Peers Examining Experiences in Research Study (PEERS): Principles for Collaboration

Updated April 2019

The intention of this document is to set out principles for collaboration between research team members on the Peer Researcher Project, including guiding goals and values for the project, roles and responsibilities of team members, and project processes to reflect those values, roles and responsibilities.

This is intended to be a living document that can be revisited as the needs of the project change, and as members join or leave the research team.

Responsibility for implementing these principles jointly rests with all members of the research team, with acknowledgement that our different positioning in relation to academic (and other forms of social) power affects our capacity (and therefore, responsibility) to enact them.

Guiding Goals and Values

This project is guided by a shared goal of promoting meaningful and ethical inclusion of community members in research. In keeping with this overarching goal, we explicitly recognize the value of lived experience as an essential compliment to other forms of knowing (e.g., academic, theoretical) that are relevant to our work on this project. Also in keeping with this overarching goal, we aim to be attentive to and wherever possible, mitigate power imbalances within our team, associated with project role, academic affiliation, and social location, among others.

Defining our Four Communities

We acknowledge that language is of critical importance in describing communities that experience stigmatization and discrimination. The language we use reflects our project's guiding values through consideration of who should hold power over naming and defining community experiences (i.e., acknowledging that being able to name oneself/one's community can be a form of empowerment), and through making explicit the inequitable distribution of power associated with these socially constructed categories. For example, individuals may be forced to use particular language in naming their experiences (e.g., psychiatric diagnoses) in order to access essential supports (e.g., ODSP). In this way, we acknowledge that language can be used strategically; it is fluid, and can shift across time and in different contexts. The language that we use in this document may require revision over the course of this

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project, and will not reflect all of the ways in which individual community members describe themselves.

Even as we define these four communities for focus in this study, we acknowledge their intersections: members of our team and our participants will often locate themselves within more than one of these communities, and their experiences (with research and otherwise) will often be profoundly shaped by the intersection of these identities.

The four communities of focus in this study are:

1) communities of people who use drugs

   By *communities of people who use drugs*, we refer specifically to people who use drugs in ways that are stigmatized and/or criminalized (a particular form of discrimination that, to our knowledge, does not have a specific name). This is because our interest is in how and why some forms of drug use come to be socially stigmatized, rather than in individual experiences with drug use. We use the language "people who use drugs" in order to indicate agency on the part of the person, and do not use terms such as "drug abuse" or "addiction", recognizing that these are not neutral terms, but rather imply judgement of drug use as problematic or immoral. Our use of first person language ("people who use drugs") in reference to this community acknowledges that historically (and often in contemporary settings) drug use is stigmatized in ways that deny the basic humanity of individual drug users. We fully acknowledge that individual community members may self-identify in other ways (e.g., drug user, addict). However, considering the largely negative relationship between this community and the health care (and inter-related) systems, and considering that this project is led out of an academic school of public health, a definition including first person language is likely necessary in order to ensure that the team is not seen to be using community language (e.g., drug user) in pathologizing ways. (For more about language related to drug use: https://www.unodc.org/documents/ungass2016/Contributions/Civil/INPUD/DUPI-Stigmatising_People_who_Use_Drugs-Web.pdf)

2) consumer/psychiatric survivor/ex-patient and mad communities

   By *consumer/psychiatric survivor/ex-patient and mad communities*, we refer to people who experience distress and/or have had contact with mental health systems, either voluntarily or involuntarily. Other language that is sometimes used by members of these communities includes: person with a psychiatric disability, person with lived experience (PWLE) and mental health service user. Our interest is not in the specific mental health experiences/diagnoses people may have, but rather in experiences of discrimination and social stigmatization associated with distress, disability

difference, and the systemic responses that result; i.e., experiences of sanism (a term originally derived from legal scholarship to denote discrimination associated with one's mental state) or mentalism (a term posed by consumer/survivor community leader Judi Chamberlin to similarly refer to these experiences of discrimination). Our use of "consumer/survivor/ex-patient and mad communities" moves away from an individual-level analysis, drawing attention instead to the social and structural forces that are at play in the construction of certain behaviours as sick or deviant, and in the function of social systems (e.g., hospitals, prisons, child welfare) to control these behaviours (Voronka, 2016).

3) lesbian, gay, bisexual, trans, queer and two-spirit (LGBTQ2S+) communities

By *lesbian, gay, bisexual, trans**, queer and two-spirit* (LGBTQ2S+) communities, we refer to all those whose sexual orientation or gender identity falls outside of heteronormative and cisnormative expectations. This includes those who self-identify as lesbian, gay, bisexual, queer, two-spirit and/or transgender, but also those who choose to identify in other ways (e.g., queer, pansexual, genderqueer, asexual, aromantic) or who choose not to categorize or are fluid in their sexual orientation or gender identity. Our use of '+' at the end of the LGBTQ2S+ acronym is meant to denote inclusion of this wide array of potential self-identities. We acknowledge that the order of terms included in this acronym reflects the historical (and in some ways, contemporary) privileging of some groups within the LGBTQ2S+ communities over others. We also recognize vast diversity in the experiences of those captured by this definition (particularly as a result of differences in experiences associated with sexual orientation as compared to gender identity); again, our interest is in the shared experience of social stigmatization and discrimination associated with non-normative sexual and gender identities (i.e., homophobia, heterosexism, biphobia, monosexism, transphobia and cissexism). (For a list of definitions for LGBTQ2S+ and related terms, see: https://lgbtqia.ucdavis.edu/educated/glossary.html)

4) racialized communities

By *racialized communities*, we refer to people who have been marked as 'Other' as a result of their race, ethnicity, culture, skin colour, religion or other related identifier. In using the term 'racialized', we recognize 'racial' differences as socially constructed for the purpose of establishing and maintaining social hierarchies on the basis of race, operating through forms of discrimination including racism, colonization, and imperialism, and specifically for the purpose of maintaining white privilege. We understand racialization to be the social process that marks race/ethnicity/skin colour as a socially significant identifier, and particularly for those who are constructed to not be white. We also use the term 'racialized' to call attention

to the inequitable distribution of social power associated with whiteness in contemporary (and historical) Canadian society, as well as on a global scale.

We acknowledge this land on which the University of Toronto, and thus our project, operates. For thousands of years it has been the traditional land of the Huron-Wendat, the Seneca, and most recently, the Mississaugas of the Credit River. Today, this meeting place is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work on this land. In this project, our definition of racialized communities includes Indigenous people, in recognition of the ongoing impact of structural racism in the form of colonization that profoundly harms Indigenous peoples, and benefits non-Indigenous peoples, in Canada (and elsewhere in the world). We also explicitly recognize that Indigenous people are members of the other three communities of focus in this study. However, in recognition of the principles of Indigenous ownership of knowledge produced about Indigenous communities (e.g., the OCAP Principles, see http://fnigc.ca/ocap.html), and recognizing that our project team does not include Indigenous peoples, our team has agreed that participatory projects led by Indigenous communities are not within the scope of our study. However, the experiences of Indigenous people participating as peer researchers within studies focused on any of our four communities, and that are not led by Indigenous communities, are within the scope of the PEERS project. As part of our work on this project, we will work to connect with Indigenous researchers who are examining analogous issues within their communities, in order to facilitate opportunities for shared learning across Indigenous and non-Indigenous-led participatory research.

Roles, Responsibilities, and Rewards

In this section, we document our agreed upon roles, responsibilities and desired rewards associated with our involvement in the project, with the joint aims of transparency and accountability, and to ensure that the priorities of each team member can be considered from the outset of the project.

Lori Ross: In Lori's role as Principal Investigator on the project, she commits to the following responsibilities:
-overall coordination of all aspects of project planning and execution, including active support of the project team
-hiring, supervision and support of all staff and students who work on the project (though this responsibility can be shared with or delegated to other team members if appropriate for specific staff/trainees)
-management of the project budget
-adherence to policies of the University of Toronto Research Ethics Board and SSHRC

-management of all required project reporting (e.g., to the Ethics Board, to the funder)
-oversight of data storage and security
-completion of key project deliverables, i.e., although all team members will share in the production of these deliverables, Lori is ultimately responsibility for ensuring that key project deliverables are completed and disseminated.
-ensuring appropriate acknowledgement of all project contributors on any deliverables.

Lori's desired rewards from the project include:
-being acknowledged as the project's Principal investigator on any deliverables to arise from the work
-first authorship of the first major academic paper to arise from the work.

Adrian Guta: In Adrian's role as Co-investigator on this project, he commits to the following responsibilities:
-active participation in research team meetings and project decision-making
-contribute to development of the interview guide
-contribute to data analysis

Adrian's desired rewards from the project include:
-coauthorship on at least one paper to come out of the project.

Carole King: In Carole's role as research assistant on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision–making
- contribute to interview guide
-contribute to data analysis
-support in recruitment of participants from consumer/survivor/mad communities
-input on KT products, development
- contribute to report
- review manuscript, (some writing?), need support
- co author manuscript, need support

Carole's desired rewards from this project include:
-being acknowledged or recognized as a research assistant on this project
- contribute to sharing of KTE products
- possible involvement in conferences

Kinnon MacKinnon: Although Kinnon's official role on the project is Collaborator according to SSHRC requirements, in practice, his role on the project will be as Co-investigator. In this capacity, he commits to the following responsibilities:
-active participation in research team meetings and project decision-making
- assistance with outreach for recruitment of research staff and participants within LGBT communities.

- contribute to development of interview guide, data analysis, and co-writing of KT products as required.

Kinnon's desired rewards from the project include:
-to gain experience in the conceptualization, design, and guidance of a research project
-coauthorship on some KT products.

Arlette Martinez: In Arlette's role as research assistant on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision–making
- contribute to interview guide and code book
-contribute to data analysis
-support in recruitment of participants from racialized and LGBTQ2S communities
-input on KT products, development

Arlette's desired rewards from this project include:
-to gain further experience in all possible aspects of the research project.
 -co-authorship on some KTE products.
-being acknowledged or recognized as a research assistant on this project.
-co-authorship on at least one manuscript to come out of the project, particular interest in the autoethnography component of the project.
- Possible involvement in conferences

Liz McLean: In Liz's role as research assistant on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision–making
- contribute to interview guide
- participate in interviews with people from communities of people who use drugs
-contribute to data analysis
-support in recruitment of participants from all of our communities
-input on KT products, development
- contribute to report
- review manuscript, (some writing?), need support
- co author manuscript, need support

Liz's desired rewards from this project include:
-being acknowledged or recognized as a research assistant on this project
- contribute to sharing of KTE products
- possible involvement in conferences and presentations
- a reference

Chandrashri Pal: In Chandrashri's role as a research assistant on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision making
-contributing to interview guide, open code book, and writing

-recruiting participants from racialized communities
-screening, following up and scheduling participants for interviews
-co-interviewing research participants
-regular reflection to potentially contribute to a team auto-ethnography product
-contributing to data analysis
-contributing to knowledge translation
-helping with transcribing data
-actively designing and developing KT products
-manuscript writing and revising

Chandrashri's desired rewards from the project include:

-learning and applying new research methods
-being acknowledged as a research assistant in the project
-training for data analysis and support in accessible writing process for manuscript
-lead authorship for one manuscript
- a reference

Merrick Pilling: In Merrick's role as Project Coordinator, he commits to the following responsibilities:
-supporting the research assistants on the project
-co-interviewing of research participants
-supporting recruitment of research participants
-active participation in research team meetings and project decision-making
-contributing to data analysis
-contributing to knowledge translation
-adherence to policies of the University of Toronto Research Ethics Board and SSHRC

Merrick's desired rewards from the project include:
-first authorship of one academic paper to arise from the work

Kendra-Ann Pitt: In Kendra's role as co-investigator on this project she commits to the following responsibilities:
-active participation in research team meetings and project decision-making
-contribute to development of the interview guide
-contribute to data gathering and analysis
-support in recruitment of participants
-support project coordinator and research assistants
-contribute to design and sharing of KTE products

Kendra's desired rewards from the project include:
-co-authorship on at least one manuscript to come out of the project.
-being acknowledged as a co-investigator on any deliverables to arise from the work

Yogendra Shakya: In Yogendra's role as Co-investigator on this project, he commits to the following responsibilities:
-active participation in research team meetings and project decision-making
-contribute to development of the interview guide
-contribute to data analysis
-support in recruitment of participants from newcomer communities
- strategic advice on research assistant training and mentoring
- contribute to design and sharing of KTE products

Yogendra's desired rewards from the project include:
-coauthorship on at least one manuscript to come out of the project.
- feedback from study findings on how Access Alliance's CBR tools and resources can be improved.

Carol Strike: In Carol's role as Co-investigator on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision-making
-contribute to development of the interview guide
-contribute to data analysis
-support in recruitment to communities of people who use drugs

Carol's desired rewards from the project include:
-being acknowledged as a co-investigator on any deliverables to arise from the work
-coauthorship on at least one manuscript to come out of the project.

Jijian Voronka: In Jiji's role as Co-investigator on this project, she commits to the following responsibilities:
-support the autoethnography component of the project, including participating in monthly meetings to review research assistants' reflections
-support the project coordinator and research assistants on the project

Jiji's desired rewards from the project include:
-co-authorship on at least one paper that is entirely peer authored

We acknowledge that the roles, responsibilities and desired rewards outlined here may change over the course of the project. Each individual team member takes responsibility from bringing proposed changes relevant to their own roles/responsibilities/rewards to the attention of the team as soon as they are identified, so that responsibilities can be redelegated if needed, and new priorities can be held in mind as our work moves forward.

Charmaine Williams: In Charmaine's role as Co-investigator on this project, she commits to the following responsibilities:
-active participation in research team meetings and project decision-making
-contribute to development of the interview guide
- contribute to data collection

-contribute to data analysis
-support in recruitment to communities of people who identify as racialized or otherwise participate in peer research projects.

Charmaine's desired rewards from the project include:
-being acknowledged as a co-investigator on any deliverables to arise from the work
-coauthorship on at least one manuscript to come out of the project.
- first or co-authorship on a paper or presentations that are relevant to her research interests, if it is agreeable and useful to the rest of the research team.

<u>Decision-making</u>

All of the project investigators are jointly responsible for decision making related to key project issues, including issues related to research questions, research methodology, interpretation of data, and major budget expenses. Other members of the research team (e.g., project staff, students) will be invited to contribute their perspectives on relevant project decisions, but they will not be considered to be in a decision-making role.

As Principal investigator, Lori has the discretion to make decisions on day-to-day activities of the project, including hiring of project staff, execution of specific research tasks (e.g., in data collection and analysis), and minor budget expenses, without consultation with the co-investigators. [team note: I'm totally open to negotiation about what kinds of things you want to be consulted on and what kinds of things you don't] Lori also has veto power in relation to any team decisions that are in conflict with her responsibilities in relation to the University of Toronto Research Ethics Board or SSHRC.

Our decision making process in this project will aim to: encourage the participation of all project partners; be transparent, open and clear; and provide opportunities for exchanges of learning that draw on the various skills and areas of knowledge of different team members. We will strive for consensus decision-making, but acknowledging our diversity of experience and perspectives, agree to aim to come to consensus around decisions 'we can live with', rather than necessarily expecting to come to consensus on our first choice for every decision. If a decision arises where it is not possible to come to consensus, we agree to make decisions by way of a majority vote in which every investigator's opinion must be sought. In cases where decisions must go to a vote, we commit to debrief and seek opportunities to address the concerns of team members who disagreed with the ultimate decision.

<u>Meetings</u>

We recognize regular project research team meetings are important spaces for information-sharing, decision-making, and relationship building, and so commit to

make every effort to participate in them. To facilitate this, we will set standing meetings well in advance. These meetings will be on a monthly basis, with the option to cancel meetings if there is no business to discuss, but also to schedule additional meetings as needed to move the work of the project forward.

We acknowledge that if we are unable to participate in any given meeting, the research team may move ahead on project decisions in our absence. Lori commits to circulating meeting agendas in advance to allow opportunity to weigh in on any decisions to be made at that meeting. Lori also commits to sharing meeting minutes promptly following each meeting.

Data Ownership, Publication and Sharing

The data produced in this study will be jointly owned by the project investigators, such that each of the investigators is entitled to use them for any purpose that is consistent with project's goals and values, as outlined above.

The first publication to come out of the study will be first authored by Lori and will address the primary objective of the study as outlined in the grant proposal. All team members (including project staff) will have the option of participating as a coauthor on this and any other publications to arise from the study, with the exception of any publications where sole or limited authorship is most appropriate (e.g., specific reflexive pieces).

To be a coauthor on academic publications arising from this project, team members must a) make a substantive intellectual contribution to the work (that is, have contributed to the development of the ideas, analysis or interpretation), and b) read and provided feedback on a draft of the publication (at minimum, read and approved the draft as is). Members of the research team with academic publication experience commit to supporting team members without experience in achieving these criteria. Final author order will be determined at the time of submission on the basis of contribution to each individual publication. Any team members who do not meet criteria for authorship will be named in the acknowledgments.

When team members are interested in leading a publication or other project output, they will draft an abstract for circulation to the rest of the team for feedback. This will provide opportunity for others to express interest in coauthorship, and to ensure that the project won't overlap with work that others are already planning.

Outside researchers not affiliated with the project team (e.g., graduate students, community researchers) may request to use our data for additional analyses. The project team is committed to ensuring that our data are used to the broadest capacity possible to address concerns in line with our project goal. At the same time, the research team bears the responsibility for ensuring data are used in

accordance with the protocol approved by the Research Ethics Board, as well as in ways that do not stigmatize or otherwise harm the communities being researched. Thus, all additional research will be considered to be collaborative projects with the original project team, and must be approved by the project investigators before moving forward.

Review and Revision of this Agreement

We agree to review this document and revise, if needed, on at least an annual basis.

Signatures

By signing below, we agree to these Principles of Collaboration:

_____   _____
Lori Ross   Date

_____   _____
Adrian Guta   Date

_____   _____
Kinnon MacKinnon   Date

_____   _____
Yogendra Shakya   Date

_____   _____
Carol Strike   Date

_____   _____
Jijian Voronka   Date

_____   _____
Kendra Pitt   Date

_____   _____

Carol King   Date

_____   _____

Elizabeth McLean   Date

_____   _____

Arlette Martinez   Date

_____   _____

Chandrashri Pal   Date

_____   _____

Merrick Pilling   Date

_____   _____

Charmaine Williams   Date