

# Community-Based Research –

## Opportunities For Productive Collaboration

A brochure for member organizations of the Coalition  
des organismes communautaires québécois  
de lutte contre le sida (COCQ-SIDA).



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# Why this brochure?

As a community organization, you have certainly been asked to participate in research. Perhaps you have also asked yourself how to launch a research project on a topic of ongoing concern to your organisation.

**T**his brochure is intended to be an easy-to-use reference tool for demystifying the research process, and to be used by your organization or the people you serve to derive the maximum benefit from it. Its main focus is community-based research, which has the greatest potential for your involvement as well as responding to the concrete needs that emerge in your everyday practice. The categories and points raised in this brochure will also help you assess other types of research, such as medical and clinical.

Each research project is obviously different and adjustments are often made during the process. Flexibility is even welcome! Instead of presenting a typical research project, this brochure presents the main parameters of an ideal approach to one. In all cases, scientific rigour and the participative process, which clearly benefit the community, are the hallmarks of a successful community research project.

In these pages you will find a series of definitions, guidelines and tips of a general nature that will giving you an overview of winning approaches to actively engaging your organization in this process. If you would like more detailed information on the way to conduct community research, go to the section entitled Online Resources.



# What is Community-Based Research?

Community-based research involves **partnership with community actors**, such as community organizations, putting them at the heart of the process.

In contrast to a strictly university-based team of researchers, a research partnership concretizes principles such as equality among partners from different backgrounds and fields, consensus decision-making, and knowledge transfer to the community. Along with the concept of community health in the health sciences, community-based research is a close relative of other research traditions such as action research (envisioning social change) or participatory action research (based on the active engagement of all parties).

The idea of community here refers to a group of people who share concerns or share a common experience – for example, people living with HIV. It is a reference group involved in the partnership process. In no case is it a group of people regarded as homogeneous. The research partners that represent this community and engage in the planning and implementation process can be individuals (people living with HIV, members of their family, people involved in the fight against HIV/AIDS) or groups (organizations such as yours who fight against HIV/AIDS).

**Forming a partnership depends on the identification of a research topic and on the interests of various partners.** A university team can invite community actors to join a project, but community actors themselves can identify a research need and ask university researchers to form a partnership with them. This means that in contrast to traditional university research, a community-based research project can be launched and guided by a community group.

# Building bridges

between universities and the community –  
solutions at hand

One of the *raison d'être* of community-based research is to build bridges between the university and the community that facilitate and encourage exchange in both directions. In the context of your everyday work, you have acquired expertise that can constitute a major input into the design and implementation of a research project. With regards to the input of university researchers, their expertise is based on their experience, knowledge and *savoir-faire* acquired in research. Working together should therefore be based on mutual respect and an understanding of the contributions and limits of each party.



## A SOLID FOUNDATION – defining a research need

Very often the definition of a research need comprises the first step in creating a partnership. Three choices are possible in the first step – 1) assess the university projects submitted to you in light of your needs, 2) ask COCQ-SIDA to assist you in the process of formulating research questions, and 3) knock on the door of a university researcher's office.

Here are some possible needs of your organization that can be transformed into research questions:

- Evaluation of programs or services, such as easy or difficult access, known or unfamiliar activities, well or poorly adapted to your target population, outcomes that are very satisfactory or unsatisfactory in light of attaining program goals, etc.
- Attitudes towards a certain group in society and needs related to sensitizing the public (stigma, discrimination, and their effects; advocacy etc.)
- Studies on various facets of quality of life and health in order to implement or improve interventions in areas such as mental health, housing, food security, sexuality, prevention, etc.
- Updates on or synthesis of knowledge, the goal being to provide appropriate interventions such as new approaches on prevention, testing, treatment, etc.
- Best practices related to supporting people living with HIV (treatment adherence, testimonial, etc.)
- Any other need that emerges in your daily practice



## BUDGET AND FUNDING

Although a small research project can be conducted without specific funds begin devoted to it, most of the time the costs will require finding appropriate funding.

Having a budget to hire a project coordinator, cover travel expenses, or compensate community workers' salaries, can greatly facilitate the implementation of a research project in all its various stages. Preparing a budget listing potential expenses can help anticipate the means by which the needs of everyone's particular job in the project can be adequately met. If the project has been initiated by a university, community actors can plan for and share the potential costs (training, creation of communications materials) associated with their participation to ensure they will be included in the project budget.

Many funding possibilities are available from provincial and federal government departments and agencies (see the list in Little glossary). With regards to partnerships, most funds can only be solicited by the university researchers involved. However, some funders may accept community researchers as well. In all cases, the budget will be first approved upon acceptance of the grant application, then the various budget items can be administered as planned. The budget will usually be managed by the researcher or the principal applicant of the grant and his institution.

## SEALING THE PARTNERSHIP – parameters of active engagement

You have formulated your research need or a research team has submitted a project to you that seems relevant. How do you ensure the active engagement of your organization and the population you serve?

### 1. Clear communication

- To maintain clear communication between your organization and the research team, you can designate a contact person in your group and try to identify a member of the university team who would be most effective in communicating with you. In addition, don't hesitate to ask for help from COCQ-SIDA, who will ensure that communication channels remain open.
- Ask yourselves what your participation in the project means in terms of time and resources. These elements should be described in a more formal way in your project cover letter being sent to funding organizations.

### 2. A pilot project conducted by an inclusive and representative team:

- Think of the way your concerns could be addressed by the research team at every step in the process (research needs, negotiation on the data collection method, involvement in the recruitment of participants, etc.). Given this, it is prudent, indeed of prime importance, to write a partnership agreement between your organization and the university and/or request the creation of an advisory committee, comprising a relatively large number of community representatives.
- Evaluate first then make suggestions on increasing the participation of people living with HIV and other populations concerned in the research process, e.g. become a member of the advisory committee, research team as a researcher or research assistant. Discuss compensation of participants, be it for recognizing the expertise they bring to the project or advisory committee, compensating them for the time taken to fill out a questionnaire, or for covering daycare or transportation costs.
- Think about the status of the members of your organization on the research team with regards to the imperatives of the grant proposal. Will you be co-researchers, collaborators, knowledge users (see Little glossary)? A clear definition of your status can ensure your active involvement throughout the research process.

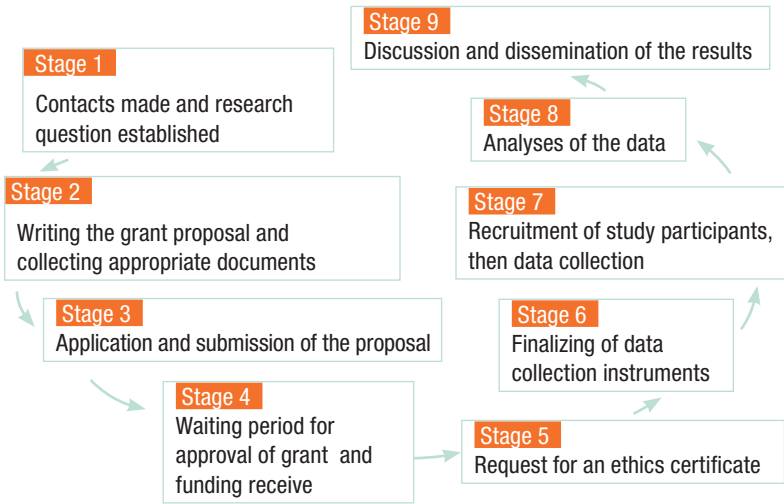




### 3. Deadline, knowledge transfer and mobilization:

- Ask for a schedule of the main stages in the research process. If the project encounters delays, you can at least assess progress in light of these stages and key benchmarks when needed to be more actively involved.

**Example of a project timeline** (it can range between 1 and 5 years, depending on the type of research, its goals, and/or funding obtained):



- Establish procedures for receiving updates on the preliminary results or hypotheses at key stages in the research process before it concludes. With your team you can define a plan to apply the knowledge obtained from the research project (see next section). With partial results you can redirect the analyses if needed so that they better match your needs and concerns. They can also help you gain a better understanding of the major communication and dissemination issues that will soon arise.
- Clearly establish the partners' (including community actors) right to review the publications to come and the possibility of being co-authors of them. If applicable, arrange to indicate in the publication that it does not represent the opinions of your organization before it is published.

# Knowledge mobilization

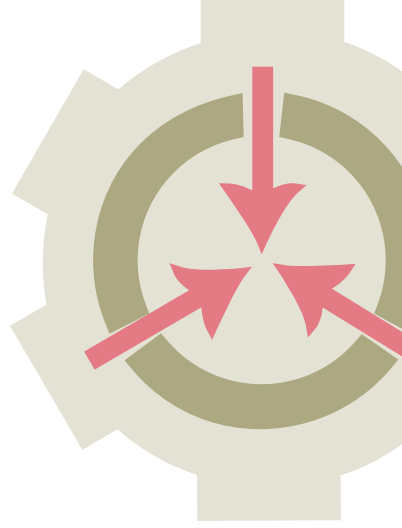
The results or impacts of a research project can take many forms, and these will manifest themselves at the beginning of the process, be they scientific, clinical, academic, or involving the improvement of capacity-building for individual or collective action. Each type of result is certainly interesting in itself; however, the project should provide you with a set of solutions or directions for action which respond to the concerns you identified as primary at the beginning of the process. This means mobilizing your organization to apply the findings (the knowledge acquired), in other words, to put into action the knowledge you now have in your hands to formulate concrete responses to expressed needs.

## MOBILIZATION PLAN TO APPLY THE FINDINGS

Before engaging in the data collection process, it is important for the research team to focus on a mobilization plan, meaning a strategy that ensures the findings of the research will translate into significant impacts on the community. This is how your organization will clearly indicate its needs and expectations and include them in the funding proposal or partnership agreement. The mobilization plan can have four major components:

- 1 Predictions/Forecasts:** What knowledge and savoir-faire will the research likely generate? Will these be productive for the community?
- 2 Dissemination strategies:** What pre-defined actions will be taken to disseminate and make accessible the knowledge and experience acquired? Will the documents or presentations designed for the community be written in a clear, non-technical language? Will your organization participate in the data analyses process as a result of ongoing communication among the partners?
- 3 Strategies to have a concrete impact:** How will the research results transform into fulfilling your needs – targeting interventions, bringing added value of training to your organization or the populations you serve?
- 4 Long-term impacts:** How will the results of the research be used over the long term to inform public policy and decision-makers, be the engine for further research or new actions to take?

The mobilization of knowledge continues throughout the project. The process of community-based research encourages exchanges between the partners, allowing all to share their points of view and their experiences to enrich the project.



## **MAXIMIZING THE IMPACTS OF A RESEARCH PROJECT ON YOUR ORGANIZATION**

Maximizing the impacts of a research project on your organization will certainly involve promoting the project internally and reassessing certain decisions or practices in your interventions with your members or the populations you serve, all with the goal of ensuring the relevance and success of your future activities. You can therefore think of developing an internal mobilization strategy with regards to the knowledge acquired from the research, with the following components:

- Developing ways of providing opportunities for your members or the groups you serve to be involved in and to comment on the research project, its results and impact, so that all can participate fully in it
- Doing a needs assessment in terms of disseminating the results to your organization, municipality or region where the population you serve is located
- Developing ways of taking into account and including the impacts of the research project and training possibilities in your daily practice
- Establishing methods of evaluating the merits of implementing new approaches and new programs

# Little glossary

## of Community-Based Research

### MAIN FUNDING ORGANIZATIONS

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<b>PHAC</b>	Public Health Agency of Canada, who offers funding through the AIDS Community Action Program (ACAP). <a href="http://www.phac-aspc.gc.ca">www.phac-aspc.gc.ca</a>
<b>CTN</b> (Canadian Trials Network)	CIHR Canadian HIV Trials Network offers funding for pilot studies on the applicability of new research concepts which the new program Prevention and Vulnerable Populations (PVP). <a href="http://www.hivnet.ubc.ca">www.hivnet.ubc.ca</a>
<b>SSHRC</b>	Social Sciences and Humanities Research Council (Canada). The SSHRC offers grants for partnership development. <a href="http://www.sshrc-crsh.gc.ca">www.sshrc-crsh.gc.ca</a>
<b>FQRSC</b>	Fonds québécois de recherche sur la société et la culture, funding agency for research in social sciences (Québec). Accept English proposal. <a href="http://www.fqrsc.gouv.qc.ca">www.fqrsc.gouv.qc.ca</a>
<b>FRSQ</b>	Fonds de recherche en santé du Québec, funding agency for health research (Québec). Available in English. <a href="http://www.frsq.gouv.qc.ca/en/index.shtml">http://www.frsq.gouv.qc.ca/en/index.shtml</a>
<b>CIHR</b>	Canadian Institutes of Health Research, offers funding for health research (Canada) and is a major funder of community-based research on HIV. <a href="http://www.cihr-irsc.gc.ca">www.cihr-irsc.gc.ca</a>
<b>MELSQ</b>	Ministère de l'Éducation, du Loisir et du Sport du Québec (Ministry of Education, Leisure and Sport), offers funding to communities for university / community intervention projects. In French only. <a href="http://www.mels.gouv.qc.ca">http://www.mels.gouv.qc.ca</a>

## RESEARCH TEAM AND KEY STAKEHOLDERS

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### **Principal investigator (lead or main researcher)**

The person who leads the research project. Eligibility varies, but for some competitions and/or funding organizations, a member of the community can be the principal investigator.

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### **Co-applicant or co-researcher**

A person who actively participates in the scientific leadership of a project. With regards to the CIHR, members from the community can be co-researchers.

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### **Collaborator who works in the field**

Term used by the FQRSC to designate a member of the community.

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### **Advisory committee**

Group of people representative of the various parties involved in the research project, including the community, who guide the project ensuring its relevance for the various partners.

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**Ethics committee**

Any research involving human subjects, whether in basic research or social sciences, should have an ethics certificate before data collection begins. Grant funds are usually not released until the ethics certificate is received by the ethics committee. The ethics committee certifies that the project conforms to ethical standards, and if not, can demand appropriate changes be made. Research projects are usually submitted to the ethics committee of the principal investigator's university or organization (public health).

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**Peer research associates**

In the context of community-based research on HIV, "peer" is defined as a person living with HIV. Peer research are paid, and are responsible for data collection or other aspects of the project. They receive appropriate training for their tasks in the project.

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**Partner**

An organization that formally and actively participates in a research project.

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**Participant**

A person who responds to questionnaires or takes part in individual or group interviews as part of data collection. A participant usually receives compensation for the time spent responding to researchers' questions.

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**Knowledge user**

In a grant application to the CIHR, this is a possible role for members of the community. A knowledge user is primarily concerned with the practical impacts of research, though this does not exclude his participation in an advisory or decision-making committee.

## METHODOLOGY

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### Data analysis

The process that generates statistical generalizations (for quantitative analyses) or general themes that help gain a better understanding of what people experience in their lives (for qualitative analyses). Either one of these processes will eventually be enriched through the dynamics of community consultation, thereby adding depth to the interpretations made.

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### Sample

In quantitative research, the sample is the group of participants in the project who are representative of a larger population. Sampling follows strict rules in terms of verifying a research hypothesis and generalizing the results to the larger population. In qualitative research, the sample is the group of participants whose conversations with the research team will result in a wealth of data comprising a repetition of the same themes or categories. An exploratory qualitative research project (to test a method or new research topic) follows different sampling rules.

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**Qualitative research method**

Involves collecting oral histories and testimonials, photos, videos – in other words, documents that provide details on attitudes and/or experiences. The main instrument in this type of research is the interview, individual or group, based on open questions to which only a rather complex answer will suffice. Analyses of these data are based on identifying topics or explanatory categories.

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**Quantitative research method**

Involves collecting data that generate numbers (statistics). The main instrument in this type of research is a questionnaire with closed questions, to which we can only reply yes or no, or which have a choice of pre-set answers. The data collected are translated into numbers upon which statistical analyses can be conducted.

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**Mixed method**

Involves collecting both qualitative and quantitative data. The goal of using a mixed method is to clearly explain in depth all the variables in a research questionnaire.

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## DOCUMENTS

**Canadian Common CV**

Web-based form to be filled out by the principal investigators, co-researchers or knowledge users, comprising one of the documents required to complete a grant application. [www.ccv-cvc.ca](http://www.ccv-cvc.ca).

[www.ccv-cvc.ca](http://www.ccv-cvc.ca)

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**Partnership agreement**

Written document signed by the various parties in the research project which specifies the commitments and rights of each party to ensure that the benefits of the research accrue to all.



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**Consent form**

Written document designed for potential participants that provides them with all the information required to give clear and informed consent to participate or not in a research project. The consent form is primarily a document that protects the participant. The form does not imply any commitment or obligation to participate right up to the end of the project. The participant can decide to withdraw at any time (there is usually a clause that clearly specifies this).

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**Support letter**

A letter of recommendation written to a funder by a community organization supporting the grant application. It is in this letter that a project partner specifies their contribution(s), in-kind or in funds.

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**Mobilization plan**

Strategy designed to maximize the short and/or long-term impacts of the research project on the community, including the dissemination and popularization of the results and their transformation into actions that respond to concrete needs, if applicable.

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**Research protocol**

Document providing details on the topic, goals, and stages of the research project.

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**Stipend receipt**

Signed document proving that the participant has received compensation for his/her participation in the project.

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## Online resources

Good practice guide: Greater involvement of people living with HIV (GIPA). ONUSIDA.  
[http://issuu.com/aids\\_alliance/docs/gpg-gipa-english](http://issuu.com/aids_alliance/docs/gpg-gipa-english)

When researchers come calling: A guide for organisations that work with women.  
BC Centre of Excellence for Women's Health; the Women's Health Research Institute; the University of British Columbia; and the University of Victoria.  
<http://www.bccewh.bc.ca/publications-resources/documents/WhenResearchersComeCalling.pdf>

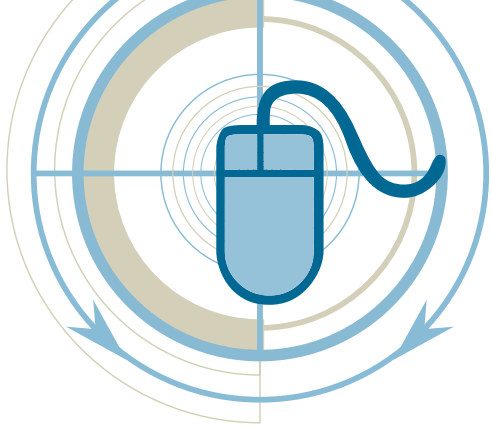
Comment mener une étude de A à Z. (in French only).  
Comité sectoriel de main-d'œuvre, économie sociale et action communautaire.  
[http://www.csmoesac.qc.ca/sites/default/files/files/methodologie\\_final.pdf](http://www.csmoesac.qc.ca/sites/default/files/files/methodologie_final.pdf)

Repenser l'appréciation des retombées de la recherche. (in French only).  
Réseau de recherche en santé des populations du Québec.  
[http://www.santepop.qc.ca/fichier.php/126/CarnetSynthese6\\_FR\\_vf.pdf](http://www.santepop.qc.ca/fichier.php/126/CarnetSynthese6_FR_vf.pdf)

Revue de la littérature internationale sur la recherche communautaire. (in French only).  
Anne Bekelynck. Centre Population et Développement, Université Paris Descartes.  
<http://www.ceped.org/?Revue-de-la-litterature>

La recherche communautaire à la COCQ-SIDA. (in French only).  
<http://www.cocqsida.com/nos-dossiers/recherche-communautaire.html>

La mobilisation des connaissances scientifiques pour soutenir des interventions communautaires visant la qualité de vie de personnes vivant avec le VIH.  
L'expérience de la recherche communautaire au Québec (in French only).  
Ghayas Fadel et al.  
<http://www.cocqsida.com/assets/files/mediatheque/resultats-recherche/casablanca2009.pdf>



## Canadian Aboriginal AIDS network fact sheets

The Essentials of Designing Research Questions in Community-Based Research Projects.

[http://cocqsida.com/assets/files/2.dossiers/DesigningResearchQuestions\\_CAAN\\_ENG.pdf](http://cocqsida.com/assets/files/2.dossiers/DesigningResearchQuestions_CAAN_ENG.pdf)

The Essentials of Setting Up Community-Based Research Teams.

[http://cocqsida.com/assets/files/2.dossiers/SettingupCBRTteams\\_CAAN\\_ENG.pdf](http://cocqsida.com/assets/files/2.dossiers/SettingupCBRTteams_CAAN_ENG.pdf)

The Essentials of Negotiating Ethical Agreements.

[http://cocqsida.com/assets/files/2.dossiers/NegotiatingEthicalAgreements\\_CAAN\\_ENG.pdf](http://cocqsida.com/assets/files/2.dossiers/NegotiatingEthicalAgreements_CAAN_ENG.pdf)

The Essentials of Knowledge Translation.

[http://cocqsida.com/assets/files/2.dossiers/KnowledgeTranslation\\_CAAN\\_ENG.pdf](http://cocqsida.com/assets/files/2.dossiers/KnowledgeTranslation_CAAN_ENG.pdf)



# In brief: 10 questions

## to test your research partnership!

Since partnership is at the heart of the community-based research process, all the stages of a typical research project can be organized in such a manner as to reflect the needs and expectations of the partners. Here are tips on assessing a research project:

- 1 Are the **goals/needs** of the research project defined and formulated in close collaboration with your organization?
- 2 Does the research team reflect a **spirit of partnership**? Do the community researchers and university researchers work together on an equal footing in terms of the strengths and limits of each group? Are you thinking of formalizing the partnership with a written agreement?
- 3 Does the training of the research team or advisory committee adhere to the principle of **the greater involvement of people living with HIV and the populations addressed by the research project**?
- 4 Were **ethics issues** thoroughly debated so that they concretely address your questions and concerns?
- 5 Have you been able to discuss a plan, a strategy of **applying the knowledge** obtained from the findings?
- 6 Is the grant proposal process based on **frequent discussions** among the various partners? As a general rule, do you think that communication channels will be open between your organization and the university research team?
- 7 Do the **methodology** and data collection processes involve peer research associate living with HIV? Will it be desirable and realistic for the target population?
- 8 Will the **analyses of the data** benefit from community input and consultation?
- 9 Is there an agreement on the **publication of the results**? Do the results, the findings, belong to the partnership?
- 10 Are there multiple, concrete **impacts of the research project** in terms of knowledge transfer and savoir-faire, improvements in health interventions, action on policies that benefit the community, or improvements in the capacities and skills of people living with HIV and relevant organizations?