Readiness to Engage Workbook

Questions for Research Teams & Partners to Consider when Planning and Evaluating Patient and Public Engagement

The George & Fay Yee Centre for Healthcare Innovation

Adapted from Shimmin et al, 2017 (BMC Health Services Research)

About this workbook

These questions are adapted and expanded upon from questions included in the 2017 BMC Health Services Research article *Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis* by Carolyn Shimmin, Kristy D. Wittmeier, Josée Lavoie, Evan D. Wicklund and Kathryn M. Sibley. This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium.

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Who this workbook is for

These questions are intended for use by research team members (including researchers, healthcare practitioners, policy- and decision-makers, people with lived/living experience of a health issue, informal caregivers, families, and communities). Questions are for completion individually and as a team (as outlined in the header for each section) to critically reflect on personal values, experiences, interests, beliefs and political commitments in the area of health that the team will be researching, how these impact the research, and how to ensure equity, diversity, inclusion and safety are addressed in planning an engagement strategy for health research.

Reflection and discussion of these questions may give rise to strong emotions. For these reasons, we recommend considering ways to ensure a safe space is established among team members by discussing what safety means together and using these concepts to develop guiding principles for moving forward with critical reflexive practice as a team. Other strategies that may be useful for addressing tension and conflict include taking time to debrief following particularly challenging discussions, check-ins with individual team members as needed, self care for teams and individuals, and ensuring time is taken to acknowledge and respect all voices involved. For more on trauma-informed approaches to engagement, visit our KnowledgeNudge blog.

This workbook also includes questions for research teams to consider, together with patient, public and community partners, in evaluating the engagement activities used in the research project.

Considerations for Online Engagement

Sense of Belonging

Physical distancing measures during the COVID-19 pandemic may contribute to feelings of social isolation and disconnection among team members. It is important for teams looking to engage with people with lived/living experience of a health issue to create opportunities to connect and build trusting relationships. This may include, but is not limited to, regularly placing a phone call to patient, public and community partners just to see how they are coping and discuss supports they may have in place; and setting up meetings solely for connecting on a personal level, such as a weekly lunchtime Zoom gathering.

Safety and Confidentiality

When assessing readiness to engage in a virtual or online context, it is important to consider the ability of people with lived/living experience of a health issue to access a quiet, private and confidential space to be able to join meetings virtually and discuss issues at hand. If access is not available, research teams should work to address this barrier. This may mean providing a quiet, private space and access to a computer or tablet; or working with a local community health organization that serves the people the research team is planning to engage with, where people with lived/living experience of a health issue can contact someone to book a private room and computer in order to join virtual meetings.

Accessibility of Online Engagement

Virtual engagement can pose barriers for people with lived/living experience of a health issue, including (but not limited to) issues around digital literacy, language barriers, closed captioning or interpretation needs, costs, access to stable internet (including rural/remote locations). Discussion with potential patient, public, and community partners prior to engagement is key to understand barriers and needs for full and meaningful involvement. Research teams should work to address barriers ahead of engagement, which may include providing devices (laptops, tablets), software (e.g. Microsoft Office access for reviewing documents related to engagement), access to services (prepaid phone/data cards), and training related to the virtual environment (e.g. session on how to use Zoom).

Internal Assessment Questions

Personal (questions to reflect upon individually)

- What are my own personal values, experiences, interests, beliefs and political commitments in the area of health we will be researching?

- How do these personal experiences relate to social and structural locations I inhabit (i.e. gender identity and expression, race, ethnicity, Indigeneity, socioeconomic status, age, ability, size, sexual orientation, immigrant status, religion) and processes of oppression (i.e. patriarchy, colonialism, racism, capitalism, transphobia, ableism, homophobia, xenophobia, sizeism, sanism)?

- From my perspective, what current health inequities (i.e. avoidable and unjust inequalities in health between and within groups of people) exist with regard to the area of health in which we will be researching?

- What are my personal values, assumptions, perspectives and experiences with regard to people living with the health condition(s) which we will be researching?

Research Team (questions to discuss as a group)

- To what extent does the team **believe** that patient and public engagement will improve the outcome of the research and or project?

- What is the **potential** for patient and public partners to influence decision-making within the research or project process?

- How **flexible** and **adaptable** is the team in response to input from patient and public partners around the engagement and research process, methods, and questions?

- What is the likelihood the team will **fully consider** patient and public partner input?

- What **resources** are likely to be available to support patient and public partners' involvement?

- What is the research problem we will be looking at?

    - How did we decide upon this research problem?

  - Did we involve people/families/communities with lived experience of this health issue in prioritizing this research problem?

  - Is there anyone we have not involved who should be?

- What assumptions (e.g. beliefs about what causes the health issue we are researching and which population(s) is/are most affected) underlie the representation of this health issue?

  - Who do we think is involved in framing and defining the health issue in that way?

  - Why do we think they frame the health issue that way?

  - Do we think that the way people look at the health issue has changed over time (i.e. historically), or is different depending on where they live (i.e. geographically)?

- How can we address feasibility and capacity of engagement in this work?
  - What are our timelines? (must allow time for partners to process information in order to be able to authentically share in decision-making)
  - What training do researchers and team members require in order to fully engage with patient and public partners and/or communities?

  - Do patient and public partners require training in order to meaningfully engage?

  - Outside of compensation, what other benefits might we be able to offer partners (e.g. letter of support/reference, training opportunities, learning about research processes, public speaking opportunities)?

- How do we think the issue of trauma may impact the area of health in which we will be researching? (Remember to think about it both on the level of violence within relationships but also on the larger systems level such as racism, colonialism, sexism, ableism, homophobia, transphobia, capitalism, sizeism, xenophobia)

- How do we think people with lived experience in this area of health would prefer to be involved and why?

- What types of challenges do we think would need to be addressed in order to make it easier for people living with this health condition as well as their families and communities to become involved in research?

External Assessment Questions

Personal (questions to reflect upon individually, and then as a group)

- What are some of the ways in which we can make sure everyone feels safe when working together on this project? What does physical /psychological /emotional /cultural /spiritual safety mean to me, look like to me, and feel like to me?

- What role(s) do I think people with lived experience, their families and communities could play and would like to play in conducting the research (e.g. sitting on steering committee, operations committee, data safety monitoring board, data collection – co-facilitating/co-interviewing/co-surveying)?

Patient/Public/Community (questions to discuss with community leaders, patient, public and/or caregiver partners)

- Is there a history of patient/public/community engagement (e.g. in previous projects by research team members, in projects about the same area of health research)?
    - If so, were the outcomes and experiences positive for patient/public/community partners?
- What inequities exist in relation to the health issue being researched?

- Who is affected differently? (e.g. sex differences on the biological/physiological level, but also looking at socially constructed categories such as socioeconomic status, gender identity and expression, ability, race, ethnicity, religion, immigrant status, size, sexual orientation)

- Who has different access to services/programs/interventions? (think about both geographical barriers and systemic barriers)

- Where are people at with their health condition? (think about people who are newly diagnosed, people who have many years of lived experience, and people who may be in recovery/remission)

  - How can we ensure diverse perspectives are included? (think about utilizing different participatory approaches in order to meet people where they are at).

- What are the strengths, values, skills, that individuals and communities have that should be acknowledged and valued?

Readiness and Level of Engagement (to discuss with community leaders, patient, public and/or caregiver partners)

- What are patient/public/community partners' values and expectations for engagement?

- What level of engagement (i.e. consultation, collaboration, user-driven) do patient/public/community partners' expect to be engaged?

- How would patient/public/community partners prefer to be engaged (e.g. discussion groups, one-on-one conversations, arts-based activities, conversation circles, dinners)?

- What types of roles would patient/public/community partners like to take part (e.g. sitting on steering committee, conducting interviews, co-facilitating focus groups)?

- Working together, how can we become more aware of and take advantage of opportunities where we can challenge each other's ideas and renegotiate power within our project team?

    - What does building resilience look like, feel like, and sound like to you?

Evaluating Engagement

Assessing the impact of engagement (to discuss as a group near the end of engagement)

- How did the way in which people with lived/living experiences were involved in the research project help to reduce health inequities (i.e. avoidable and unjust inequalities in health between and within groups of people)?

- How often were there opportunities to challenge ideas and renegotiate power within the research project team? How were these moments handled?

- How did the research team work together to actively define, address and ensure emotional, psychological, cultural, spiritual, and physical safety for all research team members?

- Was there a belief in the primacy of the people, families and communities with lived experience, as well as in the resilience of individuals and communities to heal and promote recovery?

- Was there an understanding that the experience of trauma may be an aspect that brings us all together and helps to level power differences on the research team?

- Did the research team understand the importance of differences in power and the way in which certain groups of people, historically, have not had the same opportunity to voice their concerns as well as the same choices as other groups of people, and may have received coercive, disrespectful treatment within the healthcare system?

- Did the research team make sure to address historical and present-day trauma resulting from colonization, patriarchy, racism, heterosexism, ableism, transphobia, sizeism, ageism, sanism, xenophobia, capitalism?

- Did the research team actively work to dismantle past cultural stereotypes and biases (i.e. based on socially constructed categories of race, ethnicity, sexual orientation, age, religion, gender identity and expression, ability, size, class, immigrant status, religion)?

- Did the research team leverage the healing value of traditional cultural connections?

- Did the research team incorporate policies, protocols and processes that are responsive to cultural needs?

- Did the research team have access to cultural and gender responsive support services in case a researcher or public research partner requires additional support due to past experiences of trauma?