, decisions, products or services that will be impacted by the engagement activities and how will this improve service or care delivery, or program / system redesign
- ✦ Inform physician and/or health care provider interactions with patients
- ✦ Community level supports for individuals with lived experience
- ✦ Steps toward prevention related services, supports and/or resources
- ✦ Minimize future potential for experiencing bias and stigma in their interactions with the public, communities in which they live, and/or the health system
- ✦ Improve transition in care to create a more seamless and person-centered experience
- ✦ Contribute to experiences of building trust within a safe environment free of judgement
- ✦ Ensuring any commitments made to groups and/or individuals to be engaged are documented, can be honored and are followed-up on to ensure this has transpired
- ✦ If Remuneration is included, or participation expenses being covered awareness of appropriate remuneration is critical. e.g. For someone on Alberta Works funding this may count as income and have an impact on qualifying criteria

## 10 Appendix II- Making Referrals

Within any interaction with individuals or groups there is an opportunity to be mindful of additional ways through which to support and increase the likelihood of a positive and meaningful experience. Toward this aim it can be beneficial to consider some foundational strategies for communication, highlighted in the illustration below.



## 11 Appendix III – Scenarios to Guide Unique Site Response

These scenarios are guides to the possibilities of who your lived experience individuals may be, their unique stories and why engagement is so critical but authentic and empathetic engagement is also critical.

### Considerations:

- Are you authentic in wanting to engage, are you committed to this entire process
- Do you know how much this matters to individuals with lived experience and how important doing this right truly is?
- Your site specific policies, procedures, responses (administration of Naloxone, allowing individuals with lived experience determining if they wish to be reversed etc.)
- Any guiding policies you must adhere to (AHS policies on drug overuse etc.)
- Are the right team members present to support both the individual and the staff involved
- What type of engagement are you seeking?
- Do you have knowledge of your community's supports, resources and how to refer
- What are the strengths and resiliencies of your client/patient that you wish to engage, this is not about "not doing harm" but rather caring about our community as a whole

### Michael:

You are a doctor in a Primary Care Network. Your team is wishing to develop a patient advisory group to speak into the new programs you want to provide to your community with regard to opioid overuse. You considered Michael as someone who could speak into what a patient would need who is in active drug overuse but also engaged in attending appointments and utilizing supports.

Michael has been a patient in your clinic for 4 years. He is 48 years old and has been using non-prescription opioids for 3 years. Michael fell off of scaffolding at work 4 years ago, injured his neck and back and was prescribed opioids for pain management. He began drinking to manage the financial stressors, his wife left him and he is now living in a small apartment with a street friend.

### Kennedy:

You are a registered massage therapist who has operated 4 different massage centers in Calgary. You have found that over the years you have built a strong rapport with a number of your clients, and as you look into the concept of "wellness" you want clients to guide what is missing from the services you offer.

Kennedy is a 34-year-old woman, 6 months pregnant with her 4<sup>th</sup> child, has a home in Altadore with her husband and 3 children. Kennedy started using cocaine when she and her husband split two years ago for months due to his escalating temper. They moved back into their shared home where Kennedy's husband took anger management for 3 months. Since then their marriage has managed to hang on, but he found out she was using cocaine. Kennedy had a friend provide her with fentanyl as she could hide the pill use from her husband. She comes to your massage clinic for maternal massage to assist with hip pain due to her pregnancy. She has shared during massage her history of drug use and marital problems.

**Andrew:**

You have a dental practice in Edmonton, with 7 offices, two in the inner city. You were considering engaging patients in the development of identifying and caring for those who may be engaged in drug use, identified through dental examinations.

Andy is a 69-year-old retired firefighter, married and a grandfather to 4 boys. He has attended your dental office for years, but of late, you have noticed a steep decline in dental health. Andy presents with a number of sores on his face and hands, he looks fragile and shaky. You want to consider engaging in developing more client-focussed services, Andy may be able to assist.

**Ann-Marie:**

You operate a small medical clinic in Rocky Mountain House. You work in your own clinic 3 days a week and in the emergency department of the small hospital 3 days a week. You have noticed a gap in transitions of care between hospital discharge and patients re-connecting at the clinic.

Ann-Marie is 19 years old, has 2 small children and has had McMan Youth, Family and Community Services involved in her home, supporting her. Ann-Marie has attended both your clinic and the hospital with various injuries, and most recently with a broken arm and multiple contusions and bruises. Ann-Marie is afraid to seek out medical care but cannot lift her baby due to her arm injury. Child and Family Services have informed her she may lose custody of her children unless she either leaves her husband or attends the Women's Domestic Violence Centre.

## 12 Appendix IV – Glossary

**Harm Reduction:** is one of the concepts of a public health approach to substance use. Both abstinence-based and harm reduction approaches are part of an integrated continuum of care...harm reduction services meet people “where they are” in terms of their substance use. Harm reduction may include education about safer substance use, distribution of new supplies, safer consumption facilities, programs to prevent and treat overdose and opioid substitution therapies. (HC)

**Health Equity:** means that all people can reach their full health potential and should not be disadvantaged from attaining it because of their race, ethnicity, religion, sex, gender, age, social class, socio-economic status, or other socially determined circumstance. (HC)

**Lived Experience:** for the purpose of this document, describes those who have been impacted by the opioid crisis. This may be those presently over-using opioids, those who have over-used opioids in the past or those who have been impacted by the over-use of opioids, including death.

**Naloxone:** is an effective opioid antagonist that can act as a reversal agent for the treatment of an opioid overdose.

**Opioid Agonist Therapy:** treatment that involves the use of opioid agonist medications such as Methadone or Buprenorphine / Naloxone (Suboxone®) as a means of preventing withdrawal from opioid addiction, while stabilizing the lives of those overusing opioids and reducing the harm from opioids.

**Opioid Use Disorder:** describes those who are misusing opioids or have overused opioids in the past

**Resilience:** a dynamic process in which a range of factors interact to enable an individual to develop, maintain, or regain mental health, despite exposure to adversity. (HC)

**Safe Injection:** Sites created for the specific purpose of safe injections of drugs

**Supervised Consumption:** Refers to the use of any substance, inclusive of alcohol are made safe because of the presence of supports support of services designed to improve the health of the substance user

**Supervised Consumption Services:** part of a range of evidence-based services that support prevention, harm reduction and treatment for those living with substance use challenges (CMS)

**Trauma Informed Care:** an approach to the provision of programs and services that is client-centered and build on knowledge about the impact of violence and trauma on people’s lives and health. (HC)

## 13 Appendix V – References and Resources

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AHS EPE Patient Engagement Guidebook –

<https://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-guidebook-for-engaging-patient-family-advisors.pdf>

AHS The Voice of Patients and Families: What Kind of Patient Engagement is Right for You?

<https://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-voice-patient-families-guide.pdf>

AHS Patient and Family Advisor Resources –

<https://www.albertahealthservices.ca/info/Page15876.aspx>

Fraser Health Patient Engagement: Heard and Valued Handbook –

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