

# Working Together: Considerations for Engaging Peer Researchers on Projects

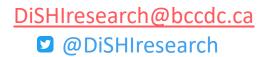
A Researcher's Handbook

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#### INTRODUCTION

#### **Authors Statement**

We are a group of researchers and community collaborators who are committed to and/or have experience with engaging peer researchers or working as a peer researchers on projects. Working Together: Considerations for Engaging Peer Researchers on Projects—A Researcher's Handbook was based on our collective experiences including facilitators and barriers to peer engagement in sexual health related research. We would like to especially acknowledge Anita David for her leadership in developing this handbook, largely based on her own experience as a Peer Researcher and Peer Mentor. We would also like to thank co-authors and many collaborators for their generosity of input. We hope you will find the information useful when including people with lived/living experience in your research of sexual health and broadly.

#### **Overview**

A Peer in the DiSHI research context is usually someone with lived/living experience who belongs to a community affected by HIV/sexually transmitted and blood borne infections (STBBI). As research approaches evolve, it is becoming common practice to involve community members with lived/living experience—Peers—who are being researched or who are most impacted by the issues being studied, throughout the research cycle.

Inclusion of peers in the research process can strengthen research in a number of ways, including enhancing the relevance of the research question and the utility of results. However, tokenism of peer engagement without careful considerations and planning can perpetuate harm and mistrust within the community.

This Researcher's Handbook aims to serve as a guide for the Digital Sexual Health Initiative (DiSHI) researchers and staff to meaningfully engage people with lived/living experience as Peer Researchers. The document will address key considerations in the peer engagement process from planning, recruitment, onboarding to support. While the content is developed for the DiSHI research context, it may be of interest and relevance to the broader research community.

## **DEFINING WHAT WE MEAN...**

#### Peer

A Peer in the DiSHI research context is usually someone with lived/living experience who belongs to a community affected by HIV/sexually transmitted and blood borne infections (STBBI). Lived/living experience means that the experiences with STBBI may have had significant impact on an individual's life and/or a shared culture, identity and/or experience.

The usage of "lived/living" when describing communities reflects and honours the reality that some parts of our identity, such as Hepatitis C status, may change over time. For example, someone who has lived with Hepatitis C may not currently be positive anymore for Hepatitis C at the time of the research, yet their insight and experiences would still be valuable to the research. Note that a peer can be someone who identifies and intersects with more than one community, for example, an individual with living experience of HIV who identifies as South Asian and has transgender experience.

#### **Community**

Community can be defined as a group of people who share similar lived experiences or a sense of belonging. It can include race, ethnicity, gender, sexual orientation, culture, religion, health, education, economic status and more. It is important to note that people can feel connected by any combination or intersection of experiences.

#### **Community Based Research**

Community Based Research flips the idea of research as exclusive to the ivory towers of academia upside down. Instead, research is carried out collaboratively and in partnership with community. Together, researchers and community members collaborate to generate knowledge and create social change that makes an impact for the community.

Community Based Research is based on the guiding principles of:

- Social Justice promotes a fair and just society in which everyone enjoys equal rights
- Inclusion ensures the rights and ability of everyone to be included in research
- Social Determinants of Health fosters consideration of the social and structural factors that influence physical, mental and social health of individuals

#### **Peer Researcher**

For the purpose of the DiSHI team, Peers with living/lived experience of STBBI who work on our research are called Peer Researchers. Peer Researchers can come from different

backgrounds including varied levels of education, job experience and socio-economic backgrounds. Their perspectives are representative of "some" of the voices from their community. The lived/living experience of Peer Researchers is central to their role since they are connected to, impacted by and relate to their community. Peer Researchers may be new to research and will require training to participate meaningfully throughout the research cycle.

## WHY ENGAGE PEER RESEARCHERS

Engaging Peer Researchers can benefit both the research team and people with lived/living experience. Peer Researchers have an inside understanding of the community being studied as experts in their own experiences. Due to their shared experience and understanding of how to communicate research with community members, they can better build trust with the community. Participants mistrustful of researchers may be more willing to engage if they feel connected to someone they can identify with or is part of their community.

Historically, marginalized communities, such as persons living with HIV, have been excluded from research. Engaging peer researchers allows people with lived/living experience to collaborate with researchers and guide the direction of research in a way that is meaningful and impactful for the community. This is in line with the commonly used phrase by people with lived/living experience, "nothing about us without us". It also helps to empower communities through mutually respectful and beneficial relationships with researchers.

Peer Researchers can also provide emotional support to study participants, since they share a common experience. Although each person is unique in their experience, the commonality in understanding challenges, allows Peer Researchers to relate to the experiences that come with living with a specified health condition or risk of a health condition (STBBI).

In addition, Peer Researchers can use their lived/living experience to:

- Help define research objective or guiding question by providing input on whether it matters to the community and how best to frame the issue
- Facilitate relationship building and reciprocity of learning with community
- Advise on appropriate ways of interacting with the community such as being culturally safe and/or trauma informed
- Share nuances and characteristics of their community that wouldn't be known otherwise
- Advise on best ways to give back and/or build capacity of community members
- Provide guidance on recruitment, engagement and retention of community study participants
- Co-design study tools, as well as data collection and analysis methods

- Co-deliver interventions that will be acceptable to community
- Interpret data and help define themes that reflect the experiences of the community
- Co-develop a Knowledge Translation plan that is appropriate and accessible to the community
- Contribute their own lived/living experience stories that can clarify and/or augment the data

For Peer Researchers, engagement in a research study can be a wonderful professional development opportunity to learn new skills and gain experience. It can also be an opportunity for personal growth, including building self-confidence and self-awareness. Moreover, through the opportunity, they can form new connections as well as deepen current relationships and help facilitate positive change in their community.

## PLANNING FOR ENGAGING PEER RESEARCHERS

#### **Clear Role Definition**

To successfully engage Peer Researchers, it is important to think through where the lived/living experience would be useful on the project in order to clearly define the roles. We offer the following questions as a starting point:

- How will the Peer Researcher's lived/living experience impact and/or contribute to the project?
- How would the project differ without the voices of lived/living experience and connection to the community?
- In what ways will the Peer Researcher benefit from participating in this research?
- Will the Peer Researchers be engaged through the entire lifecycle of the project or only during specific phases?
- What activities will the Peer Researchers perform?
- What skills will the Peer Researchers need to succeed in their role?

In addition to the living/lived experience, consider what experiences or characteristics may be useful for the project. For example, Peer Researchers could also:

- Have a good understanding of and ties to a specific areas/setting where the research is conducted
- Represent diversity in gender, age or cultural background
- Already work in peer support or for a STBBI service or community organization
- Have additional skills that can be used on the project

#### **Be Prepared to Provide Training and Support**

Capacity building will be a necessary consideration in engaging Peer Researchers. They may have various levels of research experience—some may be interested in research but have no experience, some may have been a Peer Researcher on other projects while others may be pursuing or have pursued higher education and have worked as a research assistant or health professional. It will be important to assess skill level and provide training on the skills required for Peer Researchers to successfully perform their assignments.

Ongoing support for emotional needs and flexibility are also helpful. Peer researchers may face challenges adjusting to the demand of the workload for many reasons. It could be challenging to balance personal responsibilities with new work priorities, especially when the pace of the project moves quickly.

There could also be emotional distress if the subject matter triggers personal traumatic experiences. Later in the research cycle, Peer Researchers may feel stressed about ending involvement in the project and/or anxiety about next steps in their career. Peer Researcher jobs are not readily available, and even with the training and experience, they could face the possibility of being unemployed and underemployed. Later in this document we will further address support for Peer Researchers.

## **RECRUITING PEER RESEARCHERS**

## **Creating a Peer Researcher Position or Contract**

Once the Peer Researcher role is defined, consider these administrative questions and prompts to think through the creation of the Peer Researcher position or contract:

- How long will you need the Peer Researcher on the project?
  - The duration of the project or just for targeted activities
- How many hours in total would the Peer Researcher work?
  - o Think about it in terms of per day, per week and/or per month
- What is the work schedule like and how flexible will it be?
- Will the Peer Researcher be hired as an employee or contractor?
- If the Peer Researcher will be hired as an employee:
  - o Will the appointment be hourly, part-time or fulltime?
  - Will it be a term position with a specified end date or permanent role on the team?
  - Will the position be governed by collective agreement and/or belong to a union?
- How much will the Peer Researcher be paid?

- The BC Centre for Disease Control has a useful guide for peer engagement compensation: <u>Peer Engagement Principles and Best Practices</u>: A Guide for BC Health Authorities and Other Providers (2018)
- Will the Peer Researcher be entitled to benefits?

#### **Recruitment Recommendations**

Recruiting Peer Researchers is not as straightforward as recruiting a health professional with a specific educational background or credentials. The following recommendations are provided for your consideration when conducting interviews for Peer Researchers.

- Include a Peer Researcher, Community Advisory Board member/chair or a partnering community organization representative on the hiring committee who can offer insight into the community
- Ask questions related to the job and lived experience without directly asking about the STBBI.
  - Example: Don't ask What is your diagnosis?
     Do ask How do you feel your lived/living experience would be helpful to relating to the research topic?
- Understand a candidate's prior research experience to help plan for training needs
  - Example: What experience have you had with community-engaged or community-based research?
  - Example: What experience have you had conducting focus groups and/or interviews?
- Learn about the candidate's personal or career goal to explore potential opportunities that can be offered in the Peer Researcher role to make their involvement more meaningful
  - Example: What skills or experience would you like to gain for yourself personally or towards your career goals?

It is highly recommended that at least two Peer Researchers work on a project at the same time since being the only Peer Researcher can feel isolating and tokenistic. Having more than one Peer Researcher also allows them to lean on each other when facing challenges on the project. Alternatively, having the Peer Mentor (see following section) work closely with the Peer Researchers can be helpful in creating an inclusive environment.

#### **Compensation Considerations**

<u>Flexibility</u>: Most Peer Researcher positions are part-time/hourly. Therefore, Peer Researchers tend to have multiple positions and sources of income. Flexibility in work hours will be

required to accommodate schedules as Peer Researchers likely have to juggle multiple priorities.

<u>Stability</u>: As a team proceeds through the research cycle, there may be times of more or less activity which may result in fluctuation in Peer Researcher's work hours and income. To ensure a stable and consistent income, consider involving Peer Researchers in other activities during slower periods.

<u>Earning Implications on Benefits</u>: Discuss the potential implications if Peer Researchers are receiving provincial or federal benefits. Below are examples of benefits and their maximum earning allowances. Please note that if the Peer Researchers earn an income exceeding these amounts, their benefits will be impacted.

Benefits	Maximum Earning Allowance (as of January 2021)
British Columbia Provincial Income Assistance	<ul> <li>Up to \$500 per month for a single person or couples without children</li> <li>Up to \$750 per month for families with children</li> <li>Up to \$900 per month for families with a child with a disability</li> </ul>
British Columbia Provincial Disability Assistance (Person with a Disability Designation - PWD)	<ul> <li>Up to \$15,000 per year for a single person</li> <li>Up to \$18,000 per year for a family with two adults where only one person has the designation</li> <li>Up to \$30,000 per year for a family where both adults have the designation</li> </ul>
Canada Pension Plan Disability (CPP-D) Assistance	O Up to \$6,100 per year for each person

Honorarium payments: If it is a short term engagement and/or time limited, it might be possible to pay Peer Researchers an honorarium in the form of cash, cheque, e-transfer or gift cards without setting up a formal employment or contract. If any of these different payment options are available, always ask Peer Researchers how they would like to receive their honourarium. It is also important to note that if the cumulative amount of honorarium payments reaches \$500 or above in a calendar year, the payments are considered taxable. Consult the Research Manager or Research Coordinator of the DiSHI team before proceeding with this option.

<u>Expense Reimbursements</u>: If Peer Researchers need to be reimbursed for expenses, the reimbursement should not be added to their compensation. To avoid confusion, process expense reimbursements separately so it will not be counted as earned income on their taxes.

#### ONBOARDING PEER RESEARCHERS

After the Peer Researchers are hired, consider the following for onboarding peer researchers.

### **Equipment and Supplies**

<u>Technology</u>: Peer Researchers may have differing levels of access to technology and equipment required to complete tasks. For example, they may not own a phone and/or computer or they may not have a reliable internet service.

The research manager and/or team should consider allocating funds to possibly setting up the Peer Researcher with a phone/ airtime and computer/secure internet connection.

<u>Office Supplies</u>: If Peer Researchers are working remotely, consider any materials or office supplies they will need to complete their work. A few examples are notepads, sticky notes, pens and markers. Put together a package of office supplies to avoid Peer Researchers for incurring extra expenses.

#### **Orientation and Training**

An orientation for Peer Researchers should include:

- Introductions All team members and their roles on the project as well as who their key contact will be for guidance, questions and concerns
- Provide an overview of the project—Use plain language and avoid acronyms when discussing the project and even better, provide a glossary of commonly used terms and that also explains common acronyms
- Clarify their roles, responsibilities and expectations of working on the project Explain how they will contribute to the project
  - Will they be informing, collaborating and/or sharing decision making with the research team?
- Discuss work hours and project timelines including potential issues, such as any foreseeable ebbs and flows of the project that might impact their hours and earnings
- Develop a training plan—Go over available resources/training modules and discuss other potential capacity-building opportunities within the DiSHI team or through external community partners (e.g., Pacific AIDS Network's Positive Leadership Development Institute)

Training should be comprehensive so that Peer Researchers will have a solid understanding of the project and be able to do their work independently and as part of the team. Training and resources commonly provided to Peer Researchers on the DiSHI team include:

 Overview of the GetCheckedOnline and a lay summary of the grant proposal to learn more about the research

- Relevant project resources including but not limited to: manuscripts, presentations, one pagers, infographics and/or recordings of webinars by our team on previous research findings
- Learning modules related to STBBI offered through other institutions or organizations such as CATIE and the Pacific AIDS Network
- Research study protocol, instruments and other documents such as recruitment materials, participant consent forms and surveys that are relevant to role
- Training sessions organized by Peer Mentor on targeted research skills to successfully
  perform the job such as an introduction to community-based research, peer
  leadership, facilitating focus groups and conducting interviews
- Additional administrative training that may be needed to do job such as record keeping and file management.

## SUPPORTING PEER RESEARCHERS

#### **Peer Mentor Role**

Consider engaging a Peer Mentor in supporting Peer Researchers on the project. The Peer Mentor is a leadership role that helps to connect the research team and Peer Researchers. They promote and foster inclusion of the Peer Researchers perspectives in research activities as well as provides ongoing support for Peer Researchers with a focus on the emotional side of the work, including personal and professional issues.

The Peer Mentor can act as a resource for behavioural and performance issues, navigate difficult conversations as well as organize and deliver training. They can work with Peer Researchers to identify facilitators and barriers to working on the team and collaborate on solutions

Depending on the team composition, the Peer Mentor role can also be shaped to collaborate with the research team on study content, and/or organize training opportunities for research and other skills that would be helpful to the Peer Researchers.

The Peer Mentor can facilitate a community of practice by connecting Peer Researchers of different STBBI projects, both within and external to the DiSHI team, to share experience and learn from each other.

## **Regular Check-ins**

Regular check-ins are important to ensure Peer Researchers are well informed about the project throughout the research cycle. Check-ins can help to keep the work on schedule,

communicate changes in the workplan and ensure the work is meaningful for the Peer Researchers. In addition to project administrative issues (e.g., progress, workload, duties, deadlines), check-ins can also address personal issues that may be interfering with the job such as emotions, a decline in health, housing issues or anything else that impacts the Peer Researchers. Regular check-ins also provide an opportunity for Peer Researchers to feel connected and included.

Frequency of check-ins can be determined based on the team's capacity and needs. Depending on the team's composition, separate check-ins can be organized to address the emotional and professional labour. For example:

- 1. A bi-weekly administrative check-in between the Peer Researchers and their assigned supervisor to discuss project work issues and updates.
- 2. A monthly emotional check-in between the Peer Researchers and the Peer Mentor to discuss the more personal side of barriers and facilitators to the work. If there are more than one Peer Researchers on the team, the emotional check-ins can be organized one-on-one, as a group or a combination of both.

### **Confidentiality**

Peer Researchers are the only members of the team who are required to speak about their health conditions and personal experiences. Even if other members of the team identify with the lived/living experience of Peer Researchers, they are not required to disclose.

It is important to ensure that personal details of Peer Researchers are not shared outside of the research project. This should be discussed as a team so that Peer Researchers are aware personal details are treated as confidential and that other team members understand and agree to it. It is also important to note that Peer Researchers may have different levels of comfort with sharing their experience and should always take the lead on what they choose to share.

#### **Emotional Labour**

Peer Researchers engage in emotional labour by continually drawing from their experiences, including events, emotions and insights of their lived/living. They also as well relate to and support research participants and community members through research activities. Due to the sensitive nature of self-disclosure and risk of being retraumatized by participant stories, providing time and space to debrief is critical. The Peer Researchers may also feel the extra pressure to be a role model for research participants, such as the need to be "well" or "on" all the time.

The emotional check-ins discussed in the last section can be helpful to give Peer Researchers space to discuss their challenges and debrief interactions that are triggering. Peer Researcher

will need to be well resourced with support around coping skills, self awareness and resilience to be able to do this work.

#### **Interactions with Community**

Due to their shared experience, Peer Researchers are well positioned for leading or co-leading interactions with community. For example, if Peer Researchers are responsible for conducting interviews and/or focus groups, they may be more attuned to boundaries and vulnerabilities of their peers around difficult questions and able to guide conversation to both elicit important information while protecting participant wellbeing.

Engaging Peer Researchers allows for the research to be more focused on the impact on the community. Peer Researchers may also have complicated relationships with community members and organizations based on their prior lived experience within community that they may be required to interact with in their roles. It is important to provide alternative ways of engagement with these members or organizations that allows the Peer Researcher to feel supported.

#### **Diversity and Inclusion**

It might be beneficial to include Peer Researchers of diverse characteristics (age, culture, disabilities, genders, geographic locations, languages, sexual orientations, races, religions, etc.) to allow for wider perspectives of the lived/living experience. However, some of these characteristics may be tied to sensitive or painful experiences such as being shunned by a racialized community because of gender identity. These experiences can be related to stigma or intersectional stigma at an individual, systems and/or societal level.

Attention and care should be taken when working with Peer Researchers who identify as Indigenous. Being able to learn and adapt to culturally safe and respectful practices in the work such as including an Indigenous Elder to open and close meetings with traditional prayers and wisdom from their culture. It is also important to consider the needs of Peer Researchers who belong to refugee, immigrant and ethno-cultural populations. For example, a Peer Researcher who identifies with a specific religion may not be able to work at certain times of day or days of the week. It is always important to have a conversation and ask Peer Researchers what they need.

## **Flexibility**

Peer Researchers can identify with and/or belong to marginalized populations. They may be dealing with chronic health conditions and life stressors while working on a project. For example, a Peer Researcher may be living with HIV and other co-morbidities. This may cause

them to step back from the project, take more time to complete a task or work outside of "regular" office hours.

If this is their first time working after an extended amount of time off (years), you may have to adjust the workload to gradually increase the workflow and manage the demands of the project. Peer Researchers may also be used to working and have multiple part time jobs to prioritize and maximize their earning limits and/or potential. Allow for extra time to accommodate the work in order for the Peer Researchers to balance their project timelines.

#### **Evaluation**

If the research project is long term, consider conducting periodic (e.g., every 6-12 months) evaluations to measure Peer Researcher satisfaction with the engagement on the project. It can be an informal meeting with targeted questions, or an anonymous survey if there are multiple Peer Researchers. In the latter example, to protect the privacy of Peer Researchers and provide a safe space for honest feedback, have the Peer Mentor administer the survey and compile results to communicate to the research team.

#### Potential targeted questions for informal meeting

- How is the communication between the Researcher/Manager/Team?
  - o Is there clear instruction around duties and tasks?
- Does the Peer Researchers feel engaged in their work?
  - o Is the work meaningful?
- Do the Peer Researchers feel tokenized?
  - o If so, in what way?
  - o How can the action, behaviour or situation be addressed?
- Does the Peer Researchers feel supported?
  - o Do they have enough detail to carry out their work?
  - Do they feel emotionally supported?

Based on the evaluation results, it is important to develop a plan for improvement. It is also essential to follow up with Peer Researchers on how current challenges will be addressed and to acknowledge the things that are working well.

#### Potential domains to consider for an anonymous survey

- Managers
- Co-workers
- Training
- Training
- Information shared
- Collaboration
- Engagement

#### Tokenism

#### **End of Project Capacity Building**

An often overlooked key piece of engaging Peer Researchers in research, is the conclusion of the project. Peer Researchers devote considerable time to the project and often have a developed a sense of belonging from the relationships that are built with team members. They can also discover a sense of purpose and fulfillment through meaningful contribution to their involvement in the research. Therefore, the end phase of a project needs to be navigated with due respect to, and celebration of, Peer Researcher contributions, especially since Peer Researchers can feel a sense of loss as their part of the study concludes.

It is important leave Peer Researchers with the confidence to build on their skills and experiences. Since Peer Researcher jobs are not regularly available and/or time-limited, it is important to offer job coaching through support with resumes, interviewing skills and networking opportunities. This can help Peer Researchers see more options and possibilities of transitioning to different roles either within or outside of research.

Throughout the duration of the project during one-on-one check-ins, it would be helpful to have conversations with Peer Researchers about their career goals. These discussions can offer insight into how to guide and mentor the Peer Researchers to be successful after the end of this project. Build capacity so that Peer Researchers can find other options for work once their work on the project has been completed.

## **CONCLUSION**

Hiring Peer Researchers takes time, resources and money to support, train and maintain an equitable working relationship. Peer Researchers can feel empowered by the work and advocate to improve and make positive changes at a personal, community and structural level. Their lived/living experience will contribute to a deeper context, richer data and greater understanding to your project.

## APPENDIX I – RESOURCES FOR MENTAL HEALTH CRISIS SUPPORT

## Resources for mental health crisis support

Listed below are a few resources that may be useful if Peer Researchers are experiencing distress or need extra support.

#### Websites

• Find gender affirming mental health resources throughout BC.

https://www.mindmapbc.ca

• Find information on how to manage mental health and substance use problems or learn how you can support a someone in need of help.

https://www.heretohelp.bc.ca

 A free skill-building program designed to help adults and youth to manage low mood, mild to moderate depression, anxiety, stress or worry.

https://bouncebackbc.ca

• Immediate access to barrier-free, non-judgmental, confidential support and follow-up through 24/7 phone lines and online services.

https://crisiscentre.bc.ca

Crisis Line Online Chat (only available from noon to 1am in BC and the Yukon)

https://crisiscentrechat.ca

 Mental Health and Substance Use Supports in BC https://www2.gov.bc.ca/gov/content/mental-health-support-in-bc

#### Phone

- Crisis Line available for support 24 hours a day: 604-872-3311
- If you are having a crisis or are concerned about someone else available 24 hours a day: 1-800-SUICIDE (1-800-784-2433) toll-free anywhere in BC
- To access emotional support, information and resources specific to mental health and substance use issues - available 24 hours a day: 310-6789 toll-free anywhere in BC (do not add 604, 778 or 250 before the number)

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