

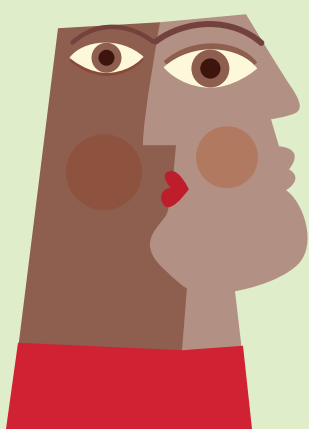
# Research and you

Why accept or refuse to  
participate in a research  
project?




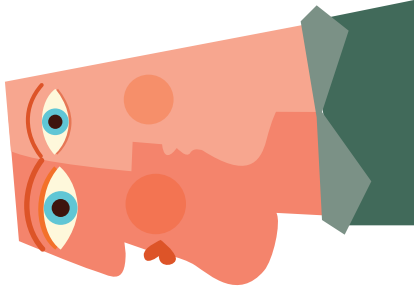


# Research **and you**



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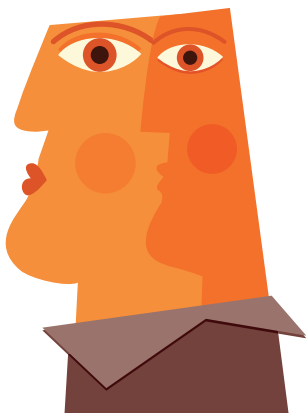




Research in the field of HIV can contribute to the evaluation of services, the implementation of programs or the testing of new drugs. The goals of certain projects are to assess the new needs of people living with HIV, evaluate the challenges they face, and attempt to find solutions to improve their quality of life and their health, or to fight against the stigma associated with the disease. These social, political or medical advances could not be accomplished without the involvement of participants such as yourself.

People living with HIV are constantly solicited to participate in all kinds of research. However, any project can have benefits and detriments for participants.

So **why accept or refuse to participate in a given research project?** The goal of this brochure is to give you information to help you make such a decision.



# Participate a little, or a lot

Research projects are not all the same! The topic, the research team, the methods, the type of participation asked of you, and above all the goals can greatly vary.

Some projects are based on community participation because of an agreement among the researchers and various actors in the community, such as organizations fighting against HIV, people living with HIV, and their family members. The goal of these projects is to facilitate the involvement of people living with HIV in all the stages of the research project.

Other projects, those involving almost exclusively university or clinical researchers, are more traditional in their methods – this is the case for most medical research.

Whatever the type of research, **the way in which your participation will help achieve the goals of the research project should be clearly explained to you.**



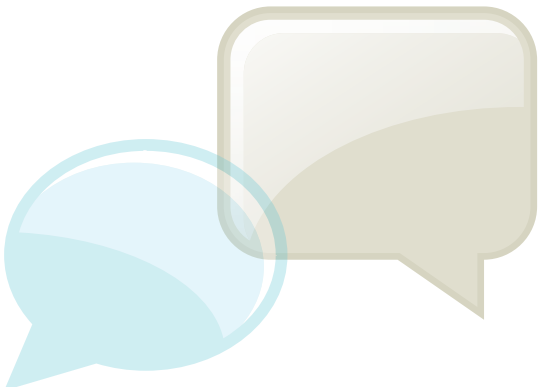
## TYPES OF PARTICIPATION:

Here are some types of participation a research project can involve:

- Responding to one or more questionnaires
- Sharing your experiences or life trajectory in an individual interview
- Talking about a particular topic in a focus group
- Testing new medical approaches or interventions (rapid HIV testing, pilot program, etc.)
- Testing new drugs or contributing to a sample bank (blood, tissue, etc.)

In addition to these usual types of participation, you may also be asked to:

- Recruit participants and conduct data collection as a research assistant
- Contribute to developing the goals, questions or planning the research process as a whole.
- Participate in a steering committee
- Disseminate the results as a Knowledge and Mobilization agent



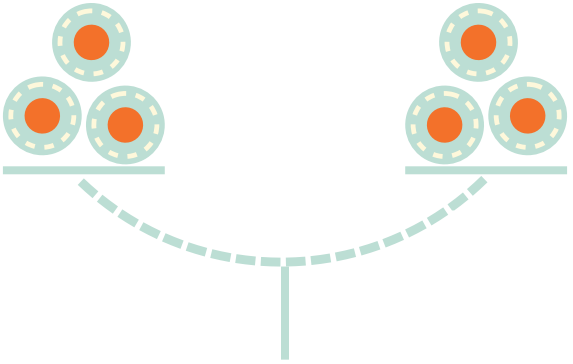
# Advantages and disadvantages of participating

Before you accept to participate in a research project, the researchers should clearly inform you of the advantages and disadvantages your participation may involve. However, sometimes it is difficult to judge the potential benefits and detriments of research on HIV over the short or long term. Here are some points that may help you assess the potential consequences of your participation.

## DIRECT AND INDIRECT BENEFITS OF YOUR PARTICIPATION

- **Evaluation or improvement of existing programs and services:** People living with HIV are obviously in the best position to evaluate programs and services designed for them. As a participant, you can add your voice to these assessments and make your needs and concerns known.
- **Make your reality known:** The goal of certain research projects is to collect testimonials or data aimed at prevention, sensitization, the development of programs and services, or to gain a better understanding of a community's experience. Participating in this type of research provides an opportunity to make your reality known, to counter ignorance and prejudice.
- **Advancing knowledge in the field of health:** Research is crucial to the advance of knowledge in the field of health. Your participation can therefore contribute to developing better treatments and care for you and other people living with HIV.
- **Recognition as a peer research assistant:** Researchers hire assistants for their expertise and experience related to the aim of the study. Your contribution can therefore be paid, while you develop new skills.





## POSSIBLE DISADVANTAGES

- **Feeling like a guinea pig:** Responding to a long list of questions, sharing personal experiences or providing biological samples can give a participant the unpleasant feeling of being treated like a guinea pig. If participating in a research project requires doing many tasks, the research team, as a matter of respect, should explain the process and take into account your concerns.
- **Feeling uncomfortable or anxious reliving painful or traumatic events:** Very personal questions or questions that elicit tough times in your life can be part of a research project. The researchers have to direct you to specific support resources if you need help. Moreover, a participant can refuse to answer any question asked of him/her.
- **Side effects or pain:** You may experience side effects or pain by participating in clinical research. Although rare, certain projects may present a risk to your health. Ensure that you have a clear discussion of possible side effects with the researchers. Before participating in clinical research, it is recommended you see your doctor or talk with a representative of a community organization.

# Consent

Before you participate in any research, the researchers should obtain your clear and informed consent. Clear and informed consent means that they have explained to you in detail, without any pressure, the approach, the goals and methods of the research project, advantages and disadvantages, possible impacts, etc.

The usual procedure is to have you sign a consent form. However, it is possible that you would be asked to participate in an online research project. Ensure that you are able to communicate with a contact person at any time and can clearly indicate that you consent to the study before participating. The consent form is a document that presents the research project to potential participants so that they can make a clear and informed decision to participate or not. The form is primarily designed to protect you and ensure you are clearly informed of the nature of the research – use of the data, who has access to the data, protection of privacy and confidentiality, etc.

## THE CONSENT FORM

The following should appear on a consent form:

- Title of the research project
- The name(s) of the research team members and their affiliations (university, agency) and contact information in case you have any questions
- The goals and/or objectives of the research
- A description of what is being asked of you as a participant (filling out a questionnaire, participating in a group interview, providing samples, etc.)
- Potential benefits, risks and disadvantages of participation
- The right to withdraw at any time and a description of the complaint procedure
- Measures taken to ensure your privacy and confidentiality of the data



- Compensation planned (travel expenses paid, daycare, etc.)
- A section for signatures, where you indicate you have read and understood the form and consent to participate, if this is the case

## **You are handed a consent form – some advice to follow**

- You are not obligated to sign immediately! Don't be rushed! Take the time to ask all the questions you have; you can also ask others for advice and arrange a meeting at another time to sign the form
- Discuss the disadvantages or potential risks with the person giving you the form
- Ensure you fully understand and are in agreement with the goals and methods of the research project and the kind of participation being asked of you
- Ask for a copy of the form for your files

## **THE ISSUE OF CONFIDENTIALITY**

It is important to analyze the implications of your participation in terms of respect for confidentiality, your personal information, and the choice of revealing or not your serostatus. The research project should respect strict rules about confidentiality. If your participation in the project is a more active one, for example being on the steering committee, you may want to establish some measures to protect your personal information. If the research is being conducted online, ask the person in charge how the data will be stored and kept confidential.

## **THE RIGHT TO WITHDRAW**

If you consent to participate in a research project, you are indicating that you agree to do what is being asked of you. This corresponds to a commitment on your part. However, remember that you can withdraw from the research project at any time without giving a reason, even if you have signed the consent form and/or have received compensation.

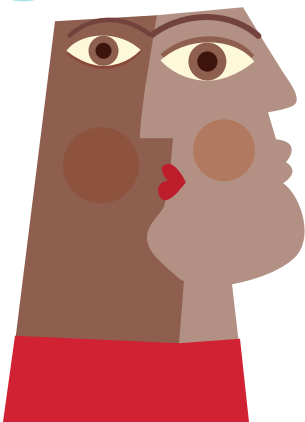
You have accepted to participate in a research project...

## so what's next?

### THREE TIPS

#### to have a good experience:

- **Don't hesitate to communicate with the researchers!** The research team is also there to respond to your questions, resolve any problem you may encounter when the project is underway, and will respond to your requests BEFORE, DURING and AFTER your participation.
- **Ask to be informed of the results of the research!** Your participation will be even more significant if you can evaluate the impact of the research project on the lives of people living with HIV and the importance of your contribution. Above all, don't hesitate to ask the researchers to send you a report or summary of the main findings. If you are dissatisfied with the results presented to you, namely they don't match your perception of reality or your convictions, tell the researchers so that they can explain how the results were derived.
- **Get involved!** If you believe in the importance of a research project for the future of people living with HIV, obtain information from the researchers on the opportunities or possibilities of getting involved on a larger scale.



## What will happen at the end of the research project?

- **Analyses of the data.** As soon as a certain number of participants has been attained or a deadline has been reached, the data will be processed and analyzed by the researchers. If the project has planned for it, it is possible to follow this process by participating in a steering committee, for example. Sometimes long, the analysis of the data is a process aimed at attaining the pre-defined goals of the research project, without knowing the results in advance.
- **Final results or conclusions.** Data analyses will generate a certain number of results, conclusions and/or recommendations. These may be listed in summaries and reports destined for participants and others publics. Certain findings may result in actions that will improve difficult situations or indicate pathways to solve existing problems.
- **Research cycles.** The end of a research cycle often means the beginning of a new research project. Indeed, if the results have led to a set of actions, they can also bring new, more precisely defined research questions or hypotheses to justify the extension of a study or the launch of a new one.





# Check-list :

Other questions  
to ask yourself



- How will my personal information, as well as other data or samples collected during the project, be kept confidential?
- What compensation may be offered to facilitate my participation in the research project (travel expenses paid, daycare, etc.)?
- Is it clearly indicated that I can withdraw from the research project at any time, without providing the reason(s)?
- Am I comfortable with the member of the research team who contacted me?
- How will the results of the research be disseminated? Will I be informed of the results of the survey or study?
- Can I get more involved in the research project, such as be on the steering committee, help with data collection, or contribute to disseminating the results?



# Check-list :

Questions to ask yourself  
before deciding  
to participate in a  
research project

- What is the goal of the project? Why have they asked me to respond to questions, to be interviewed, to try a new drug, etc.?
- What will be the impacts of the research? What will change in my life and the lives of people living with HIV as a result of the research findings?
- What exactly is involved in my participation (questionnaire, group interview, providing samples)?
- What is the nature of my participation (duration, frequency)?
- What are the disadvantages or potential risks? Are there benefits of my participation?
- Who should I contact if I have any questions or would like more information on the research?
- Who can I contact if have a complaint related to my participation in the research?



# Resources

The publication of this brochure was made possible by the work of the members of COCQ-SIDA's Community Research Committee who come from the following organizations:

ACCM, MIELS-Québec  
and Le Miens.

UQÀM and SLITSS

also collaborated on the project.

To contact member's organization of COCQ-SIDA, please visit the web site:  
[cocqsida.com](http://cocqsida.com)

or phone at 514 844 2477.



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