From collaborative research to community-based research

A methodological toolkit

Elise Demange
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anRS)
French National Agency for Research
on AIDS and Viral Hepatitis
| An autonomous agency at Inserm |

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Acknowledgements

Our thanks to all those who contributed to the creation of this toolkit.

- All the members of the Partages research group.
- To all those encountered during interviews and/or observation work and whose reflections and experiences greatly enriched the content of each unit (see the list of interviews in the appendix).
- To those who participated in pre-testing this tool, providing us with constructive comments during the proofreading stage: Mélina Bernier, Sarah Fielden, Gabriel Girard, Romain Hurand, Marion Mora, Veronica Noseda, Céline Schaer, Arnaud Simon and Emmanuel Trenado.
- The members of the editorial committee and especially France Lert for her continued support throughout the development of this toolkit.
- Anne Bekelynck for her contribution to the toolkit's introduction.
- Jude Sweeney, Isabelle Porteret, Anna Laura Ross, Sarah Fielden and Maëlle de Seze for their work on the English version of the toolkit.
- The *Public Health and the Human and Social Sciences, Research in the Developing Countries* and *Scientific Information and Communication* offices of the French national agency for research on AIDS and viral hepatitis (ANRS) as well as the Coalition PLUS secretariat for their involvement, support and collaboration.

CONTENTS

PREFACE

Towards committed reflection

Since the beginning of the HIV/AIDS epidemic, the paths of activists and researchers have crossed many times, clashed sometimes and certainly complemented one another. Identifying the virus, the first screening test, taking into consideration the epidemic's social and structural factors together with the relentless battle to make treatment available – the interactions between researchers and activists played a decisive role in the initial responses to the HIV epidemic. Therefore research on HIV infection, whether basic or applied, is closely linked with action. The exchanges between community stakeholders and researchers are also key to increasing knowledge.

In many contexts, it was the community stakeholders who alerted decision makers and the general public to the highly vulnerable situation of specific groups in regard to HIV/AIDS. They also opened the way to numerous research studies. Inside the French national agency for research on AIDS and viral hepatitis (ANRS), the representatives of community-based organizations (CBOs) have progressively found a place in the agency's different scientific and governance committees. Their legitimacy to participate in discussions on research questions and research projects is now well recognized.

After ten years of mobilization of CBOs in scientific advocacy, why and how go further?

The emerging issues in prevention research and in HIV care raise research questions which are difficult to answer without the genuine involvement of communities. This is the case for example with research on pre-exposure prophylaxis, treatment as prevention, new strategies for eradicating the infection and also for studies on those populations who are described as being "most at risk" of HIV infection. Moreover, collaboration between researchers and community stakeholders is a definite motor of innovation: innovation in the research questions raised, by drawing on knowledge of the real-life experience of communities; innovation in methods, by developing, in particular, intervention research studies; and innovation in terms of social utility, by both aiming to publish study results and translate those results into practical, real-life field interventions.

Collaborative research projects tackle these issues. In recent years, the ANRS, whose primary mandate is to support projects led by scientific stakeholders, has seen a strong increase in the number of projects being proposed by multi-stakeholder teams comprising researchers and CBOs. Accordingly, the agency made the choice to encourage and support the continued development of these initiatives. Several research studies have already been funded, including projects on rapid HIV testing (ANRS Com'test, ANRS DRAG), harm reduction associated with drugs use (ANRS AERLI) and disclosure of serostatus (Partages). In 2010 a working group was created within the ANRS with the specific aim of supporting this dynamic and stimulating the emergence of new projects. It is composed of researchers from many disciplines and representatives of CBOs.

Going even further along the road of collaboration means continuing this initiative and involving increasing numbers of actors and stakeholders in "community-based research" or CBR, a collaborative approach where researchers and community stakeholders carry out a research study guided by the needs of communities. This kind of research is relatively recent and still tentative in francophone settings, where it is characterized by the participation of existing organized communities and where it focuses on social transformation. Complementing more academically-based research which has already proven its relevance, CBR can certainly help the scientific community and the world of CBOs move towards a common goal: finding an efficient and sustainable answer to the HIV/AIDS epidemic. In order to do this, CBR must be equally characterized by scientific rigor and quality.

Collaborative research between the worlds of both research and community-based stakeholders raises new challenges which must not be underestimated. How to involve communities even more? How to conceive and implement a research study whose results can be promoted in both scientific and practical, real-life terms? How to work together respecting one another's competencies? In order to enable new stakeholders engage in such collaborations, it is necessary to set the terms of the debate and start proposing methodological tools.

We wish to thank the Partages study group for having initiated this discussion and for having designed this toolkit. The first-hand accounts, experiences and tools proposed here constitute a rich source of material which will help those interested in collaborative research to find answers to their questions. This toolkit will help people already engaged in collaborative studies and who find themselves at a point where they need to reflect on the process. For others, it will give them the desire to take the leap into the world of collaboration. We are also delighted about the fact that this work is not only based on French experience, but is the initiative of an international working group from different contexts and so can be used in different settings. The range of research studies referred to in the toolkit demonstrates how relevant this kind of collaboration is for a broad range of research studies – from social science to clinical research, from descriptive to intervention research. CBR and its results also impact the key issues of basic research.

CBR is still a developing field. As this toolkit shows, there is certainly not one model to follow, rather multiple possibilities to think about collaboration and about how it might work. It is the responsibility of teams to show creativity, by adapting their working methods to both their specific research questions and to their more operational-based objectives.

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Nobel Prize in Medicine
INSERM, Institut Pasteur de Paris

Jean-François Delfraissy
Director of the ANRS

HOW TO USE THIS TOOLKIT

From practice to theory

The idea for this toolkit came from a real project in collaborative research performed in five countries on the sensitive question of disclosure of HIV serostatus. As well as investigating disclosure, the ANRS 12244 Partages study led us to closely examine the various issues of community-based research (CBR). The study was designed and implemented through close partnership between member organizations of Coalition PLUS (in Ecuador, France, Mali, Morocco, Canada, the Democratic Republic of the Congo and Romania) and universities from each of these countries.

Why the need for a practical and methodological toolkit?

In the world of research on HIV/AIDS, recent developments in issues surrounding prevention and care (PrEP, treatment as prevention, social aspects of HIV/AIDS) as well as international strategic objectives, have led to an ever-increasing interest in what is called "community-based research" or, put more generally, academic/community partnerships in research. It would seem clear that research cannot make progress on these issues without the genuine involvement of communities in research studies and intervention trials. Researchers and stakeholders from community-based organizations (CBOs) can collaborate together in the best possible conditions capitalizing on the work being carried out in ever-increasing numbers of CBR projects. Indeed, the issues raised by this type of research go beyond the questions, challenges and obstacles usually met when implementing "academic" research studies. A growing number of researchers and community stakeholders are searching for ways and practical tools which can help them work together.

What is it for?

This practical toolkit invites readers (community members and community front-line workers, researchers, CBOs, research institutions, funders and technical partners) to reflect on the questions which the CBR approach raises. It provides practical ideas about how to build academic-community partnerships, about the procedures required to implement research studies, and about the various ways collaborators can work together.

Who is it for?

This toolkit is first and foremost aimed at those stakeholders already working in, or desiring to work in CBR. There are therefore two primary audiences: researchers and CBOs. Practical ideas and considerations have been designed to help these two groups find the resources they need to effectively carry out collaborative research studies as well as to stimulate initial interest in CBR and its utilization.

More generally, we hope that all stakeholders involved directly or indirectly in a CBR study, especially in terms of HIV/AIDS research, will find this toolkit useful: research funders; international organizations (which are attaching increasing importance to community participation in research); policy makers and service providers (who are themselves developing intervention-oriented collaborative research studies and are key players when translating results into practical, real-life interventions).

How has this toolkit been designed?

This toolkit is an initiative of the members of the Partages study and is largely based on their experiences during that research study. Apart from Partages, other experiences of members and partners of Coalition PLUS as well as members of the "community-based research group" of the French national agency for research on AIDS and viral hepatitis (ANRS) have helped to enhance the toolkit (see the list of contributors in the appendices).

Details of experiences and practices were collected through semi-structured interviews conducted with various stakeholders involved in the reflection on or the implementation of collaborative research studies. These are mainly community stakeholders and researchers but some belong to funding agencies, international organizations or national programs for the fight against HIV/AIDS. The countries involved are mostly francophone (Burkina-Faso, Canada, Ecuador, France, Mali, Morocco, Democratic Republic of the Congo, Romania and Switzerland). In its final version, the toolkit was pre-tested by researchers and stakeholders from CBOs who form part of the target audience of the toolkit.

What does the toolkit contain? How can it be used?

This toolkit attempts to provide the reader with an understanding of an ever-broader range of research studies currently being undertaken within the context of partnerships between researchers and community stakeholders, from studies in social sciences to clinical research trials. It is aimed at a diverse audience. The objective is that each reader will be able to find ideas within the toolkit which help facilitate the implementation of a research study. For those reading this toolkit out of interest, the hope is that they will be stimulated into participating in CBR.

The toolkit can be used in different ways. It can be read in a linear fashion, moving progressively from general considerations, to the more practical steps involved in the implementation of a CBR study. Alternatively, the reader can search for information which directly corresponds to a particular need or question, by selecting any one of the topic-based units which have been designed to be used independently.

Overall, the toolkit examines the key steps required when implementing a collaborative research study, including the issues to be dealt with, obstacles and potential difficulties as well as facilitating factors and "good practices". The first part of the toolkit looks at CBR, its value and the challenges met by those involved in it. The second part focuses on providing practical ideas about how to build a research partnership, from ways to help both worlds (academic and community) first meet and get to know each other, to the various types of collaborations that can be formed. The final part of the toolkit examines the specificities of the collaboration and of CBR for each of the principal steps involved, from the choice of partners to the different ways of promoting the study results and their application.

In each of the three parts, the units which comprise this toolkit have elements which are similar in content, especially:

- Stakeholders' first-hand accounts of their experiences in CBR.
- Ideas for and accounts of "good practices", thanks to lessons learned in collaborative research studies.
- Practical tools which can be used to build and facilitate collaboration.
- Ideas for reflection and more theoretical elements of CBR.
- Bibliographical references for further reading. The toolkit is in no way exhaustive regarding the points it discusses.

Each unit of the toolkit comprises paragraphs of text, boxes highlighting practical or theoretical points as well as "memos" highlighting key elements to note within the unit. Also included are lists of questions the various stakeholders can ask themselves in order to move the collaboration forward.

The inspiration for this toolkit came from other toolkits mentioned in the bibliographical section of the units. We see it as a complementary tool to be used in conjunction with these others, in that it focuses on real-life experience and practical ideas.

Browsing the toolkit using symbols. A reader's guide.

The toolkit contains the following symbols, some of which are associated with a text box. They symbolize:

An **intervention** to implement.

A **methodological** consideration or practical methodological suggestion.

A **theoretical** consideration.

Questions to ask oneself.

Bibliographic references for further reading.

Lessons learned from collaborative research studies which have already been implemented.

Verbatim transcripts of comments by researchers and community stakeholders.

INTRODUCTION

A brief history
of community-based
research

Introduction. A brief history of community-based research[1]

Community-based research was born from the development of closer ties between researchers and community-based organizations, together establishing an ever-increasing number of research activities. Using a scientifically recognized methodology, it is based on a specific approach: the "community-based approach".

1 | The community and the community-based approach: cornerstones of community-based research

Community-based research evolved from the community-based approach. It asks the question: "*Who* is the community and who *represents* it?" Here we provide some ideas to help explain what these terms mean. If you would like to understand these issues in greater detail please consult the bibliography at the end of this unit.

► What is "community"?

In current terminology, "community" refers to communities of identity as well as to the very general term "community-based organizations" (CBOs). When one speaks about CBOs, one usually considers "communities" as synonymous with "populations in which individuals objectively share common characteristics". For example, they may live in the same geographical area and/or be affected by the same problem. However the term "community" is much more complex and has various meanings.

The first reflections on the nature of "community" appeared at the end of the 19th and beginning of the 20th centuries. They stressed that a community is a natural entity, the result of an affective, emotional or traditional connection between its members (Tönnies, 1988; Weber, 1978; Eboko *et al.,* 2011).

Since the second half of the 20th century this perception has evolved: a community does not really exist in itself, but is the result of a social construction in which individuals share a common identity which differentiates them from the rest of the general population.

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1 The introduction was written with the support of Anne Bekelynck. It must be cited as follows : Demange, E., Henry, E., Bekelynck, A., Préau, M. A brief history of community-based research. In Demange, E., Henry, E., Préau, M. *From collaborative research to community-based research*. A methodological toolkit. Paris. ANRS/Coalition PLUS. Coll. Sciences sociales et sida. 2012

Several definitions have been proposed for the concept of "community":

- *The "natural community" is founded on pre-existing connections (e.g. geographical, social, etc).*

  For example, it may refer to all persons who have the same practices (e.g. sex workers), or to those with the same condition (e.g. people living with HIV). This "natural" community is not "self-defined" as such by its members. Rather it is classified as such by an external observer.

- *The "socially constructed community" is based on a sense of belonging, of identification and shared norms, values and needs.*

  For example, men who have sex with men are a "socially constructed community" if they identify themselves as gay, are conscious of belonging to the same group, of sharing the same norms, values and practices and have to face the same issues.

- *The "organized community" is founded on common institutions. Its members engage in joint action, according to a collective intentionality.*

  For example, gay men who are members of a CBO created to defend their rights in their own country constitute an organized community.

Researchers engaged in community-based research identify with this interpretation of the community as an organized entity. For example, according to MacQueen *et al.* (2001), the community *"is a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings"*.

An organized community may take the form of a "community-based organization". This latter is a non-profit or a non-governmental organization which has a very particular mindset and is consistent with a very specific approach, the so-called "community-based approach".

In the context of HIV/AIDS, homosexual men, the first group to be identified as stricken by the disease, very quickly organized themselves to mobilize both scientific research and the medical profession and to fight against any attempt to discriminate. They also aimed to promote solidarity within this group threatened by the HIV epidemic. They rapidly extended their approach to other equally affected groups, including sex workers, national, cultural and ethnic minorities and drug users. They supported the emergence of collective movements in countries where legal and social obstacles prevented the construction of collective links despite the existence of common practices and conditions of particular groups/cross-sections of the population. In spite of the emergence of autonomous organizations in recent years, this structuring of "organized communities" remains fragile.

► What is the community-based approach?

The community-based approach refers both to the determination of individuals who mobilize themselves to defend common interests inadequately addressed by society as a whole and to their desire to *"act together"*.

The community-based approach (Spire *et al.*, 2010):

- Is based on the mobilization of concerned groups expressing interests and needs.
- Is rooted not only in the idea of acting "for the community" but rather "for, by and with the community".
- Is a bottom-up approach (from community members towards the public spheres of political power).

- Mobilizes "non-expert" community knowledge as well as individual and collective experience.
- Promotes both individual and group *empowerment* and autonomy.
- Aims at social transformation, notably in terms of the recognition of rights, needs and self-expression of minorities.

► What is community-based research?

Community-based research (CBR) is based on the principles of the community-based approach (Morin *et al.,* forthcoming) and of academic disciplines. One example of this is community psychology, which considers individuals in their environment and tries to promote social justice by basing community psychology on the participation of people from the community (Rappaport, 1987; Rappaport and Seidman, 2000).

CBR is collaborative research between researchers and community stakeholders who are all part of an equitable partnership. Each partner brings his/her own expertise and shares responsibilities. CBR arises from the needs and concerns of specific communities. It aims to respond to these needs by combining a scientific process with action.

It has two objectives:

> Community-based research is first and foremost a collaborative approach. Researchers and community stakeholders carry out research *together* which is guided by the needs and concerns of the population(s) studied and aims at social transformation and increasing scientific knowledge.

- *A scientific objective:* to contribute to the advance of knowledge, by offering access to new information and to a variety of analyses. This contribution is particularly significant in the case of minority groups, for whom current scientific knowledge is not relevant and for whom specific approaches, concepts and means of investigation are required.

- *A social utility objective:* to strengthen community capacities and transform research results into action in the form of practical field interventions.

North American researchers specialized in community-based research in the health field have described several principles particular to this type of research. These are notably that community-based research (Israël *et al.,* 2005: 7-9):

- Is carried out with existing communities.
- Utilizes and builds upon the strengths and resources within the community.
- Is based on equitable partnerships.
- Encourages capacity building among partners.
- Incorporates the translation of knowledge to action.
- Addresses problems which the communities involved consider fundamentally important, using a global approach to health.
- Engages partners during every stage of the research process.
- Disseminates results to all partners and involves them in the wider dissemination of results.
- Is a long-term commitment.

Community-based research is always oriented towards action. It can take many forms (→ Unit 10):

■ *Research associated with immediate social transformation.*

This research concentrates directly on interventions for and with the populations concerned. It focuses on adapting current practices and on the emergence of new practices to mobilize existing community capacities. This is the case for example with the ANRS Com'Test[2] and ANRS DRAG studies, which both evaluate rapid HIV testing performed by community members.

■ *Research possibly resulting in social transformation.*

The objective of this type of research is to explain and understand the determinants of current practices (socio-political context, psycho-social determinants, etc). Interventions may be implemented once the research results are known. This is the case for example with the study Partages, which aims to understand the conditions in which HIV positive individuals disclose or do not disclose their HIV status to their close family circle and friends. Once these conditions are known, tailored support measures may be implemented.

Evolution of the term "community-based research" in the English and French-speaking contexts

Community-based research is rooted in social psychology in action research which appeared in the 1940s in the United States with Kurt Lewin, and in participatory research which emerged in the 1970s in both high- and low-income countries.

The concepts of *"Community-based research"* (CBR) and *"Community-based participatory research"* (CBPR), as such, largely developed in North America from the 1990s onwards. They referred to the collaborative practices of researchers whose objective was to get closer to the realities and needs of the populations studied. In the beginning the term *"Community-based (participatory) research"* represented research oriented towards collaboration and social transformation. Other approaches included *"participatory action research", "cooperative inquiry", "feminist research"* and *"participatory evaluation".* During the 1990s, "community-based research" became the preferred term for all research regarding communities, irrespective of whether the communities concerned were actively involved as research partners or not.

Faced with this expansion of the term's use, researchers working in community health research, guided by Barbara Israel's work, defined CBPR in public health as "a collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process." (Israël, *et al.,* 1998).

In the French-speaking context, community-based research was first developed and institutionalized in Quebec in Canada, notably through the creation of the Institute Community Support (ICS) Program in 2004, financed by the Canadian Institutes of Health Research, before emerging in France at the end of the 2000s, where it was introduced by CBOs engaged in the fight against HIV/AIDS.

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2 The main research projects mentioned in this guide are briefly summarized in the appendices.

2 ❘ Community-based research: the result of closer ties between CBOs and researchers

The development of CBR is very recent, especially in France (→ see previous box). It is the result of a long and complex relationship between the world of research and that of CBOs.

► Researchers and CBOs

HIV/AIDS research was first built on community-based collaborations between people living with HIV/AIDS, doctors, researchers and communities in order to understand a newly emerging condition. Since the beginning of the HIV/AIDS epidemic, organizations have been indispensable partners of researchers from various disciplines:

■ To date CBOs have primarily been engaged by researchers at the data collection stage to help enroll study participants and encourage populations to participate in research projects.

In Africa for example, the numerous healthcare institutions run by CBOs and the people who use their services are mobilized both to participate in clinical trials and in social science research.

■ Researchers participate in the creation of CBOs. Their involvement is the result of their personal and/or professional experience of HIV/AIDS.

In the context of the fight against HIV/AIDS, these relationships between researchers and CBOs drive research questions based on the realities encountered by CBOs when performing their routine field activities.

► How did CBOs become interested in research?

Faced with a rapidly fatal disease severely affecting particular sub-groups and with unknown means of transmission, biomedical research was crucial from the beginning for the most exposed groups and for those infected. This in turn very quickly led to HIV/AIDS CBOs taking an interest in research (Barbot, 2002).

The objectives of CBOs change with time according to different health contexts and the situation of research in their own country. Their motivations are quite different when, for example, communities are already "over-researched" or, on the contrary, when there is a call for greater involvement of researchers.

CBOs and research when communities are "over-researched"

Research has been carried out for many years in certain countries and communities which are vulnerable to the epidemic. Examples include African countries, like Cote d'Ivoire, Senegal and Uganda, where numerous studies on HIV positive individuals have been carried out since the 1990s. Gay men are also a good example of a community where numerous studies have been carried out.

In these contexts where community members are very often asked to participate and/or facilitate contacts with the individuals to include in a specific research project, there are several reasons why CBOs have decided in recent years to become involved in research activities:

■ CBOs want studies to give greater and more immediate attention to the needs of communities. Sometimes the knowledge acquired from "traditional" research studies does not seem immediately useful either to strengthen existing field interventions or to inspire ideas about new ones to implement.

- CBOs want to ensure that research studies have direct and positive impacts on the researched communities and that those members who agree to participate in studies are the first to benefit from their results.

- CBOs want researchers to show greater appreciation of the participants' decision to take part.

- CBOs want to ensure that research studies genuinely conform to ethical requirements. When research which is carried out under the auspices of CBOs does not fulfill its ethical obligations towards the study participants, the day-to-day field work, the trust built up and the relationship between the community and the CBO are all put at risk.

CBOs and research when communities are "under-researched"

On the contrary, research has been insufficient in other countries and amongst some communities.

Sometimes social, political and even scientific thinking prevent the severity of the situation from being recognized, block the needs of the people concerned from being taken into account and prevent any contribution to knowledge which would help characterize the situation and propose new solutions. In Romania for example, the involvement of public institutions in the nosocomial infection of children made HIV a politically taboo subject, with subsequent repercussions for research. In France, the fear of harmful consequences for the populations concerned in the context of strong politicization of immigration on the one hand, and opposition at all levels to cultural essentialization of social differences on the other, have created an obstacle not only to the true gravity of the epidemiological situation in sub-Saharan African migrants being recognized, but also to the design of research projects focusing on the problem of immigration and HIV/AIDS.

> Whether communities are "over" or "under"-researched, CBOs always ensure that researchers place a strong emphasis on a community's real needs when developing research agendas.

In these contexts, the mobilization of CBOs encourages the recognition of the problem and legitimizes a scientific approach as soon as those directly concerned call for it.

▶ A shared desire for more ethics in research

The interest CBOs take in research is also the result of the ethical challenges seen and experienced in the field, especially in African countries during the initial stages of the HIV/AIDS research. At that time research had not yet been regulated by ethical principles which took into account the concrete conditions of study participation for people living in poverty and/or in settings where human rights could easily be violated.

For example, consent was not systematically "well-informed", and often the respondents did not really understand the consequences that participation would have on themselves and on their lives.

The experiences of CBOs and the growing ethical concern among researchers led to the codification of ethical principles.

In 2002, the French national agency for research on AIDS and viral hepatitis (ANRS) published an Ethics Charter for Research in Developing Countries (→ see bibliography). This same determination to strengthen ethical principles resulted in researchers creating stronger collaborations with community stakeholders. Ethics is therefore one of the fields of collaboration between researchers and community stakeholders.

3 | When CBOs throw themselves into surveys and become research actors themselves

In parallel with this interest in research, the evolution in their activities and in funding-related issues is increasingly leading CBOs to become research actors themselves. Indeed, some even now include research in their objectives and organization charts.

► A long-standing involvement in studies and surveys: from diagnosis to monitoring and evaluation

Diagnosis as well as monitoring and evaluation activities have long been an integral part of CBOs' regular activities. These activities are focused on the organization's projects within the context of "project cycle management"[3]. In this regard, needs assessment is carried out as a preliminary step before implementing an intervention: this is what we call diagnosis or identification. Instead, monitoring and evaluation aim to maximize the effects of the intervention implemented.

The regular diagnostic and evaluation studies which CBOs carry out use instruments which are very familiar to people working in research: questionnaires, observations, in-depth interviews (individual, focus groups). Indeed, for many CBOs, the use of such instruments constitutes the entry point into the world of studies and surveys and also provides them with the fundamental methodological understanding required to enable them become part of research activities.

► Specialization of skills and creation of research departments

The development of surveys and studies in a CBO leads to increased competencies and specialization. When research becomes a full-fledged activity within an organization, the structure of the organization adapts. Research, monitoring and evaluation departments are put in place.

For example, the primary receiver of funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria in Romania helped the organization ARAS (Asociata Romana Anti-Sida) to implement a monitoring, evaluation and research unit in 2007. Monitoring and evaluation, which had previously been the responsibility of each project leader was consequently centralized within a specialized unit.

At the organization AIDES (France), the need for solid data on both communities' and individuals' needs as well as on the relevance of interventions already in place, led to the creation of a "Methodology, Innovation, Research and Evaluation" department (MIRE) in 2007.

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3 "Project Cycle Management" envisions a project not as linear but cyclical. This cycle is composed of several phases, for example: Identification – Preparation – Appraisal – Proposal preparation, approval, financing – Implementation – Evaluation. Monitoring is implemented throughout the whole cycle which facilitates project evaluation.

4 | Policy makers: the third partner in community-based research?

CBR, which is based on partnership, is built upon the interaction between communities and researchers. As its objective is firmly directed towards action in the field, the question of the place of policy makers in CBR naturally arises, as they are the decision makers and funders of interventions.

- Can CBR expand its partnerships to include policy makers, be they national or international (national AIDS committees, UNAIDS, etc)?
- What levels of the public sector should be involved? Ministries and national agencies that plan and finance health programs? Specialized local authorities? Clinicians and health professionals in health centers?
- What place can policy makers and public sector professionals have in CBR?

Policy makers are often the "target" of community stakeholders as they are the ones who determine general program orientations and define frameworks for intervention, regulation and funding. The implementation of large-scale actions leading to social transformation is often the result of their decision-making process: they are the ones who can change regulations, provide funds and implement large-scale interventions which in turn have large-scale consequences.

They can also become research partners, as their involvement facilitates the translation of research results into action and can change the context of interventions. It seems logical therefore that partnerships be developed with these public institutions.

Such comprehensive partnerships bring advantages and limitations:

- Collaboration with policy makers, whether they are national or local, may increase operational impact.
- However, the involvement of another kind of stakeholder makes the partnership more complex.

The system of partnership on which CBR is based – an equitable partnership between operational and research partners – is open and applicable to diverse stakeholders as long as partnerships are guided by a community-based approach and partners are willing to question their own policies and actions.

+ Further reading

ANRS (2008). Ethics charter for research in developing countries. Retrieved December 2, 2011 from http://www.anrs.fr/Ressources-et-publications/Publications/Publications-ANRS/Ethics-charter-for-research-in-developing-countries

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PART

1

Reflections
on community-based
research and its value

UNIT 1

Overview of the common beliefs about community-based research

1 | Common beliefs of community stakeholders: research is not useful enough, is a waste of time, and is not attentive enough to real-life experience

2 | ... and the common beliefs of researchers: CBR is research without researchers and has little scientific quality

1. Overview of the common beliefs about community-based research

There are many common beliefs surrounding community-based research (CBR) which hinder its development and recognition. Here we provide an overview of these beliefs.

1 Common beliefs of community stakeholders: research is not useful enough, is a waste of time, and is not attentive enough to real-life experience

► "Research isn't really all that useful"

The researcher is often asked classically provocative questions: "So, you're doing research? Have you found anything? And if you have, how useful is it?"

This rhetorical, humorous and slightly sarcastic question refers to the use of results and their impact on action. *What use is a researcher? What good is research? What does it bring to society?* There is quite a widespread belief that research has no social utility.

In fact:

The primary purpose of research is the contribution to knowledge:

- Research helps us discover, understand, explain and think about the world and the way it functions in biological, social, physical, etc, terms. Each piece of research has a fundamental component whose primary aim is to increase knowledge.
- The social utility and practical applications of research are not systematic. When they do exist, their direct impact varies. Furthermore, it is difficult to predict whether or not the results of a research project will have any immediate practical effect(s).
- These applications of knowledge have in turn changed – sometimes very quickly, sometimes more slowly – the daily lives of people living with HIV/AIDS.

For example, in order to better understand why HIV becomes resistant to treatments it is necessary to first disentangle the processes which lead to mutations of the virus and then to develop a range of molecules which act at different levels of the virus' replication cycle. These become second- and third-line treatments.

Research may also be directed from the beginning at experimenting with a possible solution to specific health needs. For example in biomedical research, this includes treatments, prevention methods and testing techniques while for social and human sciences it includes intervention methods and strategies.

Studies orientated towards practical interventions have a more visible social utility than other studies and also have more immediate applications.

When research has a more direct relationship with action, it principally helps to:

- Produce knowledge about communities concerned with a problem:
  Understanding their habits, their practices, their needs and the underlying social processes involved.
- Test the efficacy of new and experimental interventions.

In other words research can lead to social transformation. Its "utility" is simply a question of how direct and visible it is. The more research is directed towards action, the more it is perceived as "useful" by community stakeholders.

If we want to implement new interventions, we need intervention research studies which produce useful data for our work [...]: how do we reach our target? What kind of messages can be understood? Can this messages bring about change? (Community stakeholder, France).

► "Research is a waste of time for the community front-line worker"

Research is sometimes considered a waste of time for the community front-line worker engaged in communities and community issues.

In fact:

The participation of a community-based organization (CBO) in research can stimulate and reinforce the quality of field interventions

Community stakeholders greatly appreciate the critical distance which research provides them from field interventions. Often working so hard that they may lose some of their objectivity, critical distance helps community stakeholders to remobilize, as it helps to reinforce the meaning of their actions.

In 1997, the CBO AIDES (France) teamed up with Inserm and InVS (French Institute for Public Health Surveillance) in a survey of needle exchange and harm reduction programs (Emmanuelli *et al.,* 1999). Participation in this survey had a mobilizing effect within AIDES: interventions targeting drug users not only evolved but multiplied and national harm reduction meetings were organized more frequently within the organization. AIDES also started participating in national committees for harm reduction and drug use where it had previously not been present.

Research helps to develop new interventions

The Pouvoirs Partagés program, developed by the Chair of Education in Health at the University of Quebec in Montreal (UQAM), helped to implement workshops on (non-) disclosure of serostatus for women living with HIV in thirteen sites in Quebec, Canada.

Research helps us to reach new populations

The E-SANHOD survey on gay men in Cameroon had a very important mobilizing effect. Alternatives-Cameroun, the CBO involved in the research project, subsequently recruited new members and saw activity increase at its "well-being" center.

The conditions and duration of study participation differ depending on the stakeholders involved

In every CBO involved in the study Partages, a designated community focal point dedicated some of his/her working time to monitor and coordinate the study. During team meetings, this focal point consulted community front-line workers from each participating organization (social workers, volunteers and program supervisors) in order to feed information from the field back into the research project. The time devoted to the project varied therefore depending on the person involved – from the community focal point who dedicated some of his/her working time on a daily basis, to the community front-line workers and other community members who gave over some of their time more occasionally.

> The time devoted to research is much more an investment than a waste. It helps develop new interventions and/or remobilizes community front-line workers. Finding time for research can therefore be beneficial to future activities. Achieving the right balance between time devoted to research and time devoted to action must be considered before beginning the research project, and the CBO as a whole must be taken into account.

Time management is important when a CBO decides to engage in a research project. It is therefore necessary to consider time management before the project begins. Different solutions exist to achieve a balance between the time dedicated to research and that dedicated to operational work, especially in situations where the community front-line workers are also "research team members" (→ Units 13 and 14).

► "Research is only about "disembodied" numbers which have no concrete connection with real people"

Research establishes facts and proposes causal relationships. In terms of the health of populations, these facts and relationships may or may not be easily calculated. CBOs, like all stakeholders, look for numbers. Numbers help explain tendencies seen in particular populations and constitute an effective argument when convincing funders and decision makers.

Paradoxically, some members of organizations are quite reticent about numbers, because they believe that numbers do not accurately reflect human realities.

 In fact:

- *Depending on the research disciplines required and the research questions, one can choose to use quantitative or qualitative methods* (based on observation, interviews, institutional or documentary analysis).

What is important is the relevance of the choice of methodology in relation to the question being addressed. Research results always fall under the umbrella of a specific scientific context which combines different scientific methods and disciplines.

- *Research often connects a quantified (i.e. calculated) analysis of reality to contextual data and to an analysis of individual or collective experiences.*

Research in social sciences, particularly relating to HIV/AIDS, is not only based on "letting the numbers speak for themselves" but also on the real individuals and communities concerned. This connection between numbers and real-life experience is found in the complementarity of quantitative and qualitative methods which may both be used in the same study.

- *Quantitative data shed new light on concrete situations and real-life experiences, be they individual or collective.*

Numbers sometimes provide a simplistic idea in terms of experience and knowledge about a specific setting. Nevertheless they help to broadly describe these phenomena within populations. Indeed, the reason for collecting quantitative data is precisely to interpret the real-life experiences and life trajectories of the individuals and communities being studied. On the contrary, observations and qualitative methods provide a greater understanding of mechanisms and meanings.

" I work more on the relationship with the person. When we see the data, we re-adjust our work: quantified appraisal of our work shows us the effects of our interventions in a different light (Community stakeholder, Romania). "

2 | ... and the common beliefs of researchers: CBR is research without researchers and has little scientific quality

Today, an increasing number of researchers are working ever more closely with community stakeholders, and some are engaged in CBR. However, even in the latter group, there are those who would still be reluctant to call what they do "community-based research". The following common beliefs about CBR may perhaps have something to do with this.

► "Community-based research is research without researchers"

Is CBR "research without researchers"?

- Research could lose its objectivity and be orientated to meet the expectations of community stakeholders.
- The increasing importance which CBR places on the participation of non-academic stakeholders in research studies may be considered a threat in the current international context where academic research is experiencing significant change, and where the roles of higher education and research professionals are becoming increasingly precarious.

By denouncing CBR as "research without researchers" these individuals defend their knowledge and their know-how, as well as their position in the field of research. They also defend the idea that research must be based on freedom of thought.

In fact:

- *Research carried out without the collaboration of researchers is not research and therefore cannot be "community-based research".*

CBOs may carry out surveys and studies themselves, just like any company or public institution. Irrespective of their utility, not all studies can be considered research. When organizations engage in research, they may partner with outside researchers, or provide them with full-time positions. CBR, following the same scientific standards as any other research, is necessarily based on the participation of researchers.

- *By taking part in research, community stakeholders run the risk that they will be criticized, and that the efficacy of their proposed interventions will be challenged by those who support non-oriented research.*

Médecins du Monde (Doctors of the World) and the organization AIDES (France) are currently taking part in an intervention research project which proposes an educational session on harm reduction for injecting drug users (ANRS AERLI). One of their aims is to get such sessions legalized. In order to convince policy makers to do so, it will be imperative to demonstrate that the results of their intervention generate a measureable and significant advantage over the current situation. If the results show otherwise, then other intervention strategies will have to be envisaged. As stakeholders in this research, it will not be possible for the organizations to contest the results.

- *CBR is based on the appreciation of each other's skills, notably the researchers' skills.*

Apart from the few CBOs with internal research positions, in general such organizations do not have a lot of research expertise. They are aware of this fact and never want to carry out research projects without researchers. CBOs bring something else to CBR: the personal experience of community members, the intimate knowledge of the community acquired through outreach work, the capacity to interpret situations and to encourage community members to express themselves.

- *The researcher keeps his/her objectivity and freedom of thought throughout the research process – from the definition of the objective to the contents of publications.*

The Omega study, carried out in Canada between 1996 and 2003, included a steering committee composed of study participants. The committee gave its opinion about the study's publications. Publication topic had to be justified and not cause harm to the community. The consequence of using this procedure was that researchers explained the importance of the results more clearly and were more attentive to any possible damage they might cause to the community, without the publication of the articles themselves ever being prevented.

- *CBOs do not take part in research with the sole objective of demonstrating that "they are right".*

CBOs want to better understand the communities they work with, to comprehend the problems these communities face and to find innovative solutions.

► "The scientific quality of community-based research is poor and does not lead to publication"

CBR is sometimes seen as research which is carried out exclusively by organizations, with their members or with people who take part in their activities – that is to say a specific population. The belief therefore is that CBR could never have the generalized impact which, in principle, academic research has, and that this lack of scientific rigor will always be reflected in the application of methods. In short, the research quality is going to be poor as researchers are not involved.

In fact:

- *CBR is not research carried out by CBOs, but by an equitable partnership between researchers and these organizations.*

Researchers therefore maintain their important position and are guarantors of the scientific rigor of the research.

- *CBR meets the same methodological and scientific standards as other research.*

After a successful bid for funding, the Partages study was financed by the French national agency for research on AIDS and viral hepatitis (ANRS) and Sidaction. The objectives, hypotheses and research protocol were evaluated by several committees composed of researchers specialized in HIV/AIDS. The latter gave the green light to the project as it fulfilled all scientific requirements.

■ *CBR offers a kind of scientific value which complements traditional academic research.*

The close collaboration between researchers and community stakeholders works at every step of the research process. Observations made by community stakeholders and the questions they ask are integrated into the research hypotheses. Studies are implemented with their involvement. Finally, data is interpreted together.

The involvement of stakeholders who have practical knowledge and are members of the study populations helps the team to adapt the study's research hypotheses as closely as possible to the realities in the field and to the populations studied. The importance of collaboration for the internal validity of the research project is even greater when the researchers are foreigners and are not familiar with the national sociocultural context.

CBR is a *partnership* between community-based organizations and researchers. The respective contributions of these actors are different and complementary, overlapping at every step of the research process. By deciding to engage in research, community-based organizations are led to question their own perceptions and practices based on the methodological and critical standards essential to all scientific research.

■ *CBR can lead to publications in internationally recognized scientific journals.*

The CBR study on men's health in Douala, Cameroon (E-SANHOD), carried out by the CBO Alternatives Cameroun with the support of the organization AIDES and the INSERM research unit 912 in France, led to the publication of an article in the journal *Sexually Transmitted Infections.* It was selected as the editor's choice.

Further reading

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UNIT 2

Community-based research: challenges and assets

2. Community-based research: challenges and assets

Still a relatively recent development in the context of academia and activism, community-based research (CBR) presents a number of challenges for those who engage in it. Nevertheless, thanks to the collaboration between community and academic stakeholders, the kind of quality research that emerges has proven to be a valuable asset and offers new benefits to each type of partner.

1 | The challenges of CBR

" Commitment is essential. Community-based research requires a great deal of investment from researchers and community stakeholders. It is not possible to carry out community-based research without commitment, because the university world will continue to stay as it is, with its culture, its constraints, in terms of performance, funding... (Community stakeholder, Canada). "

► Partnerships: a sustainable engagement

Reports of successful collaboration and mutual trust refer almost exclusively to shared experiences:

- Already having quite a lot of experience in collaboration.
- Having collaborated on a research project, jointly obtained the initial results and carried out the subsequent "actions" together (for example meetings where study results are shared).
- Having knowledge about each other's culture.

Engaging in CBR must be thought of as a long term commitment and not a one-off collaboration: the conditions for a good partnership are often met once experiences are shared.

Time is always needed to develop relationships, create common working practices and build trust between the organizations involved, or between a researcher and an organization (→ see Unit 4 on how to facilitate trust-building).

A good partnership is therefore a long-lasting one which may continue beyond the initial collaboration.

► Collaborative work: an additional investment

Collaborative work, with partners from different backgrounds and sometimes from different countries, requires a special effort on all sides, especially in terms of time commitments.

CBR requires researchers to carry out tasks they would not normally do:

■ Applying for complementary funding for activities which are specific to the community-based approach and which are not provided for by traditional research funding mechanisms: organizing meetings, workshops, community consultations, etc. (→ Unit 9).

Participating in CBR leads researchers and community stakeholders to take time out of their work schedules or use some of their free time to carry out tasks which at first may seem to be of little future interest. Involvement in CBR requires a commitment to social transformation and working with the community.

■ Participating in the CBO's activities, such as educational workshops or meetings (→ Unit 5).

■ Translating their research into a language that the community can understand.

For community stakeholders:

■ Familiarizing themselves with research: attending scientific conferences, participating in research training (→ Unit 5).

■ Sometimes supervising/conducting data collection, integrating this activity into their daily work schedule.

■ Translating research into activism and/or making it understandable to a wider audience.

▶ Funding community-based research

One of the greatest challenges for CBR is funding.

Funders differ depending on the context: national research agencies, international organizations, foundations. One thing that funding procedures do have in common however is that they are rarely adapted to CBR.

Time spent on research activities by community front-line workers is not generally funded by programming budgets. Research funders hesitate at the idea of financing activities which are outside of those listed in a traditional research budget. Moreover, the functions and jobs of those engaged in performing CBR tasks are not usually included in the job description of investigation teams which agencies traditionally support.

Furthermore, CBR can be costly, as the budget for the individual project must simultaneously cover the costs of all the surveys, interventions, staff and research events. Some budget lines may be difficult to finance in a CBR budget, for example, the organization of public meetings on the research topic.

The budget lines usually included in research funding application forms are not very well adapted to collaborative research. Responding to calls for project proposals is therefore a challenge for partners.

In times of budgetary restrictions, research teams are finding it increasingly difficult to locate a single funder to finance all elements of a CBR project. Consequently, the need to look for several funders increases the complexity and the time which must be dedicated to funding applications.

For practical ideas on how to meet this challenge see → Unit 9.

2 ▌ The assets of CBR

► Innovative research

Community-based research participants: vulnerable populations and under-researched environments

The main reason for carrying out CBR is that it can access particular populations (people and settings) which other types of research cannot. This is especially true for minority populations for whom traditional scientific methods are not well adapted.

Survey respondents in CBR are members of communities (in the sense of "natural communities" or "socially-constructed communities" → Introduction) which research partner organizations work with. They are not necessarily people who regularly go to a CBO's premises.

The HSH-LRE survey, carried out by Groupe Sida Genève (AIDS Group, Geneva) in collaboration with other Swiss and French community-based organizations (CBOs) as well as the University of Lausanne, targeted men who have sex with men (MSM) and who frequent outdoor cruising areas. During one particular outreach activity, organization volunteers met the MSM at least once, providing them with a questionnaire. For some, these encounters were the only direct contact they had with these organizations.

Depending on the situation, "CBR survey respondents" are people who:

> CBR presents a real added value by providing researchers with access to people who frequent settings where CBOs provide services. Often these are vulnerable or minority groups who are difficult to reach. Sharing their knowledge of these populations, CBO's provide researchers with access to under-researched environments and research questions.

■ Participate in CBO activities (members, volunteers, etc).

■ Regularly benefit from the services provided by a CBO (care, psychosocial advice, etc).

■ Frequent the places where community organizations work (pick-up areas, squats, and sex work areas).

■ Are members of communities with whom CBOs work (people living with HIV, gay men, immigrants, drug users, etc).

The contribution CBOs make is not limited to simply providing researchers with access to these settings and communities. Generally, volunteers and other community front-line workers are the people who know the community best.

Cutting-edge research questions

In CBR, research questions are determined by changes observed in the field. The delay between the moment when a problem or change in the field occurs and when researchers take it into account is therefore quite short.

In collaborative CBR projects between UQAM, the CBO Cocq Sida and Action Séro Zero (which then became REZO, an MSM network) in Québec, Canada, any concerns raised by community front-line workers during team meetings are regularly integrated into the research carried out. For example, the problem of group sex and the absence of condoms and lubricants in "backrooms" have been raised as discussion points and subsequently addressed in the actual research project.

A co-analysis of complex situations

In some domains, there is a real need for community-based research, that is to say research where there is a real co-analysis of situations which cannot be understood using traditional research tools. Questions which are too complex, for which there are no efficient tools, and which therefore need joint investigation [...]. The situation of African populations, for example, is extremely difficult. Traditional research tools are not suitable because the populations are African, with different origins, roots and cultures. Considering all the discrimination, one must identify important social questions connected to health (Researcher, France).

Co-analysis is very effective for interpreting data: the diversity of the stakeholders leads to multiple interpretations and ensures that these same interpretations are better grounded in the cultures of the communities studied.

Among the various validity criteria in any research project, those associated with "credibility" deserve special attention. "Validity of meaning"[1] is particularly relevant to CBR. Indeed this type of research gives the data a value which much more closely reflects both the individual person surveyed and the setting. Moreover, CBR also involves "triangulation" of data: triangulation encourages the combination of different research methods in order to improve the reliability of the collected data and results (Apostolidis, 2006 ; Flick, 1992).

Co-analysis and triangulation are particularly necessary when the research topic – be it those surveyed or the research question – is under-researched and is complex (e.g. strong heterogeneity of the population, a closed highly codified community, sensitive questions, etc).

Methodological innovations?

CBR contributes to the implementation of innovative research methodologies, particularly in social sciences.

■ *Randomized trials in social sciences?*

In the field of HIV/AIDS, CBOs are quite familiar with clinical research. This has led to the methodology of randomized trials[2] being adapted to the social sciences. Accordingly, randomized trials based on intervention strategies (educational programs on injection, community HIV testing, etc) have been implemented.

■ *Adapting existing tools to address real-life issues*

The partnership between UQAM, community organizations and members of the MSM community has given rise to the development of one measurement scale on the feeling of belonging to the gay community. This scale was developed in collaboration with community members following proposals from key informants in working meetings.

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1 "Validity of meaning" was proposed by Desmet and Pourtois. It refers to the sense stakeholders want to give to their actions and to their words in order to ensure that data remain meaningful to them. It is important that people recognize themselves in data: "What we mean by Validity of Meaning is the verification of the fact that the data which come from the use of an instrument are the result of a real understanding on the part of the participant and of a definite agreement between the objective of the questions and the perception that these questions provoke in the participant (Pourtois and Desmet, 2007: 57)."

2 A randomized trial is a trial in which participants are divided randomly (randomization) into at least two groups with comparable characteristics. Random allocation helps to determine the most effective and best tolerated treatment or strategy for the group as a whole. Sometimes the trials are "double-blind", that is to say that neither the participants nor the researchers know who receives the treatment. One variation of randomized trials in social sciences is to implement an intervention in a group and compare it with a control group who have similar characteristics but who either do not benefit from the intervention or benefit from a different one.

► Research orientated at protecting people

CBOs place great emphasis on the protection of people. This is a cornerstone of their work and equally applies when they engage in research projects. They ensure therefore that people's rights are respected in any research project which is carried out within their organizations and especially in CBR projects which they themselves directly participate in.

► Research with a greater impact on action

Partnership research aims not only to enhance action, but also has a strong impact on political decision makers.

■ *The partnership itself contributes a great deal to legitimize the research study in the eyes of decision makers.*

Alone, the researcher sometimes has less access to political decision makers and fewer levers for action. Alone, community stakeholders do not have the "evidence" justifying the need for action. CBR combines both legitimacies – that of the community front-line worker and that of the researcher – in order to convince decision makers more easily.

■ *Accordingly, international organizations, funders and policy makers (UNAIDS, World Bank, government ministries) are increasingly looking for research and evaluation projects which involve both researchers and community stakeholders.*

The double legitimacy which CBR enjoys provides stakeholders with much greater weight when advocating for policy change or when seeking funding.

Partnership research is an essential tool therefore to influence interventions already implemented by CBOs and to help funders decide which interventions are worth funding. More generally it influences policy-making at a national level.

3 | What does community-based research bring to those who are engaged in it?

CBR is of great benefit to all partners involved. At the beginning of the collaboration however this benefit is often difficult to identify, and this fact can prevent engagement in the partnership. The following is what emerges from experiences of stakeholders engaged in collaboration:

► Benefits shared by all partners

As a collaborative effort, CBR provides everyone involved with the benefits that a partnership between stakeholders with different cultures and practices brings:

■ Knowledge and skills to work in a collaborative and participatory manner.

CBR has all the assets of any successful collaboration: getting to know the "other", building a network, keeping a critical distance and enhancing your own practices.

■ Mutual strengthening of skills and capacity building.

■ Creation of a wider network of shared knowledge and work skills.

■ Learning new ways to reflect on one's own work.

■ Considering techniques and working tools from a new perspective.

■ Increasing knowledge about the life experiences, work culture and methods of collaborating partners.

- More focused comprehension of the strengths and limitations of each partner.
- Development of the capacity to design research projects and innovative interventions.

► Benefits for community stakeholders

The benefits for community stakeholders lie in their relationship with research in general and their specific CBR projects...

- Obtaining data which not only highlight the relevance of their concerns but which serve as evidence for the media, policy makers and funders.
- Obtaining the academic "seal of approval" in order to be taken seriously by policy makers and funders.
- Having direct access to preliminary research data, which enables them to quickly adjust their interventions if required.
- Being more closely connected to developments in international research and ensuring that their scientific knowledge is up to date.
- Developing greater knowledge of and trust in research results. Participating in research helps community stakeholders to understand the validity and limitations of results. In turn this encourages community organizations to use these results in their work.

...and with action:

CBR gives community stakeholders the chance to develop their skills and maximize the impact of their studies on policy makers and funders.

- Acquiring a sense of objectivity which enables people to take a critical view of implemented interventions.
- Getting to know the community they are working with better, by going beyond intuition. Having a global and critical view, understanding how the community operates, both in detail and as a whole.
- Research enables community stakeholders to reflect on the possibility to reproduce interventions.

► Benefits for researchers

The principal benefit researchers enjoy from collaborative research, and even more from CBR, is that it helps them have a clear understanding of the impact of their work. This is often the principal motivation that researchers have for doing CBR.

More generally, the benefits which researchers enjoy are the following:

- The validation of research questions.
- Working on new topics.
- Acquiring a detailed knowledge of the community members being studied and their environments.
- Escaping from the "academic" world of the university to see the real problems faced by community front-line workers.

CBR enables researchers to rapidly see the real-life impact of their work.

- Researchers ask questions in order to improve society. Consequently they want to see what concerns a population has, especially through the eyes of its members.
- CBR allows researchers to see the tangible applications of their projects' results.

► Benefits for funders and decision makers

" This "community-based research" method has shown itself to be the most relevant way to work. Because we have a long history of unsuccessful research projects: when we present concluded [non-CBR] research to NGOs, they do not agree with the findings. NGOs need to be involved right from the start in order for ownership to happen (International stakeholder, Morocco). *"*

Research funders, those who finance interventions and decision makers – like UNAIDS or national policy makers – are also interested in CBR.

In practical terms, funders are interested in CBR for the following reasons:

- ■ The interplay of different points of view leads to the enhancement of research questions.
- ■ It leads researchers to think about research questions from a new perspective.

By supporting and financing CBR, agencies and public institutions invest in high quality and ethical research which is based on the needs of populations studied and which contributes to the quality of both research and action.

- ■ It helps organizations develop their capacities.
- ■ It creates a direct link between research results, evaluation and the subsequent interventions implemented.
- ■ It helps community front-line workers become more involved in research.
- ■ It offers a complementarity which acts as a catalyst both for research and action.
- ■ It defends patients' interests.
- ■ It meets high ethical standards.

? **Thinking about your commitment (collective and individual) to CBR**

✔ What has brought you to consider participating in CBR?

✔ How well do you know your project partners and the field they work in (community, university?)

✔ How long do you think you will work with these partners?

✔ How long do you think you will work in CBR?

✔ Have you discussed this partnership with other members of your organization?

✔ How much time are you prepared to devote to additional tasks which do not fall under the umbrella of your own main activities?

+ **Further reading**

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PART

2

Developing
and organizing
the research study
partnership

SECTION 1

Interpersonal skills
in partnership research:
trust, openness and appreciation
of the other

3

UNIT

Getting to know each other to facilitate mutual appreciation

1 | Self-definition and guiding principles of the different worlds

2 | Appreciating each other's assets

3. Getting to know each other to facilitate mutual appreciation

Trust is the cornerstone of every partnership. While shared experiences contribute to building mutual trust, it is true that at the beginning the "other" and his/her world are often not very well known. We are not familiar with his/her ways of working and often our portrayals of him/her are incorrect.

The objective of this unit is to facilitate this job of discovery by proposing some ideas which will help you to understand the world the "other" comes from as well as his/her assets.

1 | Self-definition and guiding principles of the different worlds

Community-based research (CBR) brings together partners with different cultures, identities, norms and values, and whose capacities are promoted in different ways. To help better understand the "other", here are some ideas which emerge from interviews in which various stakeholders defined their organizations.

► The world of research: objectivity, independence, scientific rigor and committed researchers

 "Objectivity", "independence", "freedom" and "scientific rigor" are words which often come up in interviews with researchers when they are asked about the values which define their professional identity.

> ■ *The production of knowledge and refutable results, open and transparent to evaluation, is the fundamental principle of research and of the scientific community.*

From this comes the importance of publishing the work carried out, as this leaves the work open to objective evaluation and criticism.

> ■ *Researcher autonomy is guaranteed by academic peer evaluation.*

The means of evaluating a "good researcher" are all based on academic peer validation: presenting at nationally and internationally-renowned conferences, having one's work published in distinguished scientific peer-reviewed journals and books, being recruited in universities or research centers, etc. Accordingly, peer evaluation provides researchers with the independence they require from any kind of non-research based pressure.

> ■ *Researchers attach a great deal of importance to independence: one must be sufficiently free to "discover something which was not being looked for".*

Independence in the academic world guarantees that the researcher can carry out his/her job in a completely objective fashion. Indeed, there is a certain amount of reticence about

university chairs financed by businesses, as some believe the former are ultimately working for specific interests as opposed to working for the common good. Some community stakeholders from community-based organizations (CBOs) have underlined the fact that they have occasionally met with the same doubt from researchers, the latter believing that CBOs have only their own interests at heart.

■ *Theoretical foundations and methodological rigor are the core of science, whatever the scientific discipline.*

The rigorous use of scientific methods is the main tool researchers use to help understand and explain realities (psychological, clinical, biological, social, etc). A specific scientific language results from this methodological rigor. This language refers to very well-defined scientific notions or concepts. It helps researchers to clearly distinguish from everyday terminology, and therefore from "pre-notions", which refer to "false assumptions" based on intuition and not on a detailed and objective analysis of the real (Durkheim, 1894).

These elements of researchers' self-identity need to be put into perspective with the following points:

■ *Because CBR is based on co-construction between researchers and the community (at each step of the process) it does not threaten the researcher's independence.*

The fear of losing one's independence is also "inversely proportional to the trust which is built in the partnership" (Researcher, Quebec).

■ *For several years now, many researchers have expressed a desire to use the conclusions of their research to further social transformation.*

Pierre Bourdieu, among others, wanted to show that the social sciences and activism represent two sides of the same coin. The analysis and criticism of social realities feed one another and contribute to the transformation of social reality (Bourdieu, 2001). In this perspective, *"working with certain organizations is in fact a concrete and real action which represents a clear positioning and a form of activism"* (Researcher, France).

How does one become a full-time researcher or a university lecturer who both teaches and works in research?

In every country, researchers and lecturers are recruited after they complete their PhD, and often after some or many years of post-doctoral research.

After a Master's degree and consent from their university's scientific committees, junior researchers complete a doctoral degree which lasts for at least three years (the actual duration will depend on the discipline and country). In Europe, this system is standardized: 3-5-8 years (Bachelor's- Master's-PhD). Once they become doctors, these scholars look for post-doctoral positions which will help them become increasingly autonomous in their scientific career. A small number obtain permanent positions through competitive processes, sometimes as full-time researchers, but more often as university lecturers who carry out teaching work as well as research. Competitive processes with additional selection procedures may occur at a national level or may be organized by each university. In France, for example, the National Committee of Universities carries out a pre-selection process for all those wishing to apply for a lecturer position in their discipline. Only one third of those initially expressing interest are then actually allowed to apply for lecturer positions in French universities.

► The world of community-based organizations: social transformation, non-judgment and proximity

Three principles often emerge as being fundamental to CBOs: social transformation, non-judgment and proximity.

We can distinguish between two main types of organizations and cultures in the vast world of NGOs involved in the fight against HIV/AIDS:

- Service organizations which have a culture of support.
- Advocacy organizations which have a culture of activism.

CBOs often have a "dual culture", being both a service and advocacy organization:

- Created out of the mobilization of AIDS-affected communities, they often initially propose mutual aid to their members. At first this aid is spontaneous, then it grows, becomes long term and eventually transforms into a service.

- Beyond solidarity (dealing with the symptoms of the problem), they aim at *social transformation* (tackling the roots of the problem) which means they are grounded in a culture of activism.

In practical terms, they strive to bring about change in access to healthcare, to fight against discrimination (discrimination against people living with HIV, but also against those populations vulnerable to the epidemic), and also to enforce patients' rights.

- Non-judgment of community members is another fundamental principle of the mutual aid provided by CBOs in their field of intervention. Furthermore, judgments must not interfere in the relationship one has with other people within the organization and must not prevent others from expressing their differences.

- CBOs are closely linked to the community.

It is difficult to distinguish between those who benefit from the organization's activities, those who engage as volunteers and those who are employees.

Many move from one "role" to another, either simultaneously or at different moments in their life. Many volunteers and employees benefit from the services offered by CBOs. Employees may devote some of their free time to do volunteer work, while some volunteers may later become employees (Maguet and Calderon, 2007).

This particularity of CBOs puts them in close proximity to the community, a proximity which is not just geographical, but emotional and identity-based too.

A practical exercise to get to know your research partners

(adapted from The Examining Community-Institutional Partnerships for Prevention Research Group, 2006)

To break the ice, to get to know each other and to build trust, try the following practical exercise:

Each partner presents him/herself to the rest of the group. Depending on the specificities of the partnership meeting, one can either dedicate enough time so that all the partners can introduce themselves, or invite one partner to introduce him/herself at each different meeting.

Presentation of the community stakeholders:

- Who is part of the community?
- What are the principal issues the community is facing?
- What concerns does the community have in regard to research in general and to this research project in particular?
- How can this research project benefit the community?

- What directions might this research project take? What are the most important questions for the community?

Presentation of the researchers:

- What is their personal and professional trajectory and how did they become involved in CBR?

- Why did they change from traditional research to CBR?

- What is their commitment to CBR and partnerships?

- How can the research project at hand be a tool for social transformation and advocacy?

- What is the value of the project on a scientific level? Why is this research question relevant at this point in time?

The academic world puts great value in knowledge and in providing quality evidence, sanctioned by academic qualifications (a PhD) and validated by academic peers (publications in journals etc).

The community world values the experience of community members and a commitment to social transformation.

2 | Appreciating each other's assets

❝ *A community stakeholder who participates in research is not really a researcher. It's easy to say that we do the same job. But that would be saying that just because I dealt with malaria and HIV, I am a doctor. We share the same objectives and similar struggles, but our jobs are different* (Researcher, France). ❞

❝ *When working with medical staff, we don't claim to be doctors. However "non-expert" community knowledge is just as worthy as academic knowledge* (Community stakeholder, France). ❞

Appreciating the assets and competencies of each other is indispensable to build trust; all the more so as different professional habits may lead to misunderstandings.

- For the researcher: *"you cannot claim to be a sociologist just because you have a Master's in sociology"* – because in that case, being a researcher would no longer be a profession.

- For the community stakeholders: *"you cannot expect community stakeholders involved in research to do a PhD"* – because this would mean that their in-depth knowledge of the community is of no value to the research project.

On the contrary, CBR is based on the idea that each partner can offer different and complementary assets to the partnership.

▶ Two types of knowledge: scientific knowledge and "non-expert" community knowledge

- *The scientific world values scientific knowledge, structured around established scientific disciplines and different types of sciences:*

Life sciences and medical sciences (biology, biochemistry, virology, public health, etc), as well as human and social sciences (psychology, anthropology, sociology, etc).

■ *Each researcher is an expert in one scientific discipline.*

Nevertheless, multidisciplinarity through the complementarity of scientific disciplines is increasingly recognized as necessary when approaching problems from a scientific point of view. Does this mean that community stakeholders - who are not researchers – cannot contribute to research with their own knowledge?

■ *Community stakeholders have "non-expert" community knowledge.*

In the domain of health, "non-expert" knowledge or "hands-on expertise", is based primarily on the experience of people affected by the disease. In the early days of HIV/AIDS, this expertise was needed as doctors were not able to get a grasp on the new disease. Furthermore, it led to a rebalancing of the doctor-patient relationship. The importance of "non-expert" community knowledge for other medical issues is also increasing, one example being in cancers associated with industrial pollution (Calvez, 2009).

Deliberately echoing the terminology describing various academic disciplines, Bruno Spire, President of the CBO AIDES in France talks about "lifology" and "nothingology":

" *I've always said that we aren't virologists or infectologists or immunologists, we are in fact "nothingologists" and "lifologists", that is to say that we are experts of nothing or only experts of our own life experience. Or rather of the life experiences of all of us, collectively, because in an organization, each person has their own life experience but as we also hear our colleagues talking about their own lives we are therefore participants in this collective experience. And it's because of this collective experience that we claim our place* (Spire, 2011: 158-159). "

The contribution of "non-expert" knowledge to research and action is underlined in numerous fields (Callon *et al.,* 2009). CBR is based on the complementarity between scientific knowledge (via researchers) and "non-expert" community knowledge (via community stakeholders).

► Appreciating the assets and contributions of community stakeholders

Beyond their general appreciation of the value of "non-expert" community knowledge, researchers also underline the important contribution made by community stakeholders to research. Above all, they:

- ■ Bring their knowledge of the groups being studied.
- ■ Shed light on the real concerns and problems of the populations studied.
- ■ Have an important role in the formulation of research hypotheses and research questions.
- ■ Bring their own special communication skills which they have fostered with communities.
- ■ Are able to translate research results into practical interventions for the people concerned and can argue for change when meeting policy makers and international organizations.

► Appreciating the assets and contributions of researchers

"Being a researcher is a profession!". Through his/her professional experience, a researcher brings:

- ■ Knowledge of scientific literature, of theoretical instruments and of current issues in the scientific field.
- ■ Know-how in formulating research questions and hypotheses.

- Knowledge of the context of the country and the major issues surrounding the study topic.
- Rigorous methodology (definition of variables, of the sample, etc).
- Know-how in producing scientific communications (editing of results, oral presentations, scientific articles, etc).
- A framework for presenting scientific arguments to contribute to advocacy.

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UNIT 4

Building trust and reciprocity between partners

1 ▌ What interpersonal skills are necessary for the development of a partnership?

2 ▌ How can we create a climate of trust and a positive group dynamic?

4. Building trust and reciprocity between partners

Building close collaboration between stakeholders from different backgrounds and sometimes from different countries is one of the principal benefits of community-based research (CBR). Nevertheless, creating a real partnership is a challenge – a job – in itself, and one which is often neglected. Over the long term, project partners need to understand each other in order to agree on the goals to be reached and the individual contributions to be made. Creating the conditions for an equitable partnership where the capacities of every partner are fully used is fundamental. This is what encourages not only trust but also the possibility for stakeholders to feel they can express disagreement or different points of view without being judged.

1 | What interpersonal skills are necessary for the development of a partnership?

Constructing a partnership and initiating a positive group dynamic between individuals from very different backgrounds requires know-how and interpersonal skills which are not greatly promoted in some settings. These skills facilitate access to the world of CBR (Wallerstein *et al.,* 2005).

► Reaching out to the "other", "committing" to the partnership

■ *Considering the development of the partnership as an objective in itself.*

In CBR, the partnership itself and mutual capacity building are just as valuable for further research projects as the research results of the project at hand. It is therefore necessary to devote time as well as financial and human resources to the partnership.

■ *Investing yourself, including "physical investment", in the settings where your partners operate.*

In order to create a connection, it is not enough to simply have a "theoretical" knowledge of one's partners acquired during meetings. Physically going to the places where they live and work – community events, the community-based organization's (CBO) offices, the university, scientific conferences and so on – facilitates mutual appreciation.

■ *Respecting the "other's culture".*

The term "culture" refers to the norms and social practices of each social environment, and to professional or activist cultures. Each person must be aware of these "cultures" and not try to impose his/her own on project partners.

■ *Showing one's willingness to share power and resources.*

► Take the time to collectively identify each other's interests and constraints

The partnership will work all the better if each person clearly expresses what he/she can bring to the table and why he/she does so, while anticipating the inherent difficulties associated with collaboration between different worlds. For each partner, this primarily involves:

■ *Identifying and acknowledging his/her own capacities, resources and responsibilities as well as those of the organization he/she is a part of.*

■ *Acknowledging that each partner has his/her own motivations and may have different objectives for the CBR study.*

■ *Acknowledging that each partner has his/her own needs and requirements.*

The reasoning inherent to each partner's setting governs his/her action: time constraints (university calendar for researchers), funding (program funding for organizations), etc. Being clear about these constraints at the beginning of the partnership enables the group to adapt its procedures.

■ *Clearly stating his/her own concerns.*

Not everyone necessarily feels at ease about clearly expressing disagreement, criticism and difficulties or even about expressing his/her objectives and points of view within the group, for fear of being devalued or of hurting others' feelings. Leaders on both sides have, among other duties, the responsibility to encourage people to speak up in order to ensure the full participation of everyone.

> Two interpersonal skills are central to building a strong partnership:
>
> • Reaching out to the "other", showing commitment and openness.
>
> • Being aware of yourself, of your assets, capacities and constraints (reflexivity).

2 │ How can we create a climate of trust and a positive group dynamic?

We often consider that trust is only acquired with time and shared experience, and that a positive group dynamic is only the result of a special kind of chemistry, something which may or may not happen. Strategies do exist however to facilitate the construction of both a group dynamic and trust.

► Openly discussing potential obstacles to collaboration

Although the partners may never have previously worked together, they may have been involved in other collaborations in various forms. Naturally, they will have different opinions about how positive each experience was or was not. Such previous experiences (especially negative ones) together with each partner's personal life experience will necessarily have an impact on the new partnership being created. Discussing these stories, fears and expectations right from the beginning enables partners both to overcome some of the obstacles to collaboration and to trust each other much more quickly.

> **Openly discussing potential barriers to collaboration: a practical exercise**
>
> (adapted from *The Examining Community-Institutional Partnerships for Prevention Research Group,* 2006)
>
> During one of the first partnership meetings, ask each partner to list, either orally or in writing :
>
> - 3 reasons why they themselves or the organization they belong to would not trust/would be reticent about working with the other partner.
> - 3 factors/attitudes/actions which would help them to trust their partners.
>
> Divided into groups or as a whole, the participants can then discuss the difficulties mentioned and produce recommendations to overcome them.

► Implementing strategies to build trust right from the beginning of the partnership

The more quickly trust is established, the more the research project will benefit from the assets of the partnership. Some strategies are more effective when implemented right at the beginning of the partnership, and will evolve as the partnership progresses.

These strategies are based on work organization:

- *Being very inclusive at the beginning of the partnership.*

  For example, inviting a large number of stakeholders to the first meetings.

- *Creating a strong core by inviting people who are motivated to make an even greater commitment.*

- *Showing appreciation of the actions carried out by other partners.*

  Always taking the opportunity to compliment partners on actions carried out well.

- *Agreeing to delegate.*

  It is often difficult to delegate tasks when respective competencies have not yet been concretely tested. Nevertheless, engaging in a partnership demands the delegation of tasks or activities, thereby demonstrating trust in partners' capabilities.

- *Taking into account partners' concerns and demands.*

  When partners see that their concerns are being listened to and accepted by others, initial mistrust can be transformed into real collaboration.

And ways to carry out research:

- *Giving priority to the real and immediate research concerns of the community rather than to those which are externally induced.*

  Priorities may differ – for researchers they may involve the construction of a theory or the testing of a hypothesis, for community stakeholders they may involve arguing for an activist stance or promoting new forms of practical interventions. These different priorities must be clearly articulated in the joint project definition.

- *Showing flexibility in ways of thinking and methods.*

  Find a compromise between the scientific requirements and the concerns of community stakeholders.

- *Adapting oneself to the language the other partners use/decoding scientific vocabulary.*

  Researchers and community stakeholders often have different vocabularies and sometimes can even understand two different things for the same word. Therefore, it

is essential that project partners make an effort to explain themselves clearly in order to avoid misunderstandings and to ensure real communication between everyone.

These strategies, which help to create trust at the beginning of the partnership, change over time. One example of this is to change group size: initially inviting all or a large part of the community to participate in the first meeting encourages debate and ownership of the planned research project. It also helps identify motivated individuals who may then become partners once the group becomes smaller.

Practical Exercise: a workshop to build trust in the partnership

Creating trust right at the beginning of the partnership helps save time later on. The impact of trust and group dynamics on the quality of research tends to be underestimated in an area which emphasizes deep reflection more than interaction.

Prevention research centers from *Centers for Disease Control and Prevention* (CDC) have developed a tool to build trust in partnerships (CDC, online tool). A questionnaire measures both the importance partners assign to various elements of trust, and their perception of these elements with respect to their current research partnership. Partners are also asked to provide examples and recommendations. A workshop then enables the group members to collectively debate the issues raised in the completed questionnaires. See "Further reading" at the end of this unit.

► Uniting a small group around precise objectives

Research groups which work well (Becker *et al.,* 2005):

- Have clear operational objectives.
- Comprise quite a small number of members. While the partnership should be inclusive, limiting the number of members nevertheless encourages partners to get to know each other better and helps decision-making.
- Promote working in sub-groups.
- Hold meetings regularly, with meeting minutes being accepted by all those present and then distributed to all group members.
- Implement ongoing communication in between meetings.

► Paying particular attention to power relationships and to the mechanisms which maximize equity, in terms of the contribution made by each partner

Achieving a balance between the partners and between all the participants is one of the objectives of CBR, and an ambitious one at that. The fact is that inequality exists in the available resources, not only between different environments (i.e. between researchers and community stakeholders) but also inside each environment (e.g. between doctoral researchers and research directors or university professors, or between members of the community studied, etc). When organizing CBR, the possible negative impact such relationships might have on building collaboration should be anticipated and prevented.

Allocation of roles and functions in the partnership

The authority associated with the different roles in the collaboration is a source of power within the partnership. Duties must therefore be allocated, especially between researchers and community stakeholders. Many CBR projects are led by two principal researchers (co-investigators), one being an "academic" researcher, the other coming from a CBO. Other project committees may involve multiple stakeholders (→ Unit 6).

Becker *et al.* (2005) identify two types of *leadership:*

- "Technical leadership" where experts discuss the content of the project (asking for or giving information, etc).
- "Socio-emotional leadership" which is based more on group dynamics (encouraging participation etc).

Both these types of leadership may be shared between community and academic stakeholders. The overall structure of the partnership, the allocation of roles and work organization (→ Unit 6) are all essential to build trust in the partnership over the whole duration of the collaboration.

Skills transfer

Although skills diversity is fundamental to the strength of a partnership, it may also be the basis for inequality if certain gaps are not bridged. This is particularly true for the technical aspects of the partnership, which novices find intimidating and which lead some people to feel excluded. It is also the case for the real-life knowledge of community members.

Working in collaboration can lead to skills transfer for certain tasks. This may be a spontaneous process but most often it requires specific training, leading to capacity building inside the group which in turn helps the partnership to work more effectively (→ Unit 5).

Capacity building

Besides skills transfer, it is necessary to think more generally about capacity building in CBOs. One asset in this regard is the recruitment of "research facilitators", individuals whose job is to bridge the gap between the research and community worlds and to facilitate community involvement in research (→ Unit 5). Another possibility is community meetings, where community stakeholders can discuss issues among themselves and create a unified voice. In doing so, they reinforce their presence within the partnership.

> An equitable partnership which benefits from the inherent diversity of skills is strengthened by skills transfer between the partners. To be real, this transfer must be organized, for example through training.

? Some questions to ask yourselves at the beginning of a partnership

✔ Have we dedicated time to the building of the partnership itself (and not only to the research project)?

✔ Have we taken the time to discover our partners?

✔ Have we discussed how we would like the group to work together and about group dynamics?

✔ Have we considered our own capacities, resources, motivation, interests and constraints?

✔ Have we talked about conflict management?

✔ Have we shared these reflections with our partners?

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UNIT 5

Facilitating the encounter between the two worlds

1 | Opening up brainstorming platforms to others

2 | Relying on research facilitators to bring the different worlds together

3 | Capacity building for an equitable partnership

5. Facilitating the encounter between the two worlds

At the beginning of the HIV/AIDS era, collaboration between researchers and patient associations was established very quickly, especially because of the need to react to what was a fatal, stigmatized and stigmatizing condition. This interpenetration of the two worlds, which has continued to grow with the development of HIV/AIDS community-based organizations (CBOs) and the field of HIV research, is now tending to become institutionalized. Nevertheless, this increased collaboration still needs to be translated into concrete strategies by those stakeholders directly involved in field interventions and research projects. Only in this way will the symbiosis necessary for the future development of community-based research (CBR), as we understand it here, be possible.

Several very practical activities exist which can help researchers and community stakeholders to understand each other's language and work methods. Some are easily accessible and cost little time and money. Others need to be thought about over the long term.

1 | Opening up brainstorming platforms to others

In the field of HIV/AIDS, all the large international events are created in partnership between the scientific community, the world of non-governmental organizations[1] (NGOs) and international agencies. This is because the political dimension of the epidemic has been recognized for a long time. This type of collaboration can be extended to a more local level by joint participation in smaller events, be they scientific or CBO-based events. Large scientific or CBO meetings provide stakeholders with the opportunity to observe the issues currently being debated in their partners' environment.

► Researchers at community-based events

Researchers can participate in:

- Events associated with the topic of their research: general meetings concerning drug users, European meetings on harm reduction, etc.
- Important community-based events: general or ordinary meetings etc, anywhere the strategic plans of the CBO are discussed.

Researchers may be invited by CBOs to their headquarters:

- For an informal presentation of the work of one or two researchers, within the context of a team meeting or internal meetings.

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1 A CBO is a specific type of NGO which is both non-governmental and community based.

- To informally discuss predefined issues with those responsible for a specific program, possibly on a regular basis.
- To share their expertise in thematic and/or scientific meetings.

In parallel with its annual general meeting, the NGO Solthis France holds an annual one-day scientific meeting where community stakeholders and researchers present their respective work.

A scientific committee for a CBO.

The example of a scientific committee in the French harm-reduction network

In 2010, the recommendations issued in a collective scientific expert report by Inserm in France on medical care for people living with HIV/AIDS, suggested that research in harm reduction amongst drug users should be developed. The French harm-reduction network chose therefore to create a scientific committee. Its objective is to catalyze research, to highlight real-life issues to researchers, to carry out research which can be used directly to develop practical interventions, and to disseminate the results of research studies to front-line community stakeholders. For the harm-reduction network, this scientific expertise also helps advocacy with policy makers.

This committee is required to meet three times a year. The first part of the meeting occurs between researchers. They are then joined by front-line community stakeholders.

► The participation of community stakeholders in researchers' activities

- Several scientific organizations (such as the *International AIDS Society)* are structured to include NGOs in advisory committees and in the organization of a large number of activities.
- Community stakeholders can meet researchers and build bridges thanks to their participation in conferences and scientific meetings:

  International AIDS conferences, International AIDS Society conferences, Addiction-Hepatitis-AIDS symposium, AIDS Impact, International HIV Social Science and Humanities Conferences, scientific meetings at the French national agency for research on AIDS and viral hepatitis (ANRS) sites, workshops in research centers, etc.
- Community stakeholders may participate in research training sessions for junior researchers, for example, at the "junior researchers' summer school" (→ see box).

The "junior researchers' summer school", an introduction to multidisciplinary HIV research initiated by NGOs

The "university for junior researchers", a weeklong series of workshops originally created by AIDES France, is organized by Sidaction every two years. Its primary objective is to encourage junior researchers to become involved in HIV/AIDS research over the long term, and to ensure that the different scientific (social, epidemiological, etc) and medical aspects of HIV infection are brought to the forefront over the week. A meeting place for junior researchers but also to encourage communication between junior researchers and community front-line workers, its aim is to put these academics in touch with a different, more practical reality of the epidemic, and to "broaden their horizons" through an awareness and appreciation of the interventions being carried out by community stakeholders. Besides the junior researchers – who are the primary audience – medical doctors and community stakeholders already involved in CBR studies are also welcome as attendees.

■ In France, CBOs are invited to participate in smaller advisory groups, specific to research settings.

This is the case for example with the participation of NGOs and CBOs in ANRS working groups. Moreover, community stakeholders can establish themselves as essential members of a research project. An example of this is the inter-organizational group TRT-5, whose positive participation in the implementation of HIV clinical trials in France is widely acknowledged (→ see box).

Researchers can also solicit the participation of community stakeholders in these groups.

TRT-5, inter-organizational group: Treatments and Therapeutic Research:

Bringing the needs and rights of people living with HIV to the attention of researchers

In the early 1990s, French NGOs like Act Up (through its medical committee), Arcat Sida and AIDES started taking an interest in biomedical research progress and in the discovery of new drug molecules. They also started disseminating information about scientific HIV/AIDS research to the HIV community. In order to create a unified voice in meetings with government agencies and pharmaceutical companies, they created an inter-organizational group, TRT-5, in October 1992.

Collaboration with the ANRS was very quickly established after that. Since then, the TRT-5 has reviewed clinical trials supported by ANRS and made recommendations. Early work concentrated essentially on ethical aspects of research (consent forms). Then the group widened its focus to encompass the rights of clinical trial participants in general.

TRT-5 carries out in-depth work: monitoring research about medication, acting as an ethical watchdog in clinical trials, defending the interests of people living with HIV in such trials, advocating that adverse side effects of treatment be taken into account, etc. It alerts the French national agency for the safety of medicines and health products when it believes that the safety of patients is not being ensured during clinical trials. It has also been solicited by several offices (for example the Ministry of Health, the High Authority for Health, etc) and has widened its activities to encompass the issues emerging from the reform of the French healthcare system, as well as those more recently raised by biomedical prevention research.

> In order to facilitate the contact between the two worlds, you must not hesitate to solicit your partner and ask him/her to participate in your activities. The ways in which you might open up your activities to him/her include showing your way of working, involving him/her in advisory groups and in the planning of activities.

► Multi-stakeholder conferences: the role of funders and policy makers

When we carry out research, we ensure that no one has been forgotten in the steering committee or in the workshops. [...] In our daily work, we make sure that everyone who has something to bring to the table is present, especially the community-based organizations. We operate using "collaborative work" processes (International stakeholder, Morocco).

One of the main ways of facilitating the encounter between community stakeholders and researchers is to organize multi-stakeholder events in a more neutral setting. Research funders and policy makers are in the best position to organize such meetings.

Multi-stakeholder meetings

Every two years Sidaction organizes a National Convention which brings CBOs and researchers together in order that they can collectively reflect on relevant issues in the fight against HIV/AIDS. The sessions provide the opportunity for these stakeholders to discuss and exchange their views about their respective concerns, as well as about analyses and field interventions.

The Uganda AIDS Commission created the *Uganda Think Tank on AIDS.* These are biannual meetings which invite researchers and community stakeholders to discuss a thematic issue in the fight against HIV/AIDS.

The ANRS also organizes "scientific meeting days" in countries where it has "research sites" (Brazil, Burkina Faso, Cambodia, Cameroon, Cote d'Ivoire, Egypt, Senegal, and Vietnam). These are sometimes preceded by "NGO days", where researchers and NGOs/community stakeholders meet during thematic workshops (e.g. discussing research priorities identified by the NGOs, investigating the role of NGOs in providing scientific information to PLHIV and vulnerable groups, etc).

Thematic working groups

The ANRS implements coordinated activities and sets up working groups to define priorities and research programs based on relevant topics. These groups are open to participation by NGOs. Among them is the "community-based research group" which is open to researchers and community stakeholders. It aims to help these individuals get to know each other better and to facilitate the emergence of research questions which everyone agrees on.

Local multi-stakeholder work sessions

The city of Marseilles in France and the INSERM/IRD Research Unit 912 jointly organized a discussion session on the work of a Canadian researcher on supervised injection facilities. Because of this collaboration a diverse audience was able to attend. According to those who participated in the session, developing such meetings in the future should be encouraged in order to promote meaningful exchange between various local stakeholders.

Creating a common platform for reflection: the ANRS community-based research group

In 2010, the ANRS undertook a process of reflection on the principles which govern CBR, the latter being defined as the active collaboration of communities in research projects (ranging from study participation solicitation to project co-direction) in compliance with the criteria laid down for scientific quality. Since then several projects have been implemented dealing with prevention and testing: experimentation with non-medicalized HIV rapid testing, HIV and hepatitis C prevention interventions in crack-users, and evaluation of educational harm reduction sessions on the use of psychoactive products for intravenous drug users. A "community-based research" working group was also created in partnership with AIDES France. It focuses on the issues and methods surrounding the participation of "communities" in ANRS-supported research projects.

Research funders and policy makers (local authorities, state organizations and international organizations) are in a privileged position to get to know all the stakeholders involved around a specific topic. In turn, they can organize meetings, debates or working groups, focused at encouraging researchers and community stakeholders to get to know each other. You must not hesitate to solicit them to complement your own initiatives.

These multi-stakeholder meetings take place at local and national levels. In the field of HIV/AIDS, funders often see it as their mission to catalyze research by creating relationships between the various stakeholders in the fight against HIV/AIDS. They are therefore essential to the organization of these meetings.

However, other stakeholders may also carry out this function:

■ International organizations (WHO delegations, UNAIDS or similar organizations in different countries).

■ State organizations (national commissions, inter-ministerial commissions, departments within a ministry).

■ Local organizations.

2 | Relying on research facilitators to bring the different worlds together

"Research facilitators" are intermediaries between the world of research and that of community intervention. Not very numerous, some of these stakeholders devote all their time to this job of facilitation. They work in CBOs (or in groups of organizations) to help them develop their research skills. They must be familiar with both the community and research worlds.

The development of the position of "research facilitator" started in Canada at the beginning of the 2000s. This was the result of a commitment made by the Canadian Institutes of Health Research when they implemented a funding program to develop CBR[2]. Today, research facilitator positions also exist in other countries (France, Morocco, etc) but the lack of any specific funding limits their development.

The main tasks of the facilitator are to:

- Involve the communities so that research projects emerge from real community questions.
- Facilitate the participation of communities during the course of research.
- Strengthen the research skills of communities.
- Help to establish partnerships with researchers.
- Raise awareness of CBR in organizations engaged in research (research agencies, funders).
- Facilitate the dissemination of research results and their translation into interventions.

In practical terms, the activities carried out by the facilitators are quite varied. They can be broken down into:

- *Capacity building activities for community-based stakeholders.*
- *Multi-stakeholder activities.*
  - Organization of multi-stakeholder work meetings.

  The facilitator helps to implement partnerships. They can therefore identify potential partners and organize work meetings in order to facilitate the emergence of new research projects.

  - Implementation of a scientific committee within the CBO.

  The Methodology Innovation Research and Evaluation (MIRE) department within the French CBO AIDES has implemented a scientific committee. Its objective is to develop research questions which are not only closely tied to the organization's strategic plan, but are also considered by the researchers to be truly important as research material. The scientific committee meets 2 to 3 times a year.

- *Activities directed at the community.*
  - "Research cafés":

  These are an extension of the "science boutiques" and "scientific cafés" implemented in the 1980s. Their objective is to promote scientific culture and can be adapted to the field of HIV/AIDS. The Ontario grants program for CBR recently implemented a system of "research cafés" which consist in informal conversations in small groups, with various speakers invited to talk about research topics associated with HIV.

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2 At the time of writing this toolkit, the program's funding was being threatened, putting research facilitators' jobs at risk.

■ *Activities directed towards researchers.*

• Interventions for junior researchers.

Junior researchers starting out on their career are a target audience for CBR. For example, research facilitators may choose to raise junior researchers' awareness of the importance of adequately addressing the concerns of the community when defining their research topic, or of the possible ways to present their research findings.

• CBR training sessions for students (master classes).

CBR will not be recognized or practiced if it is not taught. Working together, the researcher and research facilitator can propose introductory seminars to CBR and highlight its importance as one of the research methodologies.

Facilitators also carry out the job of partnership consolidation during the research.

■ Their role is particularly important in communities when the latter have not been involved in the research project right from the beginning and/or when they require someone to explain the research project to them.

■ They have knowledge of the "community culture". The fact that they belong to the same world helps overcome any community reticence that may exist (→ see box).

Moving from mistrust to collaboration: a community stakeholder's first-hand account

A community activist talks about the work he had to do to build trust and understanding between the researchers and community stakeholders who were partners in a research collaboration:

Activist:

"I kept the activists informed about all the project phases and about how their demands were being taken into account all through the project. I showed them that their demands were acknowledged. That is how, little by little, trust was built [...]".

Interviewer:

"And in practical terms, what actions did you carry out? What means did you use? Meetings, phone calls?"

Activist:

"1) I created a document on the community partners' expectations and the minimum requirements that the project had to fulfill.

2) I obtained a copy of the project protocol and adapted it for a PowerPoint presentation.

3) As for the research team, I always provided them with feedback about the community partners' feelings on the survey, their understanding of what the survey was about and I also made recommendations.

4) With respect to community stakeholders, I sent emails with explanatory notes, and I also provided progress reports at every community meeting."

Research facilitators "speak two languages", that of the community and that of research. This privileged position means they can enable communities to become involved in research and strengthen their competencies as well as raising researchers' awareness of CBR.

Only a few individuals devote all their time to the role of facilitator. Sometimes community stakeholders involved in research projects temporarily fill this role, especially when the context of the project comes under the umbrella of their own area of work.

3 | Capacity building for an equitable partnership

Capacity building contributes to creating equity between the partners in the collaboration. Developing competencies, participating in research training or in volunteer training effectively provides stakeholders with the resources needed to better understand and collaborate with their partners.

Several activities may be carried out:

► Capacity building activities directed at community stakeholders

■ *Organizing workshops in research capacity building.*

The facilitator or the other partners (community- and/or researcher-based) can implement workshops to sensitize community stakeholders to the importance of the link which exists between research and action, or to familiarize them with the various stages of the research process.

Community capacity building workshop on CBR, organized by Coalition PLUS in Burkina Faso

General objective of the workshop: to enable the CBO's research committee members to strengthen their knowledge, interpersonal skills and know-how in scientific advocacy, research ethics and CBR. The objective is to improve the quality of their current interventions and to help them develop complementary ones.

Participants: People working in a CBO who have already taken part in a research project and who are sometimes engaged in research collaborations.

Workshop organization: 3 days, divided into 6 working periods, each 1/2 day long:

1) Research and action: personal opinions and thoughts of research, how research is valuable in terms of practical intervention.

2) What the organization's research questions are: standing back from daily activities to have a more global perspective, in order to identify research questions arising from field-based interventions.

3) Issues related to the academic-community partnership: factors facilitating and hindering a "good partnership".

4) Research processes and methods: research stages, protocol, role of community stakeholders at different steps.

5) Formalizing research partnerships: working on a collaboration charter.

6) Research ethics: the ethical principles and questions one should think about when reading a project proposal.

■ *Direct aid for the preparation and implementation of research projects.*

Research facilitators or indeed anyone who has already had previous research experience can support community stakeholders, working with them to identify research questions and to set up the project. This includes creating the protocol and applying for funding.

■ *Help in preparing abstracts to be submitted to scientific conferences.*

AIDES, ALCS, Coalition PLUS and Sidaction have implemented a special tutoring system for CBOs, in order to help them draft abstracts for francophone conferences on HIV/AIDS (Casablanca 2010, Geneva 2012, etc). The community groups not only benefit from guidance on how to prepare an abstract but also from the assistance of experts who read their work and provide advice on how it can be improved before submission.

> Capacity building is both a prerequisite for involvement in collaboration and a result of collaboration. Research training workshops are often needed at the beginning in order to construct a partnership. Support can then be given throughout the research project by research facilitators and/or partners.

■ *Setting up and carrying out a research project – "learning by doing".*

Participating in CBR is still the best means of building one's research capacities. It was thanks to this concept that the international organization Coalition PLUS chose to construct the CBR project Partages, which involves the organization's various international CBO members. This multi-country experiment enables each CBO to benefit from the experience of all the others, and to strengthen its own research capacities in order to then carry out research projects with researchers, either alone or in partnership with other CBOs.

► Capacity building activities directed at researchers – getting to know the community better

The means researchers usually use to familiarize themselves with the culture of their community partners is through participation at important events in the community organization's calendar (meetings, conventions, symposia). Such participation brings about a greater understanding of the internal and external issues the community has to face, and in turn encourages researchers to take better account of the community's concerns during the collaboration process.

One example of this is the participation of a researcher in team meetings discussing the needs of the community members.

Further reading

Bessette, G. (2004). *Involving the community. A Guide to Participatory Development Communication.* Laval. Southbound/IDRC.

Canadian Institute of Health Research (CIHR) website. http://www.cihr-irsc.gc.ca/

Partnership know-how: structuring the collaboration and defining procedures

6

UNIT

Structure and functioning of collaborative research

1 ▌ Objectives and aims of involving communities
in research committees

2 ▌ Participatory research: new committees
to ensure communities have a role

3 ▌ Integrating community stakeholders in standard
research methods: community-based research (CBR),
equity between partners

6. Structure and functioning of collaborative research

An effective partnership requires joint consideration, right from the start, of the way community/researcher teams will interact and function together, as well as the modalities of community stakeholder involvement throughout the different stages of the research project. There are different ways to involve communities. As well as the participation of community stakeholders in the standard committees set up for research projects (scientific committees, steering committees, etc), project-specific "community committees" (community-based organization (CBO) committees, research study participant committees, etc) can be set up. Here we present a few ideas based on the experience of past and ongoing collaborative projects.

1 Objectives and aims of involving communities in research committees

Two essential issues must be taken into account when project partners set up the overall organization of their research project:

► The objectives of community involvement – a means or a goal?

- Is the group looking for the participation of community members?
- Does the group want community members to be represented in the research project? (→ Unit 8)
- Does community participation constitute an objective in itself, following on from the "principle of the greater involvement of people living with HIV/AIDS" (GIPA[1])?
- Is community participation a means both to engage in a different type of research which is more adapted to the contexts and needs of communities, and to facilitate the transformation of research results into action?

Many research projects have also demonstrated the real added value for research itself in involving communities. Community participation, considered as a means, encourages greater equity in relationships between researchers and communities. It also contributes to the choice of community representatives – stakeholders who are provided with the skills and legitimacy needed in order to carry out this representation.

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1 GIPA (Greater Involvement of People living with HIV/AIDS) "aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives" (UNAIDS, 2007a).

► **The expected degree of involvement and equity between the different stakeholders in the partnership**

Civil society must always have a place in collaborations. Depending on the type of research, its role will vary from basic consultation to leadership (International stakeholder, Morocco).

The responses to the questions above guide the choices to be made when designing any research project: the objectives (desired nature and degree of involvement of the community studied) will determine the type of committees chosen to structure the research project, their composition and their operational procedures.

Objectives of community involvement

Type of committee

Composition of committee
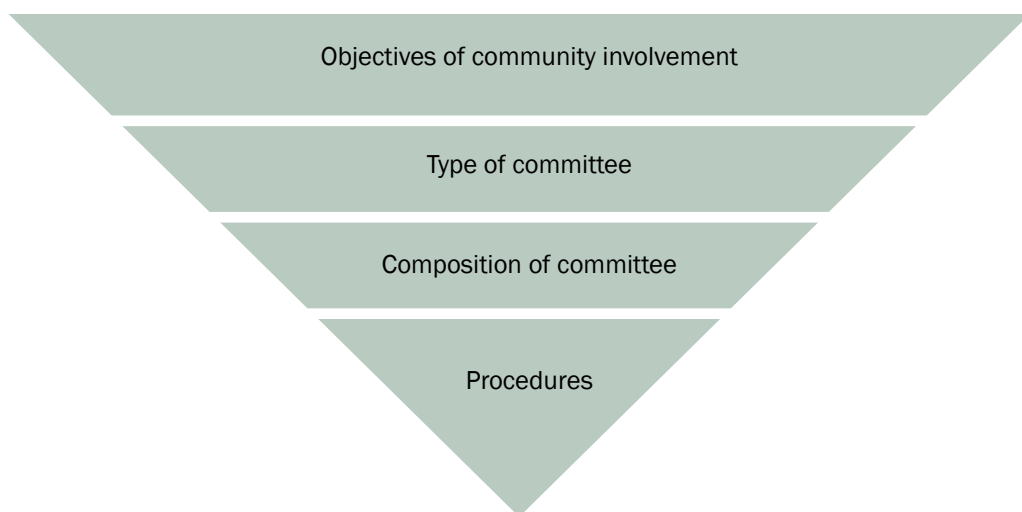
Procedures

Diagram: From the objectives of community involvement to the procedures of committees associated with the research project.

2 | Participatory research: new committees to ensure communities have a role

Giving communities a role in research immediately raises some practical questions:

- Does involving communities mean involving CBOs?
- Does involving communities mean involving the "members" of a community? What community are we talking about exactly?
- What place should be given to research participants?
- How can participation and expression by community members be encouraged, especially when this community is stigmatized or socially marginalized?

These questions may arise at the beginning of the research project or during it, when the idea emerges of formalizing the community's participation through the use of project-specific community committees.

► Why do we need to create project-specific community committees?

The creation of committees specially dedicated to community participation enables us to:

- Clarify and provide visibility to community participation.
- Guarantee community participation throughout the entire research project.

► What are the aims of these committees?

The reason for encouraging CBOs to participate in these committees is often because they *represent[2]* the community in the research project and committees:

- CBOs have in-depth and long-standing "grass roots" knowledge of the community. They also deal with the issues raised by research questions.
- CBOs have the ability and legitimacy to speak for the group.

Different means are possible to ensure community participation in a research project. By putting "formalized" project-specific community committees on an equal footing with the standard committees involved in a research project, the durability of this participation is guaranteed. Partners may also decide on the formats of these formalized committees, depending on whether they are seeking *representation* of community members or their *participation*.

Encouraging the direct involvement of members of the concerned populations (as individuals and not as representatives) in these committees has the following aims:

- One hopes to create a group whose composition reflects the community – its heterogeneity, its concerns, its experiences.
- To promote the *participation* of the community in research as an objective in itself.

The forms and expectations of community participation depend on how well the community is internally organized and recognized by others. Some communities are recognized; their organizations are well known and participate in public debate or in consultation committees. Others are hidden or emerging and are still in their infancy, are fragile or controversial (drug user or sex worker CBOs for example).

► Depending on the project partners' objectives, several forms of community participation are possible

The CBO's advisory committee

- Brings CBOs together to participate in a research project.
- Supports the project, gives its opinion on the direction the research study should take. It may participate in drawing up the research protocol.
- The CBOs represented in the committee may have a role in project-related communication or in the recruitment of study participants.

Why a CBO advisory committee?

- It involves CBOs in the research project. It enables the other stakeholders to benefit from their knowledge, their relationships and their involvement in the community.
- It may include a variety of CBOs concerned by the same issue and therefore limit the number of voices which need to be listened to.
- It encourages dialogue between different CBOs and may even encourage a common position regarding the research topic in question.

2 P. Braud (2008) defines representation as a "political activity based on dual delegation: to take the place of... to decide for".

■ It does not exclude the committee members from participating in "standard" research committees (e.g. steering or scientific committees).

The ANRS Ipergay trial on pre-exposure prophylaxis in gay men in Canada and in France established a CBO advisory committee. Participation is open to all CBOs concerned by the issue. In addition to those CBOs in the advisory committee, AIDES is a member of the trial's scientific committee.

The CBO committee does not however guarantee that the interests of all the community's members will be taken into account. This is the case when such organizations do not represent certain parts of the community, because they do not know them very well (blue-collar workers, ethnic minorities, rural and remote communities) or because they are concentrated on specific issues.

Community consultations or workshops

■ Their objective is to hear what the people concerned by the research project have to say and to highlight their needs and expectations.

■ Their goal is to collectively discuss the value, hypotheses, nature and conditions of the proposed research project, as well as its compliance with ethical rules.

■ Besides the community *leaders* (such as members of CBOs), these consultations involve other members of the community concerned by the research project.

The consultation organized by TRT-5 on pre-exposure prophylaxis in homosexual men in France and Canada: organizational procedures

In parallel with the ANRS Ipergay trial and with the participation of the CBO AIDES in the steering committee, an *ad hoc* group, composed of several CBOs, was created to organize a community consultation (on the acceptability of a pre-exposure prophylaxis study). The objective of the French part of the trial was to extend consultation on the topic beyond the CBOs which were already involved in the research project (TRT-5, 2010). The breakdown of the process was as follows:

■ At first, a national meeting of representatives of the CBOs concerned was organized (CBOs in the fight against HIV/AIDS, LGBT CBOs and media).

■ Subsequently a process of consultation was carried out at local level by the voluntary CBOs. These meetings took the following forms:

• Seminars (Presentations/Discussions & Exchanges).

• Plenary meetings which could then be complemented by workshops to better understand the issues at stake (groups of 10 to 15 people in order to ensure that everyone could speak).

■ These direct consultations were then supplemented by online consultations via chats and forums on the communities' internet sites.

■ A public meeting providing information on the trial was organized alongside the community consultation by Act Up-Paris.

Does community consultation really mobilize "communities"?

The limitation of community consultations is that they mainly collect opinions of activists, that is to say people who are already fighting for the "cause" of the community, who are mobilized and who do not necessarily reflect the community in all its diversity. Many activists find it difficult to make a distinction between the "I" and the "we", or to put it another way, they find it difficult to clearly define their position when they are speaking. Do they speak as individuals from personal experience or as activists whose experience and position have been collectively constructed?

In the form of a CBO advisory committee or community consultation, it is relatively easy to mobilize the CBOs concerned and their members for the related research project. The latter participate both as representatives of the concerned community – as they themselves are concerned by the research topic – and as stakeholders expressing the needs and expectations of this community.

These types of committees must ensure that all those who make up the community are taken into account.

It is important therefore to go beyond mobilizing only the most committed volunteers in CBOs and to ensure that others can voice their individual opinions.

Mobilizing beyond activists – some ideas:

■ Discussion groups can be used to gather opinions from members of the communities involved in the research project.

■ Scientific methods (surveys, interviews) can be used to gather opinion or measure the acceptability of a research project in a genuinely representative sample of the chosen community. For example, the ANRS Ipergay trial was preceded by a survey on acceptability, carried out by AIDES and Inserm (Lorente *et al.,* 2011).

The research study participant committee

■ Brings study participants together.

■ Its objective is generally *participatory*: it provides study participants the right to monitor the research study in which they are participating.

■ It usually entails having *participants* talk about *their* experience of the study.

■ It may aim to represent the community in all its diversity through the participation of people with heterogeneous profiles.

■ The "participant" is in fact less engaged, and probably less informed and sensitized than the community-based activist.

■ To acquire a wide enough range of opinions but still remain a group which expresses itself directly, a compromise must be found when choosing the ideal number of members for such a committee.

■ It provides community members with a space for exchange and reflection on the research topic, free from external points of view.

 • It helps to build a collective voice which spokespersons can relay to the steering and/or scientific committees.

 • It gets around the difficulty of having to speak in public for those people who are not used to it. This is even truer for members of stigmatized communities.

The Oméga cohort's participant steering committee, Quebec, Canada

Oméga was a CBR project on HIV transmission in the gay community, carried out between 1996 and 2003 in Montreal. It brought together researchers and two CBOs – Action Séro Zéro (Rézo) and Cocq-Sida. Its objective was to measure HIV incidence, identify risk factors which could lead to infection and study the context of relationships between men. This project was based on the establishment of a cohort, whose members benefited from six-monthly medical follow-ups. On each follow-up occasion, a questionnaire collecting data on demographics, sexual behaviors and psychosocial aspects was administered to them.

During the first year of the cohort study, a participant committee was created.

Systematic invitations were made to the study participants.

The committee's mandate was primarily to:

- Monitor the content of the questionnaire.
- Propose ethical guidelines about the implementation of the research project.
- Make the research team aware of possible risks brought to the community by the research project.
- Propose guidelines about publications.

> Having a research study participant committee encourages the direct participation of those studied, and allows the research team to benefit from direct feedback. There is however a temptation to consider this committee as a reflection of the community. Although the participants do indeed come from the concerned community, nothing guarantees the *representativity* of this type of committee.

The research study participant committee cannot easily be seen as representative of the community. It is more a group of individuals. The risk it faces is that it may not be able to organize sufficiently meaningful discussion on the research project during the course of the project. Therefore, in order to facilitate meaningful involvement by these participants, it is necessary for researchers and research facilitators involved in the project to train committee members.

Multi-stakeholder committees: the North American "Community Advisory Board" (CAB) model

CABs emerged in the United States in the mid-1980s. Although first set up in certain high-income countries, they have also been established in low-income countries since 1990 when Uganda created a CAB for vaccine-based trials. Today CABs are essential in vaccine research, in prevention research (UNAIDS, 2011) and more generally in HIV/AIDS research.

- The members of CABs are stakeholders from different settings:
  - CBO representatives.
  - Representatives of the various segments of the concerned population, depending on the context (people living with HIV, women, young people, religious leaders, traditional chiefs, etc).
  - Community members locally elected to become representatives in the CAB.
    Eligibility criteria may be defined by the members of the research team (interest in health issues, male/female representation, literacy, etc).
  - Research study participants and/or participants of similar past research projects.
- CAB members alternate over the duration of the research project.
- CABs are unique exactly because of their diverse composition which:
  - Increases the number of points of view;
  - Combines the functions of *representation* and *participation*.

- CABs regularly meet, every one to two months.
- CABs may have very different functions:
  - Provide advice about the protocol, the tools and the implementation of the survey.
  - Act as a bridge between the community and the research team.
  - Participate in communication about the research project.

The diversity of members within CABs is one of their greatest assets.

Every type of committee which aims to involve community members has assets, but also real limitations. The research team must make informed decisions. It may also think about the possibility of establishing several complementary committees (CABs, community advisory committees, etc).

Nevertheless, their very strong connection with all the components of the community raises the risk – greater than for any other committee – of reflecting the tensions and power relationships which already exist within the community.

This may be the case for example when the members of the CAB are politically elected representatives, distinguished members or the elders within the community. These internal community issues may not be visible to outsiders, and this is why an in-depth sociological analysis of the concerned community is a prerequisite.

Open consultation of the research study participants

In a CBR study, the study participants are often regularly consulted, independently of the creation of any specific participant committee. The continued interplay between research and practical field interventions, and therefore those benefiting from these interventions, lies at the heart of CBR (→ Units 16 and 17).

- Within the context of intervention research studies, participants' experience of the study is indispensable for adapting the particular intervention.
- Debate-style meetings can be organized by the research team in the places where the survey is being carried out throughout the whole research process.
- Questionnaire-based surveys can help collect the opinions of participants about the research project.

However, open consultation of potential study participants does not guarantee that the role community stakeholders have in the research project will be an important one or that they will be involved throughout the whole duration of the project.

Besides, as the participants' presence is unpredictable, they cannot benefit from real information or training, and their knowledge of the research project may be incomplete.

Research training for the members of the committees representing the community

In order for committees to function and make a real contribution to the research study, it is necessary that their members have at least minimum general research training as well as some training in the specific topic being explored by the particular research project.

Training can be carried out by researchers and/or research facilitators involved in the project. It can combine general elements of capacity building in research (→ Unit 5), with more detailed elements focusing on specific training intended for those implementing the research project (→ Unit 14).

> The members of committees representing the communities benefit from research training which helps them to acquire a greater understanding about the issues of the project at hand. Consequently they are better equipped to form their own opinion and critical viewpoint.

Today, participatory research is an internationally recognized tool for carrying out ethical research on HIV/AIDS. Accordingly, UNAIDS has defined community participation as the second "guidance point" in its *Ethical considerations in biomedical HIV prevention trials* (UNAIDS, 2007b), and has devoted a full guide to "good participatory practice" for communities in biomedical HIV prevention research. According to UNAIDS, all CBR projects must fulfill two criteria of equal importance: rigorously respect the scientific requirements and the principle of active community participation (UNAIDS, 2011).

3 | Integrating community stakeholders in standard research methods: community-based research (CBR), equity between partners

Participatory research enables the *participation* of communities in research, without necessarily defining the terms of the partnership. Several CBR projects have focused more on the *integration* of communities into research, where community stakeholders partner the researchers throughout the whole research process, and the competencies of all the stakeholders are always respected. Integration strives to bring real equity between CBOs and their academic partners. In practical terms this means the integration of community stakeholders into standard research committees.

Although every research project which is sensitive to the needs of communities can integrate community stakeholders into research committees, CBR stands out by the magnitude of this type of involvement. Community stakeholders are present in all the project's committees and at every step of the process. Indeed, very often they will have the same number of seats in each committee as their academic counterparts. This choice to create equity at every step reflects both the *scientific* and *political* desire of all the stakeholders involved in the research study. This equal distribution of project responsibilities goes hand-in-hand with the co-construction of the study and aims at community *empowerment*.

All the responsibilities can be shared between the stakeholders:

■ *Ensuring the scientific coordination of the research project.*

In every research project, only one or two people are responsible for the conception, design and supervision of the scientific element of the research project.

■ *Ensuring the scientific quality of the research project.*

A committee is generally assigned to guarantee the scientific and ethical quality of the research project.

■ *Ensuring the design, implementation and monitoring of the research project.*

The project group is directly involved in the project and guides it from the beginning to the end of the process (developing hypotheses, choice of research methods, creation of data collection tools, monitoring data collection, etc).

■ *Working on specific questions.*

Work may be shared between the research partners in order to move a specific question forward (assessing the overall context, defining the populations to be studied, drawing up questionnaires, communication, etc).

Objective	Examples of corresponding "committees"	Examples of shared responsibilities
Scientific coordination	Principal investigators Scientific coordinators	*ANRS DRAG, ANRS Com'Test, Partages:* Scientific coordination performed by a researcher and a community stakeholder working together.
Guaranteeing scientific quality	Scientific council, Scientific committee	*Partages :* Scientific council with 16 members: 8 researchers, 8 community stakeholders. *ANRS VESPA:* Scientific council composed equally between researchers, health professionals and representatives of CBOs.
Developing, implementing and monitoring	Steering committee, Research team	*An RDS (respondent driven sampling) survey on MSM* (Men who have sex with men) in Morocco: Steering committee composed of international (UNAIDS), state (national AIDS program) and community (ALCS) stakeholders as well as researchers.
Working on specific questions	Working group	*Parcours:* Partner CBOs participate in different working groups. These include the group which drew up the study participant questionnaire (under informal academic leadership) and the group in charge of communication (under informal community leadership).

Table: Examples of shared responsibilities between partners

The composition of these different committees and the equity between them help to make the CBR projects truly community-based.

A possible continuum exists in the partnership between the two dominant extremes (community and academic):

Equitable
Partnership

Community
dominance

Academic
dominance
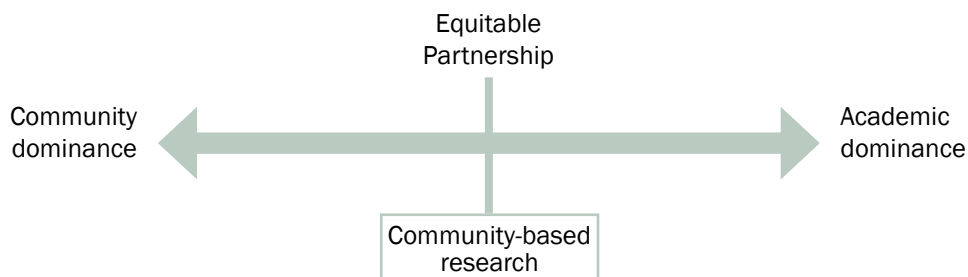
Community-based
research

Diagram: The partnership continuum.
Equity and complementarities between community and academic dominances.

Everyone involved in a CBR project tries hard to make these principles of equity and sharing a reality. Equity between stakeholders does not only depend on the composition of the project's committees and the respective participation of the community representatives and researchers. It also depends on the personal investment that each individual makes in the research project and on the efficient operation of these committees: decision-making procedures, definition of responsibilities of each research partner (→ Unit 7).

> The type of partnership depends on the research topic. Not all research projects involve the same procedures.
>
> The equity of the partnership will vary depending on whether the community stakeholders are present in all the project-specific committees, and whether they have the same number of seats or not in each committee as the other research partners.

When one type of stakeholder has a dominant role, be it a researcher or a community stakeholder, the other person's role is more that of a "consultant" or expert. This corresponds to more traditional types of research practices and is the least equitable type of partnership. Consultants are for example recruited by research teams to carry out specific tasks and are not involved in the decisions concerning the research project.

When community stakeholders are present in research committees, the question arises: **which stakeholder, which person from the CBO should be called upon to participate?**

> The community stakeholders involved in "standard" research committees may sometimes be representatives of the community, and consequently can shed light on a wide variety of community needs, interests and practices which need to be taken into account. Thanks to this involvement, the research project can be adapted to the community in all its diversity.

■ It is very important that the community stakeholders participating in a scientific council or steering committee not only have as wide a knowledge as possible about the interests and needs of the groups concerned by the project but the ability to communicate them clearly.

■ Grass roots experience, reflexivity (being aware of yourself, of your assets, capacities and constraints), and openness (with regard to adapting practices) are also highly important for these committee members.

These individuals who represent the community may just as easily be the people in the CBO responsible for the issue being addressed by the research project, as research facilitators striving to collect the experiences and points of view of the community.

? **Some questions to ask yourselves to translate community involvement into research committees**

✔ Do our research objectives and our political will orientate us towards equitable partnership or are traditional forms of participation enough?

✔ Is it more useful to look for equal distribution of seats within every research committee or to strive to create overall equity between the different committees (for example, one committee may be entirely community-based, another entirely academic, etc)?

✔ What are we looking for by involving communities?

  • that the diversity of their interests is represented in the development of the research project?

  • the direct participation of community members in the research project?

✔ Do the project's committees, their composition and their role (advisory or regulatory) correspond to what is expected in an equitable partnership?

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UNIT 2

Formalizing a common working framework: collaboration charters and conventions

1 | Who can create a charter? Why regulate?

2 | What different types of charters exist?
What are their contents?

Formalizing a common working framework: collaboration charters and conventions

For a partnership to work, it is vital that each partner's expectations, assets and roles are carefully considered at the beginning of the project. It would therefore seem beneficial to everyone involved if the terms of the partnership were written out (e.g. the roles and composition of different committees, regulations governing interactions, specific procedures defining the application of ethical principles, etc). This formalization is not a series of restrictive norms. Rather it is the result of joint reflection by the different partners after outlining their sometimes contradictory positions about how they envisage working together. It is a reference framework which guides the setting up and implementation of the project. Nevertheless, such documents are still rarely drawn up in practice. This unit invites the reader to think about formalizing collaboration.

1 | Who can create a charter? Why regulate?

► What is a charter? A convention?

A charter is a document which:

- Describes the *commitments* undertaken by the signatories.
- Is not legally binding: it consists in a *declaration* of commitment.
- Describes objectives, rights and duties.
- Often has moral value and impact.

  It acts as a guide, a "good practice code" for those who recognize the legitimacy of the stakeholders who created the charter.
- Circulates values and messages to external actors.

  In this way it serves as a kind of "position statement" for the stakeholders which have produced it.
- Serves as a reference framework in case of disagreement or difficulty.

There is a difference between a "charter" and a "convention":

- A charter is created by one or several organizations. Its objective is to lay down standard norms with a general scope that goes beyond the framework of any one research project or specific intervention.
- A convention is an agreement between two parties (or more). It is contractually binding. It includes general principles and practical rules. The norms it lays down are applicable only to the signatories.

A charter enables the principles and values recognized by those who create it to be developed and widely disseminated. It constitutes a commitment on behalf of its signatories. It defines a working framework between partners and contributes to the external legitimacy of both the project and the collaboration.

In terms of content, charters and conventions may be very similar. The latter may perhaps regulate roles in a more detailed manner (see the section below on different charter types and their contents).

Here the focus first and foremost is on the *formalization* of policies and procedures, and on the types of content in both types of document. For ease of reference, we use "charter" here to refer to both "charters" and "conventions".

► Who can create a charter? For which audience?

Charters are being used ever increasingly, especially in the field of research. Although different types of stakeholders engaged in research are now producing charters, they do not all target the same audience:

Research funders: charters applying to the projects they finance

Faced with the numerous research-related problems encountered in developing countries (the lack of national frameworks for research regulation, sometimes the absence of ethical committees, etc), the French national agency for research on AIDS and viral hepatitis (ANRS) decided to formalize the ethical principles and good practices it wanted to follow when carrying out research in such countries. Accordingly, it created an "Ethics charter for research in developing countries" which acts as a reference for researchers carrying out projects financed by the agency in these countries (→ see Further reading).

Professional associations of researchers: charters which apply to the association's members and to those who identify with the association

Both the American and the French sociological associations have created ethical charters on how to carry out research in the discipline (→ see Further reading). The charters are targeted at researchers and university lecturers/professors also engaged in research. All association members must comply with the charters. They also act as a guide for the target audience at large as well as for junior researchers who recognize the association's legitimacy.

Community-based organizations (CBOs) involved in research

The Canadian Aboriginal AIDS network created "Principles of research collaboration" (→ see Further reading). This charter applies to the network's members as well as to those participating in research studies with the network.

Research groups

Charters for research studies can be created by various stakeholders. Their scope varies depending on the stakeholders' type of involvement in the research field.

The Partages team created an internal collaboration charter which applies to all those participating in the Partages project.

► Why create a charter?

"Practice requires flexibility and fluidity, it cannot be structured."

"We all know what the good practices are and our work is based on trusting relationships, so why do we need a charter?"

"A charter isn't binding, so why waste time?"

There is a great deal of resistance to the current trend of "chartering" research. So what are the advantages of defining the partnership within a charter?

- A charter leads to the creation of good practices.
- A charter ensures that each stakeholder's role and responsibilities are clarified.
- A charter makes the common values of the signatories explicit.

A charter is the product of mutual reflection on the specific issues surrounding a collaborative research project, including how the collaboration will work and the associated implications. It creates a common platform for all the partners involved at the beginning of the partnership.

- The product of reflection, debates and in-depth consultations, a charter serves as a reference point in order to answer the complex questions which come up in every research project. It can also serve as a reference point in times of difficulty: in negotiations, for example, a partner can be reminded of his/her commitments.

Within the context of collaboration between different settings (CBOs and researchers, different countries, etc), formally writing down the partnership procedures is all the more important as expectations and practices vary from one setting to the next.

2 | What different types of charters exist? What are their contents?

► There is a wide range of possible contents in a community-based research charter

In terms of community-based research (CBR), charters may include several types of content:

The principles: these include the broad principles, values and objectives which the creators of the charter and its signatories identify themselves with

In the case of CBR, principles may refer to equity within the partnership, respect for each other's competencies, improvement of people's health or capacity building (→ see Introduction).

Ethical considerations: the points relating to potential ethical problems

Different elements regarding ethical considerations are addressed depending on the type of research (e.g. data protection, obtaining consent, care and medical follow-up of study participants, conflict of interests, etc).

National legislation in certain countries is sufficiently rigorous in terms of the rules governing medical research and in terms of protecting humans, but not all countries have regulations and institutions which guarantee the respect of people who participate in research. Charters can extend the question of ethics to include issues which are not usually the subject of regulation. Examples include maintaining patient care at the end of a clinical trial and protecting participants who may be subject to threats or sanctions.

Roles and responsibilities

A charter may define the responsibilities the project team have towards the study participants, or the responsibilities of community stakeholders to their academic counterparts and vice versa.

If the charter for a particular research project is considered as binding by the stakeholders concerned, it can define the committees which oversee the project, their role, their composition, and even the allocation of roles for each stakeholder type. The amount of working time each partner dedicates to the project may also be included.

Rules for internal communication and interaction: specifying the partnership procedures

The charter may go so far as to detail the procedures within the collaboration, specifying, for example, the frequency of meetings and the people responsible for organizing them, or even the responsibilities and procedures concerning budget management.

Some handbooks on CBR also suggest inserting dispute resolution procedures.

Rules of data ownership and publication

Every partnership must decide whether it is in its interests to create a charter. If the decision is "yes", the type of content included in the document will depend on the objectives and the scope that the partnership wants the charter to have.

This is a critical issue in collaboration. Nevertheless, partners are often quite vague about the subject, considering that the final decision is "obvious". However, this is not necessarily the case, especially when publication represents very different issues to those coming from different settings (→ Unit 17). Formalizing rules of data ownership and scientific publications in a charter ensures that agreement on these issues is reached at an early point in the collaboration. It also serves as a reference point should there be any disagreement.

► Charters with different scopes

Not all types of content are necessarily relevant in the document formalizing the collaboration.

Here we consider three specific types of document, ranging from the "charter" type to the "convention" type:

A charter having a general scope, defining the principles and good practices of CBR (a "charter" in the strict sense of the term)

A group of organizations heavily involved in CBR can, for example, agree on a set of principles and values which are, in their opinion, necessary to implement a CBR project. They can also agree on the minimum responsibilities of each partner, as well as their responsibilities towards the study participants.

A collaborative charter of "medium" scope, defining the principles and rules for those research partners wishing to collaborate with an organization

A CBO may, for example, define a set of principles and values of ethical behaviors and responsibilities which researchers must comply with in order to carry out research *inside* or *with* the organization. It may also specify the existence of any research-associated committee within the organization ("internal research committee", "internal scientific committee", etc).

The Canadian Aboriginal AIDS network created a charter which applies to all its research partners and proposes principles, which are quite well defined, about how research should be conducted[1] (→ see Further reading).

A charter whose scope is limited, defining the rules of the partnership within the context of a specific research project (a "convention" in the strict sense of the word)

The Partages team created a charter for the community and academic stakeholders working in the Partages project. It defines:

- The principles: collaborative research, equitable partnership, ownership of the research study.
- Ethical considerations (obtaining consent, confidentiality, etc).
- Role and procedures (general coordination, scientific committee, etc).
- Storage procedures for questionnaires and data (safeguarding data, making backup copies, etc).
- Rules governing publication and dissemination of results.
- Potential benefits of the study.

	Principles	Ethics	Roles	Communication	Publications
General scope - charter (group of organizations)	✗	✗	✗		
"Medium" scope (a CBO with its partners)	✗	✗	✗	✗	
Limited scope - convention (between partners in a CBR project)	✗	✗	✗	✗	✗

Table: Possibilities for the content of different charters according to their scope

1 For example the charter states that "the research team understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. The parties agree to review findings in a timely manner (e.g. two months [before submission])."

?   **Some questions to ask yourselves regarding the necessity to create a charter for your partnership**

✔ Do existing texts or charters constitute a satisfactory reference framework for the CBR project in question?

✔ What are our motivations for creating a charter?

✔ Is there anything which we are reticent about?

✔ Are some partners in favor of a charter?

✔ Have we already worked together in the past? If yes, were there any problems in the collaboration?

✔ Have we experienced problems in other research collaborations?

✔ Is everybody's role clear to all of us?

✔ Have we discussed the values and principles which guide the collaboration?

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PART

3

The stages of
a community-based
research project —
how to work together

Guaranteeing the human and material conditions required for the research study

8

UNIT

Choosing partners

8. Choosing partners

Choosing working partners is a crucial moment in collaboration. The expectations we have of our future companions are often high (strong working skills, similarity in terms of ideas and working methods, etc). Moreover, it is sometimes difficult to find *a* partner to collaborate with, never mind an ideal partner. Here we present some criteria – the result of the experience of stakeholders already engaged in collaborative research – as well as some practical ideas, to help you identify who to work with.

1 | Deciding on what expectations to have of future partners

Clearly stating expectations is an essential step and facilitates the choice of partner. Expectations are not only based on ways of working but also on the strength of interpersonal skills and know-how.

► Community-based organizations' (CBOs) expectations of researchers: between method and activism

CBOs count on a researcher's know-how

- ■ *To ensure methodological skills:* creation of the protocol, definition and/or calculation of participant sample, designing questionnaires, ability to conduct interviews and lead focus groups, etc.

  The community stakeholders' primary expectation concerns the study's methodological aspects. Collaboration with researchers must help them transform their existing "non-expert" community research and evaluation activities into methods which meet scientific research criteria. As part of this process, the researcher is expected to be able to integrate the conditions specific to the community stakeholders (time constraints, values and principles of intervention, intervention means, etc).

- ■ *To have a good knowledge of scientific literature* in order to advance the research project and to add to the existing literature.

CBOs count on the researcher having the interpersonal skills of an activist

- ■ *To share the CBO's values and its vision of social issues.*

  In order to commit to a partnership for a certain length of time, it is necessary that the researcher and the CBO share values and have a similar vision of the social issues surrounding the research topic.

■ *To have a genuine interest in the day-to-day living conditions of community members.*
The willingness of the researcher both to occasionally accompany the CBOs in their field interventions, and to take an interest in the experience of community front-line workers, signal his/her engagement with the CBOs' practices.

► Researchers' expectations of CBOs: intermediaries rooted in the community

Researchers generally expect their community partners to be community representatives.
More specifically, they expect them:

■ To be genuinely involved in community life and express ideas which are "rooted in the community".
■ To relay concerns and questions arising from their daily work in the community in order that the researchers might be able to translate them into research questions.
■ To represent the communities' interests, needs and concerns.

At the same time, researchers also expect community stakeholders:

To have the capacity to move from field-based observations to research questions, and to formulate research hypotheses from their field experience when working together with the researcher.

This presupposes some familiarity with the research tools being used and the capacity to "move between two worlds". Researchers require special partners who are able to participate in discussions which are sometimes complex (definition of research hypotheses and variables, analysis of collected data, etc) and who bring a global and analytical point of view of what is happening in the field.

Moreover, it is important that they guarantee the presence of one community focal point throughout the project.

CBOs often work using a system of collegiality. When a CBO participates in a research project, several colleagues are responsible, sometimes by taking turns, for representing the organization. According to researchers however, the complexity and especially the duration of the research process requires continuity of reflection and therefore the need for continuous engagement by the same people throughout the entire collaborative process.

To be part of a collective force, that is to say to be able to understand research results in order to transform them into interventions or to introduce them into public debate at the end of the research process.

For example, community stakeholders must be able to ensure that a successful intervention, implemented within the context of intervention-based research, can then be extended to field-based interventions. They must also advocate for research results to be taken into account by other institutions (local or national decision makers, media, health professionals, etc). The latter can then take these research results into account when developing their practices and policy guidelines.

These expectations show how important it is to consider the diversity of community stakeholders engaged in a particular research project. This vital element must be taken into account by all the partners involved.

Ideally, two types of community-based partners will emerge:

- *A main focal point from the CBO or a small "contact" group,* who participates in all the research stages, organizes and centralizes community participation. This role is often performed by a research facilitator (→ Unit 5).

- *Community front-line workers,* who are professionals involved in the community or are community members. They each bring different expertise to the research project. They guarantee the community's contribution to the project and also ensure that this contribution is grounded in the community's real needs and concerns.

► The expectations other partners have of CBOs

Other institutional stakeholders involved in research (local public institutions, ministerial departments, research agencies, international organizations, etc) and especially funders, also have demands when they meet with community partners or when evaluating applications for research project funding. They expect:

- Expertise and credibility in the CBO sector.

- Clear organizational charts, so that there will be no problem carrying out tasks when the research project starts.

> The expectations partners have of each other concern both competencies and shared personal opinions and thoughts. For researchers, a truly representative link between the CBO and the community is a decisive element.

- The ability to assess and evaluate.

- Having already carried out internal studies or previously participated in other research studies is an asset.

- Financial capabilities.

The organization must have sufficient financial resources to ensure that the level of human and material resources will remain constant throughout the entire project.

For all these reasons, funders and institutional partners often favor national NGOs which have a proven track record of long term commitment to the particular research topic being studied.

2 | Issues to consider

Besides practical expectations, building a partnership between the worlds of academia and CBOs often raises broader issues.

► Choosing community partners: issues surrounding their role of representation

The primary expectation researchers have of community stakeholders, and indeed the basis for community-based research (CBR), both lie in the community stakeholders' capacity to be genuine spokespersons for communities. It is important therefore to focus more precisely on the relationships between CBOs and communities:

- What is the CBO's perception of the community?

- To what extent does the CBO really represent a community?

  • Is the CBO comprised of activists who are members of the communities concerned?

- Do the organization's members or its beneficiaries reflect the community in all its diversity, or only a part of it?
- Is the CBO comprised of professionals speaking about the community from their professional experience?
- Does the CBO present itself as "service-based" or is it engaged in a process of social transformation and advocacy?
- What place does the CBO give to the community-based approach in its activities?

■ What mechanisms ensure the representative link?

These questions help partners to become aware of the nature of the link between the CBO and the community, in order to understand what the organization's real participation in the research project might consist of.

What we describe as a "community-based organization" should indeed have a community base and should provide community members with a role in setting up its strategic guidelines. Electing community representatives to the organization's board (PLHIV, MSM representatives, etc) is one way to ensure this.

More specifically, regarding the research project itself, several mechanisms may be put in place to ensure a strong "community-based" foundation. They help to create a strong link between the stakeholders responsible for monitoring the project and the organization's community base:

■ The organization of community consultation by the CBO.

The consultation carried out by TRT-5 for the ANRS Ipergay pre-exposure prophylaxis research project in men who have sex with men is one example of this (→ Unit 6).

■ The use of the CBO's own consultation procedures within the research project.

For the ANRS AERLI research project – in partnership with AIDES, Doctors of the World and INSERM – AIDES followed its own established consultation process: the project was discussed with a group of activists, involving three activists per region.

A whole series of mechanisms exist to ensure that the CBO is closely associated with the community studied and is genuinely committed to the project at hand. These mechanisms also guarantee that communities are genuinely represented when research projects are being designed. Expectations and terms of involvement in the research study to be carried out may differ depending on whether the organization consists of professionals working with populations or has been established as a peer-based organization representing the community.

■ The appointment of a community research "focal point".

The idea emerged in some CBOs to have "research volunteers". Being right at the heart of field interventions and having a thorough understanding of the concerns of the community's members, the activists' job would be to bring grass roots needs to the attention of those in the CBO who are more directly involved in research, for example research facilitators.

■ The implementation of a system to highlight the concerns and issues raised in CBO team meetings.

CBO team meetings promote exchanges between community front-line workers and research partners. In this way the problems which emerge can be shared with the other partners in the project. In Canada, bi-annual questionnaires in the Oméga cohort were partially amended to take into account the concerns CBOs expressed in team meetings.

► Choosing academic partners: taking into account scientific specialties

The expectations community stakeholders have of researchers depend above all on *methods*. Depending on their needs, these stakeholders will prefer to work with researchers with expertise in qualitative methods (interviews, observations, *focus groups,* etc) or those with expertise in quantitative methods (questionnaire-based surveys etc).

Before considering which methods researchers use, it is important for community stakeholders to think about the researchers' scientific *disciplines*:

- *Many human and social science specialties require the use of both qualitative and quantitative methods.*

  This is the case for example of psychology, sociology, economy, political science and history.

- *Researchers using similar methods (qualitative or quantitative) will nonetheless have a different approach to the research topic, depending on their particular academic discipline.*

  The various specialties provide researchers with conceptual tools and theoretical frameworks with which they construct the research topic.

  For example, on the question of HIV status disclosure, a psychologist will focus on and use theoretical tools in order to analyze the psychological and psychosocial determinants of disclosure of a person's serostatus. In order to do this, he/she will try to highlight a link between some psychological characteristics of the individual and the process of disclosure. Instead, a sociologist will focus on gender relations and their impact on disclosure or non-disclosure within a couple, a family or between sexual partners.

AIDS research: different academic disciplines and a variety of topics

- **Basic Medical Research:** this aims to understand human biology and physiology as well as pathological processes.

  Virologists, for example, can study and aim to understand the functioning of HIV reservoirs, that is to say, the places where the virus is protected from current treatments (for example, in the brain, or in intestinal mucosa).

- **Clinical Research:** this is mostly based on the results of basic medical research with the aim of hypothesizing and testing the efficacy of new treatments and techniques.

  Clinical research evaluates, for example, treatment strategies.

- **Epidemiological Research:** this is based on the physical, psychosocial and sociocultural determinants of a particular population's health, as well as on interventions aimed at improving health.

  Epidemiological studies, for example, may be implemented to evaluate a population's adherence to drug treatments, explain gaps in adherence and adapt population-specific interventions.

- **Economics:** this discipline studies the allocation of resources.

  For example, one can evaluate the feasibility and sustainability of various types of treatment or prevention procedures in countries with an underdeveloped health system, with no health insurance system and where there is no pharmaceutical industry.

- **Sociology:** this discipline studies the organization, functioning and transformation of societies.

  Sociology focuses, for example, on the role of patient organizations in terms of HIV care, or the impact of gender inequality on the evolution of the epidemic.

- **Psychology:** this is the study of psychological facts and behaviors.

  Research can, for example, be based on the psychological experience of serodifferent couples or on the evolution of PLHIV's trust in their doctor.

- **Anthropology:** the study of human beings as a whole and in their specific living environment, anthropology aims to understand the specificities of the human being (the relationship humans have with death, with their bodies, with groups; the effect of culture, religion, etc).

  Anthropologists work for example on the role that context plays in the meaning PLHIV give to HIV or on the vulnerability of certain populations or persons at risk of HIV infection.

Depending on their scientific discipline, researchers use methods, as well as conceptual and theoretical tools, which lead them to take very different approaches to the same research topic. The methods used and the academic discipline of interest are equally important when searching for partners.

It is important to discuss which scientific discipline(s) will enable us to respond as best as possible to the research questions asked and to the possibilities the particular setting offers. Multidisciplinary teams combine the assets of researchers from different scientific disciplines using various methods to help improve the quality of the research study.

► Being aware of the fact that the choice of partner will have consequences on the partner's position in his/her own setting

The choice of research partners will have an effect on internal power relationships, both in academic and CBO work settings:

- The participation of researchers in CBR gives them access to a field of research which is unexplored, offers them new networks and may modify their position within the organization of the academic world.

- Not all CBOs have the capacities to take part in research. The participation of the biggest CBOs in research tends to reinforce their position in their specific setting. The development of evaluative research and intervention research studies (→ Unit 10) may increase the "gap" between CBOs which have the means to carry out such studies – which are considered as providing more solid proof of intervention efficacy – from other CBOs with less means. Indeed, this may eventually have an important effect on future demands for funding, if funders prefer "scientifically-based evidence".

Because CBR is the bridge between two worlds, it enables stakeholders who engage in it to combine different sources of legitimacy, specifically scientific legitimacy and "action-based" legitimacy.

3 | How can we meet our future research partners?

It is possible to use existing networks to approach researchers potentially interested in and capable of collaborating. At the same time, searching for partners outside of existing networks may encourage more creativity and a rethink of approaches. It may also provide for such partners the opportunity to express new viewpoints in a specific field.

Two main types of stakeholders can be solicited to help identify partners:

■ *People with a dual affiliation*
  - Community stakeholders with the status of associate researchers.
  - Researchers with activist/community-based responsibilities.

  In both cases, these individuals know the two worlds and have (at least to some degree) everyone's trust. They are excellent resources to help identify the most suitable partners and the places to search for them.

■ *Research funders*

  Organizations financing HIV/AIDS research, or health research more generally, often have the explicit mission to give stakeholders from civil society a say in the definition of research objectives and, sometimes, even in the choice of programs. They regularly have knowledge therefore, both personal and functional, of individual researchers and community stakeholders. They can be solicited to put you in contact with potential partners working on the same topics.

Other practical ideas can also be considered to help identify partners:

■ *For researchers*
  - Through researchers from other disciplines who are already in contact with CBOs within the context of their research (sociology, anthropology, etc).
  - Making contact with national and international organizations working in the fight against AIDS (UNAIDS, National programs in the fight against AIDS, CBOs within multi-sectoral partnerships, CBO networks, etc).

■ *And for community stakeholders*
  - Consulting the programs of national and/or international scientific conferences in the field of interest.

  This helps to find potential local and foreign partners. The former contribute in terms of proximity (geographical, cultural, linguistic, etc), the latter in terms of new networks and opportunities.
  - Using interpersonal networks (researchers who have previously trained members of the organization (employees or volunteers), teachers of students doing an internship within the CBO, etc).

If these first avenues, which are the quickest to implement, prove unsuccessful, it is also possible to focus on "mixed" spaces, for example conferences and working meetings where several types of stakeholders are involved (→ Unit 5).

One can also think about soliciting consultants and individuals encountered during external assessments. Some of these may also be researchers or may be connected with the world of research.

Many CBOs meet their future research partners when the latter carry out consultancy work for public or international institutions.

4 ▏ When should a partnership be created?

The sooner the collaboration begins, the more time the partners will have to take ownership of the different aspects of the research study. It is preferable therefore to start looking for a partner as soon as the idea for the study emerges, so that the project is genuinely constructed together. Partnerships created at a later point risk provoking inequity between partners, difficulties getting fully involved in the project and less commitment from the new partner.

Here are **some practical ideas to help new partners acquire a sense of ownership of the research project when the partnership starts later on:**

■ *For CBOs*

- The research facilitator or the community focal point for research-related projects can facilitate the community's ownership of the project (→ Unit 5).
- Ensure that the principal bodies of the CBO (board, president and vice-president of the organization, director general, etc) support the project and make this support visible.

■ *For researchers*

Ownership of the research project is also more difficult for researchers when the partnership is created after the protocol is drawn up. Possibilities in this case include:

A real partnership requires the involvement of all the partners as early on as possible in the research process.

Nevertheless, different means do exist to help new partners who join the process later on to take ownership of the project.

- Reworking the protocol together; increasing the number of exchanges and discussions about the protocol.
- Devoting a great deal of time and promoting the role of researchers in the construction of research tools.

When a new partner is brought on board at a very late stage, for example, at the point of data analysis, the work performed is more consultancy than partnership-based. This can however constitute a preliminary step for future partnerships.

? Some questions to ask yourselves

For everyone

✔ Have we identified the persons or the institutions which can help us in our search for partners?

✔ What do we expect of our partners?

✔ To what extent are our future partners able to meet our expectations and vice-versa? Are the respective expectations clear to everyone?

✔ Have we had a glimpse of the way our future partners work (presentations at a conference, meetings during consultancy work, visiting venues, other kinds of meetings, etc)?

✔ At what point in the research process are we going to involve partners? Must we create learning opportunities to help these partners take ownership of the project?

For the researchers

✔ Who is the "community"? Who represents it?

✔ What is the nature of the link between our potential partners and the communities? Are they involved as individuals or as community representatives?

✔ Are there practical mechanisms in place to ensure that the concerns of the studied populations are brought to light?

✔ Have we discussed the practical terms of the CBO's presence and participation in the research project (one or several individuals etc)?

For the community stakeholders

✔ Do the researchers share our values?

✔ Are their methods adapted to our ways of working?

✔ Do the researchers' academic disciplines match our ways of thinking and the questions we are currently asking?

✔ Have we thought about multidisciplinary partnerships?

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UNIT 9

The details of funding community-based research

9. The details of funding community-based research

The traditional means of funding a research project take little or no account of the financial burden which community involvement brings. Yet we have already seen that there are various forms of participation and integration of the two worlds (academic and community), that they require time and therefore have costs. If funding does not take these costs into consideration, it may contribute to inequity between the partners. It is important therefore to anticipate the terms of community involvement in the research project (→ Unit 6) as well as the particular working conditions (and financial compensation) of the community stakeholders (→ Unit 13), in order to plan the budget accordingly.

1 | Who should you ask for funding?

Research funders differ greatly from country to country. Nevertheless, some trends can be observed:

- *Funders are more present at the international level and in high-income countries.*

  At the international level, submissions to the Global Fund to fight AIDS, Tuberculosis and Malaria may contain an "operational research" component, which includes community-based research (CBR). This component may represent from 5 to 10% of the proposal's total budget.

- *Researchers and community-based organizations (CBOs) often turn to countries which speak the same mother-tongue or second language* for cooperation in research and for applications for funding.

- *It is often easier to obtain funding within the context of a partnership with a team from the country where the funder is based.*

- *Research projects may be financed both by funders focusing specifically on research and by others who are more program oriented.* The latter mostly fund field interventions.

Different potential funders of CBR projects exist:

"General" funders finance research projects and/or interventions irrespective of the topic.

Examples of "general" funders are national research agencies (e.g. the French National Research Agency and the Swiss National Science Foundation) and foundations (e.g. Fondation de France).

"Specialized" funders finance research projects and/or interventions in a specific area – health, HIV/AIDS, etc.

"Specialized" funders include:

- Large international funders, such as the Global Fund to fight AIDS, Tuberculosis and Malaria.
- National research agencies, such as the National Institutes of Health (NIH) in the United States, the Canadian Institutes of Health Research and the French national agency for research on AIDS and viral hepatitis (ANRS).
- Non-profit organizations, such as Sidaction in France or the American Foundation for AIDS Research (amfAR).

This list of examples, which is by no means exhaustive, may be used to help identify potential funders of research in your own country, especially funders of CBR.

2 ▌ Placing community stakeholders on an equal footing when applying for funding

Funding application forms do not necessarily take into account the possibility of a community-based partner. Even when it is specifically mentioned, the role of such a partner is sometimes limited.

When researchers and community stakeholders wish to create a partnership, they can solicit funders beforehand in order to see how much they can adapt their response to a call for project proposals to the specificities of CBR.

The questions relate to:

- *The choice of the non-academic co-principal investigator.*

The pairing of two principal investigators, one academic and one community-based, is one of the key strengths of CBR (→ Unit 6). Nevertheless, it is not always possible to have this kind of co-involvement recognized in funding applications.

- *The community stakeholder's curriculum vitae (CV).*

Community stakeholders involved as co-researchers must sometimes include their CV in applications for funding. The specifications for an academic CV – often requested by research funders – differ greatly from those for a standard one. The latter is concise and emphasizes professional experience while the former is based on the individual's scientific career path, publications, expert work and recognition in academia.

Some funding organizations, such as the Canadian Institutes of Health Research provide specific forms to create a **"Curriculum Vitae for community leaders"**. Despite being inspired by the type of content found in an academic CV, these forms place much greater importance on expertise, professional and voluntary experience.

Curriculum Vitae for community leaders

(Source: Canadian Institutes of Health Research)

This CV model helps to highlight and promote the experience and abilities of community stakeholders, while still fulfilling the specifications required for an academic CV. It contains the following sections:

1) *Personal details (including address, contact number, etc)*

2) *Expertise and education*

    10 key words which describe the individual's research and community-based skills (technical skills etc).

3) Professional and voluntary experience

4) Distinctions/scholarships/qualifications

All accredited qualifications can be detailed here, including community-based credentials.

5) Summary of contributions

Publications, presentations and copyrights. Community-based publications are included here (reports etc).

6) Supervision experience

7) Funding

This section details all the kinds of grants received during the previous 5 years.

8) Detailed contributions

Applicant's principal contributions to research and other activities (demonstrated community leadership, committee membership, consulting activities, etc).

When applying for funding, you must not hesitate to contact the relevant funder beforehand, in order to adapt the existing application forms to meet the needs of collaborative research projects, and to include modifications if possible (for example including a community-based curriculum vitae).

■ *When a non-academic organization wishes to manage the project.*

A CBO can ask to become the administrative organization overseeing the research project. In that case, the CBO must meet financial stability and management criteria, in order to guarantee the funder that funds will be allocated correctly and that adequate human and material resources are available to do so. Using such non-academic management bodies may also require some flexibility on the part of the funders.

3 | Specific budget categories to take into account

The specificities of CBR (level and type of community involvement, extra time, etc) must be anticipated in the budget, for example by creating specific budget items or lines.

Here are some recommended budget categories to be taken into account when applying for funding:

■ *Community participation meetings.*

Whatever their format (→ Unit 6), the different means used to consult communities (community consultations, community forums, etc) require a specific budget which ensures the coordination and implementation of meetings and communication. A specific communication strategy is also required to mobilize those members of the community who are not members of the partner CBOs. This strategy has a financial cost.

■ *Working time for co-researchers.*

The funding of jobs and positions specific to CBO may be envisaged to help ensure the smooth implementation of the project.

- One can ask for funding for between ¼ and ½ of the research facilitator's working time, so that this time can be fully dedicated to the research project.

The regular participation of a community focal point at meetings, the "translation" of the research project so that it is clear to the community members, and ensuring that the link with communities is kept throughout the research process, all take a considerable amount of time. To carry out these tasks well, each CBO should dedicate a specific amount of working time. In many countries, positions in CBOs are effectively financed through projects. Carrying-out several projects simultaneously helps to create a full-time position. If working time is not taken into account in the application for funding, the CBO can only dedicate a limited amount of time to the specific research project, and this makes it difficult to genuinely involve the community.

- When the academic co-coordinator of the CBR project is a lecturer or a professor, one can ask for funding for between ¼ and ½ of his/her working time, so that this time can be fully dedicated to the research project.

In order to facilitate the involvement of these academics in the research project, some funders finance teaching release. This involves releasing the lecturer/professor from part of his/her teaching obligation and providing the university with the financial means to find a substitute teacher.

Teaching release is particularly relevant for CBR as the academic requires extra time to familiarize him/herself with a different environment and to build partnerships.

■ *Anticipate compensating community front-line workers and/or interviewers for their working time.*

In CBR, the question arises of how to compensate interviewers and community front-line workers, as they are not professional researchers and therefore are not compensated under the same conditions (→ Unit 13). One must take into account:

- The interviewers and/or community front-line workers participating in the research project during their work time.
- The interviewers and/or community front-line workers participating in the research project within the context of their volunteer work.

The research team may decide to provide compensation or not, depending on the type of interviewer/community front-line worker (volunteers or employees within the CBO) working on the project (→ Unit 13). Compensation may be provided for the CBO as an organization (e.g. compensation for working time) and/or for the interviewer/community front-line worker as an individual.

■ *The different ways to present research findings.*

CBR projects, even more than their "standard" counterparts, place great importance on the different ways to translate and disseminate research findings. Presenting results may occur at different stages of the project. As is the case for the project's initial preparation, presenting research results entails communicating, preparing and holding (sometimes numerous) meetings. This has an inherent financial cost which must be taken into account.

4 | Is a special application procedure required when applying for community-based research funding?

Some institutions have implemented specific funding arrangements for collaborative research projects, providing specific calls for such project proposals. Funding may be general in scope or may focus on expenditures specific to collaborative research projects.

This is the case for the Canadian Institutes of Health Research and the Ile-de-France regional council in France (→ see box).

Citizen-institution partnerships for research and innovation (PICRI): funding dedicated to collaborative research.

In 2005, within the context of its Research-Innovation directorate, the Ile-de-France regional council implemented a program aimed at promoting collaborative research projects with public research institutes and non-profit civil society organizations. This program especially helps to finance events intended to mobilize civil society involvement in research projects, for example, community participatory meetings.

Projects are examined by a multidisciplinary committee, equally composed of researchers and members of civil society. Project evaluation criteria are very similar to those of CBR: scientific quality, an equitable partnership, and the nature of the relationship between the partner from the CBO and the local population (Conseil régional d'Ile-de-France, 2011).

Other funders have also made an effort recently to adapt in order to integrate community stakeholders as research partners, without necessarily creating specific calls for CBR project proposals. These efforts must be continued, as they encourage the development of new projects, enable new partners – from both the research and community settings – to enter the world of research and guarantee project quality.

Different solutions can be found to ensure funding which is more suited to equitable partnerships, while keeping traditional-style calls for proposals.

For example, application forms may provide the possibility to include a non-academic co-investigator or specific budget lines which take into account the diversity of partners and their specific needs.

Funders can create funding application forms specifically adapted to CBR without infringing on existing project evaluation procedures. Such applications can then be evaluated in the same way as traditional ones. Specific calls for proposals which only target collaborative-based research may also be created.

Moreover, although the scientific quality of the project remains the principal criterion, some elements of the implementation of CBR projects may be considered differently by members of the scientific committees who evaluate project applications but who may not be very familiar with this kind of research.

It is absolutely essential therefore that an effort be made to raise awareness of CBR and its specificities in all members of such scientific committees.

? **Some questions to ask yourselves before making an application for funding**

✔ Have we fully anticipated the costs of community involvement?

✔ Have all the partners (academic and community-based) discussed these financial costs?

✔ Have we considered requesting funding for the academic and community partners' working time?

✔ Do we need to adapt the structure of our funding application? If yes, have we contacted the funder beforehand?

+ **Further reading**

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SECTION 2

Constructing the scientific content of the research study

UNIT 10

From problem identification to the choice of research methods

10. From problem identification to the choice of research methods

A community-based research (CBR) project can be implemented on the initiative of researchers and community stakeholders alike. The close link between the identification of the problem in the field and formulating the relevant research question is a special feature of this type of research. In order to ensure that the questions asked are relevant for all the partners concerned, one must consider not only the added value that the research can bring in terms of concrete interventions for the community but also the practical details of the collaboration at this early phase.

1 | The community-based organization's (CBO) trajectories and issues: from the identification of a problem to the decision to engage in a research project

Engaging in research is an unusual approach for community stakeholders and occurs when they identify a particular need or when they recognize that a greater understanding of a particular issue is required.

► Community front-line workers are faced with community dissatisfaction, or with a lack of comprehension about an important issue

Faced with this dissatisfaction, the community front-line workers and community members express their need to *act* and to *know*.

A need to act

CBOs try to develop an innovative intervention to resolve the problem identified.

For example, having identified inadequate uptake and obstacles in regard to testing members of the gay community, stakeholders from the French organization AIDES devised a different, less medicalized type of testing, which would test people directly in gay meeting places. This led to the ANRS Com'test and ANRS DRAG studies which both evaluated the feasibility of testing in community venues and/or by community stakeholders. A comparison of this innovative testing method with its traditional counterparts was also performed.

A need to know

However, in order to carry out this innovative intervention, it is important to know: what are the initial obstacles? What are the social and psychological characteristics and/or constraints? Is this intervention adapted to the community's needs? Is it effective?

At this point, it is important to identify two types of needs: a need to act should only lead to research when additional *knowledge* is necessary to identify, construct and implement a possible field-based intervention. In other words, if the answers can be found within the context of the intervention itself or in other similar contexts, it is not necessary to engage in a research project.

► Responding to the need to know and to act: should we set up a preliminary needs assessment or engage in a research project?

Organizations often carry out a needs assessment before implementing a project. This is the "diagnosis" phase of the project cycle (→ see Introduction). The question arises therefore of whether or not to undertake such a needs assessment (carried out by the organization with the possible support of an external person) or to engage in a CBR project (which meets scientific criteria).

Implementing a needs assessment?	Implementing a research project?
■ Provides a greater understanding of the context, the population, the feasibility conditions and implementation context of the intended intervention. ■ Presupposes that a possible field-based intervention is already close to being identified by the community front-line workers. ■ Is carried out within a short amount of time. ■ Enables a more immediate implementation of a field-based intervention. ■ When circulated externally, the study report may help to raise awareness among policy makers or other stakeholders engaged in the issue. ■ The study report may also stimulate research on a problem which is "under-researched".	■ Helps contribute elements of understanding and rethink the questions to be addressed, when the community front-line workers find themselves at an impasse. ■ Brings greater credibility to the results, something which is particularly important for advocacy for controversial research topics. ■ Evaluates an intervention in an exploratory context and proposes its modeling, especially when such an intervention is not recognized in the country or not yet integrated in the country's recommendations. ■ A research project which is recognized by national authorities provides extra protection to communities, especially criminalized communities (drug users, men who have sex with men, etc).
= An effective means to obtain complementary information, in turn leading to rapid field-based intervention implementation and/or external attention to a specific research need.	= An effective means to obtain objective data in order to support interventions directed at social transformation in difficult or unknown contexts over the medium or long term.

The results of any research project must increase scientific knowledge. This is in contrast with a needs assessment, whose results are only useful for developing field-based interventions.

► Carrying out a research project: a decision which requires internal ratification by the CBO

Embarking on a research project generally implies having preliminary internal discussions and ratification by the organization's governing bodies.

► Towards the joint identification of "knowledge gaps"

Identifying "knowledge gaps" to create research questions is the work of the researcher.

Collaborations can therefore start immediately after the identification of potential research topics, or "knowledge gaps". Researchers want to have a better understanding of the issue at hand while community stakeholders want to create or improve interventions.

> For a community-based organization, the decision to engage in a research project arises from a need to *act* and to *know*. It is particularly necessary in difficult contexts (politically and/or legally unfavorable contexts, etc) or when there seems to be no way to resolve the problem encountered.

Certain types of "mixed" spaces where researchers and community stakeholders are brought together are more conducive to identifying research topics and therefore to joint initiation of research projects:

- CBO or inter-CBO internal scientific committees (→ Unit 5).
- Multi-stakeholder research groups (→ Unit 5).

By the end of this first phase, community stakeholders, sometimes in partnership with researchers, have generally set out the broad parameters of the research topic. Examples include access to treatment for sex workers, disclosure or non-disclosure of one's serostatus, the health of those frequenting MSM meeting places, etc.

2 | Interactions between intuitive findings and knowledge: is collaboration needed in the exploratory phase?

The exploratory phase happens once the decision to undertake a research project has been made. Its aim is to define the research goal and associated objectives.

CBR is based on identifying needs at the grass roots level. It is action-focused. Creating a link between the intuitive identification of real-life community issues and concerns and a possible future research project is therefore a very important step. In other words, CBR involves creating bridges between community and academic knowledge, in order to accurately define the parameters of a real CBR project.

► In practical terms, what do the concepts "creating bridges between community and academic knowledge" and "creating a link between real-life community concerns and research" really mean?

Faced with a given community concern, community stakeholders, including community front-line workers, first formulate "intuitive findings": by observing the situation, by analyzing the problem, they may find ways to explain the concern in question.

For example, the Partages study is currently investigating serostatus disclosure. From their daily exchanges with people living with HIV, CBOs participating in the study have intuitions as to the reasons why people do not disclose their serostatus and the factors which might help them disclose it.

In CBR, these intuitions, based on community knowledge ($\rightarrow$ Unit 3), inform the construction of the research topic. However, research implies going beyond these intuitions, confronting them with existing scientific knowledge from different disciplines which have already investigated that particular topic (articles from scientific journals, scientific books, etc).

Therefore, besides the "traditional" methods associated with this phase of the project (exploratory interviews, exploratory observations, etc), the exploratory phase of CBR incorporates the crossover between community knowledge, field experience and scientific knowledge.

The objective is to succeed in defining the expectations (which, for community stakeholders, are very much focused on action), the topic, the problem and the objective of the research, in order to develop the research protocol.

► How can interactions between community-based "intuitive findings" and academic knowledge be carried out?

Two primary ways have been identified which can lead to new practices:

An iterative process[1] of consultation between the community, research facilitators and researchers

In the Partages and ANRS AERLI studies, for example, discussion sessions were first carried out at various levels in order to precisely define the research topic. Based on these experiences, one can proceed as follows:

- The research topic may be discussed during team meetings, in order to bring community knowledge and initial intuitions to the attention of the group.
- Discussions may also be organized with community and/or CBO members (without necessarily going to the point of full-scale community consultation at this stage of the research process).
- A summary of these meetings may be completed by the research facilitator ($\rightarrow$ Unit 5), or CBO focal point.

The cross-over between community and scientific knowledge in order to define the research problem, may occur both through:

- Exchanges between the research facilitator and (a) researcher(s).
- Discussion of community knowledge at CBO team meetings in the presence of researchers.

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1 An iterative process consists in repeating an action on several occasions. Research is "iterative" when interactions involving the study analysis and realities seen in the field (or between analysis and intervention) occur *on several occasions*.

Preliminary reflection on the research problem provides the CBO with a sense of ownership of the research project to be carried out. These exchanges are more productive when the interaction with a researcher occurs quite early on in the process.

Building an "exploratory research team"? The Rapid Assessment Process method

The aim of the Rapid Assessment Process (RAP) is to quickly (1 to 6 weeks) succeed in understanding a problem and clarify it from the point of view of insiders – i.e. community members and/or front-line workers (Beebe, 2001). This process can be used to precisely define the research problem through collaboration between community stakeholders and researchers. RAP is effectively based on the close interaction between stakeholders, especially between community front-line workers working directly in the field and those external to the issue being studied. It has been widely used to develop harm reduction programs for drug users in countries reticent to implement them, especially in the former Soviet bloc.

In practical terms the RAP involves:

■ *Constructing an exploratory research team whose members bring different perspectives and expertise (insiders and outsiders, non-researchers and researchers) to the table.*

A team consists of two to six members, with at least one insider and one outsider. In CBR, one possibility is a small mixed team composed of researchers and community stakeholders, including community front-line workers.

■ *Carrying out (collective) interviews as a group.*

To clear the way, qualitative interviews are carried out with relevant people (community members, professionals in contact with the community, etc). These interviews are carried out by the whole RAP team in order to increase the number of different points of view and expertise during data collection so as to acquire a wider understanding of the issue to be explored. Depending on the research topic, the interviews may be carried out with individual respondents or with a group of respondents *(focus group).*

■ *Analyzing data as a group.*

After data collection, the team discusses the data, exchanges points of view and progressively constructs its analysis of the situation.

This method, when adapted for CBR, may lead to a more formal collective construction of the research problem, based on the skills and expectations of all the community and academic stakeholders:

■ Community front-line workers and community members who are interviewed by the exploratory research team share their experiences, knowledge, needs and expectations.

■ The "mixed" community-based/academic exploratory team can collectively identify the research problem and can therefore take account of the different perspectives and needs in terms of action and research.

> Identifying the research problem and the objective of a CBR project requires interaction and collaboration between the world of action and that of research. This is to ensure that the knowledge and needs of those on both sides drive the project forward. Practical means may be considered to implement this co-construction.

Interpersonal skills necessary for researchers involved in community-based research: researchers must identify the research needs of the community through direct field interaction rather than simply having CBOs validate their ideas.

Research which is based on the needs of the community will lead the researcher to formulate his/her hypotheses only after a period of work with community front-line workers.

The researcher can:

- *Help the CBOs to identify problems experienced during field activities, the topics of interest and the needs that engagement in a research project might help to address.*

  As CBOs are sometimes caught up in the immediacy of action, it is often necessary to set up discussions in order to listen to one another and create opportunities for further discussion.

- *Use inductive research methods* (that is to say starting from the specific and moving towards the general) to look for information about and acquire an understanding of the field experience of CBOs, in order to define research topics for the collaboration.

- *Avoid pre-formalization of the research projects before the end of the joint exploratory work.*

  It is easy for researchers to quickly conceptualize the possible avenues for research and propose them to community stakeholders, without necessarily having real-life community needs as their starting point. This kind of research is collaborative but may not necessarily meet the needs identified by the community partners and may miss out on innovative research questions. It will therefore not meet the standards of CBR.

3 | Joint identification of the types of research and researchers necessary to carry out the project

Another element of this exploratory phase is to identify the type of research and the partners to be contacted in order to build a team and develop the research protocol.

► Identifying the type of research

Intervention-orientated research (such as CBR) can take two different forms:

Research associated with immediate social transformation: "intervention research" and "evaluative research"

Both intervention and evaluative research are directly related to an intervention which itself forms part of the research topic.

They may evaluate different types of interventions:

- *A biomedical intervention* (for example, community testing with rapid HIV test).

- *A health promotion intervention* (for example, workshops designed to provide women with the necessary communication tools to enable them to disclose their serostatus. These workshops are provided as part of the Canadian Pouvoir Partager/Pouvoirs Partagés intervention research study).

- *A more global public health strategy* combining several interventions.

The intervention itself can be created prior to or as part of the research project:

- *The intervention conceived is a component of the specific research project and does not precede it, at least not in the same format.*

  It is determined by the research protocol, and often designed specifically for the research project.

The ANRS AERLI research project evaluates an educational intravenous injection assistance intervention. Although the two organizations involved in the research – Doctors of the World and AIDES – were already implementing assistance interventions before the research project began, specific intervention procedures were established during the preparation of the project itself.

This kind of research may be based on very different models: randomized trials (→ Unit 2), before-and-after comparisons, or even observational studies.

For ease of reference, we shall refer to this kind of research as "intervention research".

- *The research carried out emerges from an intervention which has already been implemented in the field: "evaluative research".*

An intervention has already been implemented within the operational framework of the CBO. When this intervention is already well-established, a research study may be carried out to evaluate its effects or to model it.

For ease of reference, we shall refer to this as "evaluative research".

Research potentially aiming at social transformation: research which focuses on the context and/or the intervention's target population(s): "descriptive and analytical research"

This kind of research aims to better understand and explain the problem that the intervention will try to solve.

The CBOs involved in the Partages study wanted to implement support interventions on the topic of serostatus disclosure. Nevertheless, they considered that they had insufficient information about the factors, notably psychosocial, which led to someone disclosing their serostatus or not and feeling comfortable with their decision. Still ongoing, this "descriptive and analytical" research project will provide the organizations concerned with a greater understanding of these determinants and help them to create appropriate interventions.

For ease of reference, we will refer to this as "descriptive and analytical research".

In order to help choose the type of research to be used in the project several questions may be asked

It is possible to formulate these questions based on research needs:

- What is the objective of the research study?
- What types of information and data are needed?
- What types of results are we aiming for?
- What do we want to measure?
- What do we want to demonstrate?

It is also possible to formulate these questions using intervention as a departure point (→ see the following diagram):

Is an intervention
already in place?

✓ Yes

✗ NO

Is it suitable?

Has an intervention
been considered?

Evaluation

✓ Yes   ✗ NO

✓ Yes   ✗ NO

Do you need more
knowledge about
the target
population? About
the problem?

Do you want to
understand the
shortcomings/
weaknesses of the
intervention so as
to improve it?

Do you have
to compare
its efficacy
with existing
interventions?

Do you have
to demonstrate
its efficacy
before being
able to
implement it?

Do you need more
knowledge about
the target
population?
About the problem?

✓ Yes   ✗ NO

✓ Yes

Descriptive and
analytical
research

Evaluative
research

Intervention research

Descriptive and
analytical research

Results are available and help stakeholders
to develop a specific intervention

► Identifying the researchers

The identification of researchers likely to take part in the project depends on the type of research to be carried out, as well as on community stakeholders' first intuitions regarding the research questions:

- ■ What is the objective of the research project?
- ■ What are the questions to be addressed?
- ■ What type of information and data is needed?

Depending on the answers to these questions, different academic disciplines may be necessary: clinical research, psychology, epidemiology, sociology, anthropology, etc (→ Unit 8).

Moreover, researchers who already have contacts with the community can help identify other researchers who may look at the community from a different and new perspective. There are many practical ways to identify researchers (→ Unit 8).
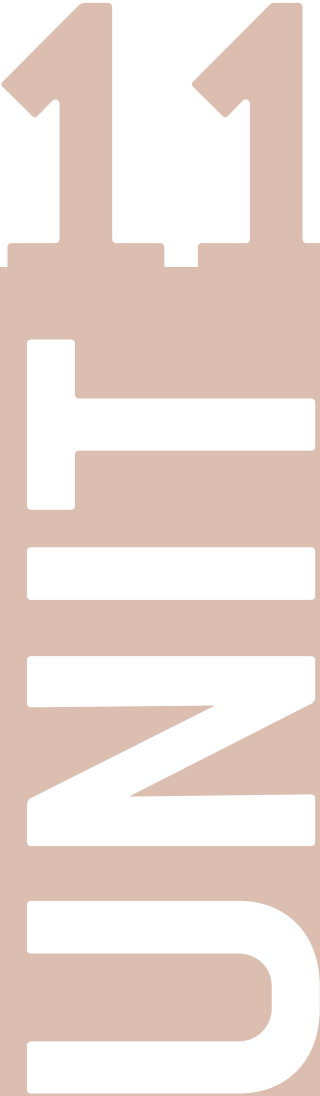

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UNIT 11

Defining the research protocol

1. What is a research protocol?
Why is collaboration necessary at this point?

2. Practical ideas for working together
on the research protocol

3. From the design of a "field intervention project" to
the design of a "research project": what possible
contributions can each type of stakeholder make?

11. Defining the research protocol

The development of the research protocol (perhaps because it is often mistaken with the drawing up of the larger research project submitted to funders when applying for funding) is generally perceived by the partners involved as a step requiring very little collaboration. Furthermore, some community stakeholders consider it too technical and therefore not very accessible. It is also the moment when two fundamental requirements of research confront each other for the first time: respecting the complexity of the realities faced by the communities to be studied and respecting scientific requirements. Yet the objective of implementing a framework ("protocol") for the research process is precisely to enable us to account for what happens in real life through observation and analysis.

Researchers are often the driving force at this crucial step of the research project. Nevertheless, one of the added values of community-based research (CBR) is that community stakeholders can also contribute to the design of the protocol.

## 1 What is a research protocol? Why is collaboration necessary at this point?

► The research protocol

The "protocol" is the research project's "roadmap". It generally takes the form of a document which details the different steps required for the collection, construction and analysis of study material. Usually, the protocol is designed and drawn up when an application for funding is made, as the coherence between the research hypotheses and the study framework is a key element in the funding decision.

The research protocol is a methodological tool which specifies how the research question is going to be addressed in order that a valid, verifiable response is found and that the results obtained can be generalized.

The epistemological principle of research is that results can be refuted, something which is made possible by explaining how the knowledge was initially acquired. The methods chosen will depend on the academic disciplines involved in implementing the project.

In practical terms, *the protocol adapts the methods and the implementation of the research project* (studied population, practical steps and procedures, budget and research timeline) *to the scientific questions being asked and to their contexts* (scientific and intervention-based). All of these elements are interconnected.

Context (need for knowledge and action)

▼

Research questions

▼

Methods

▼

Practical flow chart of the research project
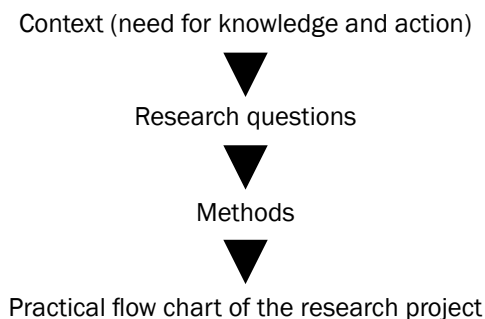
► The added value of collaboration

Some experiences of suboptimal collaborations have shown that disagreement between community stakeholders and researchers when drawing up the protocol can often be a warning sign of future difficulties in implementing the project.

The following difficulties have been noted during implementation:

- Non-compliance with study participant inclusion procedures, despite being clearly described in the research protocol.
- Non-compliance with the various steps of the survey which are also clearly described in the research protocol. This would include information sheets not being completed, or some questionnaires or interviews not being administered.
- Deterioration in relationships between the partners due to frustration.

These difficulties are directly linked to the fact that some points were not sufficiently explained when the protocol was being drawn up.

Very often, deviations from the protocol during the project may be explained by insufficient collaboration when the protocol is drawn-up. In terms of community front-line workers, for example, deviations from the protocol may occur if the data collection procedures outlined are not adapted to the real conditions in which the intervention takes place. Yet, in order for the research project to meet scientific requirements, certain data must be collected during its implementation, and certain forms filled in at a specific moment of the process. Prior collaboration helps the study partners to overcome these difficulties by defining and drawing up more realistic protocols together which include clear conditions regarding the project's realization.

In-depth discussions which lead to consensus about the protocol generally facilitate project implementation and therefore quality data collection.

One organization's contribution to the drawing up of a protocol.

The experience of a biomedical research project on sex workers in Bucharest

The Romanian community-based organization (CBO) ARAS was a partner in a biomedical research project on sex workers in Bucharest, with whom it carries out regular interventions. In order to help determine as best as possible the sample size and its geographical distribution within the city, ARAS mapped sex work in Bucharest, using the database where all the organization's beneficiaries are recorded.

The knowledge that ARAS has of the community also enabled it to specify the time slots when the research project interventions could be carried out, as well as the feasibility of the study's implementation.

Partners must work together to define each step of the research process: definition of the population(s) and study locations, choice of groups to include in observation, choice of data collection tools, choice of questionnaire content. Each of these steps is crucial and may raise disagreements among partners. Time is therefore needed to allow members of the research team to express their positions in order to reach consensus.

Exchanges and close collaboration during the drawing up of the protocol help all the partners to find common ground. Staying focused on the main research question of the project can, for example, help partners to agree on the indicators to be used in the data collection tools (→ Unit 12).

In order to determine the practical organization of the research project, for all of its steps, one must first consider how it is going to be implemented. In the context of a CBR project, it is important to take into account, and therefore anticipate, the specificities linked to the survey interviewers or the community front-line workers (→ Unit 13) as well as to the locations where interventions are planned (→ Unit 15).

An important part of the collaboration consists in finding the practical means to reconcile the scientific requirements of the data to be collected with the practical conditions of data collection.

These discussions are essential right from the point where the protocol is first drawn up. They involve anticipating as much as possible the practical conditions of data collection (→ Units 13 and 15).

Co-construction enables more realistic protocols to be developed in terms of the practical conditions of the project's implementation. It also helps to ensure that the implementation of the project in the field complies with the procedures defined in the protocol and therefore guarantees high quality data collection. On the contrary, if there is disagreement between the various stakeholders during the drawing up of the protocol, there is a potential risk that problems will arise during the project's implementation.

The protocol provides the occasion to allocate tasks, roles and responsibilities to each of the partners.

Open discussion about the budget is also necessary. The size and breakdown of the budget must comply with the individual elements of the project, as listed in the protocol.

The key points to be agreed upon during the drawing up of the protocol:

■ The research hypotheses, data collection tools, data to be collected, collection procedures.

■ Organization of the practical data collection conditions.

■ Roles and responsibilities of each partner.

■ Budget.

2 | Practical ideas for working together on the research protocol

As with the exploratory phase (→ Unit 10), the complementarity between the work carried out by the community front-line worker, the "facilitator" and the researcher, lies at the heart of the co-construction of the protocol.

Research projects involving the co-construction of a research protocol use the following working methods:

- *Establishment of a small working group responsible for the design and drafting of the protocol:* two or three people, at least one of whom is a community stakeholder, for example the community "focal point" for the research project, and another a researcher. This is where researcher/community stakeholder "pairings" can be created (→ Unit 6).
- *Discussions about each component of the protocol involving a larger group,* including researchers, the community focal point and community front-line workers.
- *Exchanges between the small working group and the larger group.*
- *A workshop to draw up the protocol.* This working method is desirable as it enables all the partners to discuss the key points of the research project in a large group early on in the process. A dedicated budget should be anticipated for this workshop.

It is equally possible to work in two distinct groups at this stage – a "community" group and a "researcher" group. These two groups individually discuss the issues and possibilities surrounding the protocol before exchanging their views.

> The design and drafting of the protocol can be performed collaboratively using inclusive working groups (researchers and community stakeholders). Having a community stakeholder as a member of the small group responsible for the design and drafting of the final document is an asset to the project's co-construction.

3 | From the design of a "field intervention project" to the design of a "research project": what possible contributions can each type of stakeholder make?

Once the *protocol* has been jointly constructed, the *research project* is generally drawn up and submitted to potential funders: the protocol is the core, but only a part, of the research project.

Although the objectives and methods used in research projects and field intervention projects are very different, similarities do exist in terms of how both are designed and drafted. The rationale behind the construction of both types of project (and indeed their corresponding project documents) is very similar. The comparative table on the following page is, first and foremost, designed to clarify in greater detail the definition and content of a research project for the readers discovering the concept.

That said, it is important to remember that the research *protocol* is a methodological tool which specifies how the research question is going to be addressed in order that a valid, verifiable response can be found and that the results obtained can be generalized. For its part, the field intervention project is based on recognized professional practices in a given profession or sector and only serves its own purposes.

Field intervention project	Research project
Context	
Need for the field intervention	Knowledge gaps
Objectives	
General and specific objectives	General, specific, scientific and interventional objectives
Description of activities	Methods
What types of activities are planned? How shall activities be organized?	What type of research project is planned? What is the design of the project? How shall the data be collected and analyzed?
Resources	Study implementation
Resources implemented in the field to accomplish activities	Resources implemented in the field to carry out the research project
Expected results	Expected results and benefits
Expected impact on the problem	Expected scientific results and potential impact for intervention
	Ethical considerations
	Measures taken to ensure that research ethical criteria are met
Evaluation	
Indicators, sources of verification	
Schedule	
Budget	

Table: Field intervention project and research project.

The different elements comprising the research project vary. They depend on the type of project and the teams involved but mostly on the information requested in funding application forms produced by research agencies and/or funders.

In the summary table below, we list the "traditional" elements found in most research projects. They may be organized differently.

We present the principal contents of each element comprising a research project: what needs to be done together and some ideas about specific contributions that community stakeholders (left column) and researchers (right column) can make.

Ideas for contributing: community stakeholders	Ideas for contributing: researchers
Context/Rationale for the research project	
■ Specify the context/the public health needs ■ Specify the context/the needs of the particular community(ies) in terms of the research-based intervention ■ Specify the context/the scientific needs	
■ Situation of the studied population with respect to the research topic (data from previous community field interventions). ■ Justification for the research project with regard to the research-based intervention. ■ Justification for the research project with regard to public health needs.	■ Justification for the research project with regard to the state of scientific knowledge. ■ Justification for the research project with regard to public health needs.
Objectives	
■ Define the scientific objectives ■ Define the objectives for the research-based intervention	
■ Share field observations in order to define the research project's objectives. ■ Define the objectives in terms of the research-based intervention. ■ Prioritize primary and secondary objectives.	■ Identify the research questions based on field observations. ■ Define scientific objectives. ■ Prioritize primary and secondary objectives.
Hypotheses	
■ Contribute to the research hypotheses. ■ Ensure that the proposed hypotheses are formulated so that the research-based intervention's objectives can be fulfilled.	■ Scientifically formulate the hypotheses to be tested so that objectives can be fulfilled, using field observations and a review of existing literature.

Ideas for contributing: community stakeholders	Ideas for contributing: researchers
Methods	
■ Define the research methods ■ Define the study sample, the participants and the sub-groups to be created (especially when using randomization) ■ Define the type of data to be collected and the quantitative (e.g. questionnaires) and/or qualitative (e.g. individual interviews, focus groups) methods for data collection ■ Choose support tools ■ Define the procedures for evaluating the research-based intervention	
■ Define the procedures for participant recruitment in the study according to their feasibility and their acceptability to the population studied. ■ Evaluate the feasibility of the data collection and/or the research-based intervention methods and their acceptability: what methods (focus group, self-administered questionnaire, etc) can provide the most relevant results? What methods seem difficult to accept? Are the intended locations suitable for carrying out the research-based intervention? ■ Define support tools (personal logbooks, counseling, etc). ■ Define the criteria of the expected social transformation resulting from the research-based intervention.	■ Define the sample, the participant recruitment and inclusion criteria. ■ Propose data collection methods according to the objectives and hypotheses. ■ Define the means for evaluating the expected social transformation resulting from the research-based intervention.

Ideas for contributing: community stakeholders	Ideas for contributing: researchers
Study design and implementation	
■ Set the duration and sequencing of the different steps of the research project (data collection, research-based intervention, counseling, workshops where study results are disseminated, monitoring, etc) ■ Define the participant's course through the research-based intervention	
■ Guarantee that the sequencing of steps takes into account the needs of the participant and those of the research-based intervention (counseling provided at the right moment etc). ■ Make a field-based evaluation of the feasibility of the participant's involvement: this includes practical issues for the participant, the community front-line workers involved in the research and the center the participants attend for the project (e.g. ensuring that the community front-line worker can fill in the required form at the right moment, etc).	■ Propose a sequencing of steps for the research project with regard to scientific requirements.
Expected results and benefits	
■ Scientific results and their promotion ■ Benefits for practical field interventions and the utilization of the study results by the CBO involved in the project	
■ Define the expected results and benefits for practical field interventions.	■ Define the expected scientific results.

Ideas for contributing: community stakeholders	Ideas for contributing: researchers
Ethical considerations	
■ Specify conditions of anonymity if necessary	
■ Ensure data protection and confidentiality	
■ Define how the research project will be explained to the community	
■ Define how information will be provided to the participants and how their voluntary informed consent will be obtained	
■ Plan support measures for the study participants, community front-line workers involved in the research and/or survey interviewers	
■ Ensure that the necessary steps for compliance with the ethical rules are laid out in the research protocol, and that the necessary resources are available (training of community front-line workers involved in the project in research ethics etc).	■ Ensure that the necessary steps for compliance with the ethical rules are laid out in the research protocol, and that the necessary resources are available (training of community front-line workers involved in the project in research ethics etc).
Schedule	
■ When establishing the schedule, ensure that full advantage can be taken of the CBO's project cycle management competencies. ■ Ensure that the research project's schedule is compatible with the CBO's ongoing and planned activities.	■ Define a schedule which respects the requirements laid out in the protocol and those for collecting high quality data.

Table: The steps in designing the research project: some ideas regarding the contributions of different partners.

12

UNIT

Building research tools for the project

12. Building research tools for the project

The research tools used in the project (observation protocol, interview forms, questionnaires, guidelines for focus groups, etc) must meet the requirements of objectivity, and take into account the characteristics of the community studied in order to provide complete and valid research material. Building tools *with those for whom they are destined* (i.e. community members) should increase their suitability in the context of the community. Furthermore, their joint development *with those who will implement them* (community front-line workers involved in the research project) should also guarantee their optimum use during the data collection phase.

1 | Developing interventions in community-based intervention research

Community stakeholders know how to develop interventions. Nevertheless, in order for the intervention to be research-based, it must follow certain scientific regulations. Consequently, the joint contribution of community stakeholders and researchers is necessary to ensure that the research-based intervention can be assessed according to scientific methods but that it is also adapted to the context where it is implemented.

► Designing a "measurable" research-based intervention: the requirements of intervention research

In order to evaluate research-based interventions and measure their results both quantitatively and qualitatively, the interventions themselves must first be precisely defined and subsequently implemented according to explicit procedures. Furthermore, they must always be applied in the same way, that is to say, in a standardized fashion.

In practical terms,

■ *It is necessary to draw up a standardized intervention protocol.*

The intervention must be identical for all the project sites, for all research staff involved and for each study participant.

For example, in the context of the community-based research (CBR) project ANRS AERLI, community front-line workers in one of the study sites wanted to use an educational video as a tool in an intervention on drug injection. However, the use of this new tool would have required the modification of the intervention protocol for all the study sites. Consequently it was not possible to use the video.

■ *A standardized intervention protocol ensures that data from different sites can be compared. It also ensures that cross-comparison between data collected either by different research staff or at different points of time over the research process can be performed. Standardization means that one unique and clearly identified intervention is evaluated.*

A research-based intervention must be implemented in strict compliance with a standardized protocol so that any related measurements performed using collected data are fully attributable to that specific intervention. If the intervention protocol is not clearly defined and respected, there is a risk that different intervention procedures will be implemented by different people and/or in different sites. Any divergence observed in collected data could therefore be the result of this procedural variation. Consequently it would be impossible to reliably interpret such data.

For example, a recent study found that the satisfaction rate for a community HIV testing intervention was higher in people who had certain social characteristics or behaviors. The fact that the study's protocol was strictly followed ensured that this finding was not the chance result of different practices being implemented by the various research staff who performed the interventions.

■ *The contribution made by researchers therefore is primarily to ensure the uniform implementation of the research-based intervention, the sequencing of actions and the standardization of the study participant's journey through the process.*

This guarantees standardization, comparability and scientific quality when evaluating the study's intervention.

► Designing a "feasible" research-based intervention: thinking about how it will fit in with field-based intervention

In CBR, **the interventions planned as part of the research project ("research-based interventions") are implemented within organizational structures which already carry out other actions (or "field-based interventions").**

Indeed a field-based intervention which has already been implemented by an organization may be quite similar to a research-based one in terms of the practices carried out, the study population and the various stakeholders working on it. One can therefore ask:

■ *Can a research-based intervention and a field-based intervention co-exist?*

• Is it possible in terms of staff, the capacity of the intervention site and, more generally, the available resources?

■ *Should the research-based intervention replace the field-based one?*

• Is this really possible considering the number of people currently benefiting from the field-based intervention?

• What are the effects for those currently benefiting from the field-based intervention? Is there a risk that they will lose access to this service?

More generally, it is important to **take into consideration the impact that the research-based intervention will have on field-based interventions already implemented** by the organization:

■ **What impact might the research-based intervention have on the existing structure** in terms of workload, continuity of ongoing activities and even the possible influx of new people?

■ *What does the CBO think about the fact that participants in a research project receive more services and/or care than the other people cared for by the organization?*

What effect could this difference have on these other people?

For example, if participants in the research project are provided treatment free of charge, is it ethically acceptable not to propose this same treatment free of charge to those not participating? If free treatment is only provided to those included in the project, does this not act as a huge incentive to participate? If everyone benefits from free treatment, what will be the effects on the care structure (in financial terms, in terms of the influx of new patients, etc)?

2 ▎ Developing data collection tools

The development of clear and precise data collection tools which meet scientific prerequisites is a key moment in the collaboration and requires a joint effort from both community stakeholders and researchers.

Various data collection tools are used in CBR projects:

- Observation guides
- Interview guides
- Questionnaires
- Community front-line worker's personal logbook
- Refusal forms, summary sheets, follow-up sheets, etc.

Depending on the tool, the main impetus for its inclusion comes from either type of partner. For example, community stakeholders propose community front-line worker personal logbooks, researchers propose interview guides, etc. The proposed tool is then discussed and worked on by all, to ensure that it is suitable, valid and easy to use for data collection.

► Collaboration during the development of data collection tools improves their acceptability

■ *Community participation ensures that the content and form of tools are adapted to the context of that particular community.*

The participation of community stakeholders in drawing up questionnaires helps to ensure that real community issues are taken into account when developing the research project's data collection tools.

In practical terms, joint development also tends to guarantee that data collection tools are adapted to the reality of the community, in terms of when data collection with each study participant will take place, how long it will take, and what vocabulary and language will be used.

■ *Researcher participation ensures that the data collected can be used for scientific purposes.*

Tools which do not meet scientific standards and requirements produce information which cannot properly be analyzed scientifically. This is as true for questionnaires as for more action-oriented tools. An example of the latter is the community front-line worker's personal logbook, which can be studied statistically within the context of an implementation analysis[1].

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1 The objective of the implementation analysis is to be able to transpose an intervention to other contexts and/or to maximize its effects (→ Unit 17).

A community stakeholder discusses the limitations of an initial survey developed by his organization which led them to seek closer partnerships with researchers:

" *We drew up the questionnaire totally by ourselves with all the limitations which that brings: we didn't have much training in the methodology to use and it was difficult to analyze the data. Some of the relationships we noticed appeared interesting but we realized that they had no statistical value and therefore that we could not use them* (Community stakeholder, Switzerland). "

- **The participation of community front-line workers** (professionals or volunteers) from CBOs ensures that the data collection tools used are practical, both in terms of producing general knowledge and analyzing the interventions carried out. Although this is not a primary goal, it is something that community stakeholders nevertheless expect.

► Here are a few practical ideas for co-developing tools

- **Think together about the acceptability of the data collection tools for your specific project.**

  Some tools used in research projects in other contexts may not be acceptable to community front-line workers.

- **Identify whether some of the tools already being used by the community front-line workers involved can also be used for the research project. More generally, develop new tools based on existing ones.**

For example, during the pilot phase of one particular CBR project, as they went along about their work, research team members were supposed to fill out a form which would provide a summary of the research carried out that day (the number of people the study was presented to, the number of refusals, etc). However, it turned out that filling in this form while carrying out their activities proved impractical. Collaborating together, community front-line workers and researchers succeeded in adapting a pre-existing tool which was already being used on a daily basis. This was finally used as a data collection tool.

Examples of how community stakeholders can contribute:

- Propose topics for questionnaires or for interview guides.
- Provide feedback to the team about the real-life community constraints which must be taken into account when developing research tools.
- Ensure that the tools to be used are adapted to the various intervention contexts (format, vocabulary and expressions, acceptability).

Examples of how researchers can contribute:

- Suggest tools which correspond to the concepts put forward during the first steps of the research project and/or tools usually used and already validated.
- Ensure that the questions asked in questionnaires/interviews can be scientifically analyzed with regard to the method(s) chosen.

Collaborative development of data collection tools is a long and costly process which involves both researchers and various stakeholders from CBOs. As well as the design of the tools themselves, it is important to have meaningful group discussions about their acceptability and about how they can be adapted, if required, to the context of the specific intervention.

► **It is important to pay careful attention to those issues which regularly create misunderstandings between community stakeholders and researchers at this phase of the project**

■ *The trade-off between the time the respondent dedicates to the survey and the quantity and quality of the information to be collected.*

It is necessary to balance the amount of information to collect with the study participant's time availability and his/her level of acceptability of the research project, an issue which can give rise to interpersonal tensions.

■ *The choice of the questions to be included (or not) in the questionnaires.*

Sometimes researchers believe the questions proposed by the community stakeholders are unsuitable in regard to the planned scientific analysis. Conversely, researchers sometimes suggest questions which at first make no sense to community stakeholders. For example, this is the case for measurement scales. They are designed and validated with very general statements and are potentially irrelevant for particular populations or contexts. When it comes to such scales, the modifications of the wording sometimes desired by community stakeholders cannot be considered without adversely affecting the possibility of using the results obtained for data analysis.

■ *Using quantified evaluations of the results.*

Biomedical interventions come under the umbrella of clinical research protocols in which quantified and standardized evaluation is the norm, as it produces results which can be generalized. It may be difficult for community front-line workers – who usually try to adapt their field actions as best as possible to each individual's needs – to adopt standardized evaluation criteria for their research-based interventions. Community-based culture places more emphasis on the quality of the process and on the result for the beneficiary. In this perspective, CBR focuses on the possibility of understanding the processes and subjective dimensions involved.

> Disagreements and tensions between community stakeholders and researchers are generally linked to different interests and to a different point of view with regard to the issues surrounding field work. Such difficulties can be resolved through group exchanges, pre-tests and pilot phases.

3 | Pre-tests

A pre-test essentially tests a data collection tool before the actual implementation phase. The goal is to verify that the tool is suitable, coherent and understood.

Ideally, the pre-test takes place under similar conditions to those of the actual research project. Depending on the project and on the complexity of the tool to be developed, different test phases and feedback may be necessary to adjust the tool.

Pre-tests can be performed thanks to the collaboration with the CBOs. There are many possible ways to do this:

■ *Employees and volunteers from CBOs whose members also belong to the research study's target community can participate in pre-tests and/or provide feedback about the tools.*

When a CBO is involved as a partner in a research project, it is easier to mobilize its employees and volunteers to carry out pre-tests than when its contribution is that of a "service provider" for participant recruitment or data collection.

More generally, when it has volunteers or employees who are also members of the community studied, a CBO brings an added-value to the project which its "service-based" counterparts cannot.

- *Data collection tools are most often pre-tested on community members.* The CBO's role would therefore be to recruit study participants for this test/pilot phase.

- *When the study's interviewers themselves come from the community studied* (→ Units 13 and 14), training sessions can provide "live" feedback about the contents of the tool, especially the wording of interview questions.

The CBO network may facilitate the organization of necessary, sometimes numerous, pre-tests before the study's launch.

Anticipating the implementation of the research project

13

UNIT

Data collection – community front-line workers and/or interviewers

1 Functions and roles of research staff involved in data collection

2 Choosing interviewers: external or community-based?

3 Community front-line workers: accepting the difference between a "field-based intervention" and a "research-based intervention"

4 Reconciling commitment to immediate social change with research: what practical approaches can be used to facilitate the work of community stakeholders?

13. Data collection – community front-line workers and/or interviewers

Once the study protocol has been defined and the decision has been made about which methodology and data collection tools to use, practical questions about the data collection process itself and the implementation of the research-based intervention arise. Here we present the roles and functions of interviewers and community front-line workers, and give food for thought about the assets and limitations of each, especially in terms of institutional affiliations.

1 | Functions and roles of research staff involved in data collection

Depending on the specific research project, two kinds of research staff may be involved:

- Interviewers
- Community front-line workers

Both participate in the process of high quality data collection. However, their roles and their practical involvement in the project differ.

▶ The interviewer: collects information from interviewees

Whether s/he uses a quantitative or qualitative method, the job of the interviewer is to collect information about the situation, the behaviors, the attitudes, the personal opinions and beliefs of the population studied. The interviewer must gain the trust of the interviewee in order to encourage responses as accurate and honest as possible. It is essential that the interviewee express him/herself as personally and freely as possible, whatever the subject being addressed.

The interviewee's answers may be affected by different processes:

- *The interviewee's interpretations:*

    The information provided by the interviewee is about his/her direct experience. The interviewee relates events s/he has lived through: these events are thus a personal interpretation and not an "objective reality".

- *The interviewee's memories and memory:*

    Accurate information can deteriorate over time. It is possible to reduce this "recall bias" by asking the interviewee to provide information about a shorter period of time (e.g. asking him/her about the previous six months instead of the previous year).

Particular interviewing strategies can also be used to help him/her remember. Depending on the context, this information can be cross-checked with other data when available.

■ *The interviewer-interviewee relationship:*

The interviewer's characteristics (age, sex, social status, etc) and his/her behaviors (e.g. reactions to the interviewee's comments) – as perceived by the interviewee – as well as both persons' respective social positions, may all influence the way the interviewee answers. A social desirability-bias may also exist: the interviewee provides an answer that s/he believes is acceptable or expected.

■ *To limit these effects, the interviewer must adopt a stance of empathic neutrality.*

Reflexivity (being aware of one's own characteristics and ideas/beliefs about the research topic), practice and comprehensive training help to achieve this.

These potential constraints must be fully taken into account during analysis. They are not specific to community-based research (CBR) and may occur in any interviewer-interviewee interaction. In order to conduct an interview, interviewers must acquire strong interviewing skills and/or learn how to correctly administer a questionnaire. Furthermore, they must be able to adapt. Specific training programs for the study at hand help them to develop this capacity (→ Unit 14). Conducting an interview and complying with the research project's defined methodologies is therefore a crucial step in the effective implementation of the project.

► The community front-line worker: implements an intervention

The role of the **community front-line worker** is not solely to collect information. Indeed his/her primary role is *to implement an intervention which must then be evaluated within the context of the research project.*

In intervention research projects, the community front-line worker may for example:

■ Perform project-specific tasks (welcoming participants, providing information, etc)

■ Carry out a health promotion intervention which is evaluated by the research team (interviewing and testing, providing drug users with educational support in injecting practices, etc).

The community front-line worker brings his/her know-how and real-life daily working experience to the research project.

Although the intervention must meet the requirements of a specific protocol, it is usually quite similar to the community front-line worker's standard practice, and therefore falls under the umbrella of his/her existing know-how. In some situations, the community front–line worker may also be involved in collecting data from the study participants or data on the intervention process (e.g. by completing a personal logbook).

► In practical terms, how does the research project interlink with the interviewers'/community front-line workers' daily activities?

Each interviewer's/community front-line worker's involvement in the implementation of the research project is different:

■ Some integrate the project into their daily work routines (additional activities are added to routine ones).

■ Others devote a specific amount of working time to focus exclusively on the research project.

We can distinguish between the following:

■ *Community front-line workers who integrate the research project into their daily routine activities.*

The ANRS AERLI study is currently evaluating an intervention on providing drug users with educational support in injecting practices. It is being carried out by community front-line workers from the community-based organization (CBO) AIDES and the international organization Doctors of the World. Although they have integrated the intervention into their daily work routines in the field, they nonetheless follow a well-defined protocol.

■ *Community front-line workers mobilized specifically for the research project and who are tasked with implementing a project-specific intervention.*

For the ANRS DRAG study, AIDES community front-line workers implemented a new intervention – peer HIV testing – which they performed outside of their routine activities (e.g. in an anonymous and free HIV testing center).

Like the interviewers (see the following point), they could also carry out other routine activities within the population studied. Nonetheless they dedicated a specific amount of their working time to focus exclusively on the intervention.

It is important to clearly define the roles of interviewers and community front-line workers, and to specify how the time dedicated to the research project will integrate (or not) with that dedicated to routine activities.

■ *Interviewers mobilized specifically for the research project and who are tasked with conducting interviews.*

Interviewers may also devote time to other routine activities with the population studied, but interviews are distinct from these other actions and must be conducted at a specific time and under specific conditions. Interviewers may be "professional interviewers" or members of research teams.

2 | Choosing interviewers: external or community-based?

Depending on the situation, CBR may be organized using:

■ *"External" interviewers*

Among these we can distinguish between:

• Research assistants, who are sometimes students (they are part of the research team but not part of the community).

• Professional interviewers working for a survey institute (they are neither part of the research team nor the community).

■ *"Community-based" interviewers*

Among these we can distinguish between:

• Professionals and volunteers from CBOs.

• "Peer-interviewers", who are members of the study's target population.

These last two categorizations are nonetheless quite artificial and the boundaries between them are often blurred as:

■ In CBOs, many volunteers and employees are themselves beneficiaries of interventions within their structures. For example, they may be people living with HIV/AIDS, or members of the most vulnerable populations in terms of HIV infection.

■ External interviewers and interviewers from CBOs may be members of the population being studied, without this fact being necessarily known.

In a CBR project, the involvement of each type of interviewer brings its own advantages and disadvantages which are associated with the research principle of neutrality, with access to potential participants and community involvement.

▶ "External" interviewers

Two types of external interviewers may be mobilized in collaborative research projects: research assistants – sometimes students – and interviewers from survey institutes. The former are already trained in research methodology, while the latter are trained in data collection in various settings. Both of these types of interviewers have in common the fact that they usually do not have social relations within the community.

Assets for the research project

■ *Ethics:*

They are motivated by the research ethics principles of neutrality, confidentiality and anonymity.

■ *Data quality:*

- There is less subjectivity: the external interviewer is less involved therefore more objective about the research topic, even though s/he often has personal opinions and thoughts about it and/or about the populations studied.
- External interviewers are selected and trained to administer questionnaires as closely as possible to the guidelines set out in the research protocol.
- Their training encompasses general elements of research and data collection and is not just focused on one specific study.

Possible limitations

■ *The interviewer-interviewee relationship:*

External interviewers may not be able to establish the relationship required to effectively administer questionnaires or conduct interviews. This is especially the case for the most vulnerable populations if the external interviewer lives *geographically* near the interviewee. The latter may fear that the interviewer will divulge confidential information within the surrounding area. This is the risk, for example, for external interviewers interviewing stigmatized populations (people living with HIV, men who have sex with men, etc) in a small town or city. In such cases, there may be a high risk that study participants will withhold information.

▶ Professionals and volunteers from the CBOs involved in the study

These individuals work either on a daily professional basis or on a regular voluntary basis with the community studied.

Assets for the research project and for interventions

■ *Relationship with interviewees:*

- They know how to interact with the populations participating in the study. This is especially important for vulnerable populations, as these interviewers are familiar with their specific norms and lifestyles.
- They have easy access to the study's "target" population and generally have their trust.

■ *Ethics:*

- They are motivated by the community-based principles of non-judgment, confidentiality and anonymity.

■ *Ownership of results and translating them into interventions:*

- Their participation in the study contributes to the collective ownership of the research project at the organizational level, and facilitates the implementation of interventions by the CBO once the project results become available.
- By participating in the study, community front-line workers get to know the populations they work with from a different and more global perspective, distancing themselves from their daily activities.

■ *Assets for interventions and the people involved:*

- The role of interviewer is seen as rewarding and motivating, for individuals and for the CBO as a whole.
- Involvement in the study encourages capacity-building, both at the individual and team level.

Possible limitations

■ *Subjectivity:*

- These interviewers may lack the critical distance required in a research study, when the study focuses on the activities they are routinely engaged in.
- Their role as community font-line workers means that interviewees identify them in a context which is different from that of the research project. As such they are seen in a very particular light within the community where they work. If they mention their affiliation with their CBO or if the interviewee is aware of this affiliation, then he/she may provide biased answers which are in line with the CBO's values.

■ *Ethical considerations:*

If the community stakeholders also deliver services, there is the risk that participants in the research project will become confused between, on the one hand, access to a service and, on the other hand, their participation in the study. It is crucial that those solicited to take part in the study understand that participation has no impact on their access to services provided by the CBO.

► Peer interviewers

Interviewers who are members of the "target" population or "community" have intimate and personal knowledge of the problems which the research project is seeking to address.

Assets for the research project and for interventions

■ *Relationship with the interviewee:*

The shared sense of belonging helps to "narrow the distance" between the interviewer and interviewee, and encourages trust, even if these shared characteristics (serostatus, sexual orientation, personal history, etc) are not necessarily revealed.

■ *Ownership of results and translating them into interventions:*

The participation of peer interviewers in the study contributes to the collective ownership of the research project at the organizational level, and facilitates the implementation of practical, real-world interventions in the community once the project's results become available.

■ *Assets for the people involved:*

- For community members who become peer interviewers this may help create a process of integration and personal development. It may also increase their capacity and reduce possible marginalization (i.e. it may empower them).
- The role of interviewer may count as professional experience.
- The role of interviewer can enable individuals to come out of isolation and to discover they share common experiences with others.

Possible limitations

■ *Subjectivity:*

The interviewer and interviewee are in the same situation. The study might bring up memories and emotions in the interviewer which may interfere with how s/he conducts the interview or administers the questionnaire.

■ *Relationship with the interviewee:*

The interviewee may meet the interviewer in community meeting places (venues for socializing, etc) at a future point in time and may be afraid of such encounters. It is essential to clearly indicate, possibly by using clear procedures, that the interview time is different from the time and relationships developed in day-to-day community life.

When respondents are interviewed by somebody who understands them, but does not know them.

The example of ANRS VESPA 2 study in French overseas regions.

During the ANRS VESPA 2 study in the French overseas regions, a system was put in place to ensure that no interviewee would be interviewed by someone they knew. This was important as the study region is sparsely populated and geographically confined.

CBR offers a very wide choice in terms of the "nature" of the interviewers. It is important to choose the most suitable type of interviewer for the specific project, to understand his/her assets and limitations and to invest heavily in interviewer training and monitoring.

When setting an appointment with an interviewer, his/her photo was shown to the future respondent. If the latter recognized the interviewer, s/he could then ask to be interviewed by someone else. In the case of ANRS VESPA 2, interviewers and interviewees lived in small localities where the risk of knowing one another was higher than elsewhere.

This practical idea, conceived in a study which did not use interviewers from the targeted populations, but who potentially live in the same neighborhoods, may be adapted to "community-based" interviewers. See also Girard (2010).

► Be aware of potential biases in order to limit them

The limitations outlined above give rise to a number of biases which are well known by members of research teams. The interviewer is always culturally and socially situated[1] and this situation necessarily influences the interviewee. The interviewee too is socially situated. Biases are therefore inevitable during an interview or when administering a questionnaire. It is impossible to be totally neutral. Although we cannot avoid biases, we can certainly identify and try to minimize them.

The following are some biases associated with the interviewer/interviewee relationship:

■ *The interviewer effect:*

The interviewer's age, sex, job and environment may all have an effect on the nature of the respondent's answers. Some of the interviewer's characteristics may be an asset, as they help interviewees feel that they can trust him/her. Despite their positive effect however, these same characteristics may create a bias which must be minimized.

■ *Social-position bias:*

The interviewer does not have the same relationship with all the members of the community. He/she has his/her own social and professional networks. These affinities may be known to the respondent and may influence the relationship with the interviewer.

> Every interviewer may unknowingly transmit subconsciously internalized beliefs (ideas, values, etc) to the interviewee. Accordingly, there is a risk that the interviewee will be influenced. By identifying their own personal ideas beforehand, interviewers can strive to avoid revealing them during the course of the interviews.

■ *Social desirability bias:*

Interviewees may seek to be seen in a favorable light by the interviewers. There is a risk therefore that they will provide answers they believe the interviewers desire instead of "true" answers.

For example, interviewees may choose not to divulge information about extra-marital sexual relations in a society where such relations are stigmatized.

How can we limit biases?

■ The interviewer should identify and express his/her own beliefs, perceptions and judgments regarding the research topic, in order to work on limiting their influence.

■ Training helps interviewers become aware of biases and provides practical ideas to limit them.

■ Practical exercises in conducting interviews and administering questionnaires provide a real-life demonstration of these biases. Comprehensive training means that personal opinions will not be an issue when administering a questionnaire.

■ The effect of visible characteristics may be limited by choosing an interviewer whose characteristics are similar to those of the interviewee. The interviewee's answers may therefore be less biased. This is especially the case for questions about sexuality and especially HIV/AIDS.

■ Increasing the number of interviewers helps reduce the impact of the "interviewer effect" on the study as a whole. This however gives rise to additional costs.

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1 The interviewer and interviewee, like any person, are "socially situated", that is to say that they occupy a particular place in society. Certain characteristics (socio-economic, cultural, etc) are associated with this fact and have an influence on the individual, on the way s/he thinks and the way s/he sees reality.

3 | Community front-line workers: accepting the difference between a "field-based intervention" and a "research-based intervention"

In intervention research, the intervention differs from "traditional" interventions not only in its design (→ Unit 12) but also in terms of the work that the community front-line worker does.

Essentially, while performing the intervention the community front-line worker *simultaneously* collects data on it.

The consequences of implementing an intervention within the framework of a research project are that:

- More documents need to be handled and completed (→ see box).
- The community front-line worker must complete each document at a specific moment in the intervention.
- The community front-line worker must scrupulously comply with the intervention protocol and therefore show little flexibility when implementing the intervention (→ Unit 12).

The rigor required when implementing a researched-based intervention is appreciated by the community front-line workers (it reassures them) but they also see it as a burden (it restricts them).

The documents handled by community front-line workers in the ANRS DRAG study
- Information sheet
- Pre-HIV testing questionnaire
- Documents for randomizing participants
- Post-HIV testing questionnaire
- Post-HIV testing results questionnaire
- Personal logbook

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4 | Reconciling commitment to immediate social change with research: what practical approaches can be used to facilitate the work of community stakeholders?

► Working time and compensation of community stakeholders engaged in the research project

Professional interviewers, generally employed by survey institutes, are the study *professionals*. Interviewing is the main job for which they are compensated.

Community stakeholders engaged in research projects are in a different situation. They may be:

- Professionals employed by the CBOs whose main job is to implement routine interventions.
- Volunteers who give over some of their free time to CBO activities.

In both cases, **several questions arise about the nature of the time that these individuals devote to the study:**

- For professionals from CBOs, will the time they devote to the research project be integrated into their work schedule and therefore be included in their normal salary? Or will it correspond to overtime? How will they be able to combine time for "routine" and "research-based" activities in their work schedule?
- Should volunteers from CBOs be compensated for their time? How can we guarantee the continued involvement of volunteers throughout the whole project?

The answers to these questions influence the quality of the data-collection process. If these questions are not discussed and clarified, they may give rise to misunderstandings between researchers and community stakeholders from CBOs. They must also be anticipated when creating a budget for a funding application ($\rightarrow$ Unit 9).

In very practical terms, **the questions of how and when to devote time to the research project need to be answered,** as it does not fall within the normal work schedule.

The following are some solutions which have already been identified and implemented by CBOs:

- Plan a reduced routine workload for the interviewer throughout the duration of the research project.
- Divide up the study/intervention time schedule between the different interviewers/community front-line workers at a site, such that their normal activities are not greatly disrupted.
- Limit the number of hours to be dedicated to the research project and increase the number of interviewers/community front-line workers.

Another element which must be taken into consideration is the turnover of employees and volunteers in CBOs and the impact which this can have on a research project. It is possible that individuals involved in a research study and who have received training may leave during the course of the project. This is especially but not exclusively the case for volunteers (who, for example, no longer have enough time to continue their participation). Other causes of staff turnover are sick-leave, resignation, etc. In such cases, the project team may nonetheless wish to continue the project. Training of new staff may therefore be necessary. However the possibility also exists that the team will decide to discontinue their involvement in the project, thereby reducing the number of data collection sites.

> It is essential to think about the practical organization of the work schedule and compensation for interviewers from CBOs: is their workload going to be reduced while keeping their salary unchanged or are they going to be provided with paid overtime?

► Dealing with questions which are difficult to ask and stories which are difficult to listen to

Research topics about HIV/AIDS require the interviewer to ask difficult questions and to listen to distressing stories.

Conducting interviews and carrying out interventions may therefore prove to be difficult moments for both the respondent and the interviewer/community front-line worker.

Individuals may have to remember difficult moments of their lives (serostatus disclosure, experience of discrimination, the death of family members and friends, etc).

Therefore, respondents, interviewers and community front-line workers may all need support.

To cope with such difficult moments, CBOs can propose:

■ *Support groups for participants in the research project.*

It is important however not to mention the questionnaire process during support group meetings attended by both the project's current and potential future participants, as there may be a risk that the latter could prepare answers in advance for their future interview. This would mean that any data collected would be biased.

■ *Regular and frequent group support meetings for the interviewers/community front-line workers.*

Implementing the research project (whether intervention or analytical research) may bring up difficult memories and lead to individuals being confronted with difficult experiences. The psychological consequences of this – for the study participants and research team members alike – must not be underestimated. CBOs generally have know-how in providing suitable support and can help to limit such psychological consequences.

■ *Debriefing with a psycho-social counselor:* at the end of the interview/intervention for study participants; regular, individual debriefing for interviewers/community front-line workers.

CBOs involved in the fight against HIV/AIDS generally have know-how in providing support, which can be offered both at the individual and group level. Discussion groups are common in many CBOs and most have psycho-social counselors or even psychologists on staff.

■ *Training is also of key importance for these stakeholders (→ Unit 14).*

Further reading

Girard, G. (2010). Relations d'enquête, tensions identitaires et implications du chercheur dans une enquête sur la prévention du VIH/sida parmi les homosexuels en France. In Chabrol F., Girard G. (dir.). *VIH/sida. Se confronter aux terrains. Expériences et postures de recherche.* Paris. ANRS : 105-100.

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Levinson, S. (2008). *La place et l'expérience des enquêteurs dans une enquête sensible.* In N. Bajos, M. Bozon (dir.). Enquête sur la sexualité en France. Pratiques, genre et santé. Paris. La découverte : 97-113.

UNIT 14

Training interviewers and community front-line workers

1 Training: a common base which can be adapted for the specific targets of an individual research project

2 Practical ideas to provide suitable training for interviewers and community front-line workers

3 Training provides the opportunity to strengthen the partnership

14. Training interviewers and community front-line workers

Training is a key step which ensures the quality of the research study. It provides those working on the project with a greater understanding not only of the protocol, but also of the study participant's involvement, the associated research-based intervention(s) and study or intervention techniques. It is also a key step in mutual discovery and in team-building, as it is co-developed and co-organized by both researchers and community stakeholders.

1 Training: a common base which can be adapted for the specific targets of an individual research project

► Training objectives and content

Community-based research (CBR) training aims to guarantee both the quality of data and the respect of people participating in the research project. Its objectives are:

■ *Data validity.*

The entire research staff needs to be made aware of the importance of respecting the methodology defined by the research team. The quality of the intervention, the data collected and therefore the results will all depend on compliance with this methodology. Consequently, study interviewers and community front-line workers involved in the research-based intervention have an important role to play in ensuring that the project is implemented efficiently.

■ *Respect for study participants.*

It is important that the rights of all those participating be respected throughout the course of the research project. Besides being an ethical requirement, respect for participants leads to greater scientific validity (e.g. people are more willing to take part, the quality of participant responses improves, etc).

■ *Respect for interviewers/community front-line workers.*

The objective of training is to help research staff feel at ease in their work. Once again, this is not only an objective in itself but also improves the quality of collected data. Training should help to create both team spirit and the conditions for building self-confidence in each team member.

Generally, the objectives of training are to enable interviewers/community front-line workers:

- To understand the research project's objectives and be able to explain them to study participants.
- For interviewers: to be able to administer a questionnaire, conduct interviews with study participants and carry out observations as comprehensively as possible.
- For community front-line workers: to implement a research-based intervention in compliance with the study protocol criteria.

Most training programs on HIV/AIDS research have modules focusing on:

- The research topic.
- The research protocol and the practical organization of the research project.
- The research tools (questionnaire/research interview/intervention/observation) with practical exercises.
- The roles and responsibilities of the interviewers /community front-line workers.
- Research ethics.
- Study participant orientation when necessary (medical care, emotional support, questions about rights).

The contents of training programs differ and must be adapted for the specific objective and target audience. This is easier when training programs are jointly developed by the community stakeholders and the researchers: their diversity of practices – adult education and teaching, knowledge transfer and the sharing of know-how – leads to greater flexibility in training content and the methods used. Joint development of training content also builds team spirit and encourages knowledge transfer among team members.

► How can we guarantee quality data collection once training is completed?

Should we use a validation process for interviewers?

When external interviewers are hired (for example from survey institutes), a validation process is usually planned upon the completion of their training. The research partners define the elements of this validation process (e.g. capacity to administer the questionnaire, good interaction with the participants, etc).

When the interviewers and community front-line workers chosen are members of the community, several practical ideas may be considered to ensure the quality of their work:

- *It is possible to set up trainee meetings with the trainers to assess the efficacy of the training.*
- *Trainers may advise the CBO about each trainee's suitability for the research project.* The CBO will then decide. This system ensures that both the project's scientific requirements (trainers' opinions) and organization-based experience (final validation) are taken into account.
- *It is possible to reallocate some community stakeholders to other tasks within the research study* when persistent problems are encountered. Here are some examples: participating in the initial mobilization of potential study participants; organizing group discussions for study participants or interviewers/community front-line workers; monitoring study participant inclusions; checking that data collection tools have been filled-out properly, etc.

Focusing on trainee follow-up

Training is an important event at the beginning of data collection. The team, which until this point, often comprises only a small number of community stakeholders and researchers, now becomes larger. A greater number of people become fully involved and the project really gets underway. But initial training is only a starting point in the overall process of supporting and monitoring the interviewers/community front-line workers (→ Unit 15). Refresher courses may be necessary. The interviewers/community-front-line workers may also be provided with post-training support once they commence field work. Time must also be devoted to discuss this support during the training so that the trainees feel they are sufficiently equipped to carry out their work, are conscious of their limitations and know where to go and who to contact for help if they have problems.

The diagram below gives an example of how to organize a training program, including trainer-trainee assessment meetings.
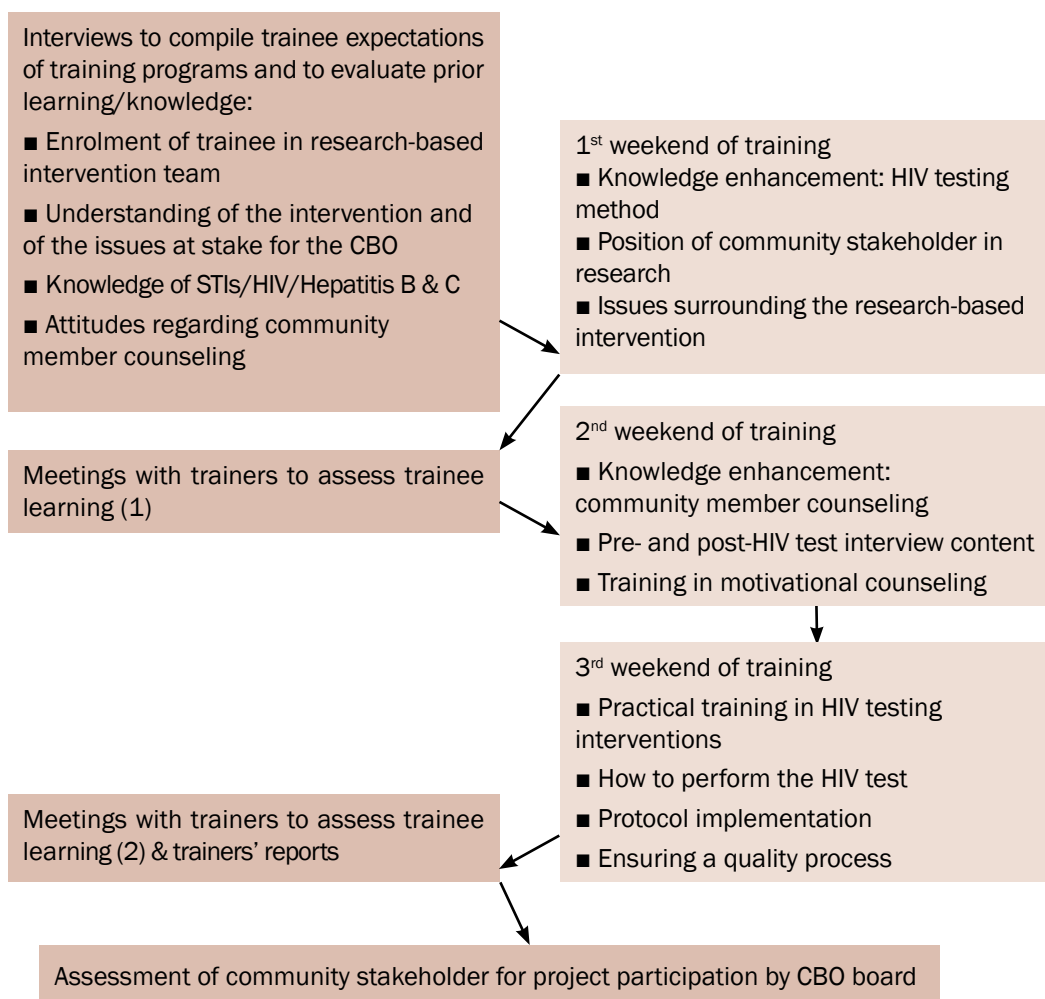
Interviews to compile trainee expectations of training programs and to evaluate prior learning/knowledge:

■ Enrolment of trainee in research-based intervention team

■ Understanding of the intervention and of the issues at stake for the CBO

■ Knowledge of STIs/HIV/Hepatitis B & C

■ Attitudes regarding community member counseling

Meetings with trainers to assess trainee learning (1)

Meetings with trainers to assess trainee learning (2) & trainers' reports

1st weekend of training
■ Knowledge enhancement: HIV testing method
■ Position of community stakeholder in research
■ Issues surrounding the research-based intervention

2nd weekend of training
■ Knowledge enhancement: community member counseling
■ Pre- and post-HIV test interview content
■ Training in motivational counseling

3rd weekend of training
■ Practical training in HIV testing interventions
■ How to perform the HIV test
■ Protocol implementation
■ Ensuring a quality process

Assessment of community stakeholder for project participation by CBO board

Diagram: Training flowchart for community front-line workers in the research project ANRS COM'TEST

2 | Practical ideas to provide suitable training for interviewers and community front-line workers

► Training of community front-line workers: ensure that they understand the importance of and reason for the research protocol

The principal issue regarding the training of community front-line workers is to establish the clear distinction between a traditional field-based intervention and one which is implemented in the context of a research project (→ Units 11 and 12).

■ *Pay special attention to the research protocol.*

The absolute necessity to fully comply with the research protocol when implementing the research-based intervention is one of the most difficult issues for community front-line workers, as they are often initially trained to modify their interventions to the specific situation or person. It is imperative that they understand the importance of following the research protocol carefully to ensure data quality, while showing empathy with study participants.

> During training, it may be helpful to discuss in detail the utility of the project's protocol and of the data collection tools with the community stakeholders involved. This would help them understand why following the rigorous and sometimes difficult protocol is of great importance. The realities of interactions between the two different worlds – community and research – must be taken into account.

■ *It is important to clearly reiterate the use and utility of each data collection tool.*

Community front-line workers need to handle many more documents in an intervention-based research project than they would in a traditional field-based one (→ Unit 13). It is important to reiterate not only how each tool must be used, but also the tool's utility for the research project's results and the possibility that the research intervention may be extended and adapted to practical field interventions once the research project is completed.

► Training on administering questionnaires: provide key competencies to combine neutrality with action

The particularities of "community-based" interviewers with respect to their professional counterparts must be taken into account during training:

■ *When the interviewers are themselves members of the community being studied: discuss their feelings about the questionnaire.*

The questionnaire may have an impact on the interviewers themselves if they are part of the community being studied. The future process of conducting participant interviews can be facilitated by group discussion during training, where each trainee interviewer expresses his/her feelings about the interviews. In this way, potential future questionnaire-based problems can also be anticipated.

■ *Pay special attention to the importance of asking questions exactly as they have been scripted.*

Community stakeholders often have a personalized relationship with individual community members. It may at times be difficult for some of them to ask the questions exactly as scripted. It is important to emphasize that a lot of thought has gone into formulating the questions in a particular way and for a particular reason. A great deal of work must therefore be carried

out during training to ensure that the interviewers have a sound understanding of the questionnaire, both in form and content. These aspects are probably more difficult for community stakeholders than for external interviewers who are used to working with standardized questionnaires.

- *■ Do not confuse administering a questionnaire with providing information to the respondent.*

"Community-based" interviewers are usually directly involved in field interventions. They often consider data collection from the point of view of such interventions and especially in terms of prevention and/or support. They may therefore consider the research interview or questionnaire as an opportunity to provide participants with advice on these issues.

It is important that the time allocated to the research project and that allocated to routine activities are respected and do not overlap:

- *■ Performing prevention interventions or providing advice at the end of the interview or upon completion of the questionnaire does not influence the interviewee's answers, and therefore data quality is maintained.* The method most commonly used is to follow the survey with a discussion during which prevention interventions can be performed. Presenting the contents of the prevention toolkit and discussing them with the interviewee facilitates moving from the survey to a prevention intervention and to providing individual support.

Comprehensive practical exercises are indispensable when training "community-based" interviewers. They help these stakeholders to familiarize themselves with the project's standardized interview, which is very different from the work they usually carry out in the field. Such exercises also help to reconcile research and intervention.

- *■ On the contrary, trying to change a participant's opinion about some of his/her practices (for example if the participant doesn't take his/her treatment) during the interview interferes in the survey and affects the results.*

3 | Training provides the opportunity to strengthen the partnership

Training provides one of the rare moments when all the CBR project's team members come together: research facilitators, community-based organization (CBO) employees (e.g. the person responsible for training or for activities related to the project's research topic etc), researchers and interviewers/community front-line workers.

In practical terms, training:

- Provides trainees with more time to build their relationship with their partners.
- Helps foster team spirit and renews interest in the project. This is especially true for interviewers/community front-line workers who have not been involved in the preliminary steps of the project.
- Helps to overcome common beliefs that community stakeholders have about researchers and vice versa.
- Enables every training participant (trainees and trainers) to become aware of and appreciate the competencies of their partners and encourages self-confidence.

Apart from its content, the time dedicated to training provides the opportunity to strengthen the partnership, discover the other and develop friendly relationships. It also helps to build team spirit and promotes the competencies of the different partners collaborating in the project.

During the training sessions for the Partages study in Morocco, the researchers not only commented on the excellent quality of the training session developed by the "Association de Lutte Contre le Sida" (ALCS), but were equally impressed by the level of knowledge of community front-line workers. For the community stakeholders, this was a confirmation that the competencies they brought to the project were worthwhile and valuable.

UNIT 15.

Survey sites and monitoring

1 | Study sites and material conditions: what are the specificities of community-based research (CBR)?

2 | Procedures for quality control and data-collection monitoring

15. Survey sites and monitoring

The implementation of a research project in the field often calls for some flexibility with respect to the procedures set out in the research protocol. Adjustments to the protocol are more frequent at the beginning of field work but may occur at any moment, especially when the study or intervention takes place in community venues or public places, or when carried out simultaneously with normal activities. It is fundamental therefore to first prepare the research site and then closely monitor what happens in it, including all the difficulties which arise, in order to ensure the safety of all the research team members and study participants, as well as the quality of research materials.

1 | Study sites and material conditions: what are the specificities of community-based research (CBR)?

Three principal sites may be used for data collection:

- The premises of the community-based organizations (CBOs) participating in the research project.
- Health care structures which are not community-based (hospitals and clinics, HIV testing centers, harm reduction information and support centers for drug users, etc).
- Outdoor spaces, such as places where CBOs work (outdoor cruising areas for MSM, mobile HIV services for drug users or sex workers, etc).

The challenge is to set up research activities in these places and preserve research quality without too much disturbance to individuals and their routine activities. Close collaboration between the researchers and community stakeholders enables them to plan the data collection process as well as possible, by adapting to site-specific constraints.

Indeed, in addition to the need for an adequate number of interviewers/community front-line workers and premises of sufficient size, a wide range of material conditions must be met to guarantee the efficient implementation of the research project ($\rightarrow$ see box).

> **Materials necessary to administer the MSM survey at outdoor cruising areas**
>
> **(HSH-LRE Study, Groupe Sida Genève)**
>
> ■ Questionnaires printed (front side only) in sufficient quantity
>
> ■ Information sheets in case of non-response
>
> ■ Clipboard
>
> ■ Pens
>
> ■ Flashlights/light
>
> ■ Magnifying glass
>
> ■ Ballot-style boxes and B4 envelopes
>
> ■ Previous MSM survey report from 2009
>
> ■ Usual intervention materials
>
> ■ Business card or "infotestvih" leaflet

► What are the risks if the conditions are not completely suitable for data collection?

Among the main problems encountered when adapting a site to suit study conditions are:

- ■ Inadequate spaces to perform interviews:
  - • Using the offices of the organization's employees, which means they must work elsewhere in unfavorable conditions.
  - • Using spaces where confidentiality is limited (e.g. busy locations).
- ■ Insufficient staff numbers with respect to the number of study participants.
- ■ Tools which are unsuitable for the study conditions.

The consequences may include:

- ■ A negative impact on the organizations' activities – overcrowded offices.

CBR is performed with and within organizational structures which have their own procedures. It is indispensable therefore to involve community stakeholders who are already present in the field – especially the study's future community front-line workers and interviewers – in order to create the most favorable conditions possible for data collection.

- ■ Psychological fatigue of the organizations' employees, volunteers and beneficiaries.
- ■ Extreme difficulty trying to mobilize community front-line workers who are overloaded by the study conditions, leading, for example, to problems recruiting study participants.
- ■ Difficulty respecting confidentiality, as the spaces used for the interview or intervention do not guarantee total confidentiality (i.e. an ethical problem).
- ■ Poor data quality due to a breach in confidentiality (e.g. greater risk that the answers given by the participant are incomplete or inexact).

► What are the practical ways to ensure good data collection conditions?

Consider coherence between the research protocol and the data collection/intervention conditions

- ■ The protocol, and especially the duration of data collection/the intervention, can be adapted to the specific characteristics of each research site.
- ■ If needed, consider temporary reorganization of the study site.

Consider availability of staff

- Identify all the positions necessary to efficiently implement the research project: staff in charge of participant recruitment, interviewers/community front-line workers, staff in charge of administrative forms and study participant compensation.
- Evaluate, as accurately as possible, the time necessary to complete each task. Overestimate if in doubt.
- Ensure that a sufficient number of people are involved in performing the study, with respect to the positions and working time required.
- Organize a meeting to bring together all the staff (CBO- and/or hospital-based) to present the research project and its implementation.
- Ensure that the appropriate hospital administration staff have been informed of the research project and have authorized its implementation.

Consider research sites and materials

It may prove difficult to adapt some spaces to meet the material conditions set out by the research protocol (confidentiality, full compliance with protocols which sometimes require the management of several different study documents, coexistence with the organizations' normal work activities, etc).

Flexibility and innovation are necessary therefore to respect both the study's scientific requirements and the working conditions of the participating structures.

- Guarantee that the study sites used for carrying out the research project are suitable: ensure that they can provide confidentiality; ensure that a sufficient number of sites are available.
- Give priority to spaces which can be fully reserved for the research project throughout the entire duration of the study (a reserved room).
- Think about the space's configuration to help the study participants feel at ease. The layout of the room where data collection occurs can have an influence on the participant (face-to-face configuration, no desk between staff member and participant, providing refreshments, etc).
- Data collection presumes that all required materials (research materials such as questionnaires, pens, etc, as well as coffee, tea and snacks) have been factored into the budget.

► Consider the possible risks for the study participants and research staff as a result of their participation in the research project

CBR is particularly interesting in that it allows research partners to study populations which are vulnerable, often marginalized, and at times criminalized because of some of their practices and/or because of political and social contexts (sex trade for sex workers, sexual relations with people of the same sex for homosexuals, illegal immigration for migrants).

Even the simple fact of participating in a research project means that the study participants, the community front-line workers and interviewers all run the risk of discrimination, the risk of retaliation, etc. Such risks are real and/or cause anxiety for potential participants. Accordingly they must be anticipated:

The risk that the local authorities will prohibit the study

Although research projects, especially those performed in criminalized populations, receive the backing of national research and health authorities (ministries, ethical committees, etc),

local authorities may not always be informed. In particularly complex situations, the research study partners may ask the appropriate officials (Ministry of Health etc) to contact local authorities and more generally to reaffirm their support for the research project. In any case, the question of the feasibility of performing the research project in such complex situations will have already been raised in order to avoid any possibility that study participants and research team members are put at risk.

The risk of police arrest

In the E-SANHOD survey, performed with MSM in the city of Douala (Cameroon), interviewers and interviewees ran the risk that they would be identified as members of a criminalized population in Cameroon and would be arrested. Several measures were taken following concerns expressed by the members of the CBO Alternatives Cameroun (a community-based stakeholder in the research project): a telephone number was made available in order that survey participants and interviewers could report any problem, so that it could be acted on quickly. The interviewers had to inform the project "focal point" of their project-related movements outside the CBO's office. Moreover, they could never travel alone (i.e. interviewers always worked in pairs). As it turned out, no incident was ever reported but all those involved in the study felt much safer working under these conditions.

2 ▌ Procedures for quality control and data collection monitoring

Although "standardized" monitoring procedures can be implemented, there is always the risk that unexpected problems will arise during data collection. It is thus very important to monitor data collection so that the project's implementation can be quickly adjusted.

The following monitoring procedures are generally used:

- *Monitoring visits*

  These are as much to ensure that the research project is being implemented correctly as they are to collectively formulate solutions to unexpected problems. They provide research partners with a clear understanding of how the study is being implemented in practice. Deviations from the research protocol can be recorded for future analyses. They also maintain direct links between the community front-line workers and the research team. These links are important in terms of coping with the sometimes tedious nature of data collection, the repetitiveness of tasks and indeed any real-world difficulties which arise during data collection (e.g. refusal of people to participate, interviewer's or interviewee's post-interview emotional distress, the inability to help someone in difficulty, etc).

- *Monitoring sheets*

- *Community front-line worker's personal logbook*

  This logbook is a tool for intervention implementation assessment. It is used to plan how the intervention might be used in the future outside the context of the research project at hand (→ Unit 17). It can also be used during data collection within the current project to further general understanding of the difficulties faced by community front-line workers/interviewers and in this way to comprehend particular problems arising at a specific stage of the intervention.

- ***Checking that questionnaires have been completed*** (for research projects where questionnaires are administered by interviewers).
- ***Follow-up calls***
- ***Follow-up emails***
- ***Project coordination meetings*** between the research project coordinators (both community- and research-based) and the community front-line workers.
- ***Intervention tools,*** such as an intervention activity log.

Some of the research project's monitoring tools may not be very well understood by the community front-line workers in the field.

Flexibility and imagination may lead to the identification of alternative tools which are already being used by the community front-line workers. The intervention activity log is one such example.

Supporting or checking? : monitoring interviewers

Scientists and CBOs may have different points of view regarding how interviewers should be monitored. Researchers must be meticulous when checking the work of CBO interviewers, especially when working with them for the first time, in order to ensure quality data. Some CBO staff fear that interviewers will be inspected during interviews instead of being monitored/supported (i.e. talking to interviewers about their problems and verifying their work by checking that questionnaires are completed). Both approaches – strict control and support – can be carried out together in a constructive fashion by combining monitoring tools. This approach helps researchers to detect problems without the interviewer feeling that s/he is being inspected. On the contrary, the feeling is more one of support – group support for the work s/he is performing.

The objective of monitoring interviewers is to ensure transparency with respect to the conditions set down for data collection and to ensure that the interviewers comply as best as possible to the requirements set out in the protocol. Effective monitoring is not necessarily standardized monitoring. It may be monitoring which is adapted to the specific field practices of front-line staff.

Interviewers are generally monitored more closely at the beginning of data collection, so that adjustments can be made quickly when unforeseen problems arise. Vigilance and availability are required throughout the duration of field work to ensure that any unforeseen difficulties will be responded to promptly and to ensure that the quality of both data collection and study interventions is guaranteed until the end of the research process.

? Reviewing together the material conditions of the research project

✔ Have we thought about even the most basic material conditions required to implement the project?

✔ Have we found an adequate balance between the planned number of participants, the number of community front-line workers/interviewers and the quality of conditions offered by the study sites where interviews are to take place?

✔ Do the material conditions meet the requirements as set out in the protocol?

✔ Can we cope if large numbers of people wish to participate at the same time (i.e. managing the flow of participants)?

✔ Can we cope with a change in time slots in order to carry out the study more effectively (i.e. adaptation to study participants' schedules)?

✔ Has each person involved in the research project enough time to perform his/her duties?

✔ Are any special measures required (in terms of safety, survey material, etc) in the communities being studied and in the data collection sites?

+ Further reading

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SECTION 4

Encouraging
an interconnection between
the research
study results and action

16.

UNIT

Data analysis:
a continuous process,
a closing stage

1 | The added value of collaboration in data analysis

2 | Methods to involve community stakeholders
and practical ideas for implementing a "co-analysis"
of data

16. Data analysis: a continuous process, a closing stage

Data analysis often appears to be the least collaborative stage in the research process: is the participation of community stakeholders necessary? In what way might they participate? How can we facilitate this participation?

Here you will find some ideas to help you move from reflection to action.

1 The added value of collaboration in data analysis

In many collaborative research studies, the strength of the partnership starts to weaken at the data analysis stage, as partners can be reluctant to collaborate in what we will call here "co-analysis". Therefore, the dialogue sometimes only starts again once the final results are disseminated.

► Factors listed as obstacles to community stakeholder involvement in the data analysis stage

These obstacles are generally associated with the high entry cost linked to scientific exchanges:

■ *The technicality of the analysis tools.*

The tools used in data analysis, whether qualitative or quantitative, are complex. In both cases, the methods employed are based on theoretical frameworks studied by researchers over many years during their academic training.

One way to overcome the difficulty associated with this technical nature of research is through capacity building. For example, research training sessions provide partners with the basic knowledge necessary to participate in an in-depth discussion about the study results during a data analysis meeting. Training sessions can be attended by community stakeholders, junior researchers and even experienced researchers who want to increase their knowledge on some of the techniques used in the research project.

■ *The technical nature of the vocabulary used.*

The terminology used for these techniques is also very specific (e.g. dependent and independent variables, multivariate analysis, weighting, grounded theory, coding, categorization, etc). Although used often and with ease by researchers, it is frequently unfamiliar to community stakeholders whose "non-expert" knowledge is more community or experience-based.

Consequently, the use of this specialized vocabulary during meetings could make it difficult for community stakeholders to properly understand and actively participate in discussions.

This difficulty can be reduced by making a strong effort to simplify and clarify the vocabulary used as well as by creating a climate of trust which allows partners to ask for clarification at any time.

■ *The difficulty for community stakeholders to find the working time needed to participate in data analyses.*

One of the issues involved is the need to finance working time for community stakeholders involved in the project (→ Unit 9). This difficulty may be partially overcome by organizing the timing of collaborative data analysis around the schedules of these stakeholders: one day or one week, depending on what is easiest for community-based organizations (CBOs) to implement.

■ *The risk that community stakeholders will not be able to distance themselves sufficiently from their routine activities.*

Data analysis consists in trying to explain what has been observed and what has been experimented with. It disentangles the processes underlying the phenomena studied. It does not however try to justify *reality* as experienced by the various stakeholders. Although it is not the purpose of a research study to make a judgment on the practices of community-based stakeholders, study results may be different from the latter's initial expectations and/or may bring some of their routine practices into question. For their part, researchers fear that data analysis will be deliberately oriented towards satisfying community stakeholders' expectations and objectives.

That said, researchers may themselves find it difficult to stand back a little and take some critical distance. Holding on tightly to their initial hypotheses prevents "alternative hypotheses" from emerging.

In both cases, flexibility and openness are necessary. Clearly explaining the reasons for participation in the research study right at the beginning of the project, as well as the trust which is built progressively throughout the project both help to minimize this risk.

► The various assets which collaboration can bring to data analysis

■ *A more-detailed description, a better understanding and explanation of reality thanks to the diversity of interpretations and a stronger grounding in the realities of the community:*

The in-depth knowledge community stakeholders have of community members' daily life helps give real meaning to the data, and sometimes helps researchers understand results which previously made no sense.

■ *Creating avenues for analysis:*

The proximity of community stakeholders to members of a specific community means they can suggest avenues for data analyses. These include ensuring that the right questions are asked when the research team considers how to go about analyzing the data gathered, combining particular variables and investigating a specific avenue in greater detail in order to better understand the preliminary results.

Collaboration ensures that the data analysis will meet both scientific and operational objectives. It improves the interpretation of results and allows research partners to share their different points of view regarding the relevance of study results.

■ *Developing analyses based on both scientific and operational objectives:*

The objectives of a community-based research (CBR) study are defined with a dual purpose: to ensure that the scientific and operational requirements are met. The collaboration between community stakeholders and researchers in the previous stages of the study ensures that these two objectives will continue to be met during this stage. Indeed this ongoing collaboration helps partners identify very specific problems, adds to scientific knowledge (in regard to existing scientific literature), and creates the possibility of implementing new interventions within CBOs, or rethinking and reworking existing ones.

2 | Methods to involve community stakeholders and practical ideas for implementing a "co-analysis" of data

The quality and impact of the analysis can be greatly enriched if an equitable partnership is maintained during the data analysis phase.

► Distinguishing the various phases in the analysis

Independently of CBR and collaborative research, it is possible to distinguish three distinct phases within the data analysis stage.

The technical phase of data cleansing or working with raw data

Once the data has been collected and entered into computer databases (for quantitative data) or transcribed (for qualitative data) work must be first carried out on the data before the real analysis can begin. For example, in quantitative analysis, this means first cleansing the database (e.g. typing errors which may have occurred when the data was being inputted are corrected). Then follows a phase where new data are produced, over successive steps, starting from a description of the original data and ending with the construction of new variables which are then used to develop the final results of the study. Statistical software programs (e.g. SPSS, EXCEL and EPI-info) are used to manage these quantitative analyses. In qualitative analysis, the data can also be coded and analyzed manually or with the use of software specially designed for qualitative analyses (e.g. INVivo, Atlas-ti). This technical work depends on the type of data collected, theoretical foundations and the methodology used.

Designing data analysis plans

In quantitative analysis, analysis plans are generally designed to explore the various research hypotheses. From these initial hypotheses, the specific subpopulation to be investigated and the variables to be introduced into the analysis are identified. Furthermore, depending on the nature of these variables, the appropriate statistical analysis needed to identify their interrelationship is defined. All of this constitutes the "analysis plan".

The actual data analysis stage

Once all the data are ready for analysis (descriptive analyses, in the form of tables or text, depending on the quantitative or qualitative nature of the method), one must first interpret what emerges from preliminary results: what results are in line with initial hypotheses? What results are unexpected with respect to these same hypotheses? What results are completely new? It is essential to examine these first interpretations to ensure they are valid and not biased by errors during previous steps. Once these first analyses are confirmed, different avenues of further interpretation can then be investigated. Through their own experience – scientific or field-based – researchers and community stakeholders open up further avenues for interpretation.

It is definitely easier to explain and understand the interrelationship between variables in quantitative research (especially through the use of tables). Nevertheless, the process for qualitative research is not so different. It involves first identifying what emerges from the data collected, finding relationships between different data sets (e.g. interviews with different types of informants, or informants whose positions on the research topic are different) and then assessing the significance of these data with regard to the research question(s).

These analysis phases are not really consecutive: the process is more of a continuous two-way exchange between data interpretation and the "technical" phases mentioned above. After the first piece of technical analysis is carried out on the data, preliminary interpretation then outlines the direction for a more in-depth analysis. This may lead to further technical work being necessary (e.g. constructing new variables through a "re-codification" process), and so on.

Community stakeholders are mostly involved in data interpretation, although they may also be involved in the technical stages of data analysis.

▶ Practical ideas for collaboration during the technical stages of data analysis

The technical stages of data analysis are usually carried out by "specialized technicians" often in research centers or in universities. During this stage, communication between those analyzing the data and those involved in the initial data collection ensures that the analytical methodologies chosen are consistent with the "reality" of the data collection process.

For example, in the Partages study, the technical team who carried out data cleansing (i.e. detection and removal of inaccurate data) highlighted some discrepancies in answers to certain items in the participant questionnaire. They were unsure whether to consider the absence of a tick as a "no" or as a "missing answer". Communication between the technical team and those involved in data collection helped clarify this problem. Feedback about the implementation of data collection and data entering processes helped the technical team to make an informed choice on how to statistically treat "missing" responses. This kind of communication between the technical analysis and data collection teams greatly improves data quality (i.e. their scientific value).

Facilitators and researcher/community stakeholder pairs (→ Unit 5) play an essential role in the technical phase, by facilitating communication between the technical team and community stakeholders.

► Practical ideas for a "co-analysis" of data within the context of a community-based research project

The main practical way to promote and facilitate co-analysis is through the organization of workshops.

These are often based on methods to encourage interaction and exchange:

- Small working groups (research topic-based, geographically-based, etc).
- Multi-stakeholder groups (researchers/community stakeholders).

They differ from each other depending on:

- The size of the group.
- The objectives: designing an analysis plan, refining the interpretation of data, etc.
- Their duration: one-day to week-long workshops.
- Their frequency: workshops may take place regularly or more occasionally.

Among the main types of workshop are the following:

Workshops on data analysis

The researchers and community research focal point(s) are gathered together at workshops designed to help them acquire a sound understanding of the preliminary descriptive data. This then helps them to decide on the most appropriate approach for data analysis. The objective here is not to directly carry out analysis, but rather to design the analysis framework(s), brainstorm ideas and directions the analysis will take and consider detailed studies based on preliminary findings. Responsibilities are then divided among the various partners.

Workshops which bring together community stakeholders and researchers ensure that data analysis is a "co-analysis". Such collaboration certainly strengthens the quality of interpretation of the results but also the construction of variables and the choices regarding which "technical" methodologies to use for data analysis.

Data analysis workshops carried out to date in different CBR projects have taken various forms: a week-long workshop, followed by other kinds of exchanges, or several one-day workshops spread out over time.

Community-based forums on data analysis

This involves a collective debate on the project's preliminary findings and initial interpretations. Research partners (researchers, community stakeholders directly involved in designing and implementing the research study, community front-line workers and interviewers, etc), the CBO's employees and volunteers all participate in this debate which is for all intents and purposes an element of the data interpretation phase.

► Practical ideas to involve study participants in data analysis

Dialogue with study participants for the purposes of compiling study results is based on a "data dissemination" phase, whereby researchers and community front-line workers discuss the results presented. Experience of this phase in previous studies highlights that this is the moment when study participants provide suggestions for data interpretation, propose possible new avenues for analysis and raise questions which will be examined in greater detail in later analyses.

Laurent Vidal highlights the contribution made by participants to data analysis during group debates on the study results: they *"take part in the process of explanation through the comparison of different points of view, through the sharing of experiences. So that these meetings also work as diagnostic and explanatory "laboratories" [...] : each participant has a story to tell, a personal viewpoint, an overall consideration, which when associated with each other, give shape to a form of analysis"* (Vidal, 2011).

In order to benefit from the contribution participants can make to the analysis phase, several practical ideas may be implemented:

Regular workshops involving debate on the research study results

Instead of considering the data dissemination stage and the associated debate involving study participants as a one-off event, it may be beneficial to organize such debates on a regular basis. Depending on the type of research study, these discussion-based workshops can occur during the data collection and/or analysis phases.

- *For iterative intervention research studies, such workshops provide the possibility to adapt the intervention during the study.*

- *For iterative qualitative research studies, the debate surrounding intermediate results may lead to the data collection process being adapted.*

During a research study on maternal health care in Senegal, the research team organized data presentation workshops. The study participants (medical doctors and midwives from the health centers where the study had been carried out) as well as other concerned stakeholders (medical authorities, community organization and local decision makers) came together for two days. The workshops were organized into two parts: the presentation of the study's results and then discussion. They comprised a "plenary meeting" and working periods in small, thematic groups (Vidal, 2011). The workshops helped to facilitate the overall study data analysis and were adapted as needed in order to focus more directly on the collaboration of study participants and other concerned stakeholders in the analysis stage.

Focus groups (discussion groups) with study participants

- *The setting-up of focus groups involving study participants means that their reactions to the preliminary findings can be obtained, and so subsequent data analyses may be refined.*

A *focus group* is a qualitative research method. It is much more than just a group meeting as it brings to light the participants' various points of view. Using this information, the social beliefs, opinions and thoughts which structure attitudes or behaviors can then be deconstructed. With regards to scientific studies, the organization of focus groups must follow specific criteria in terms of size, composition, population, place and recruitment and the role of the focus group's facilitator (Kitzinger *et al.*, 2004).

- *This research method can be used in two ways:*
  - First, by discussing certain difficult aspects of the data, a focus group may help researchers acquire a better understanding of a particular study result.
  - Second, a focus group can complement quantitative data if further investigation is needed.

This is especially the case, for example, when refining results from a quantitative survey by complementing them with qualitative methods to present the final results. In order to obtain genuinely valid avenues for future analyses from a focus group's discussion, it is important to carefully think about how the results will be presented at the beginning of the meeting: explain the objectives, methods and results of the study in a clear and understandable way; explain them in a "balanced" way, that is to say in the most neutral manner possible, without minimizing their complexity.

The use of a focus group or another research methodology different from those generally employed in research studies can be considered as a choice to use data triangulation and helps to consolidate the conclusions of the research study (Campbell and Fiske, 1959; Flick, 1992; Apostolidis, 2006).

?

Questions to ask yourselves about collaboration in the data analysis phase

✔ Have we planned for specific data analysis meetings and discussions between community stakeholders/focal points and researchers?

✔ Do we want to involve the study participants in the analysis phase?

✔ What practical methods for involving community stakeholders can be realistically implemented?

✔ Is capacity building necessary in order to genuinely involve everyone in the analysis process?

+

Further reading

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UNIT 17

Promoting the results of the research project and publications

17. Promoting the results of the research project and publications

Promoting the research project's results consists in ensuring their wide dissemination, their clarity and their contribution to changes in strategies, interventions and practices. This is a long and demanding phase in any research study. It can start as soon as the data have been collected and the first results – even preliminary findings – have been produced.

In community-based research (CBR) projects, the promotion of study results is even more important as the stakeholders engaged in the work not only aim for scientific progress but also want the results to be translated into practical field interventions. Accordingly, there are a great many targets, objectives and methods associated with the promotion of results. At this phase in the project, just as for previous steps, complementary skills need to be mobilized within the study group.

► Promoting results: for what purpose? To whom?

In situations like CBR where studies are oriented towards intervention, "promoting" the results consists both in:

- Ensuring that they are widely disseminated.
- Ensuring that they bring about social transformation.

Promoting results can be achieved by targeting five principle types of stakeholders:

- The scientific community.
- Community-based organizations (CBOs).
- Community members, especially those who have participated in the research project.
- Professionals.
- Policy makers and international agencies, if necessary.

Depending on the contexts, the objectives and the intended audience, it might be more appropriate to give priority to either written materials or to oral means of communication.

The impact of activities to promote results is time-dependent: some activities aimed at promotion can be carried out in the short term with short term impacts, others over the medium to long term.

Partners engaged in the project may use various methods to adequately promote study results to different audiences:

Target audience / Objective	Disseminating results	Producing change
Scientific community	■ Oral or poster presentations in scientific conferences. ■ Publications in scientific journals. ■ Books.	■ Expert report.
CBOs	■ Production of newsletters for internal use. ■ Meetings for members of the CBO, volunteers and employees.	■ Using the results to define new activities within the organization.
Study participants, members of the community studied	■ Focus groups. ■ Community forum.	
Professionals	■ Publications in professional journals, presentations in seminars, training workshops.	■ Developing recommendations for changes in practices.
Policy makers and international agencies	■ Press releases/press conferences.	■ Expert report. ■ Advocacy workshop. ■ Using the results to design, adapt and propose new strategies.

Table: Examples of activities to promote the results of a CBR project

Given the diversity of ways to promote the study results, it is important to determine priorities according to criteria which include:

- ■ Ethical requirements (e.g. first disseminating results to the study participants before making them widely known to the public).
- ■ The feasibility of immediately implementing the promotional activity (e.g. using existing communication tools versus designing new procedures).
- ■ The cost of the promotional activity (e.g. having budgeted funds for the promotion of the project results, using pre-existing methods/tools which have already been paid for).
- ■ Communication strategies (e.g. ensuring that certain information is not made public before an advocacy event is organized).
- ■ The specific context of the community (e.g. preference for written or oral communication).

1 | Disseminating the results of the research project

► The promotion of research results specifically for study participants and community members

The promotion of results for study participants and for community members in general is an essential stage in every research project, if only for ethical reasons. It helps the community to take ownership of the results and so facilitates future field interventions.

The methods used for this type of promotion – or in this case "presentation" – once again involve interaction between researchers and community stakeholders.

Below we list possible activities to facilitate ownership of the study by community members, as well as possible contributions by researchers and community stakeholders.

How can researchers contribute?	How can community-based stakeholders contribute?	How can both contribute together?
Prompt communication of final results		
■ Objective: Widely disseminate a summary of the final results of the research project to the study participants and community members. ■ Methods: Short leaflet or article in the organization's journal, presenting the main results of the study in a way which is easily understandable (i.e. non-technical).		
■ Modifications and additions to the first draft of the leaflet/article.	■ Writing the leaflet or article.	■ Mutual agreement about and definition of the results to be presented.
Focus group involving study participants and/or community members		
■ Objective: Present the results of the research project to the participants. Ensure the participants have a sound understanding of the results and feel they can take ownership of them. ■ Methods: Small focus groups where results are presented and discussed (→ Unit 16).		
	■ Identifying possible areas for discussion about the results and their implication for the participants.	■ Co-construction of the focus group framework. ■ Conducted by a researcher, a community stakeholder, or both.

How can researchers contribute?	How can community-based stakeholders contribute?	How can both contribute together?
Community forum to ensure knowledge "ownership"		
■ Objective: Disseminate the results so that all the community members understand them and take ownership of them.		
■ Audience: The participants, the CBO involved in the project and its members, partner CBOs and their members.		
■ Methods: One- or two-day workshop where the results are presented and discussed; sub-group activities (→ Unit 16).		
■ Presentation of the results.	■ Group reflection on those results which may have a direct effect on the daily lives of community members.	■ Possibility of co-facilitation of the workshop. Possibility of using facilitation methods by quite a broad group of researchers and community stakeholders.

► The promotion of research results specifically for the scientific community: collaboration in scientific production

There are two optimal types of communication which the scientific community can use when the study results about a specific research question or topic are sufficiently solid.

Presentations at scientific conferences

- ■ *Objective:* Disseminate the results to a wide academic audience.
- ■ *Conferences:* National and international, thematic (HIV/AIDS etc), academic, discipline-specific or professional.
- ■ *Methods:* Submit abstracts and give presentations at conferences.

If the presentation is accepted, the oral presentation or scientific poster (a display communicating information about the research study) must follow specific instructions, as laid out for scientific production. These instructions are similar to those for the abstract.

Publications in scientific journals

- ■ *Objective:* Contribute to scientific knowledge.
- ■ *Method:* Writing an article following strict scientific norms.
- ■ *Type of journals:* Depending on its aim and contents, the article is submitted to discipline-based scientific journals *(Journal of Health Psychology, Social Sciences and Medicine,* etc), "theme"-based journals *(AIDS Care, JAIDS*, etc) or scientific journals directed both at science and intervention *(Journal of Social Issues,* etc).

Depending on the specific case, presentations and articles are based on all or part of the results obtained for a specific element of the study. Articles and publications must comply with different scientific norms depending on the academic discipline. For example, in medicine and public health, abstracts and publications follow a standard format: background/method/results/conclusion. The formats used for publications in social sciences are more varied and flexible.

How can all types of partners be involved in the process?

Creating an abstract or a scientific article is the final step in the analysis of a specific research question. These documents not only demonstrate the reasoning and the scientific methods behind the study but highlight the important scientific contribution of its results to the understanding of a specific research question or an intervention. This requires experience, together with a broad knowledge base and very good understanding of the process of writing a scientific article or abstract. At this point in CBR, collaboration is useful and improves the quality of the analyses produced.

- The co-production of ideas and interpretation of data, that is to say the primary message which the scientific communication wishes to transmit, lies at the heart of co-producing an abstract or a scientific article. Collaboration in a scientific communication is therefore closely linked to collaboration in analysis (→ Unit 16).

- In practical terms, partners can discuss the primary focus of the article/abstract before starting to write: what is the problem? How were the results produced? How are these results interpreted in this article/abstract? What is the key message of this communication?

- Once the main guidelines have been defined, one person is usually given the responsibility of writing a preliminary draft of the article/abstract which meets the requirements of scientific writing. This draft will then be discussed in great detail, reworked and/or modified by the other members of the working group.

Publication issues: authorship and data ownership

Defining the terms of data ownership and of publication is a very important issue in CBR.

Some CBR collaborations have preferred to remain vague about this issue in order to avoid having to tackle it. Indeed, this question is made all the more difficult by the fact that many partners are involved in CBR collaborations, which in turn implies the need for much greater management of this issue. Accordingly, it may be advantageous to insert specific regulations which focus on authorship and data ownership in the collaboration charter (→ Unit 7).

- *Who do the study results belong to?*

According to the principle of equity between partners which lies at the heart of CBR, the results should remain the property of all the collaborators in the research team, that is to say both the community stakeholders and the researchers.

- *Who should be included in the list of authors? How do we decide which authors to include and the order of their inclusion?*

Equity between the partners implies that, in principle, researchers and community stakeholders should be represented relatively equally in the list of authors. The publication's authors include those who, strictly speaking, drafted the article, those who contributed to the analysis of the results and those who designed and implemented the research project.

The first author is generally, but not necessarily, the person who wrote the largest part of the article. In public health publications, the last author is the person who conceived, designed and organized the overall project. The other authors included in the list are those who contributed to the writing of the article, especially through their involvement in data analysis, or by writing parts of the article or indeed by reviewing it and making additions.

In a group project, several individuals may have "conceived" the study, or co-conceived or indeed co-written the article. Accordingly, it is important to bear in mind the equity among the various stakeholders/authors involved, by looking globally at the publications stemming from the collaborative research project to date as opposed to considering publications on a one-by-one basis.

In CBR, equity between the community stakeholders and the researcher is an essential element.

For example, first authors may be those who made a direct intellectual contribution to the article, while the subsequent authors may have contributed to the research project without having directly participated in data analysis or in the writing of the article.

■ *How do we ensure that participation is recognized in situations where a great number of people have been involved, without creating an unnecessarily long list?*

Choosing which people to list as authors as well as the order in which they are listed are two important issues for scientific publications. These choices must take into account the partners' professional requirements and must recognize the work carried out by the whole group.

In CBOs, many more people are involved in the CBR project than simply the organization's focal point. Volunteers and team members who have also contributed want their participation to be recognized in publications. It is possible to recognize everyone's participation by simply writing the name of the research group, for example: "and the Partages group", and then publishing (at the end of the article, on the research study website, etc) an appendix where the individual members of the group are listed.

2 | Translating results into action

► How to promote the research results in CBOs

There are many and varied activities/interventions which can be used to promote study results in CBOs. These range from the production of support materials in order to present the results in a clear and understandable manner, to group discussion about how the results may be translated into practical field interventions, to the design of new field intervention projects.

Although CBR focuses on equity and collaboration throughout the whole research process, some promotional activities are not directly linked with those normally associated with research activities. Consequently the question of collaboration arises once again.

For community stakeholders, most of these promotional activities are already included in their job descriptions. For researchers however, these activities are not part of their main mission.

At this stage in the process different CBR projects develop a flexible approach to collaboration, where each partner's interests and available time are taken into consideration. On the following page are some ideas for those who would like to be involved in this promotion stage.

How can researchers contribute?	How can community stakeholders contribute?	How can both contribute together?
Tools for routine information about the study		
■ Objective: To regularly inform organization members engaged in the study about any developments. ■ Methods: Newsletters (monthly, quarterly) about the study's progress as well as routine distribution of results (for example, by topic). ■ CBOs conducting several studies simultaneously have created regular newsletters to inform members about all their ongoing research projects.		
■ Selecting data according to a specific topic.	■ Writing the newsletter.	■ Joint definition and agreement on the main theme of the particular newsletter.
Prompt communication of final results		
■ Objective: To disseminate the final study results promptly to all the members of the organization. ■ Methods: A short leaflet or article in an organization journal, presenting the main results of the study in a non-technical way.		
■ Modifications and additions to the first draft.	■ Writing the leaflet or article.	■ Mutual agreement about and definition of the results to be presented.
Workshop to help the CBO take ownership of the research results		
■ Objective: To ensure that the organization members who were engaged in the research study have a sound understanding of the research results so that they can be translated into practical field interventions. To adapt existing field interventions. ■ Methods: Depending on the needs identified: presentation of results, discussion about their significance and implications for interventions. ■ Regional or national workshops.		
■ Production of topic-specific materials based on data. ■ Participation in discussions about how the research-based intervention can subsequently be translated into a practical field intervention (implementation analysis).	■ Needs assessment within the organization. ■ Identification of practical tools to facilitate understanding, ownership and translation of data/ research-based intervention into a practical field intervention. ■ Identification of possible practical interventions.	■ As with the training sessions, the possibility of a co-constructed and co-organized workshop.

How can researchers contribute?	How can community stakeholders contribute?	How can both contribute together?
Using data to develop a new field-based intervention project ■ Objective: To propose a new field-based intervention project to community members. ■ Methods: Designing a new project based on the current study's results (intervention research) and/or on the community needs identified by the current study (descriptive and analytical research). Using these data for funding applications, to justify the importance of the project. ■ Working sessions within the CBO.		
■ Participation in discussions about how the research-based intervention can subsequently be translated into a practical field intervention (implementation analysis).	■ Project design. ■ Discussion about possible changes to the organization's action plan.	■ Joint discussion about the translation of the research-based intervention into a practical field intervention.

Using the lessons learned from the implementation analysis: a tool to translate an intervention from a research-based context to a practical field-based one

"We carried out a discussion on the continuity between the research study and subsequent real-life interventions. It wasn't easy, because the methods we thought about using for the practical intervention weren't exactly the same as those that had been assessed by the study-based one. For example, during the research study, we carried out community HIV testing in centers which were both anonymous and free of charge. But now we have decided to offer HIV testing as part of the organization's services (Community stakeholder, France)."

Intervention-based research evaluates an intervention which is implemented in a strictly defined way, according to research requirements. If the genuine utility of this research-based intervention is demonstrated at the end of a research study, community front-line workers will naturally want to implement it into their routine field activities. However, translating this intervention from something which is research-based to something practical is not necessarily easy or immediate. In order to help community front-line workers evaluate the implementation, adaptation and translation of such an intervention for practical use, an "implementation analysis" can be carried out.

The implementation analysis which stems from the result of the intervention evaluation is both a tool for research and action

An implementation analysis helps to identify the elements or factors which change during the transfer of a research-based intervention to a practical field setting, and which could limit the efficacy of this new field intervention. In this way, the implementation analysis helps to provide improved external validity, that is to say, information about how the research-based intervention might be transferred to other contexts. The implementation analysis not only furthers understanding about the potential efficiency of the proposed intervention, but also about different stakeholders' experience of it. Furthermore it increases understanding about the factors explaining the study results, with a view to making the modifications necessary to translate the research-based intervention into an effective practical field-based one (Champagne and Denis, 1992).

Data informing the possible implementation of the field-based intervention can be collected during qualitative interviews or by using personal logbooks, filled in by community front-line workers during the intervention research study.

The translation of the research-based intervention into a practical field-based one may be facilitated when community stakeholders use the implementation analysis.

Several academic and community practices can be considered in order to facilitate the translation of results into action. Nevertheless, this is not a simple task and requires constant supervision and support over the short and medium term.

In this case, the process of translating research results into action is first tackled by the CBO which carried out the research study. However, once the organization has concluded this process "internally", the process often continues elsewhere. The aim is to extend successful pilot interventions to other organizations and professional structures. This may occur informally if the various organizations are already in contact with each other, or through workshops, training sessions, community capacity-building events, internships, etc.

► Activities specifically designed to promote research results to policy makers

In what circumstances can research results lead to a change in public policy?

In CBR, activities designed to promote the results of the research to policy makers and to other partners engaged in the fight against HIV/AIDS (e.g. other organizations and stakeholders, etc) are developed using both researcher and community stakeholder expertise.

Assessing results while taking into account the difficulties met in the field, developing a coherent public health action plan and making practical recommendations from an analysis of the study results, are all essential elements of researchers' expert knowledge and their work. CBOs committed to social transformation have expert know-how in advocacy and communication. Combined, all this expertise can be used to launch a debate, ensure that a particular concern is acknowledged and that related recommendations become part of the political agenda. CBR also permits a broader conceptualization of what expertise means, as it is pluralistic, and not simply scientific-based. It is closely associated with the expertise of both researchers and community members and the acknowledgement and appreciation of "expertise gathered from real-life experience".

Below are some ideas for activities to bring about change at the policy-making level:

How can researchers contribute?	How can community stakeholders contribute?	How can both contribute together?
Advocacy workshop		
■ Objective: To convince decision makers to review their policies by presenting substantiated arguments. ■ Methods: A meeting of the stakeholders concerned; organizing debates and presentations.		
■ Presentation of the research results (provides scientific backing for the research study).	■ Make contact with partners and decision makers. ■ Organize the workshop.	■ Joint definition of the issues to tackle and the results to present. ■ Make recommendations for public policy change.

How can researchers contribute?	How can community stakeholders contribute?	How can both contribute together?
Dissemination of the results in the media		
■ Objective: Widespread dissemination of the results. ■ Target audience: Mainstream media (regional, national, international), community-based media (community press, community radio stations, etc). ■ Methods: Press releases, press conferences, publications in various communication media.		
■ Participation in press conferences (scientific expertise). ■ Press releases/articles may contain a citation or an interview with the researchers.	■ Coordination of press contacts. ■ Participation in press conferences (community-based expertise). ■ Writing press releases/ organizing press conferences. ■ Possibility of mobilizing organization activists for advocacy-related activities in order to attract media attention.	■ Definition of the issues to tackle and the results to present.
Using the results to change national strategies		
■ Objective: Influence the content of national strategic plans. ■ Methods: Inserting related elements in national strategic plans and national action plans, producing expert reports.		
■ Provide recommendations arising from the results by highlighting the scientific expertise involved in the study.	■ Provide recommendations arising from the results, by highlighting the field expertise and the expertise brought by CBR.	■ Make recommendations for public policy change.

Activities specifically designed to promote research results to policy makers and to those in charge of implementing health policies largely come under the competency of CBOs. Nevertheless, collaboration between community-based stakeholders and researchers at this step helps to strengthen the study's perceived legitimacy and increases the impact of the arguments put forth.

Some questions to ask yourselves about promoting the study results

✔ Which audiences should we target to disseminate our research results?

✔ What resources (human, material, etc) do we have?

✔ What materials/media are most suitable in terms of our target audience?

✔ How would each partner like to participate in promoting our results?

✔ Do we need everyone to be involved in promoting our results, whatever the media? When would the presence of both researchers and community stakeholders really be an asset in terms of promoting our results?

Further reading

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Le Clerc, R., Flores, J. (2000). Outillons-nous. Modèle d'outil d'appropriation des connaissances, d'adaptation des interventions et de développement d'expertise en recherche communautaire sur la base de résultats de recherches scientifiques ou d'évaluation d'intention. Montréal. COCQ-Sida.

Weiss, C.H. (1979). The many meanings of research utilization. Public Administration Review. 39: 426-31.

APPENDICES

A list of the main community-based research and collaborative research studies mentioned in the toolkit

► ANRS AERLI

This study focuses on the evaluation of the effects of support and educational sessions on the risks associated with injecting drugs (AERLI) for people who inject psycho-active drugs. It is a collaboration between the Methodology Innovation Research Evaluation (MIRE) department of the French CBO AIDES, Doctors of the World and the research unit 912 of INSERM (France). Data collection is carried out in several harm reduction information and support centers for drug users (CAARUD) in France. This research study, funded by the French national agency for research on AIDS and viral hepatitis (ANRS), was initiated in 2011.

► ANRS COM'TEST

This research study aimed to evaluate the feasibility of offering community-based and non-medicalized HIV tests using rapid HIV testing. It was carried out by the organization AIDES on men who have sex with men (MSM). The study was a partnership between the Department of Infectious Diseases in the Hospital of Tourcoing in France and the Methodology Innovation Research Evaluation (MIRE) department of AIDES. It was carried out in four AIDES sites (Montpellier, Bordeaux, Lille and Paris) in France between 2008 and 2010 and was financed by the ANRS.

See http://depistage.aides.org/, under the heading "Les projets de recherche".

► ANRS DRAG

The primary objective of this research study was to implement and evaluate a rapid HIV testing intervention accompanied by counseling provided by a front-line worker from the organization AIDES. The other objective was to compare this type of intervention with the traditional one provided by a team from a free and anonymous HIV testing center (CDAG). The study focused on MSM over 18 years old in Marseilles, Nice and Paris. Concluded in April 2011, it was financed by the ANRS.

See http://www.anrs.fr/VIH-SIDA/Sante-publique-Sciences-sociales/Actualites/Lancementde-la-recherche-ANRS-DRAG-TEST.

► ANRS IPERGAY

The aim of this trial is to evaluate a HIV-infection prevention strategy in gays/MSM using an "on demand" antiretroviral treatment (Truvada® or Truvada® placebo). The treatment is only taken during periods of sexual activity. The trial is a partnership between the Infectious Diseases Department at Hôpital Saint Louis (Paris), the organization AIDES and an independent multi-CBO advisory committee. The pilot phase of the project started at the end of January 2012 in Lyon and Paris and will last one year. Canada is also expected to participate in this trial, which is sponsored by the ANRS. Four years of study will be required to complete the project's objectives.

See http://www.ipergay.fr

► ANRS PARCOURS

The aim of this study is to inform on the place of HIV/AIDS and hepatitis B in the life course of people born in sub-Saharan Africa and living in the Ile-de-France administrative district in France. It is being carried out by the Centre Population & Développement (CEPED). The organizations AIDES, COMEDE, FORIM, RAAC-SIDA and SOS Hépatites are involved. The study started in 2011 and is funded by the ANRS.

See http://www.parcours-sante-migration.com

► ANRS VESPA

The objective of the research study "VIH: Enquête sur les personnes atteintes (VESPA)" was to provide a detailed picture of the living conditions of people living with HIV in metropolitan France and in French overseas administrative districts. It was carried out by the research units 912 and 1018 of INSERM in France, in collaboration with HIV/AIDS organizations. The VESPA study took place in 2002/2003 and the VESPA 2 study in 2010/2011 throughout metropolitan France, in the four French overseas administrative districts and in Saint-Martin. Both studies were financed by the ANRS.

See http://www.anrs.fr/VIH-SIDA/Sante-publique-Sciences-sociales/Actualites/Vivre-avecle-VIH-une-nouvelle-enquete-ANRS-Vespa

► E-SANHOD

The aim of this study, initiated by the CBO Alternatives-Cameroun with the support of the CBO AIDES and Coalition PLUS, was to describe and analyze the sexual trajectories and sexual risk taking in regard to HIV infection in MSM in the city of Douala (Cameroon). Carried out in 2008, the study provided Alternatives-Cameroun with stronger advocacy arguments for increased consideration of MSM in programs in the fight against HIV/AIDS in Cameroon. It also permitted the community-based organization to suggest ways to implement preventive interventions specific to this population.

See http://www.ncbi.nlm.nih.gov/pubmed/19703845

► HSH-LRE Survey

This survey was carried out on men who frequent outdoor cruising areas. Its aim was to better document their needs over time, in order to adapt community-based organizations' field interventions. It was carried out by the CBO Groupe Sida Genève, in collaboration with Swiss French HIV organizations (Antenne sida du Valais romand, Profa, Empreinte, Groupe sida Neuchâtel, Groupe sida Jura, Vogay, Sarigai, Dialogai and the alpine division of the French association AIDES with the help of AIDES' Methodology Innovation Research Evaluation (MIRE) department). The work was supported by the Institute of social and preventive medicine (IUMSP) at Lausanne University, Switzerland. It was first carried out in 2009 and a second time in 2011.

See http://www.groupesida.ch/media/documents/enquetehsh.pdf

► Oméga

This study was based on monitoring a cohort. Its aim was to better understand why and, most importantly, how HIV continued to be transmitted inside the gay community in Montreal, despite prevention efforts. It was carried out in collaboration with research organizations, public policy makers, the community-based organization Action Séro-Zéro and the Quebec coalition of community-based organizations in the fight against HIV/AIDS (COCQ-Sida).

The study participants of the Oméga cohort were located in Montreal and the surrounding area. The study started in 1996 and finished in the summer of 2003.

See http://www.fugues.com/main.cfm?l=fr&p=100_article&Article_ID=460&rubrique_ID=60

► Partages

This study consists in a comparative analysis of the factors associated with disclosure and non-disclosure of serostatus in people living with HIV and registered in community-based organizations. It is a partnership between Coalition PLUS – an international coalition of community-based organizations – and a researcher from the Social Psychology research Group (GRePS) at Université Lumière Lyon 2, as well as other scientific partners in each of the participating countries. Data collection, now completed, took place in 5 countries (Ecuador, Mali, Morocco, Democratic Republic of the Congo and Romania). The study started in 2010 and has received financial support from the ANRS and Sidaction.

See http://www.coalitionplus.org/index.php?option=com_content&view=article&id=55&Itemid=64&lang=fr

► Pouvoir Partager/Pouvoirs Partagés

Pouvoir Partager/Pouvoirs Partagés is a long-term program enabling women living with HIV/AIDS to 1) appreciate the difficult contexts of their lives 2) make informed decisions 3) plan practical actions/strategies in order to take responsibility for their decision to disclose or not disclose their serostatus. This program is a partnership between several community-based organizations including COCQ-Sida. It was developed in Quebec and validated in 2006-2007 using a pilot-study, with the participation of 26 women living with HIV and four community front-line workers from the Montreal region. Following this first project, the program was culturally adapted to Mali with the financial support of the IRSC (Canada) and Fondation de France (France).

See http://www.creces.uqam.ca/Page/default.aspx

List of interviews conducted for the creation of this toolkit

► Interviews in Romania

[1]   Florin Lazăr, Researcher, University of Bucharest, 23 February 2011

[2]   Maria, Interviewer, Social worker, ARAS, 25 February 2011

[3]   Ludmila Verdeş, Research projects officer, ARAS, 25 February 2011

[4]   Traian, Interviewer, Social worker, ARAS, 25 February 2011

[5]   Monica Dan, Monitoring, Evaluation and Community-based Research Coordinator, ARAS, 26 February 2011

[6]   Maria Georgescu, Executive Director, ARAS, 28 February 2011

[7]   Emil Pâslaru, Sociologist, Operations Research, 28 February 2011

[8]   Nicoleta Dascalu, Project Coordinator, ARAS, 28 February 2011

[9]   Liana Velica, Project Coordinator, ARAS, 28 February 2011

► Interviews in France

[10] Joseph Situ, AIDES RAAC-sida, 29 March 2011

[11] Elise Bourgeois-Fisson, MIRE (Methodology Innovation Research Evaluation), AIDES, 30 March 2011

[12] Annabel Desgrées du Loû, Research Director, IRD, 31 March 2011

[13] Fred Eboko, Senior researcher, IRD, 1 April 2011

[14] France Lert, Research Director, INSERM, 4 April 2011

[15] Jean-Marie Le Gall, Supervisor of the MIRE (Methodology Innovation Research Evaluation), AIDES, 5 April 2011

[16] Pierre Chappard, ASUD, 14 April 2011

[17] Veronica Noseda, Vincent Douris, Social Sciences Mission, Sidaction, 15 April 2011

[18] Arnaud W. Simon, Supervisor of the prevention department, AIDES, 3 May 2011

[19] Daniela Rojas, Community-based Research Coordinator, MIRE (Methodology Innovation Research Evaluation), AIDES, 5 May 2011

[20] Christine Calderon, Consultant, 11 May 2011

[21] Marion Mora, Coordinator, INSERM, 25 November 2011

► Interviews in Morocco

[22] Dr. Kamal Alami, UNAIDS representative in Morocco, 22 April 2011

[23] Dr. Latifi, Service IST/Sida, Department of Epidemiology and the fight against infectious diseases, 22 April 2011

[24] Samira Abderrahim, Supervisor of Training and of the Support Fund for Project Partners (FASP), ALCS, 22 April 2011

[25] Fouzia Bennani, Director General, ALCS, 22 April 2011

[26] Hakima Himmich, President, ALCS, 22 April 2011

[27] Mehdi Karkouri, General Secretary, Training focal point at the National Bureau, ALCS, 22 April 2011

[28] Nadir, Interviewer, Community front-line worker , ALCS, 27 April 2011

[29] Dr. Mohamed Loukid, Lecturer, Cadi Ayyad University Marrakech, 28 April 2011

[30] Pr. Mohamed Kamal Hilali, Professor, Cadi Ayyad University Marrakech, 28 April 2011

[31] Alise Abadie, Research and International projects officer, ALCS, 28 April 2011

[32] Souad, Interviewer, 29 April 2011

[33] Rim, Interviewer, Community front-line worker, ALCS, 29 April 2011

► International interviews (with members or partners of Coalition PLUS)

[34] Mélina Bernier, Research Facilitator, COCQ-SIDA, Canada, 9 May 2011

[35] Henri Mukumbi, Director of AMO-Congo, Democratic Republic of the Congo, 11 May 2011

[36] Amira Herdoiza, Executive Director, KIMIRINA, Ecuador, 12 May 2011

[37] Martine Somda, President, and Brigitte Palenfo, General Secretary, REVS+, Burkina Faso, 12 May 2011

[38] Nicolas Charpentier, Project Coordinator, Groupe Sida Genève, Switzerland, 13 May 2011

[39] Joanne Otis, Chair and Professor in Health Education, UQAM, Canada, 19 May 2011

[40]   Eddy Kieto Zola, Lecturer and Researcher, Ecole de Santé publique, University of Kinshasa, Democratic Republic of the Congo, 20 June 2011

From collaborative research to community-based research

A methodological toolkit

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Collection Sciences sociales et sida

Emerging issues in HIV/AIDS prevention and care are leading to an ever-growing interest in community-based research and, more globally, in researcher/community collaborations. An increasing number of researchers and community stakeholders are now looking for practical tools in order to work together.

Coalition PLUS, together with the ANRS and the research team from the community-based research study Partages, desired to provide all those involved in the fight against HIV/AIDS – researchers and community-based stakeholders alike – with information about experiences and lessons learned from community-based research projects carried out in francophone countries over the last ten years.

This toolkit explores the various issues surrounding collaborative research, be it biomedical or social science-based, intervention oriented or not. It examines the definitions and origins of community-based research, and investigates the added value which collaboration brings to research quality. Based on the experience of stakeholders, it suggests practical ways about how to build, organize and sustain a partnership between researchers and communities. Finally, by providing feedback about real experiences, theoretical considerations and methodological elements, this toolkit invites the reader to explore the ways partners can interact and work together at each step of a research project.

Conceived and designed as a methodological guide, this toolkit helps share experiences and encourages reflection on how to practically go about constructing a research project. We hope it will provide valuable support to individuals who are already working in collaborative research and arouse interest in those who have not yet tried it, be they researchers, clinicians or community front-line workers.