Prevention in Focus
Spotlight on programming and research

What to ask when researchers come knocking

By Carol Strike and Adrian Guta

Wondering about the researcher who recently called you about a research partnership? To stay relevant and effective, organizations that serve people living with and at risk for HIV and hepatitis C must demonstrate the benefits of their programs and services and stay ahead of their clients' changing needs. However, research partnerships require considerable discussion and planning to meet everyone's needs. How will you decide if a partnership is worthwhile? Here are eight questions to ask when researchers come knocking:

1. What is the proposed research question?

Ask the researcher about what they want to study and the questions they would ask. Are you interested in these same questions and would the answers be of benefit to your organization? Research questions can often be negotiated and adapted to meet various needs and interests. Some research projects will help you and your organization plan or evaluate your programs and understand any changes in your community; other projects may provide evidence for policy changes that will benefit your clients. Understanding what the researcher is thinking of studying, and what it means for your organization will help make your decision easier.

2. How do you plan to approach the research?

Ask the researcher to tell you about the model of research she plans to use. The more you know about how she plans to approach it—the methodology and what steps will be taken to ensure it is done in an ethical manner—the more informed your decision will be.

Not all research methodologies are alike. Some are based on a traditional, investigator-driven model, some take a community-based approach, while others fall somewhere in between. The traditional investigator-driven model typically involves the researcher determining the subject of inquiry and how they will approach the study. In this case, your organization's role may be solely to allow the researchers access to the agency and clients for research purposes. By contrast, community-based research involves community members working closely with researchers on all aspects of the project—setting goals, developing the research questions and study design, collecting and analyzing data, and disseminating findings. For some community-based

organizations (CBOs), partnering with a researcher in this way can be a great opportunity to build their staff and clients' capacity and for their clients' voices to be heard. For others, this level of involvement may not be possible or desirable given other priorities.

Deciding what type of research you are comfortable supporting will help determine whether you want to partner with the researcher. But remember to also ask yourself whether your organization's needs and resources are in line with those of the research project.

You may also want to discuss what steps will be taken to ensure the work is done in an ethical manner. What ethical principles will guide the project? How will the benefits be maximized and potential harms minimized? How will the privacy and confidentiality of participants be ensured? How will you ensure that clients feel comfortable refusing to participate in the research, that they won't have to worry that this could affect the services they use?

You may want to familiarize yourself with some ethical frameworks advanced by communities you will be working with, such as:

- Greater involvement of people living with HIV/AIDS (GIPA) – an internationally recognized principle that promotes the involvement of people living with and affected by HIV, in research, programming and evaluation.

- OCAP (ownership, control, access and possession) – a set of principles that promotes the leadership and self-determination of Aboriginal communities in research as well as the collective ownership of information.

- "Nothing about us without us" – a commitment to the meaningful involvement of people who use illegal drugs in Canada's response to HIV, hepatitis C and injection drug use.

3. What decision-making process will be used for this project?

Research involves many decisions—from what the research question will be to who will present the findings and how. Discuss with the researcher who will be included in making decisions and what decision-making model he or she wants to use for the project: consensus (everyone agrees on the decision) or majority rules (proceed with whatever choice is most popular). Make sure that you are comfortable with the decision-making model from the get-go.

Writing "terms of reference" (or a memorandum of understanding) can be helpful to establish lines of communication and to document how decisions will be made.

4. What level of involvement do you foresee for our organization's staff members and clients?

Establishing expectations, roles and responsibilities from the beginning will go a long way to ensuring a positive partnership. To get the most out of a potential collaboration and avoid problems later, ask the researcher what level of involvement she foresees for you, your co-workers and clients. You'll want a clear understanding of how you will manage your current commitments along with any new ones associated with the project. And the researcher will benefit from a clear sense of the workload and potential level of commitment that you and your co-workers can offer.

You might ask some of the following questions to determine how much will be expected from your organization and when:

- Will we be asked to contribute to the design of the project (including its objectives and methods) and/or to analyzing and disseminating findings?

- Will my co-workers and I be needed for research tasks and for how long? Will we be compensated? To whom will we report? Will external research staff come to work onsite? If so, to whom will they report?

- Will our clients be recruited and by whom? How? Will they be compensated?

- Will staff and clients have opportunities to develop their research skills?

You may also want to get a sense of the researcher's other commitments. If she is working on six other studies and teaching four courses, will she have a coordinator assigned to the project being pitched? If the project is being conducted at your agency and something goes wrong, will she be available to intervene?

5. What resources do you foresee coming from my organization?

Research requires resources: money, staffing and space. Research funding (e.g., from the Canadian Institutes of Health Research) will cover most costs but there may be additional expenses that are not covered. Determine early on what in-kind resources, if any, your organization would be expected to contribute.

Some research funding offers investigators who work for CBOs payment for their time. If the research funding does not offer such financing, staff from your organization may need to take on unpaid work to see the project through to completion.

You might want to ask questions such as these to find out how funds will be distributed and to whom:

- What expenses does the funder allow for in the budget and what would not be covered? Who would cover these costs?

- How much travel/transportation money is allowed and who will have access to it?

- If needed, can equipment (such as computers and printers) be purchased? And to whom will the equipment belong once the project is completed?

- Can funds be set aside to support participants (for example, for food, honoraria, transportation)?

- Can funds be used to reimburse staff for their time worked on the project?

Universities usually manage research funds but many organizations also qualify to hold funds. Ask who will manage the research funds and if any monies need to be transferred to your organization. If funds need to be transferred, figure out what would be involved for your organization and the researchers to transfer and/or receive funds. You will want to avoid a situation where you are left for long periods of time with expenses that have not been reimbursed. Before agreeing to the project, make sure you are comfortable with what the research monies will cover and who will hold the funds.

6. How long will it take to complete the project?

While some research projects are short-term endeavours, research generally takes a long time to complete. Ask yourself (and the researcher) if you want to be involved and can be involved in a short- or long-term project. You may want to get a sense of some specifics, such as how long the researcher is going to need an office at your site to conduct interviews, how long staff members from your organization will need to recruit participants, or for how long you will need to attend advisory group meetings.

The project will probably take longer than anyone predicts because research is often impacted by factors outside the team's control—for example, multiple applications for funding, ethics applications that need to be revised, approval requirements (of both your organization and the research institution) and a longer-than-anticipated timeframe for recruiting participants. You may be surprised by the number of administrative requirements that can be part of the research process. The most important of these is ethics review, which most funders require before research can begin. Research ethics boards (REBs) ask the research team many questions to ensure that a project meets the highest ethical standards and that research will not negatively impact participants.

Any or all of these factors can extend the length of a project considerably. What started as a six-month project can easily turn into a year, leading some to ask, "why is this taking so long?" Good research takes time.

7. How will the study findings be shared and with whom?

If you anticipate wanting to use the results of the study, ask if, how and when you will have access to them. For example, if you want statistics about your clients to apply for funds to develop a program, you will want to know when you can access this data. Depending on confidentiality issues, some data may not be available to you or it will need to be modified to protect the privacy of those who participated.

In the excitement to report research results, the people who participated are often forgotten about. They have a right, ethically, to know how the results will be used. They shouldn't have to hear about it on the news. Ask the researcher and ask yourself what plans and resources you will need to ensure that findings are disseminated in a way that is respectful of the communities involved.

8. Will my organization be identified in the results?

It is important to ask how your organization will be represented in the research—will it be listed as a research partner, will staff members be listed as co-investigators, or will names be kept anonymous?

Why does this matter? Some research may investigate sensitive and controversial practices that later attract attention—for example, from the media or at a conference. How your organization is represented could influence its reputation, funding and donations in favourable or in potentially unfavourable ways.

A few concluding words

Asking so many questions and then sifting through the answers can seem like a daunting task. However, taking time to do this before you say 'yes' to a research partnership can save you time and prevent problems and disappointments down the road. It may not always be the right time to take on a research commitment; however, if it is, then research can be very exciting, present new opportunities for you and your organization and generate new knowledge to help guide your programming.

About the author(s)

Carol Strike, PhD, is an associate professor at the University of Toronto's Dalla Lana School of Public Health, with 15 years of experience in harm reduction, addiction treatment and health services research.

Adrian Guta is completing doctoral studies at the Dalla Lana School of Public Health and the Joint Centre for Bioethics, at the University of Toronto. His dissertation research explores the Canadian HIV community-based research movement and the ethical dimensions of collaborative research practices. Mr. Guta has been involved in a number of HIV CBR projects and has co-authored several articles on ethical and methodological issues in CBR.