



Key Practices for  
**Community Engagement**  
in Research  
*on Mental Health or Substance Use*

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# Why This Document is Important



Community-based research (CBR) is a dynamic research approach that considers what role communities affected by the issue under study should play in the research process itself. Community engagement in research can be conceptualized as a continuum, with participatory research methods, in which communities share equally in all decision-making related to the research, at one end of the spectrum. However, there are many other ways that communities can be involved or engaged in research, even when a fully participatory design is not appropriate or possible (e.g., in some basic science or biomedical research). As a result, principles of CBR can be applied to any research methodology, including qualitative methods, quantitative methods, and secondary data analysis. Similarly, principles of CBR can be applied to all types of health research, including epidemiological research, clinical research, and even bench science. CBR has been shown to maximize the impact of health research for communities.

This document describes key practices for community engagement in research on mental health or substance use. We address these two topics together in recognition that many academic researchers and research institutions are engaged in research on both topics, while acknowledging that different (though sometimes overlapping) communities are concerned with these two different issues. This document is intended to provide academic researchers with a foundation for conceptualizing how one or both of these communities might be engaged in their next research project in these areas.

# What is Community-based Research?

Community-based research (CBR) approaches seek to integrate sound scientific principles with social change and efforts by communities to address pressing community concerns. CBR methodologies emphasize “the participation, influence, and control [by] non-academic researchers in the process of creating knowledge and change”.<sup>1</sup> CBR approaches help to enable community participation, while ensuring that research is culturally sensitive, relevant, responsive, equitable, and reciprocal, as we describe further below. In CBR, the concept of community can refer to many types of communities, including geographic communities, communities of identity (e.g., lesbian, gay, bisexual and/or trans communities; newcomer communities), and communities of shared experience (e.g., communities of people who use drugs<sup>2</sup>).

Community involvement in research occurs along a continuum. This continuum ranges from projects which are entirely academic-led with minimal community input, to those which are entirely conceived and conducted by community members and/or organizations. **Participatory research**, or **community-based participatory research**, or **participatory action research** are terms that describe the most fully community-involved research on this continuum. In the purest forms of participatory research, the community involved in the research relationship would be a full partner in all stages of the research process, including:

- Identifying relevant areas of study,
- responding to funding opportunities and obtaining funding,
- formulating research projects and methods,
- participating in data collection and other study processes,
- determining research outcomes,
- interpreting results, and
- disseminating findings, including planning to make the results widely available and promoting their use towards the desired social change.

In studies that are not participatory in nature, community engagement may occur during various stages of the research process and may involve a variety of mechanisms including:

- providing consultation, either on an ongoing basis or at specific time points
- serving on an Advisory Committee that meets at specified periods
- acting as peer researchers; that is, community members who are hired as research staff
- acting as collaborators at key stages of the project such as data analysis, interpretation, and/or dissemination.

Common to all forms of CBR is an attempt to acknowledge, address and redress power imbalances that are inherent in the research relationship. Power imbalances are a reality in everyday social interactions, and research is no exception. Researchers are bestowed with the power to generate new knowledge. When this knowledge is distorted by unrecognized bias or lack of understanding, it has great potential to negatively affect marginalized communities. Some significant historical examples include the Tuskegee Syphilis study<sup>3</sup>, the Havasupai blood study<sup>4</sup>, and particular to research on substance use and mental health, a research project called MK ULTRA conducted by the CIA in both the United States and Canada in the 1950s and 60s. In this project, individuals were given LSD, often without their knowledge or consent<sup>5</sup>.

1 Israel et al. 2000, <http://docplayer.net/9505018-Successful-models-of-community-based-participatory-research.html>

2 Throughout this document, we use the phrase ‘drug use’ to refer to use of both legal (e.g., alcohol) and illegal drugs.

3 <http://www.cdc.gov/tuskegee/index.html>

4 <http://journalofethics.ama-assn.org/2011/02/blaw1-1102.html>

5 <http://www.cbc.ca/fifth/episodes/40-years-of-the-fifth-estate/mk-ultra>

A more common, everyday example of a scenario in which the power held by researchers has not benefited communities is so-called “helicopter research”, in which researchers go into a community (particularly an Indigenous community) to conduct research and never return and/or provide any tangible benefit of research participation to the community. In this example, researchers have benefited from this process (for example, in publications and academic promotion), while the community has not. In some cases, communities have even experienced harm.

As a consequence of the past abuses of the power held by academic researchers, many communities approach research and researchers with distrust. In CBR, researchers attempt to address this by working with communities to share power over the research process and results; that is, in ensuring that communities have an equal role in all decision making about the research process and outcomes. As a result of the attention to power in the research process, CBR approaches may be particularly valuable in work with communities which have experienced oppression or marginalization. For example, CBR principles are essential in research involving Indigenous peoples, who have particularly been harmed by exploitative and stigmatizing research in Canada. As a result of advocacy on the part of these communities, the Tri Council Policy Statement 2 (TCPS2) includes specific guidelines for doing research that involves Indigenous people in Canada<sup>6</sup>.

One way of addressing power imbalances between researchers and the researched is to acknowledge and make explicit the implicit philosophical and theoretical concepts underlying their work. Research often begins from a position of deeply embedded assumptions about marginalized groups which researchers may not be aware they are making. For example, in mental health research, there are often sane-centric assumptions that underlie research questions (such as the idea that there are some people who are mentally unhealthy and others who are mentally healthy, or that individuals labelled “unhealthy” are in need of medical treatment or other interventions). Similarly, research on substance use is often approached from the position that use is problematic and requires intervention, or that interventions for people who use drugs should have as their goal that individuals stop using drugs (i.e., an abstinence approach—in contrast to a harm reduction or self-managed use approach<sup>7</sup>). Often these assumptions lead to research projects which do not adequately account for the full reality of individuals who have lived experience of these issues.

In contrast, *survivor research* is a form of participatory research that is particular to the field of mental health, and is informed by very different assumptions about the nature and implications of diverse mental health experiences. Survivor research is led by or includes extensive involvement of the perspectives of individuals with lived experience of mental health service use. Because this document is written with academic researchers in mind, we do not discuss issues particular to survivor research here. However, there is much that academic researchers can learn from survivor research about good practices and ethical considerations in conducting research on mental health-related topics<sup>8</sup>.

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6 <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>.

7 To learn more about harm reduction, see: <http://www.catie.ca/en/printpdf/biv-canada/4/4-2/4-2-3/4-2-3-2>

8 For more information, please see Angela Sweeney et al., *This is Survivor Research* or visit <http://www.survivor-research.com/>.

# Benefits of doing Community-based Research

Community members can teach academic researchers, just as academic researchers can teach community members. In this way, CBR provides an opportunity for a mutually beneficial research relationship, and in so doing, builds relationships between academic researchers and communities. In the fields of mental health and substance use in particular, CBR approaches can be enormously beneficial. As a result of past research and treatment abuses in the field of psychiatry, as well as the criminalization of many forms of substance use (and in turn, the stigmatization and criminalization of people who use substances), potential research participants may have distrust for psychiatric/addiction research and related institutions. Including representation from trusted community members and/or organizations on the research team can alleviate this distrust, and in so doing, offer academic researchers legitimacy within the community. This may result in access to information that may not have otherwise been available, and ultimately, better research. CBR approaches can also have important benefits for communities and community members; for example, in addressing issues of immediate community concern, providing community members with employment and skill-building opportunities, and over time, building a community's capacity to undertake research without the need for academic partnerships.

While some research projects in the area of substance use or mental health may benefit from utilizing participatory approaches, others, such as many biomedical projects, may be less suited (for example, when the scientific knowledge or technical skills required to contribute meaningfully to certain stages of research are highly specialized and therefore inaccessible to community members). However, these projects may still benefit from using some principles of CBR. Incorporating community consultation or engagement into a non-participatory research project may serve to optimize the extent to which research is considered meaningful to communities, encourage the use of research approaches that are appropriate and acceptable to communities, and enable research results to have maximum impact on communities and community members. A particular potential benefit of CBR is that the validity of research findings may be enhanced, by providing access to interpretation that may not be apparent to people without lived experience of the community or phenomena under study.

In the final stages of CBR, community participation in the interpretation of data and/or review of research conclusions ensures research findings contribute to accurate knowledge production. Additionally, CBR leaves a legacy in terms of utilizing the research results, in that not only academic partners but also community partners are well-positioned to put research findings into practice.

# Key Practices

In this section, we highlight ten key practices for community engagement in research on mental health and/or substance use (see Table). These practices were developed through a review of other documents that have outlined practices and principles for CBR (see “Resources on Community-Based Research” at the end of this document). Based on our group’s collective experience with CBR in the area of substance use and mental health, from both community and academic perspectives, we identified those practices that we felt were particularly relevant to this field, and highlighted the key issues that need to be considered when operationalizing them in this context. The ten key practices we identified are:

- 1) Defining and learning about the community to be researched, from the community’s perspective, prior to initiating a study
- 2) Collaborating with community partners to ensure the involvement of diverse members of the community to be researched
- 3) Involving the community to be researched in identifying or refining a research question
- 4) Developing a research agreement to guide a partnership with community representatives
- 5) Building flexibility into the project to allow for meaningful community involvement/consultation throughout all stages of the research
- 6) Incorporating opportunities for community capacity building into the project
- 7) Involving community members/people with lived experience in the interpretation of data prior to publication
- 8) Budgeting for the compensation of community members and/or organizations for their time contributed to the project
- 9) Sharing any products or gains associated with the research, including opportunities for academic publishing
- 10) Planning for knowledge sharing and community action

Some of these practices (e.g., practices #4, 6 and 8) are specific to participatory research in which community representatives actively partner in a project. Others (e.g., practices #1, 2, and 10) are relevant to any type of research in the area of mental health or substance use. Incorporating these practices, even in the context of biomedical research, will help to ensure that communities are appropriately represented and are likely to benefit from, and not be harmed by, substance use or mental health research.

## THE ACCESS TO PRIMARY CARE (APC) STUDY

To help illustrate the 10 principles, throughout this document, we will draw from the *Access to Primary Care (APC) Study*, a CBR project that some of our members were involved in. In APC, we interviewed 85 individuals who self-identified as living with a serious mental health and/or substance use issue about their experiences accessing primary care. We also interviewed 16 service providers who work with this population about their perspectives on barriers to access. At the end of the study, most of the team members also participated in an evaluation project, to assess and learn from the successes and challenges of our application of CBR principles in the project. For more information about APC, please visit: [www.camh.ca/primary-care-study](http://www.camh.ca/primary-care-study). You can also read about the results of the study here: <http://bmcfampract.biomedcentral.com/articles/10.1186/s12875-015-0353-3>. The evaluation of the APC study revealed that it, like any CBR study, had both strengths and limitations. In this document, we offer our experiences and learnings from our evaluation simply as examples (rather than exemplars) that may be useful to academic researchers interested in engaging in CBR in this field.

# Integrating the 10 key practices across the stages of a CBR Study

STAGE	RELEVANT PRACTICES	EXAMPLES OF WAYS TO INVOLVE THE COMMUNITY
PLANNING AND PARTNERSHIP DEVELOPMENT	1) Defining and learning about the community to be researched, from the community's perspective, prior to initiating a study	<ul style="list-style-type: none"> <li>- meeting with community leaders</li> <li>- attending community events</li> <li>- asking for relevant resources</li> </ul>
	2) Collaborating with community partners to ensure the involvement of diverse members of the community to be researched	<ul style="list-style-type: none"> <li>- connecting with community-run organizations</li> <li>- seeking advice/assistance in identifying interested community members to be involved</li> </ul>
	3) Involving the community to be researched in identifying or refining a research question	<ul style="list-style-type: none"> <li>- working with community leaders/ representatives to identify community priorities</li> <li>- identifying sources of community knowledge to inform the question</li> </ul>
	4) Developing a research agreement to guide a partnership with community representatives	<ul style="list-style-type: none"> <li>- seeking input on community needs/ priorities to be included in the agreement</li> </ul>
IMPLEMENTATION	5) Building flexibility into the project to allow for meaningful community involvement/ consultation throughout all stages of the research	<ul style="list-style-type: none"> <li>- including community members/ organizations as investigators</li> <li>- establishing a community advisory committee</li> </ul>
	6) Incorporating opportunities for community capacity building into the project	<ul style="list-style-type: none"> <li>- hiring community members as paid staff</li> <li>- offering research and other training opportunities to community members</li> </ul>
	7) Involving community members/ people with lived experience in the interpretation of data prior to publication	<ul style="list-style-type: none"> <li>- seeking community partner feedback through the research process</li> <li>- holding community feedback meetings</li> <li>- meeting with community leaders to share preliminary results</li> </ul>
	8) Budgeting for the compensation of community members and/ or organizations for their time contributed to the project	<ul style="list-style-type: none"> <li>- consulting with community partners about how best to compensate involved community members</li> <li>- providing financial compensation to community partner organizations for their contributions (e.g., staff support)</li> </ul>
DISSEMINATION AND ACTION	9) Sharing any products or gains associated with the research, including opportunities for academic publishing	<ul style="list-style-type: none"> <li>- involving community representatives as coauthors in both academic and non-academic products</li> <li>- supporting community members to participate in conference and other presentation opportunities</li> </ul>
	10) Planning for knowledge sharing and community action	<ul style="list-style-type: none"> <li>- seeking community feedback on target audiences and ideal products</li> <li>- budgeting for non-academic knowledge translation products</li> <li>- applying for additional funding to support knowledge translation</li> <li>- supporting community partners in action/ advocacy arising from the research</li> </ul>



# 1. Defining and learning about the community to be researched, from the community's perspective, prior to initiating a study

Successful community engagement requires clearly defining what population will be studied, as well as who will be impacted by the research. Thoughtfully identify, and learn about, the community you are studying, including getting to know key community leaders and community-run organizations. Of particular relevance to research on mental health are consumer/survivor communities, mad communities, and/or service user communities. These communities are often organized around a shared experience of mental health-related discrimination<sup>9</sup> and/or experiences with the mental health system, although communities use different labels depending on factors such as the extent to which they feel these services were able to meet their needs (e.g., survivor communities often choose this label to reflect their experience of having survived an oppressive system). Some people who use substances may identify as part of consumer/survivor/service user communities, or may specifically identify as part of a community of people who use drugs. Within communities of people who use drugs, a shared experience of stigma and discrimination associated with drug use, and criminalization for those who use illegal drugs, shapes the community's priorities, concerns and values.

Most communities, including communities organized around substance use or mental health experiences, have their own language, norms, values, and ethical principles that often differ from those typical within traditional academic or clinical communities. For this reason, when the lead researcher on a project is not a member of the community to be researched, it is often necessary to educate oneself about the community before one is in a position to appropriately engage with the community. In relation to research on mental health and/or substance use, there are many resources that a researcher can turn to in order to begin learning about the issues and concerns of these communities, including as they pertain to

research (see “Resources on Consumer/Survivor/Mad Communities” and “Resources on Drug User Communities” at the end of the document). Once identified, community partners are often able to suggest helpful readings or other sources of information to help academic researchers further understand the history and contemporary needs and concerns of the communities they are studying. For example, some organizations (e.g., drug user groups) may provide training sessions for those interested in working in partnership with their community, including anti-oppression training (to assist academic researchers in reflecting on the impact of experiences of privilege and oppression in their research relationships). Learning about experiences such as discrimination, institutionalization/incarceration and other aspects of life associated with these issues, from the perspectives of those who have experienced them, is critical for any academic researcher, regardless of discipline, to conduct respectful research in this field.

## THE APC STUDY

Before initiating her first CBR study in the area of mental health/substance use, the lead academic investigator of the APC study started to build relationships with a consumer advocacy organization. Through these relationships, she learned of useful resources to help her develop an understanding of the consumer/survivor/mad communities (many of these resources appear in the reading list at the end of this document). She invested (and continues to invest) time in reading the recommended resources and attending local community events in order to build her understanding of community history, needs and priorities, as well as to develop relationships with additional community leaders and members. These relationships ultimately extended into research partnerships (including for APC).

<sup>9</sup> We differentiate between discrimination – unfair treatment due to a person's identity or life experience—and stigma – stereotypes associated with an identity or life experience (see <http://ontario.cmha.ca/mental-health/mental-health-conditions/stigma-and-discrimination/> for more information). Stigma is associated with both mental health conditions (particularly those often labeled as 'severe', such as schizophrenia) and drug use. However, we predominantly focus on discrimination, because it describes acts that often impact the material circumstances of peoples' lives, and also is associated with legal recourse (through the Ontario Human Rights Code, and other analogous policies in other regions, that provide protection from discrimination on the basis of disability). We use the term 'stigma' specifically when referring to individual attitudes that are influenced by widely held stereotypes about mental health problems and/or drug use.

## Collaborating with community partners to ensure the involvement of diverse members of the community to be researched

Depending on the nature of the particular study, community representation on a research project may include individual community members, representatives from community-based organizations that are composed of or work directly with the community under study, or both. Ideally, individuals with lived experience of the subject under study should be involved. It is preferable to reach individuals through relevant community organizations (e.g., peer advocacy organizations and/or organizations or networks of people who use drugs), so that communities have the opportunity to choose who will be their representative(s) on a given project. This serves to ensure community accountability, but also to ensure that community researchers do not feel pressured to agree with the researcher's ideas or plans. It also avoids the tendency for researchers to select (even if without conscious intention) community representatives who are most similar to them or most likely to agree with their ideas.

For research on mental health, consumer advocacy organizations can often provide consultation from the perspective of community members. Academic researchers and the leaders of such groups/organizations can discuss together the variety of lived experiences that would best inform the research. Community groups will then be able to draw on a range of service users who are both new to and familiar with research. Depending on the local context, organizations for people who use drugs can similarly provide consultation and outreach support; however, organizations of this nature with sufficient resources to actively support research partnerships are less common. An alternative approach where such organizations do not exist is for academic researchers to develop relationships with local harm reduction services, and through them, their clients. In this way, researchers can build relationships with individual members of the community to provide the community knowledge necessary for their project.

CBR researchers also need to take into account the diversity within communities of interest for

their research. For example, among people who use substances, there are important differences between those who use tobacco, alcohol, and various illegal drugs that will need to be considered, as well as differences between active users and those with a history of substance use. Members of consumer/survivor/mad communities and drug user communities also represent a diversity of experiences with respect to, for example, their age, gender, race/ethnicity, ability, and class, which in turn are associated with interlocking forms of discrimination (ageism, sexism, racism, ableism, classism) that are also important determinants of health and/or experiences with health services. From a theoretical perspective, an *intersectional analysis*<sup>10</sup> explicitly examines the ways that forms of oppression associated with gender, race, class, sexuality, and ability, among others, intersect with a range of community experiences in important ways.

Theoretical approaches and research designs need to take into account individual differences among community members, and recognize that the most marginalized members of communities will be the least likely/able to engage with research. A helpful way for researchers to learn which differences or variables might be relevant to their research questions and to address barriers to research involvement is to seek input from community members. For example, both people who use drugs and those living with mental health issues disproportionately experience poverty, and so may experience differential barriers to research participation associated with socioeconomic status that will be important to address (e.g., through providing compensation for travel, and nourishing food at meetings). Community partners can often provide suggestions regarding potential barriers to participation, and strategies for addressing them.

Another way to determine important axes of diversity within the community under study is to examine existing research or reports summarizing the demographic characteristics within a community or communities. Such community profiles may be available as part of research

10 Bowleg, L. (2012). *The problem with the phrase women and minorities: intersectionality- an important theoretical framework for public health. American Journal of Public Health, 102(7), 1267-73.*

conducted by Social Planning Councils or government (e.g., Statistics Canada). Be mindful, however, that some communities (e.g., homeless, underhoused or incarcerated populations) may not be accurately represented in these population-based demographic data.

Diversity within the community under study also needs to be considered beyond the planning stage. For example, researchers in neuroimaging studies need to consider who their research participants are (e.g., white males) in relation to who their findings might ultimately be applied to (e.g., people of various ethnoracial backgrounds and genders). Data collection instruments should be reviewed to ensure that important sociodemographic data will be collected appropriately, so that results can be compared between important subgroups of the community. To do this, researchers may need to seek out expertise from other relevant communities (e.g., expertise within newcomer communities to understand how to appropriately ask questions about citizenship status).

It is essential that community involvement on a research project be meaningful, and not tokenistic. In the field of HIV/AIDS research, researchers are called to be accountable to the principle of Greater or Meaningful Involvement of People Living with HIV (GIPA or MIPA). This principle arose from community advocacy beginning when AIDS first emerged in the 1980s, and was formalized by 42 countries at the Paris AIDS summit in 1994. It is operationalized through ensuring inclusion of people living with HIV in all aspects of the response to the HIV epidemic, including through processes of research and policy-making.<sup>11</sup> Many lessons have since been learned from the field of HIV about what *meaningful* inclusion can look like. For example, one way to work towards meaningful community involvement is to include at least two community representatives in research teams and/or consultations, to provide a stronger community member voice, reflect community diversity, and recognize that some peoples' experiences of mental health and/or drug use can make it difficult for them to participate

in a project continuously. Truly meaningful involvement is also reflected by sharing decision-making power with community representatives (i.e., having community members represented on and actively engaged as part of the research team, rather than only in advisory capacities).

## THE APC STUDY

For the APC study, the primary community partner was a peer advocacy organization (The Empowerment Council, <http://www.empowermentcouncil.ca>, an organization run entirely by individuals who themselves are current or past clients of services for mental health or drug use). The Empowerment Council Coordinator worked with the lead academic researcher to identify other community partner organizations which would have interest in and bring important expertise to the topic. The Board of the Empowerment Council also identified two community members (one with lived experience of the mental health system, and one with lived experience of drug use) to serve as their representatives on the project, in order to reflect diverse experience in relation to service use (i.e., representing both people who had used services for mental health and people who had used services related to drug use), age, and other variables the Board wanted to see represented on the project team. In the APC study, community members and representatives of community organizations participated as members of the research team, to ensure that numerous community voices would be involved in the project at a decision-making level. In general, this approach was very successful in that our research team meetings and decision-making processes included a dominant community voice. However, we note that community knowledge on mental health issues came to outweigh that of drug use, and also that two representatives were likely insufficient to represent the range of experiences relevant to our research questions. We attempted to mitigate the impact of this by adding additional community representation in the knowledge translation stage, and ensuring specific attention to issues related to drug use in our knowledge translation products.

11 <http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf>

## Involving the community to be researched in identifying or refining a research question

CBR begins with a community-generated or community relevant research question. Ideally, the research question will be developed in consultation with community members and/or agencies before research funding is sought, so that community partners are engaged in the formative stages of research and through this process, can help set its direction and priorities. Community involvement at this stage helps maximize the likelihood that the research topic will be both relevant and meaningful to the community.

To generate a question relevant to the community, researchers often consult with community organizations or create an advisory committee of community members. When developing the research question, researchers will need to address all the usual considerations (e.g., what gaps exist in the literature? What are the feasibility and ethical issues?) in addition to considerations more prominent in CBR (e.g., is this question a community priority? Are there likely to be actionable social or policy implications of the research?). Access Alliance Community Health Centre has developed tools to assist academic researchers and community members in collaboratively developing research questions which may be useful in this process<sup>12</sup>. Sufficient time should be allocated for the development of the research question. Generally, this process takes a minimum of 1-2 months to complete.

Collaborative development of research questions is a mutually beneficial process. It provides an opportunity for scientists to be exposed to new ideas and benefit from community knowledge relevant to the area of research focus. Academic researchers can help community members determine whether their priority questions might have already been answered through their access to academic literature, and can also provide important insight into the feasibility of particular research questions. Community members can help flag potential challenges for researchers based on their knowledge of community needs and priorities (e.g., recognizing the need for interpretation services or other considerations that may not be obvious to someone from outside of the community). Community members can also highlight community-based research or grey

literature that may be relevant to the topic at hand, as well as community perceptions and beliefs about the topic that will be important to understand or address in the research.

In some cases, academic researchers may be initiating community engagement after the research question or topic has already been established. Even in situations such as this, the expertise that individuals with lived experience offer may be valuable in refining the research question or methods. Academic researchers should strive to navigate a balance between clearly communicating the reason for and parameters of the study, while remaining open to integrating the needs, interests and knowledge of the community to the greatest extent possible (e.g., providing opportunities within a standardized survey for open-ended feedback, in case a community feels that the survey options do not capture their experience). In biomedical research, it may not be feasible to involve community members in developing research questions that require an understanding of technical knowledge of the field; however, early consultation with community members can help to flag areas of potential concern (e.g., difficulties in recruiting particular groups), identify alternative hypotheses, or note or unintended harms to communities (e.g., in use of language that pathologizes or reinforces stereotypes about people who use drugs and/or live with mental health issues). It is important that researchers do not underestimate the capacity of community members to understand and reflect on complex scientific information that is relevant to their lives, once it is presented in non-technical language.

### THE APC STUDY

The APC study arose when the lead academic partner's institution identified primary care as a priority in an internal funding call. In response to this call, the lead investigator contacted the Empowerment Council and initiated discussion about a) whether primary care was a topic of community concern; and b) if so, what specific research questions were of interest. Through a series of meetings with the Empowerment Council Coordinator and Board, research questions were developed that were ultimately awarded funding through the institutional funding opportunity.

<sup>12</sup> [http://accessalliance.ca/wp-content/uploads/2015/03/CBR\\_Toolkit\\_Jan2012.pdf](http://accessalliance.ca/wp-content/uploads/2015/03/CBR_Toolkit_Jan2012.pdf) (see particularly page 102)

## Developing a research agreement to guide a partnership with community representatives

Research agreements should be negotiated with community members, partners, groups, or representatives before research commences. A research agreement guides the research project in all stages while attending to the needs of both academic researchers and community partners. Research agreements provide an opportunity for academic researchers to explicitly articulate their expectations with respect to community members' level of involvement, why they have been asked to participate in the research project, and how frequently they will be consulted. Similarly, they provide opportunity for community partners to explicitly state their expectations of the academic partners and of the research process.

A research agreement might include the following information:

- roles and responsibilities of all partners (e.g., whether community members will attend research meetings, and if so, how often)
- where the funds will be held and who will have access to them
- details of compensation for community members for their time on the project (see Practice #8 for more information about compensation)
- how confidentiality for community members will be protected (see Box 9, below)
- plans for communication between partners throughout all stages of the project
- ownership of data collected as part of the project
- expectations regarding authorship of research products
- mechanisms for acknowledging involvement in the project
- agreements regarding when, how, and by whom study findings will be released
- decision-making procedures for the research team.

A typical research agreement for a CBR study will differ from a research contract associated with an academic or industry sponsored research study. In particular, the use of extensive legal language should be avoided wherever possible. Most community agencies working in the area of mental

health/substance use, and very few individual community members, will have access to legal counsel in order to ensure their needs are being met by a research agreement. As such, it should be written in language that all parties are able to understand, and therefore enact. Various examples of CBR agreements are available for researchers to adapt for their own projects, to assist institutional legal services to develop agreements that cover off concerns relevant to them (e.g., data ownership) using language that will be accessible to all parties.<sup>13</sup>

When working on the agreement, novice community members may benefit from working in partnership with more experienced community researchers to ensure that their needs will be met by the agreement. Researchers may be able to facilitate this mentorship by consulting with community agencies that are experienced in engaging in research.

Once the research agreement has been established, academic researchers should consider establishing regular check-in points throughout the research process to determine if the research is progressing as planned, and if there is a need to respond to any issues that have arisen through revisiting or if necessary, revising the research agreement. Ideally, this could be part of a formal process evaluation of the project's implementation of CBR principles.

### THE APC STUDY

Once the APC team was formed, our first activity was to develop a research agreement. To do this, we adapted template agreements (see footnote) to address the specific needs and concerns of the project partners, including most of the topics discussed above (e.g., what each partner's responsibilities were in relation to the project). Our agreement also included an appendix indicating what each partner hoped to get out of their participation in the project (e.g., a first author publication; a report back to their community organization). We discussed the draft agreement over the first few team meetings, until all partners explicitly stated that they were satisfied with the content.

13 <http://depts.washington.edu/ccph/commbas.html#MOU>

## 5.

## Building flexibility into the project to allow for meaningful community involvement/consultation throughout all stages of the research

To allow for the fullest community engagement possible, flexibility needs to be built into research projects, and particularly into their timelines. While any research project can encounter unexpected delays, there are contingencies particular to or amplified in CBR. These might include allowing for:

- ample time for meaningful relationship/trust-building between project partners
- time to negotiate all aspects of research agreements before the research begins
- time for community consultation at all stages of the study (e.g., co-creation or feedback on interview questions and language)
- accommodation of various schedules in planning meetings (e.g., community partners may require evening or weekend meetings to accommodate their paid work schedules).

Particular scheduling accommodations may be necessary or helpful to allow for full participation of community members who use drugs and/or are living with mental health issues. For example, there may need to be accommodation for delays or absences if unwell or otherwise temporarily unable to participate (e.g., due to consequences of drug use). The fact that people living with mental health issues and people who use drugs are both disproportionately likely to live in poverty means that issues of daily survival will at times take precedence over research involvement. Attention should also be paid to scheduling meetings during times of day that are generally easier for people to commit to (e.g., avoiding early morning meetings). Finally, community members may feel much more able to participate in meetings held in a familiar community space, such as a drop-in, rather than an academic environment or medical centre. If meetings are to be held in an academic or medical environment, offer a brief tour or orientation in advance of the meeting if community members feel this would help them feel more comfortable, and also ensure that other staff with whom community members may interact (e.g., reception staff) are educated and will not behave towards community members in discriminatory ways.

Meaningful involvement of people who use drugs may require that academic researchers unpack some assumptions that they may bring to the topic of substance use—particularly that people who use drugs will need to commit to abstinence in order to contribute to the work. In addition to creating conditions that will exclude active users—an important voice in many studies of drug use—this assumption ignores the fact that some people will be able to function well and make important contributions to the project while using. Rather than focusing on use vs. abstinence, academic researchers should instead communicate clear expectations about function/behaviour that apply to *all* members of a research team (e.g. if you are unable to contribute productively to a meeting because you are too sleepy/behaving aggressively etc., you will be asked to leave)<sup>14</sup>. Expectations for meetings should be discussed in advanced in ways that are clear and simple; for example, noting that all team members must treat one another with respect, and that all information discussed at research meetings is to be kept confidential. It is important for researchers leading CBR projects to recognize that facilitating the involvement of differently situated team members in research meetings requires skillful facilitation, to ensure that community members feel supported to participate and share their ideas, and not feel silenced by other team members who are situated in positions of privilege, academic or otherwise.

CBR projects on average take more time than 'traditional' academic research projects. As a general rule, for participatory or extensively partnered projects, it may be helpful to allow approximately one year for the project development stage (i.e., all steps preceding the initiation of data collection), 1.5 to two times as long as you think you should need for data collection, and an additional year for analysis, dissemination, and project wrap-up. For projects that involve more limited community engagement (e.g., many biomedical projects), only an extra month or two per consultation (to schedule and incorporate suggested feedback) may be required.

14 For more about working with people who use drugs, see: <https://www.opensocietyfoundations.org/sites/default/files/work-harmreduction-20110314.pdf>

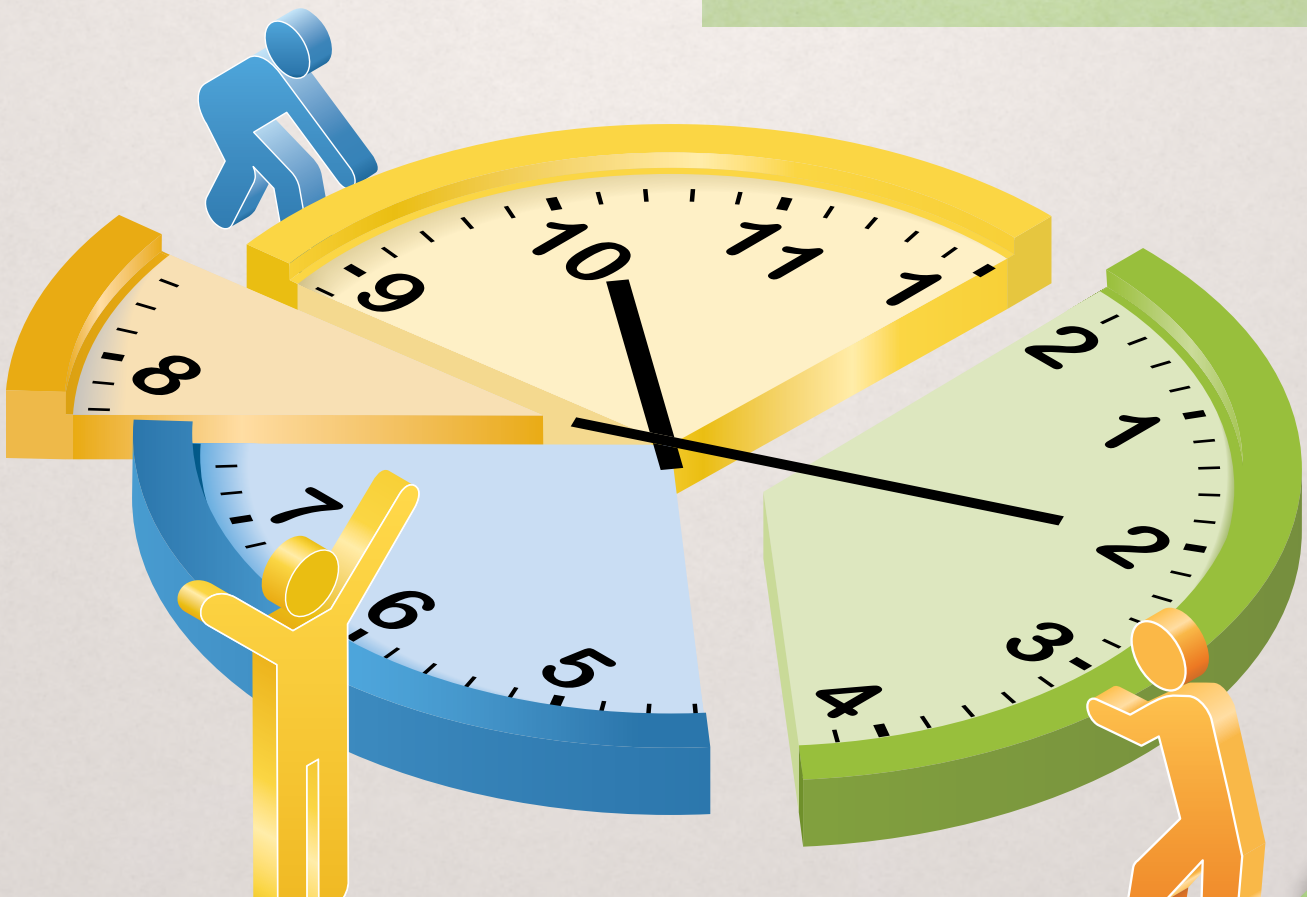
The extra time commitment involved in CBR can create challenges for academic researchers who are evaluated using traditional academic metrics (e.g., peer reviewed publications). Consulting with academics who are experienced in CBR may help in identifying potential strategies to address these challenges (e.g., budgeting to hire extra research assistants in order to move the data collection stage along as quickly as possible; structuring the project timeline to allow for publications at preliminary stages). Being transparent with project partners about specific needs (e.g., for first author publications) at the stage of developing the research agreement can also help to avoid further delays in later stages (e.g., if authorship is being negotiated only at the time the data are being written up).

Consider including time at the end of a project to enable community partners to offer feedback upon completion of their involvement. This facilitates ongoing relationship building with community partners, and provides opportunities for learning as the academic researcher goes on to develop the next project.

## THE APC STUDY

The APC study was funded as a 3-year project. Approximately 4-6 months were needed to work in partnership to develop the funding proposal prior to the 3-year funding period, and knowledge translation activities still continue well after the funding end date. The early stages of our project were time consuming, due to the time investment of developing a research agreement and hiring and training peer researchers. However, the data collection stage of our project proceeded relatively quickly due to facilitated access to recruitment opportunities through the community partner organizations on the research team.

In early meetings, the research team came to consensus about meeting days/times that were generally possible for all members. With this information, we booked standing meetings (monthly during planning and analysis stages, and every two months during data collection stages). This enabled all partners to set the time aside well in advance, and facilitated active participation of our large research team.



## Incorporating opportunities for community capacity building into the project

In CBR, there is emphasis on the research relationship as being one that is reciprocal. By this we mean that all parties—academic and community—bring equally respected expertise to the table, and also should benefit in roughly equal ways from their involvement in research. Part of this reciprocity involves recognizing and respecting the expertise that lies within the community. In order to access this expertise, researchers will need to ensure that research meetings and communications make use of accessible language and avoid unnecessary academic jargon. When language that may not be familiar needs to be used in research meetings or communications, researchers might consider providing a glossary or access to other resources that will facilitate active engagement of non-academic partners. At the same time, academic researchers should draw on community expertise to ensure that the language they are using in any public materials (e.g., surveys) is relevant and appropriate for the communities they are trying to reach, and themselves endeavor to learn the specific language of the community within which they are working (e.g., in the area of mental health, understanding the distinctions between terms like service user, consumer/survivor, psychiatric survivor, and Mad-identified)<sup>15</sup>.

In return for making use of the expertise that community members are bringing to the research, academic researchers should also support education and training of people in the community: for example, in hiring peer researchers to collect and analyze data, and offering training in research methods and/or research ethics. Considering the discrimination and other challenges that people who use drugs and/or live with mental health issues often face in securing and maintaining employment, opportunities for paid employment and/or skill development may be highly valued by community members.

There is some debate within the community of CBR researchers about whether it is necessary or important to specifically designate research assistants who are members of the community as ‘peers’. Particularly in studies on stigmatized experiences such as mental health issues and drug use, such explicit labeling could expose peer researchers to experiences of discrimination if they are not already ‘out’ about these aspects of their lives (see the Box for Practice #9 for more discussion of this issue). Further, if peer researchers are doing the same work as other research assistants on the project, such a distinction may not be meaningful and may serve to undermine the quality and significance of a peer’s work (due to stigmatizing assumptions about the capabilities of people who have experienced drug use/mental health issues, and/or associated with social class or other markers of difference). Finally, differentiating peer researchers from other research staff on a project could lead to pay inequities, if peer researcher positions are classified differently from other research assistant positions. However, some members of the CBR community argue that peer researchers are not, in fact, doing the same work as other research assistants, in that their role on the project is to represent the community and not only their own knowledge/experience. As a result of this different role, the qualifications for peer researcher positions often differ from those of other research assistant positions (e.g., formal research experience or educational qualifications may be less important, while community knowledge and connectedness may be more important). Academic researchers will want to discuss the most appropriate approach for their project with community partners before peer researcher positions are advertised, so that the expectations can be made apparent in the job description.

15 As a starting place for this, readers can refer to: <https://www.youtube.com/watch?v=pxbw7dDMX6Q> and Diamond, S. 2013. *What makes us a community?* In B.A. LeFrançois et al. (Eds). *Mad matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholar’s Press, Inc.



Researchers should consider the particular needs and concerns that people living with mental health issues and/or people who use drugs may have in the context of a peer researcher position. For example, peer researchers in studies of mental health topics may require some flexibility in scheduling (e.g., to allow for times of the day that are difficult, or for health-related appointments). People who use drugs may appreciate support in dealing with challenging situations that could arise in the context of their work (e.g., being offered drugs by a research participant)<sup>16</sup>. Conducting interviews on sensitive topics with which one has personal experience can be difficult, and interviewers may require more extensive support and debriefing than academic teams are used to providing to their staff. Both people who use drugs and those living with a mental health issue will benefit from ensuring that the work environment (including the individuals they will work with) is supportive and addresses the stigma that is often associated with these issues.

Capacity-building opportunities have budgetary implications. Budget an appropriate amount of time and financial resources for community members to participate in training, workshops and/or courses in relevant research techniques. For example, community members may receive training in research methodologies or computer software programs. Additionally, budget to pay individuals for their time spent participating in any mandatory trainings required by the funder or lead organization.

## THE APC STUDY

The APC study employed part-time peer researchers to assist with data collection, analysis, and knowledge translation. These individuals were provided with two full days of training in consumer/survivor/mad community history and qualitative research methods. An experienced research coordinator was available for further training and ongoing support as needed for the duration of the project.



<sup>16</sup> For helpful suggestions for employing individuals who actively use drugs, see <https://www.opensocietyfoundations.org/sites/default/files/work-harmreduction-20110314.pdf> and [http://www.aidsalliance.org/assets/000/001/840/Employing\\_FINAL\\_original.pdf?1445009816](http://www.aidsalliance.org/assets/000/001/840/Employing_FINAL_original.pdf?1445009816)

## Involving community members/people with lived experience in the interpretation of data prior to publication

The community should be provided with an opportunity to review the research, including interpretation of data. Ideally, this should happen throughout the process of data analysis and interpretation, in order to integrate community expertise into these processes; at minimum, it should occur before the submission of research findings for publication<sup>17</sup>.

Many researchers who are new to CBR worry that involving community members at this stage could somehow bias the results of the research. The philosophy behind participatory research suggests that we all bring biases to our research, however extensively we may try to minimize them through the scientific method. However, community involvement at this stage is not intended to change or challenge the results of the study, but rather to enrich, and ensure accuracy of the academic researcher's interpretation of the findings. That is, the lived experience that community members bring enables them to see important interpretations of the data that might not be apparent to researchers who are 'outsiders' to the community.

In addition, community engagement at this stage is important to ensure that research does no harm, in terms of further pathologizing or marginalizing communities. Again, the goal here is not to change the outcomes of the research, but rather to make sure the results are interpreted and presented in ways that can ultimately benefit communities, rather than in ways that might harm them. As an example, if a study finds high rates of substance use or mental health issues in a community, it might be very important to community members to have these rates reported together with important contextual information (e.g., correspondingly high rates of poverty or trauma also experienced by the community under study).

If community members are involved throughout the study, community review is easily done as part of regular research team meetings. To do this most effectively, researchers should share resources to help community members understand the basic principles that underlie the data analysis strategies used<sup>18</sup>. Researchers may also consider the use of 'member checking', a methodological approach often applied in qualitative research, wherein researchers share with participants their initial interpretations of data for feedback and clarification. Community forums may also be organized to offer a formal presentation of the findings to the broader community to check the researcher's understanding and interpretations; often community partners can assist in organizing these events, ensuring that appropriate community members or groups are invited to attend, and sharing in presenting the findings in ways that will be most of interest/most accessible to community members.

### THE APC STUDY

The entire research team, including both academic and community partners, participated in the process of data analysis and interpretation. To do this, we started by having all team members interested participate in the analysis of a subset of qualitative interviews, so that their insights would be incorporated into the coding framework that was applied to the remainder of the data set. The majority of analysis was completed by the project staff, which included the peer researcher members of our team.

Once the analysis was complete, our findings were drafted into a series of theme memos, that described the key findings and provided data excerpts to support them. These theme memos were distributed to all members of the research team, and through a series of meetings, we collaboratively developed a set of recommendations that drove the knowledge translation phase of our project.

17 Community members can also be involved directly in the data analysis process. For one model of this, please see: Flicker, S. & Nixon, S.A. (2015). *The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa*. *Health Promotion International*, 30(3), 616-624

18 One resource to help with this is the chapter on "Data Analysis in Community-Based Research" from the *Community-Based Research Toolkit* developed by Access Alliance: [http://accessalliance.ca/wp-content/uploads/2015/03/CBR\\_Toolkit\\_Jan2012.pdf](http://accessalliance.ca/wp-content/uploads/2015/03/CBR_Toolkit_Jan2012.pdf)

## 8.

## Budgeting for compensation of community members and/or organizations for their time contributed to the project

Communities, community members and community organizations need to be appropriately compensated for their involvement in research. Just as most academic researchers conduct their work in a paid capacity (i.e., salaried positions), community members and organizations should be fairly compensated for their time. In particular, community members should be paid honoraria for attending research meetings and other functions associated with their involvement in research. It should be noted that the topics covered in mental health and/or substance use research may be sensitive for community researchers, and compensation should adequately reflect the emotional work involved in their participation. Compensation should also take into consideration any background or preparatory work that may have been done prior to research meetings. Researchers should be sure to compensate people in accordance with their experience, expertise, and contributions to the project<sup>19</sup>.

Community members or appropriate community organization representatives can be consulted during the research proposal development phase to determine the appropriate level and method of compensation. In particular, if community members will be involved in data collection or other research work, it is important to determine whether they prefer to be paid honoraria for their time, or to be considered for research personnel positions. Some community members may be on disability or other forms of social assistance, and so receipt of additional employment income may create serious issues for them in maintaining their social assistance income and/or housing. When research involvement is short-term or sporadic, payment via honoraria may be more advantageous than creating a research assistant position. On the other hand, if full- or part-time research work is available over an extended period, research personnel positions may offer valued opportunities for community members to enter or

re-enter the paid workforce. Where payment is by honorarium, cash payment is preferable to reduce logistical barriers, assure confidentiality, and avoid stigmatizing and paternalistic assumptions that people who use drugs should not be compensated in cash. Community agencies are often experienced with using honoraria to reimburse clients, and can offer helpful suggestions in this regard. Regardless of how community researchers are ultimately reimbursed, it is important that they are able to make an informed decision about their payment options.

Grant budgets should include honoraria for community members in order to ensure that adequate funds will be available. This will require advance planning as to what extent community members will be involved in the research process (e.g., some research projects may have a community board that meets once a month, others--particularly biomedical projects-- may involve only one or two consultations over the life of the project). Also consider whether funds will be needed to provide food at meetings, and compensate community members for their transportation or other costs in addition to their time. Note that research that involves travel outside of their own city can present particular logistical and safety issues for people who use illegal drugs, so budget may be required to secure local supports, and planning for issues such as access to methadone<sup>20</sup>.

If a peer researcher model is used, academic and community researchers should discuss appropriate compensation at the outset of the study. Discussions of appropriate compensation should not only take into account education, work experience and number of hours worked but should also consider preparatory work, travel time and any additional costs to the community member such as accessing internet cafes for data input. Previous work experience and any supervisory role taken on for the research project should be reflected by an

19 For a helpful guide to considerations related to compensation, see: Guta, A., Flicker, S., Travers, R., Switzer, S., Bungay, V., Husbands, W., Masching, R., Thistle, J., & Worthington, C. (2014). *HIV CBR Ethics Fact Sheet #1: Ethical issues related to compensation. Improving the Accessibility of Research Ethics Boards for HIV Community-Based Research in Canada*. Toronto, ON. Available at: [http://www.hivethicscbr.com/documents/HIVCBREthics\\_FactSheet01.pdf](http://www.hivethicscbr.com/documents/HIVCBREthics_FactSheet01.pdf)

20 See the following document for information about these issues and recommended strategies to address them: <http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf>

increase in the base salary. Furthermore, providing a minimum guarantee of expected hours to work per week is helpful, as many peer/community researchers will reduce their full-time employment hours or other commitments to accommodate the work hours of the research project.

Community members should be appropriately acknowledged for their contributions to research. Compensation may not always be solely monetary; it may take the form of other direct benefits (e.g., authorship on peer reviewed publications or community reports, opportunities to travel to present at conferences or workshops, establishment of new resources to address community needs). In order to facilitate this, researchers should budget for community members to travel and share authorship as well as other opportunities. Budgets should ideally allow for two presenters at conferences (one community member and one academic).

Budgets should also include any costs that might be incurred by community agencies involved in a research project. For example, many community-based agencies do not have sufficient resources to manage administrative functions such as human resources and payroll costs associated with hiring and supporting peer researchers. Staff time for personnel of community-based agencies who participate in research can sometimes also be compensated through research grant budgets (where academic investigators cannot draw personnel support from certain funders as part of operating grants, costs to reimburse community agencies for staff time are often allowable). Community organizations may also be compensated through in-kind compensation, for example, through contributions of the academic researcher to other projects of the community organization where their expertise may be helpful, or through access to academic literature or software that might otherwise be inaccessible.

The costs to communities/community members of being involved in research are not always financial; for example, community researchers' personal relationships or reputation amongst other community members may be affected by their role as a researcher, particularly if the partner agency is one with which the community has historical had a difficult relationship. Non-monetary potential costs to communities and community members should be considered and appropriate supports provided (e.g., debriefing support to peer researchers following each data collection visit).

## THE APC STUDY

In this study, the peer researchers were employed by the lead academic institution as research assistants, while other community members participating as part of the research team were paid via cash honorarium following each meeting. Honoraria payments for community research team members were set according to the payment rates recommended by the academic health centre partner for client involvement in organizational committees. The pay rates for the research assistant positions were according to the relevant union pay grids; however, in retrospect we felt that the rates undervalued our research assistants, since the pay grids are heavily structured on the basis of educational credentials (for which people with lived experience of drug use and/or mental health issues can experience barriers to access) and do not credit life experience as an essential asset for the role. At various time points throughout the project, the lead academic researcher provided necessary documentation to research staff to help ensure that their employment income did not adversely affect their housing situation.

One important lesson learned from the APC study was the impact of not compensating community partner organizations, which was not done in this study due to limitations in the budget and the large number of partner organizations involved. Providing financial compensation would likely have made it more possible for some agencies to continue active engagement for the duration of the project, since staff turnover in some agencies resulted in less engagement in the final stages.

## Sharing any products or gains associated with the research, including opportunities for academic publishing

Any products or gains associated with the research (financial or expertise, for example) should be shared with community members, especially those most affected by the research topic. Be explicit about what end products are expected to come out of the research, and ensure that all commercial objectives and links to industry are communicated to all research partners. These objectives should be clearly outlined in the research agreement (See Practice #4).

Criteria for authorship on academic publications can be shared with community partners from the outset of a research partnership, so that individuals who are interested can ensure that they meet the necessary criteria. For those individuals who have not been involved in academic publications before, appropriate support from academic investigators and/or staff may be required. The order of authors should reflect the individuals' contribution to the research product, regardless of academic or community affiliation. Authorship opportunities include but also extend beyond authorship on peer reviewed academic articles to include authorship on conference presentations, community reports, community meetings, and presentations to government (see Practice 10 for more examples of research products that community members may wish to coauthor). All of these various forms of authorship opportunities represent potential capacity building opportunities for community members (as per Practice #6).

Community members may also share the resources of the research by co-facilitating presentations at conferences (See Practice #8 for budget implications). Involving community members in conference presentations has the double benefit of enhancing the effectiveness of knowledge translation as well as providing access to information (at academic conferences) that might otherwise be inaccessible to community members. Note that their role in these presentations should be as co-researchers, sharing in the presentation of the research findings. It is not appropriate to ask community members to share their own personal stories as part of conference or other presentations (though they may, at times, make a personal choice to do so).

### THE APC STUDY

The APC research assistant positions were budgeted to continue through the knowledge translation stage of the project, such that the peer researchers could participate in co-authoring an academic publication and other project outputs on paid time. Organizational representatives were also invited to participate in academic writing and other knowledge translation, though few chose to (again, this would likely have been facilitated by providing financial resources to our organizational partners). Our community partners and research assistants also took the lead in developing a novel theatre-based knowledge translation component for this project (see <https://www.porticonetwork.ca/learn/videos/access-to-primary-care> for more information). Our community representatives are credited by name in all project outputs.

One challenge that arose in the APC project was in relation to confidentiality for peer researchers. Being identified as a peer researcher in a CBR study in partnership with consumer/survivor/mad and/or drug user communities necessarily identifies someone as having lived experience of mental health/substance use issues—a highly stigmatized (and for active users of illegal drugs, criminalized) experience. As a result, our peer researchers at times expressed concern about being credited by name for their work on the project. To try to mitigate this concern, our study products do not differentiate our peer research assistants from other staff on the project. However, more discussion about this, and appropriate planning from the outset of the study, would likely have alleviated some stress experienced by our peer researchers.

## Planning for knowledge sharing and community action

Think about, and budget for, accessible knowledge translation from the beginning of the research project. Although there will be community members interested in the academic publication(s), knowledge translation strategies should consider the diversity of needs and learning preferences within the community and among other stakeholders, as well as the community's wishes for changes to result from the research. Consult with community partners about who the important audiences will be and what their needs are, and ensure adequate budget for community-based knowledge translation. Participants and community stakeholders may also be consulted about where to publish the results. Whenever possible, dissemination activities should be agreed upon in advance and indicated in the research agreement (Practice #4).

In the fields of substance use/mental health, many community members and organizations are very interested in learning about the results of biomedical research (e.g., neuroscience, genetics). Unfortunately, these studies are often particularly inaccessible as a result of technical language. Many academic institutions have in-house knowledge exchange resources that can assist with developing accessible knowledge translation products for these (and other) types of projects. Remember that ethics boards often require academic researchers to distribute a lay summary of findings to study participants; consider sharing this same summary with community members and organizations.

Other types of accessible knowledge translation activities might include community meetings to share the results of the research, publishing findings in multiple languages, in plain English language, and creating audio podcasts, films, theatre or Youtube videos for the public. Additionally, a website or community location should be determined where research participants, peer community researchers and all other interested community members can receive updates and progress notes regarding the research project.

While knowledge translation is an important component of any research, making positive social change and promoting equity through the research process is fundamental to CBR. Using the research for action-oriented knowledge translation is a key way that research can benefit the community and its members. Unfortunately, the work of moving research findings into social change is, in most academic environments (and for most major funders) not considered to be part of the 'work' of researchers. For this reason, CBR approaches require a commitment on the part of academic researchers to work around these institutional and structural barriers to see a project through beyond the endpoints typical of traditional academic studies. Often this will include working with the community to identify additional funding to support and evaluate community-based knowledge translation and action initiatives.

### THE APC STUDY

In attempt to maximize the impact of the APC study, we developed several knowledge translation products, each targeted to particular audiences. These included: an academic manuscript (to share our findings with other researchers in the area of primary care), a community report in lay language (to share our findings with community members and community-based organizations), a tip sheet for service users about accessing primary care (to share strategies suggested by our participants), a policy report (to encourage policy makers to consider the needs of people living with mental health and/or substance use issues in policy making and planning related to primary care), and a theatre-based workshop for primary care service providers in training (to address stigmatizing attitudes about drug use and mental health issues, which were one of the main barriers to primary care identified by our participants). All of these products were developed in close collaboration with community members of our research team. More information about our knowledge translation products is available at [www.camh.ca/primary-care-study](http://www.camh.ca/primary-care-study).

# Conclusion

According to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, research studies are required to be conducted in a manner which involves:

- treating people equitably and fairly
- recognizing the inherent value of human beings through respect and consideration
- maintaining respect for the knowledge held by communities
- taking the time to establish relationships in order to foster communication and trust.<sup>21</sup>

CBR approaches can assist in achieving these principles. When working with communities that experience marginalization or discrimination (including people living with mental health issues and people who use drugs), achieving these ethical principles may require that academic researchers change their ideas about the role of the ‘expert,’ in order to properly value the lived experience of communities and community members. Through establishing relationships of mutual respect, listening, and understanding, researchers may be able to more meaningfully engage with their research question, collect richer data, achieve a deeper analysis, and more effectively address the concerns of the community – all common outcomes of the successful application of principles of CBR.

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21 *Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010.*



# Resources on Community-based Research

AccessAlliance Multicultural Health and Community Services (2011). Community-based research toolkit: Resource for doing research with community for social change. Toronto: Access Alliance Multicultural Health and Community Services. Available at: [http://accessalliance.ca/wp-content/uploads/2015/03/CBR\\_Toolkit\\_Jan2012.pdf](http://accessalliance.ca/wp-content/uploads/2015/03/CBR_Toolkit_Jan2012.pdf)

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## Resources on Drug User Communities

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Toronto Drug Users Union (TDUU): <http://tduu.blogspot.ca>

Vancouver Area Drug Users Network (VANDU): <http://www.vandu.org>

