When Researchers Come Calling

This guide helps community-based organizations make decisions about engaging in research partnerships.

2025

centre of excellence for women's health

Introduction

Community-based organizations are often approached to collaborate with researchers on studies related to addressing health and social justice issues.

When Researchers Come Calling was developed by the Centre of Excellence for Women's Health based on the experience and wisdom of researchers and organizations serving women, girls, or women and gender diverse individuals, to support community-based organizations in making decisions about engaging in collaborative research.

While the majority of our projects and partnerships relate to women's health, this guide describes common steps and offers tips to help your organization make informed decisions about whether, if, and how, you might want to collaborate with researchers in ways that are mutually beneficial.

When Researchers Come Calling provides information on several important topics for making decisions about research involvement. In this guide, we discuss:

1. Types of research involvement
2. Starting the research partnership
3. Ethical considerations
4. Involvement in the research process
5. Potential for impact

The boxes offer relevant questions that you might ask a prospective research collaborator. The checklist at the end will help you evaluate if a research partnership might be a good fit.

Types of research involvement

Research is a systematic process to help us understand a particular issue. Research can be used to deepen our understanding of a topic or create new knowledge or theories about the world around us. There are many approaches and methods that can be used in research.

There are several reasons why research partnerships could be beneficial to your organization:

- You have a particular question you would like to answer
- You would like to evaluate a program or service that your organization offers
- You would like to contribute your knowledge and expertise in a specific area
- You would like to contribute to the development and application of evidence-based practice and policy

Partnerships between researchers and community-based organizations can take many forms:

- In an **advisory role**, you or your organization may be asked to provide insight or knowledge on a specific topic relevant to your area of expertise.

- If your organization is engaged as a **collaborator** or **partner**, it may include involvement at one or more stages of the research process.

The following questions can start conversations between your organization and a research team:



QUESTIONS TO ASK

- **Is this research project in line with the mission and vision of our organization?**
- **What is the scope of our involvement?**
- **Does our organization have the time and resources to dedicate to this research project?**
- **Do we have a question that this research could help us answer?**
- **Will our organization be involved in making any decisions about the research process?**

Starting the research partnership

Before you begin to work with researchers, it is important to identify if the researchers' values and research approach align with your organization's values and mission. It can be gratifying to be involved in research. Research can directly benefit your organization and/or your clients and other research participants, and your participation contributes to an expansion of knowledge.

However, research has not always been an empowering process for community-based organizations or their clients.

As a community-based organization, you are aware of the needs, concerns, and circumstances of the clients you serve. It is important that your research partners ensure that these needs are prioritized.

You can ask for examples of previous work the researchers have completed. Reviewing materials the researcher(s) have published previously may give you an idea of whether their approach is consistent with your organization's philosophy or values. It is also important to ask the research team about the research design planned for the current project, to understand if the methods proposed will be suitable for your organization and/or clients.

QUESTIONS TO ASK

- What experience does the researcher team have in collaborating with women and/or gender diverse clients facing health and social concerns?
- How have the research team previously collaborated with community-based organizations on similar topics?
- What mechanisms are in place to ensure the safety of your clients (e.g., including counselling services)?
- Will we be able to review the materials to be used for this research? (e.g. surveys, scales, interview questions, etc.)?
- Will we have regular updates on the status of the project?
- Who will we contact if we have a complaint about the way the research is conducted?
- What access will we have to the data collected during the project?
- How will the results be shared, and will we be able to review materials before they are shared publicly?



Being trauma informed is crucial

There is increasing awareness of how important it is to be trauma informed in all we do, including in research.

Being trauma informed means:

- being aware that the research participants may have experienced trauma and may have enduring effects of those experiences.
- ensuring that research encounters are made as safe as possible – emotionally, physically and culturally.
- being transparent throughout the research process, so that trustworthy relationships are fostered.
- supporting choice and collaboration with research participants and representatives of community organizations at every stage of the research process.
- bringing a focus to strengths and resilience of participants.

Ethical considerations

Most research projects need to undergo a research ethics review. This process involves submitting an application to an institutional Research Ethics Board that describes in detail the topic of research, the methods that will be used to collect and store data (e.g., surveys, focus groups, interviews), and how the data will be analyzed. In the application, information on how researchers will address these core principles is explained:

1. Respect for persons
2. Concern for welfare
3. Justice

INFORMED CONSENT

One way that researchers can uphold these principles is through **informed consent.** Informed consent means that the women participating in a study are provided with information about the benefits and risks of participating (or choosing not to participate) to make an informed choice about whether to take part. This means that potential research participants should understand:

- why the research is being done
- what they will be asked to do
- how their information will be protected, and
- that they can withdraw from the study at any time with no consequences.

Depending on the study design, informed consent can be an ongoing process or a one-time requirement at the beginning of the research encounter. Researchers should explicitly present the option to withdraw consent throughout the research process. Participants have the right to withdraw their consent at any time, even after the study begins, and regardless of having already received compensation.

Informed consent also includes consent for how the results will be used or shared.

Community-based organizations, as well as researchers, should emphasize that the experiences women choose to share in research are valuable, and what happens to this knowledge is important.

QUESTIONS TO ASK

- **What are your procedures for obtaining consent?**
- **How and when will you make clear that participants can withdraw their consent?**
- **How will you consult with us as a community organization before disseminating findings?**

PAYMENT FOR PARTICIPATION

For organizations

When your organization partners with researchers, you may wish to sign an agreement that states what financial support your organization will receive for its involvement in the research process. This may include funding for:

- Staff involvement in the research process (e.g., participant recruitment, co-creation of project materials, participation in meetings, etc.)
- Administrative support
- Specialized staff support (e.g., on-site counsellors or Elder support)
- Printing costs for material created for the research or for sharing results

QUESTIONS TO ASK

- **Will we create a partnership agreement that states what funding has been dedicated to our organization, and how the costs are to be allocated?**
- **How, and at what point in the study, should we expect payment for our involvement in the study?**

For research participants

Payment to participate in research is usually referred to as an honorarium to acknowledge the time, effort, and expertise that participants contribute. Each research project will have different procedures about when and how people receive their honoraria. For example, many Research Ethics Boards require that researchers provide the honoraria via gift cards instead of cash.



Some research projects will offer an **honorarium** before the study starts, while others offer it in increments over the course of a study (when participants meet with researchers on more than one occasion), and some offer it after the participant has finished the study. Before agreeing to take part, participants should be made aware of when and how they will be compensated. This information should always be included in the consent form.

QUESTIONS TO ASK

- **How, and at what point in the study, will participants be compensated for taking part in the study?**
- **What other supports, if any, can you provide for clients who participate in the study (e.g. bus tickets, childcare, refreshments)?**
- **How will you ensure that participants know they can leave or withdraw from the study, even after they've received an honorarium?**

CONFIDENTIALITY

Researchers are trained to see confidentiality as a fundamental right of participants, and the duty to maintain confidentiality as a professional obligation.

Community-based organizations and research participants may have concerns about how the research findings are shared or worry about a lack of confidentiality among researchers and service providers.

Researchers are required to follow rules set by Research Ethics Boards that ensure confidentiality. In a research project, participant data are anonymized and information that could identify an individual study participant can usually only be accessed by the research team. This means that the research team is likely unable to share with the community organization which clients are participating in research process.

There are exceptions to total confidentiality, but these apply only in situations where researchers have access to identifiable information - such as during direct interactions or when participants disclose identifying details. For example, if information comes to a researcher that suggests a child is in danger, or if someone is at risk of harming themselves or another person, they may have a legal or ethical obligation to report this to the appropriate authorities. These limits to confidentiality should be made clear to research participants as part of the consent process.

In research projects that involve collecting data in focus groups or other group settings, researchers cannot guarantee that confidentiality will be maintained by other participants in the group. It is the researchers' responsibility to encourage group confidentiality, and to ensure that participants know they don't have to answer anything they don't feel comfortable sharing with others. Participants can always choose how much they want to say in any research setting.

QUESTIONS TO ASK

- **How will confidentiality procedures be discussed with participants?**
- **At what point(s) in the study will confidentiality procedures be discussed with participants?**
- **What mechanisms are in place to support clients who might be taking part in the research study and also accessing services at our organization?**



Active involvement

Your organization and your clients may have an even better partnership experience when you are actively involved in the research process. This may mean maintaining collaborative partnerships with researchers who are interested in your organization's work.

Getting actively involved in research studies gives your organization and those you serve a chance to minimize any challenges and maximize benefits of research participation. This is not always easy but can be an opportunity for your unique knowledge and experiences to be recognized and utilized.

QUESTIONS TO ASK

- **How are women with lived and living experience involved in the research process? How could they be?**
- **How many hours might be involved for us as an organization to contribute to this research project?**
- **How will we be compensated for our involvement?**
- **How can you help us research the issues we know to be important and relevant to our clients?**
- **How might we and our clients be involved in sharing knowledge gained from this research?**

Potential for Impact

Policy and program change in health and social care often relies on research to identify, test, and monitor new approaches. Many women agree to participate in research in the hope that it will help others dealing with the same issues, and that the research will make things better for their community, now or in the future.

Research *can* lead to the differences women hope for when they agree to participate. However, it can take a long time to achieve real change in practice or policy. Researchers may be able to get decision makers to listen to their results, but there are many factors that affect decision making in addition to new research evidence. This is something both participants and community-based organizations should be aware of when agreeing to participate in, or support, a research study.

While this lag in action can be frustrating, and may create skepticism about research, it remains important to engage in research even while naming the same issues over and over again. Community-based organizations, as well as researchers must continue to emphasize the importance of including the experiences of your organization and your clients in making social change.



QUESTIONS TO ASK

- **What plans for advocacy have been arranged, based on the results of the research, that will improve clients' health and safety?**
- **How can we ensure that participants understand both the potential and the limitations of the study to generate change?**
- **What funds are in place to support the sharing of findings?**

Checklist

Reviewing this checklist can help you be more confident that your organization and the clients you work with are engaged in research respectfully and beneficially:

- What benefits do you see for your organization, and its service users, for involvement in the proposed research?
- Do you think the values and experiences of the research team align with your organizational interests and values?
- Will your role be as advisors or co-researchers in the research process?
- Will there be opportunities for people with lived or living experience to take an active role in the research?
- Will ethical considerations such as informed consent and confidentiality be well addressed and respected by the research team?
- Will your organization, and the research participants involved, be compensated fairly and ethically for participation in the research?
- What plans and resources do the researchers have to help translate findings into action?
- How/will you be consulted before the research findings are publicly shared?

This guide was prepared by the Centre of Excellence for Women's Health (CEWH). The CEWH is a research centre focused on improving girls' and women's health and increasing gender equity. We have engaged in research with women in over 500 projects since 1997.

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