Community-based research:
Partnering with scientists

A GUIDE FOR COMMUNITY MEMBERS

What is community-based research?

Research is not always seen as being friendly. The "men in white coats" have been known for doing things to us, not *with* us.

Community-based research (CBR), in contrast, is about community folks being partners in *doing* the research. We can decide the questions that the research will answer. We can explain the answers.

Communities can be involved in research in many different ways. Community members can:

- come up with questions to research

- decide how the research will be done
  (e.g., through interviews or filling out forms)

- oversee how information is collected
  (e.g., how people will be asked to participate)

- interpret the results (e.g., judge whether the results apply to all community members)

- decide how to communicate what was learned.

Linking science with values

Community-based research is also about values. CBR connects social change and anti-oppression values with science. Historically there has been an enormous power imbalance in research. The scientist has been in control, and has explained what the research means. The people being studied have not had a real voice in what was happening, or in explaining what was found. Terrible abuses have been inflicted on communities in the name of science (such as experiments conducted on psychiatric patients for the CIA at Montreal's Allan Memorial Hospital in the 1950s and 1960s). Understandably, communities who have been harmed by research are distrustful of researchers and science in general.

CBR is a way for communities to take control of the way science gathers information, and to use it to help the community. This does not mean that community influence creates biased research. It means that the community can get at truths that people outside the community may not see or understand.

The CBR approach is especially vital in communities that have lived with oppression and marginalization, such as racialized and LGBTQ communities and people with mental health challenges and/or experience with substance use. CBR creates an opportunity for mutual education between scientists and community members.

Sharing power

There are different degrees to which power can be shared. In *collaborative research*, power is shared between researchers and community partners. In research in mental health, for example, "survivor research" is about people who have been on the receiving end of services having more decision-making power than the professional researchers.

Power imbalances are not just about how present research is done. It is also important to examine and question the assumptions that underlie a lot of past research. For example, in mental health research it has been assumed that there are some people who are mentally unhealthy and some who are mentally healthy, and that those in the "unhealthy" category need treatment to correct the "problem" and therefore should be studied. Often these assumptions lead to research projects that ignore the insights and experiences of people who have had the very experiences being labelled and judged.

Questions to ask

Here are some questions, based on the principles of CBR, that communities may want to ask when they are invited to be involved in a research project.

- If I become involved in this project, what's in it for me? What's in it for my people?

- Are community members invited and able to be involved in every step of the project?

- Is the research important to the community? Could it result in meaningful changes that benefit community members?

- Are the right questions being asked?

- Will we have meaningful input into the interpretation of the results before they are shared or published?

- Does the researcher really know the community with which they wish to partner? Communities can be more diverse and/or more specific than most people understand from the outside. This may require some explanation by community members. Organizations representing community members should be involved to provide perspective beyond that of individuals, to ensure that community involvement is more than tokenistic.

- Is the process respectful of community members' time and schedules? For example, will community members have a say in when meetings are held? Does the project timeline leave room for changes based on community feedback?

- Will a research agreement be created to guide the relationship and the process? Ideally, this will be a formal written document that addresses expectations about contributions, inclusion, authorship and possible gains from the research. An important part of the agreement will be a check-in about how the project is going for the community folks involved midway through the project, as well as at the end. In CBR, communities and researchers can learn from each other.

- Is there an opportunity for community members to gain skills from this experience? How will the community benefit from the research process?

- Is there space in the budget for the financial costs to community members (e.g., honoraria, travel, child care) to be compensated? Is food available if some community members have few resources to afford food? Are meetings held in settings convenient and comfortable for community partners?

- How will community members be acknowledged for their contribution? Are there opportunities for community members who are interested to co-author publications?

- What will be done with the results of the research? Will they be presented to the community? How?

These questions can be asked at the beginning to help community members decide if they want to get involved with a project; partway through to check how things are going; and at the end to determine whether the partnership is productive and should be continued.

Researchers may sometimes misrepresent themselves, the project or their goals. If this happens it is important for community members to talk among themselves and decide how to communicate their concerns, and what steps to take if this does not have a positive result.

In summary, a research partnership can open doors for a community to meet its goals in ways that have previously been controlled by others. Evidence can be gathered of realities that have been dismissed as "just stories." Services that are needed can be advocated for using evidence that funders understand. Services that are *not* helpful can be evaluated using criteria that mean something to those using the service. Research can leave its dusty cupboard and be used to effect social change.

EMPOWERMENT COUNCIL

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Centre for Addiction and Mental Health