Engaging Individuals with Lived Experience

A Working Guide

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1 Introduction

Patients, their families, People Who Use Drugs and other individuals with lived experience within the opioid crisis have important insights, and innovative ideas to share through the opportunity for engagement. They bring unique perspectives, gained throughout their journeys that may include both experiences of having or not having accessed and navigated health services, community, and social service supports. Engaging individuals who have navigated a particular health condition or phenomena such as opioid use and/or Opioid Use Disorder, informs our understanding of the impact it's had on their day to day lives, what matters most to them, and how interactions with health care providers have influenced them.

Included in this document are Principles, a Guiding Roadmap and a Readiness Checklist. There is also a full-scope companion document, available on request that contains additional content including; risk mitigation strategies, an overarching framework to further guide and structure engagement activities and processes, and other guidance documents.

2 Principles

The process for engaging individuals with lived experience, within the context of opioid use, is somewhat unique within patient engagement activities. It requires, on the part of health care providers and other team members, an understanding of the potential sensitivities and vulnerabilities present for those 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, and loss of trust. In many cases this also includes experiences of stigma and bias from family, friends, health care providers and others in positions of power.

In order to ensure supportive and beneficial experiences for all involved in engagement activities, it is critical that any existing policy and/or any site or agency requirements are clear, understood, and discussed proactively before any engagement activities take place. It is also essential that anyone being engaged is respectfully given the opportunity to decline participation at any point in time throughout the process. As part of this process it can be beneficial to identify alternate sites and various ways in which engagement can take place. This allows for accommodating, as much as possible, the needs or requests of those being engaging ensuring they feel comfortable and safe participating.

The following principles are intended to guide health care providers, teams, programs, and project planners as they move through 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 first person insight
- An understanding that this is about "us" as a community, not "them"
- As a team explore any beliefs, values, or biases with regard to opioid and other substance use and respond in a supportive manner anchored in promoting understanding and growth. Every person carries beliefs and values as a result of training and other experiences. The opportunity

for self-reflection and dialogue around the impact and any potential for contributing to biased or stigmatizing experiences for those they care for is an important step.

- Taking steps to ensure the safety of those being engaged is critical in creating a beneficial engagement experience for everyone involved. This may mean exploring with an individual who is using opioids or other drugs how to work around or time engagement activities to manage or mitigate risk of opioid use during a meeting. In circumstances where this is not possible engagement sessions may need to take place in an environment that accommodates for and minimizes risk of harm such as a site for safe consumption services. Accommodations may also need to be made related to literacy level, mobility, weight status or anything else that could serve as a barrier to informed consent and/or participation in the engagement process. There can be benefits to conducting engagement activities in groups, in this regard, as it allows for safety in numbers, social support for those individuals hesitant or fearful of speaking up and giving voice to their experiences and bringing forth multiple perspectives at one time.

Building Resiliency and Hope

- Ensure your culture shifts include the opportunity to build capacity in those with lived experience
- Have conversations with individuals 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
- Those individuals engaged can 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 resulting from high and potentially unrealistic expectations for a particular outcome from the engagement process for those being engaged

Support for the Clinical and Non-Clinical Team Members

- Site specific training is recommended, for all staff conducting or involved in engagement related activities that includes; identification of resources and supports in place for staff if needed in follow-up to engagement and adequate knowledge of safety procedures and area-specific or role-specified Duty of care in the professional workplace environment differs when 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 Workplace 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 cultural shift is critical to the success of engaging the lived experience 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

- Creating psychological safety allows those being engaged 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
- As part of an informed consent process those being engaged are aware of any firm requirements or expectations and what the options are in regard to the following:
    - Consumption on site, do they want intervention
    - Availability of childcare or option to bring children with them
    - Is the environment a safe place to meet for all, including considerations such as welcoming to the lived experience and supportive of conversation
    - Permission to document and/or record sessions using audio and/or video are confirmed verbally and in writing
- Transparent discussion with regard to any power differentials, with agreed upon outcomes (as identified by the lived experience or the team perspective), before any discussions begin. Any potential risks (policies that must be followed) will be discussed.

Duration and Respectful Ending of Engagement

- The conclusion of engagement related activities with a particular group or individual is referred to as disengagement. This can be the result of a planned conclusion or occur unexpectedly. Ideally the ending of engagement is part of an initial conversation with those being engaged so decision making for each individual regarding participation is fully informed. An understanding of healthy disengagement has been discussed to ensure shared understanding. 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 which may put the lived experience individual at risk, 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.
- Clarify expectations in regard to proposed length of the engagement period, length of time for each engagement session, commitment expectations, type of engagement (focus group, one to one, digital storytelling, presentation, working group membership) and other considerations

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

3 Preparing for the Engagement

3.1 Populations for Consideration

As teams, organizations, planners and working groups prepare to engage individuals, they are encouraged to explore the list below to identify populations that may be of particular relevance. Identifying diverse perspectives within each is recommended:

- *People Who Use Drugs, http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0ahUKEwj09rOdr-zaAhVT3mMKHY7MCGYQFggyMAE&url=http%3A%2F%2Fcapud.ca%2F&usg=AOvVaw12SjuFL88wg0JpwUVqaPsw, http://www.inpud.net/*
- 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

3.2 Engagement Methods

There are numerous methods for gaining the voice of patients and individuals. Each method has a purpose, limitations and advantages. Identifying the most appropriate method of engagement is contingent then 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 one-to-one 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
- Developing or joining a Council or advisory

3.3 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
	• Why are we engaging? • What are your expectations and hopes? • Have we consulted with the right supports? • What will you do with the input? • Are your goals clear?	• Preparation, education, skill building within the team • What type of engagement is best for the situation • Do you have infrastructure in place prior to engagement commencing?	• Where will you recruit or seek the voice of lived experience from? • How will diversity of voices be included? • Are you aware of engagement & community resources to assist and partner with you? • Who will develop and provide orientation?	• The engagement has clear beginning, ending, and goals • How will you minimize risk and potential harm? • Are the team members involved committed to this process in a respectful and caring manner?	• What are the evaluative pieces of this engagement? • How will outcomes of the evaluation be measured? • How will outcomes be shared with the individuals who were engaged?	• Those conducting the engagement have a plan to communicate back how input was used, actioned and decisions impacted as a result • What if one party wishes to end the engagement?
Site/Leadership Readiness	• What is the awareness across the team to "why we are taking this on"? • Are leaders supportive of this engagement • Do you truly believe in the value of the lived experience • Is empathy authentic • Does leadership ensure support, time, resources	• Who is already engaging individuals with lived experience in our area/community • Should we consult with: AHS Provincial Patient and Family Advisory Group, AHS SCN Patient Engagement Reference Group, community agencies/partners, other AMH advisory councils, etc.	• You have identified how you will seek out, engage and on-board those with lived experiences • Required infrastructure is in place (reimbursement, transportation, parking, childcare, etc.) • Documentation has been kept to a minimum but is now prepared (role expectations, consents, releases, confidentiality etc.) • Develop and provide appropriate level of orientation to the initiative	• Development of ORI engagement methods has occurred based on uniqueness of the site and expectations and goals • The engagement has begun, tools and resources are in place to guide the team and support the lived experience participants to build relationships through the process • Leadership is aware and visibly supporting the engagement	• Will this engagement be evaluated not just for its outcomes but also areas to grow in future engagements • Does leadership commit to ongoing culture change as determined by the team and the lived experience engaged • Honest and safety around how the team perceived the engagement • The team can identify successes and goals or areas for improvement before the next engagement	• Ensure responsibility for respectful ending to the engagement relationship is clear • Impacts and outcomes of engagement are shared broadly and supported in future initiatives
Lived Experience Engagement	• What support do we need, or have we offered supports before we engage (community, friend) • Are there unique needs you have to enable participation • Who are your resources and supports • What are your goals for engaging • How can this opportunity enhance your life and your community • Do you feel safe in this environment and trust the team to be respectful • Are you able to share openly regardless of what your story holds	• You feel comfortable with the spaces and readiness of the group you are meeting with • You feel heard and your needs before engaging have been met • What type of engagement are you comfortable with • Who would you like to have come with you • Do you feel comfortable with the team you are consulting with, if not what do you need? • Are you prepared for what this engagement may include (emotion, vulnerability etc.)	• You have been approached in a respectful manner clearly outlining what the group is looking for • You have had opportunity to review and seek support before signing any documentation • You are clear on your role and reason for engaging • You feel prepared to engage • I know who to call with questions • I know expenses and barriers to engage will be removed	• You are invited into the engagement in a meaningful way • You feel respected, cared for, involved • You are clear on your role	• You know your feedback on the engagement process is welcomed and will be listened to • You know how your input was used or why it was not	• How will you ensure you are well and ready to end the engagement • Do you feel safe to end the engagement at any time • What are your goals after this opportunity (future engagement, community referral etc.) • You are aware that your role was critical and created change • You know the outcomes and next steps • You felt respected and cared for • You know how your input and experience impacted changes • You are clear when the engagement has concluded
Changing Practice Culture	• Do we need consultation with specialists on changing culture • Has the team developed trust among themselves to take on this journey • Clear communication channels and responsibilities established • Is empathy authentic • The difference between engaging lived experience because it is the right thing to do and that is where the wisdom lives vs. tokenism • Are supports in place for team debrief, processing and caring	• Have your team members developed relationship, rapport and trust (this is a time component) • Training is complete and the team has addressed barriers, concerns, biases, fears and feels supported and ready to engage • Are you familiar with protocols for each unique type of engagement	• Leadership supports the direction of engagement • Orientation for all is complete and a sense of understanding the importance of engagement now exists	• Awareness of the importance of ongoing support for all involved has been addressed • Capacity is built within the team to support future engagement activities • If the reasons why either party is engaging change, a pause and re-evaluation will occur	• The team has a debrief process in place • All parties identify what worked and what needs to change or grow • Engagement was purposeful and positive	• A culture of mutual trust and respect has been developed • Teaching what ending needs to look like may need to occur for all parties • Next steps will be set if engagement activities will continue or take new directions
Special Considerations	• What type of engagement is best (video, teleconference, audio,1:1, written etc.) • Has a conversation occurred about space (will a child be present, will there be active use, is lived experience person still grieving a loss?) • Who will be designated as the 'liaison' or contact and support person throughout the process • If the reasons why either party is engaging change, a pause and re-evaluation will occur • Awareness and respect of hopes and expectations for all parties is critical to success	• 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.) • Are there adaptations needs to your space to be welcoming and safe for everyone • 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)	• Recruitment is about building relationship, this is a time commitment by all • Orientation is ideally held face to face to build relationship and trust; conducted by leaders/ facilitators leading the initiative • This is where the risk of tokenism vs authentic engagement can become blurred	• During engagement is the most vulnerable time for those with lived experience; this has been planned for and mitigated • Processes are in place to support applying the learning's from the engagement processes	• Do all parties understand the risks, expectations and goals of the other and how to open conversation up if these change	• A disengagement plan is in place that is positive • There is no failure, but rather this is a journey • How to reconnect if an abrupt ending occurs • Referrals for on-going support made if requested • At no time should an engaged lived experience individual feel "dropped" or suddenly alone. Clear support is critical.
Tools & Resources to support	• The Voice of Patients and Families: A Getting Started Guide www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-voice-patient-families-guide.pdf • Engagement Readiness Checklist http://insite.albertahealthservices.ca/assets/pe/tms-pe-readiness-checklist-for-partnering-with-patient-and-family-advisors.pdf • Empathy Mapping https://www.albertahealthservices.ca/assets/info/hp/cdm/if-hp-cdm-empathy-mapping-summary.pdf • Seek support in your zone through AHS Engagement & Patient Experience zone-based consultants as well as local Patient/Family Advisors	• AHS online learning modules: Patient Engagement 101 • (Available Spring 2018) Meaningful Engagement Module1: Roles & Responsibilities of Patient Advisors; Module 2: Roles and Responsibilities of Staff; Module 3: Creating Meaningful Engagement • AHS EPE Patient Engagement Guidebook- https://www.albertahealthservices.ca/assets/ info/pf/pe/if-pf-pe-guidebook-for-engaging-patient-family-advisors.pdf	• AHS Patient and Family Engagement toolkit http://insite.albertahealthservices.ca/assets/pe/tms-pe-patient-engagement-resource-kit.pdf • AHS Patient and Family Advisor Resources- https://www.albertahealthservices.ca/info/Page15876.aspx • How to Involve People Who Use Drugs http://towardtheheart.com/assets/uploads/15161442266vojisI05U2QPZPuPU4p56pnp6FOSjcoMnObC2L.pdf	• Ways to include the voice of patients and families • http://insite.albertahealthservices.ca/17294.asp • Existing AHS Engagement & Patient Experience toolkits can be leveraged and customized as needed for PHC Contact: patient.engagement@ahs.ca • Seek support in your zone through AHS Engagement & Patient Experience zone-based consultants as well as local Patient/Family Advisors	• (coming soon Spring 2018) Evaluation Tool for Patient Engagement in SCNs • Contact: patient.engagement@ahs.ca • https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_workbook-fraser-health.pdf • http://insite.albertahealthservices.ca/assets/pe/tms-pe-the-value-of-engaging-patients-and-familes.pdf	• AHS EPE Patient Engagement Guidebook https://www.albertahealthservices.ca/assets/ info/pf/pe/if-pf-pe-guidebook-for-engaging-patient-family-advisors.pdf

4 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 the 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

5 Appendix II – 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 Patient and Family Advisor Resources –
https://www.albertahealthservices.ca/info/Page15876.aspx

Fraser Health Patient Engagement: Heard and Valued Handbook –
http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf?sfvrsn=2

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