



BUILDING TOGETHER

A reflection on community-based participatory research priorities in relation to HIV/AIDS in a remote region of Quebec

Oscar Labra, Gabriel Gingras Lacroix, Augustin Ependa, Sylvie Isabelle, Juan Pablo Bedoya Mejia, Gilles Tremblay, Marie-Ève Giroux, Alexandre Viau, Mélanie Beaucage, Kent Monteith, Dominic Bizot, Ray Bustinza et Tommy Cousineau

Volume 37, numéro 2, 2020

URI : <https://id.erudit.org/iderudit/1075112ar>
DOI : <https://doi.org/10.7202/1075112ar>

[Aller au sommaire du numéro](#)

Éditeur(s)

Canadian Association for Social Work Education / Association canadienne pour la formation en travail social (CASWE-ACFTS)

ISSN

2369-5757 (numérique)

[Découvrir la revue](#)

Citer cet article

Labra, O., Gingras Lacroix, G., Ependa, A., Isabelle, S., Bedoya Mejia, J. P., Tremblay, G., Giroux, M.-È., Viau, A., Beaucage, M., Monteith, K., Bizot, D., Bustinza, R. & Cousineau, T. (2020). BUILDING TOGETHER: A reflection on community-based participatory research priorities in relation to HIV/AIDS in a remote region of Quebec. *Canadian Social Work Review / Revue canadienne de service social*, 37(2), 77–96. <https://doi.org/10.7202/1075112ar>

Résumé de l'article

L'objectif de l'article est de souligner l'importance de la recherche participative communautaire, impliquant des acteurs locaux et les chercheurs institutionnels, dans l'établissement des priorités de recherche locales et régionales en matière de VIH/SIDA. Les auteurs décrivent un processus de réflexion de 11 mois mené par un collectif de recherche dans la région de l'Abitibi-Témiscamingue, dans le Nord du Québec. Parmi les résultats importants du processus de réflexion et de discussion conjoint, mentionnons : le développement des capacités locales de recherche et d'action collective, impliquant des universitaires et des praticiens; la valorisation de la recherche participative; et l'accessibilité accrue des connaissances issues de la recherche pour les acteurs communautaires impliqués dans la lutte contre le VIH/SIDA. Contrairement aux méthodes de recherche plus traditionnelles, l'approche participative situe le pouvoir au sein d'un collectif de recherche qui détermine conjointement, tout au long du projet, les priorités qui reflètent le mieux les besoins locaux en matière de recherche sur le VIH/SIDA. Ce processus initial de discussion a également abouti à la validation conjointe d'une prochaine demande de subvention qui sera soumise aux Instituts de recherche en santé du Canada (IRSC).

BUILDING TOGETHER:

A reflection on community-based participatory research priorities in relation to HIV/AIDS in a remote region of Quebec

Oscar Labra¹

Gabriel Gingras Lacroix

Augustin Ependa

Sylvie Isabelle

Juan Pablo Bedoya Mejia

Gilles Tremblay

Marie-Ève Giroux

Alexandre Viau

Mélanie Beauceage

Kent Monteith

Dominic Bizot

Ray Bustinza

Tommy Cousineau

Abstract: The objective of the article is to underline the importance of community-based participatory research, which involves institutional

Oscar Labra and Augustin Ependa are associate professors in the Département du développement humain et social, at the Université du Québec en Abitibi-Témiscamingue. Gabriel Gingras Lacroix is a doctoral student in health sciences at the Université du Québec en Abitibi-Témiscamingue. Sylvie Isabelle is the president of the Coalition d'aide à la diversité sexuelle de l'Abitibi-Témiscamingue. Juan Pablo Bedoya Mejia is a physician at the Centre de Santé et de Services Sociaux des Aurores-Boréales. Gilles Tremblay is a professor at Université Laval. Marie-Ève Giroux is the executive director of the Centre des R.O.S.É.S. de l'Abitibi-Témiscamingue. Alexandre Viau is a street outreach worker at Arrimage Jeunesse. Mélanie Beauceage is a health worker at the Centre de santé Mino-Tehevin. Kent Monteith is the president of the Coalition des organismes communautaires québécois de lutte contre le SIDA. Dominic Bizot is a professor at the Unité d'enseignement en travail social at the Université du Québec à Chicoutimi. Ray Bustinza is a physician at the Institut national de santé publique du Québec. Tommy Cousineau is the director of Groupe Image.

Canadian Social Work Review, Volume 37, Number 2 (2020) / Revue canadienne de service social, volume 37, numéro 2 (2020)

researchers and community practitioners, in establishing local and regional research priorities in relation to HIV/AIDS. We describe an 11-month-long reflection process conducted by a research collective in the Abitibi-Témiscamingue region of northern Quebec. The significant results of the joint reflection and discussion process included: the development of local capacities for research and collective action, involving academics and practitioners; the valorization of participatory research; and the increased accessibility of research-based knowledge for community actors involved in the fight against HIV/AIDS. In contrast with more traditional research methods, the participatory approach situates the balance of power within a research collective that jointly determines, throughout the course of the project, the priorities that best reflect local needs for HIV/AIDS research. This initial process of discussion resulted also in the joint validation of a forthcoming grant application to be submitted to the Canadian Institutes of Health Research (CIHR).

Keywords: research collective, community-based research, HIV/AIDS, action research

Abstré : L'objectif de l'article est de souligner l'importance de la recherche participative communautaire, impliquant des acteurs locaux et les chercheurs institutionnels, dans l'établissement des priorités de recherche locales et régionales en matière de VIH/SIDA. Les auteurs décrivent un processus de réflexion de 11 mois mené par un collectif de recherche dans la région de l'Abitibi-Témiscamingue, dans le Nord du Québec. Parmi les résultats importants du processus de réflexion et de discussion conjoint, mentionnons : le développement des capacités locales de recherche et d'action collective, impliquant des universitaires et des praticiens; la valorisation de la recherche participative; et l'accessibilité accrue des connaissances issues de la recherche pour les acteurs communautaires impliqués dans la lutte contre le VIH/SIDA. Contrairement aux méthodes de recherche plus traditionnelles, l'approche participative situe le pouvoir au sein d'un collectif de recherche qui détermine conjointement, tout au long du projet, les priorités qui reflètent le mieux les besoins locaux en matière de recherche sur le VIH/SIDA. Ce processus initial de discussion a également abouti à la validation conjointe d'une prochaine demande de subvention qui sera soumise aux Instituts de recherche en santé du Canada (IRSC).

Mots-clés : recherche collective, recherche communautaire, VIH/SIDA, recherche-action

ACKNOWLEDGMENTS

This project was made possible in part by financial support from the

Canadian Institutes of Health Research (CIHR). Application Number 398806.

COMMUNITY ACTORS HAVE INVARIABLY PLAYED a leading role in bringing help and support to populations affected by the HIV/AIDS pandemic (Otis, 2015). It is important to note from the outset that, for the purposes of the present study, the term “community actors” will be used to denote social and health professionals working with people with HIV/AIDS. Given their engagement and efforts in developing new intervention methods, these actors want to contribute to research projects that impact their communities (Cargo & Mercer, 2008; Girard, 2016). Moreover, HIV/AIDS research has accorded increasing importance to the inclusion of the knowledge and expertise of local actors, and Canadian research institutions, in particular, are notable in this respect (Bernier et al., 2015). Community-based research is gaining recognition as a highly fruitful avenue for the co-construction of knowledge (Israel et al., 2013; Israel et al., 2017).

Community-based participatory research (CBPR) aims to create balanced and equal collaborative partnerships between researchers and actors, who contribute a breadth of knowledge and expertise to understanding and improving community health (Cargo & Mercer, 2008; Demange et al., 2012; Guta et al., 2013). Community-based research, therefore, prioritizes the concerns of community actors (Israel et al., 2013; McIntyre, 2007; Riffin et al., 2016). As a result, the approach favours both an increased focus on issues heretofore overlooked by external experts and a diversification of analytical perspectives (Absolon & Dion, 2017; Demange et al., 2012). Consequently, the engagement in which community-based research is rooted engenders an empowerment that stimulates social change (Minkler & Wallerstein, 2011; Wallerstein & Duran, 2008).

As community-based approaches have taken on an increased importance in research concerned with the health and wellbeing of at-risk groups, researchers have also increasingly attempted to better define, conceptualize, and model this approach to research (Belone et al., 2016; Berkowitz, 2001; Cacari-Stone et al., 2014; Khodyakov et al., 2013; Wallerstein et al., 2018). In the analysis of O’Fallon and Deary (2002), CBPR incorporates six core principles, which are to: 1) stimulate the collaboration of all actors during each stage of research, 2) favour a reciprocal learning environment among team members, 3) ensure that research projects are defined and directed by the community, 4) disseminate results that are useful for the community, 5) promote culturally appropriate research projects, and 6) identify and acknowledge the identity of the community under study. Flicker (2008), on the other hand, has highlighted several obstacles common to community-based research projects, including large time and energy investment

requirements, high monetary costs, and a lack of clarity in role definitions among collaborators and in decision-making.

The present article examines a joint reflection process in which researchers and a variety of local actors in a remote Quebec region together defined the priorities of a community-based research project on HIV/AIDS issues. This process of reflection sought to guide the foundation of a collaboration between university-based researchers and local practitioners, who took on the role of actors-researchers within the project's research collective. The project outlined in the present article is ongoing: the initial planning phase, including the discussion and reflection processes described below, has been completed. Subsequent phases outlined below are forthcoming. The project is scheduled for completion within five months as of this writing.

The present article describes an experiment in developing a community-based research protocol within a project aiming to study attitudes towards and knowledge of HIV/AIDS among men at risk of infection in a remote Quebec region.

Study context

Attitudes and approaches towards HIV/AIDS have evolved significantly over the years, including in terms of available medical treatments and social constructions of the disease. Advances in biomedical science, most notably, have moved HIV/AIDS from the sphere of deadly infection towards that of chronic disease (Colvin, 2011; McGrath et al., 2014). In the North American context, Quebec has been a leader in terms of mobilization initiatives in the fight against HIV/AIDS (Girard, 2016) and has experienced a reduction of new diagnosed cases (Blouin et al., 2017). Other data remain worrisome for the province, however. Notwithstanding the overall reduction of diagnosed cases, latest statistics show an increase of newly diagnosed HIV/AIDS cases among men aged 15 to 24 (Blouin et al., 2017). Moreover, data concerning the remote northern region of Abitibi-Témiscamingue, on which the present study focuses, show that the crude rate of newly diagnosed HIV/AIDS in the region has been on the rise since 2012 and was the third highest among Quebec regions in 2016 (Blouin et al., 2017). It is also worth noting that the region presents a rate of chlamydia infections that is higher than the provincial average (Blouin et al., 2017), suggesting a prevalence of at-risk practices in relation to HIV/AIDS, notably among the 15-to-24 age group.

Few data exist in relation to identifying characteristics of HIV/AIDS carriers in Abitibi-Témiscamingue or to groups particularly at risk of infection in remote regions overall. Studies carried out in Canada and the United States show that populations in rural and remote regions are more likely to lack information concerning HIV/AIDS and to exhibit less positive attitudes towards people living with HIV/AIDS; these conditions

appear linked to the remoteness of institutions and populations, lack of public discourse on HIV/AIDS, lack of first-hand experience of the realities of people living with HIV/AIDS, and lack of media coverage (Beaulieu & Adrien, 2011; Sutton et al., 2010; Veinot et al., 2006; Veinot & Harris, 2011). Such populations are also characterized by socioeconomic factors that may impact negatively on their awareness and attitudes towards HIV/AIDS, including low education levels and lack of access to public health information and to internet connectivity (Beaulieu & Adrien, 2011; Dumas et al., 2011; Institut de la statistique du Québec, 2016; LeBlanc, 2013; Sutton et al., 2010; Veinot et al., 2006; Veinot & Harris, 2011). This lack of data on the characteristics of at-risk groups applies also to the Abitibi-Témiscamingue region, and it is difficult to find any data, in either the research or professional literature, on the characteristics of people living with HIV/AIDS in the region. A study by Beulé (2012) is an exception, indicating that in April 2010, 36 HIV-positive individuals were treated by the Abitibi-Témiscamingue regional integrated HIV/AIDS care clinic. Two-thirds of them were men, while the group's average age was 45 years. Among the men in the group, the self-reported risk factors included unprotected sexual relations with other men, sharing injection drugs equipment, and unprotected heterosexual relations (p. 17). Although these data are pertinent for the present study, they do not point to the presence of characteristics specific to Abitibi-Témiscamingue.

Methodology

The research team adopted a methodology based on discussion and deliberation sessions conducted within small and large groups of participants. During these sessions, which were planned and organized by a dedicated working group, participants were asked to reflect on regional needs within the scope of community-based research into HIV/AIDS. The study participants were representatives of Centre des R.O.S.E.S, Coalition d'aide à la diversité sexuelle de l'Abitibi-Témiscamingue, COCQ-SIDA, Université du Québec en Abitibi-Témiscamingue (UQAT), Cégep de l'Abitibi-Témiscamingue, Table de santé et de bien-être des hommes, Groupe Image, Mouvement de la relève d'Amos-région, and Arrimage-Jeunesse (see Table 1). An important aspect of the study as an inclusive community-based project was the participation of First Nations community actors, and the research team adopted from the outset a central tenet of respect, dialogue, and mutual collaboration with all participants. In line with these principles, the research team invited the three largest First Nations communities in the Abitibi-Témiscamingue region—Lac Simon, Pikogan, and Kitchisakik—to participate in the project.

The co-constructed knowledge emerging from the research collective's discussions served as the basis for the study's research protocol.

The collection of data (i.e. of knowledge yielded by the collaboration between institutional researchers and actors-researchers) was conducted during two discussion workshops focusing on core themes in relation to at-risk men and HIV/AIDS in the region. Within the workshops, all participants contributed to 1) identifying knowledge needs, 2) targeting research objectives, and 3) building a grant application, to be submitted to the Canadian Institutes of Health Research (CIHR), demonstrating the project's social relevance for the community.

Profile of participants

The first workshop bringing together the research collective included a physician affiliated with La Sarre CSSS; knowledge users from Centre des R.O.S.E.S., Arrimage Jeunesse, Mouvement de la relève d'Amos, and COCQ-SIDA; and institutional researchers from l'Université du Québec en Abitibi-Témiscamingue, Université du Québec à Chicoutimi, and Université Laval. Table 1 presents organizations participating in the project.

Table 1—*Actor-researcher organizations*

Organization	Method
Centre des R.O.S.É.S. de l'Abitibi-Témiscamingue	Offers confidential services to people living with HIV/AIDS and their relatives, as well as to the general population.
Arrimage Jeunesse	Helps youth and young adults (12 to 30 years of age) to prevent, reduce, and eliminate at-risk physical and mental health behaviours, principally using a harm reduction approach.
Mouvement de la relève d'Amos-région (Street work)	Assists youth and young adults (14 to 35 years of age) in preventing, reducing, and eliminating at-risk physical and mental health behaviours.
Coalition des organismes communautaires québécois de lutte contre le SIDA (COCQ-SIDA)	Brings together Quebec community organizations involved in the fight against HIV/AIDS and exercises leadership in stimulating, supporting, consolidating, and promoting independent community action in the fight against HIV/AIDS throughout Quebec.
Integrated health and social services centre, Abitibi-Témiscamingue and La Sarre CSSS	Maintains, improves, and restores the health and wellbeing of the regional population by providing access to a range of integrated professional health and social services in order to contribute to the social and economic development of Abitibi-Témiscamingue.
Groupe Image	Offers professional intervention services to men in distress and experiencing relationship troubles in order to promote personal autonomy and freedom.

Association québécoise de défense des droits des personnes retraitées et préretraitées	Defends the cultural, economic, political, and social rights of retirees and pre-retirees.
Council of the First Nation of Abitibiwinni (Pikogan)	Pikogan is an Algonquin community, founded in 1954 and located three kilometres to the north of the town of Amos, in Abitibi-Témiscamingue. The locality has a high importance for the members of the Abitibiwinni nation, who have inhabited the area for the past 200 years.
Coalition d'aide à la diversité sexuelle de l'Abitibi-Témiscamingue	Contributes to the health and wellbeing of lesbian, gay, bisexual, and transgender people in Abitibi-Témiscamingue
Table de santé et de bien-être des hommes	Improves and clarifies the needs of men in Abitibi-Témiscamingue to make a statement of resources and gaps in services offered.
Université du Québec en Abitibi-Témiscamingue	Transmits knowledge through teaching, advances knowledge through research, and retains knowledge in institutions that resist fashions, eras, and time.
Cégep de l'Abitibi-Témiscamingue	Offers its students and its partners training and services of excellent quality in a warm and enriching living environment.

The collaborative process

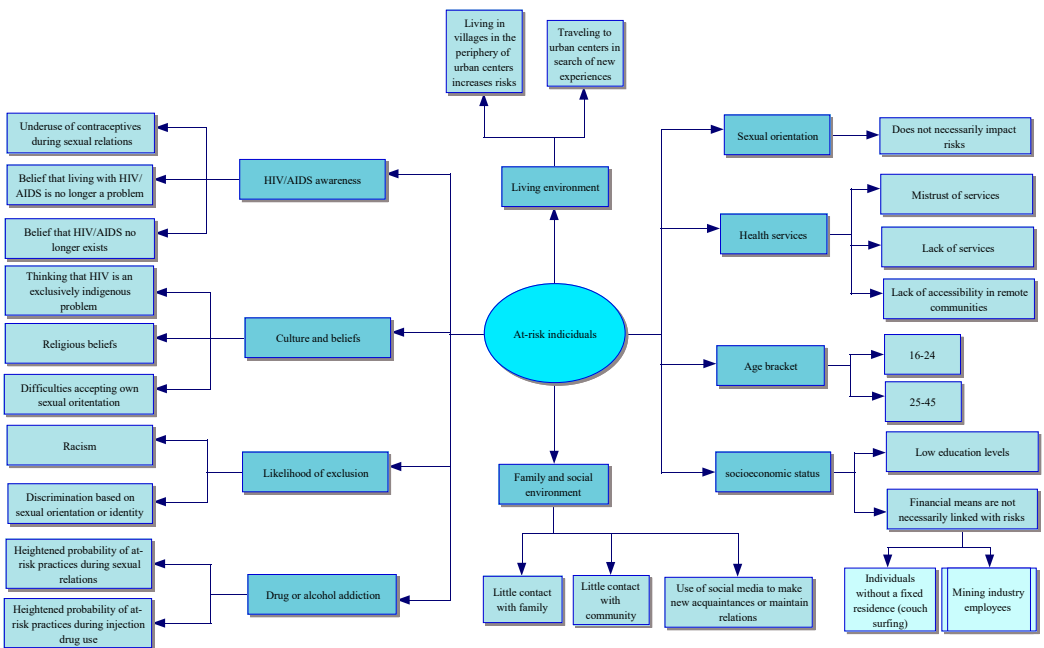
Three sessions brought together the participating institutional researchers and community actors in common reflection on local research priorities relevant to the region; the available literature on community-based research underlines the importance of developing balanced partnerships among actors (Bernier et al., 2015; Cargo & Mercer, 2008). Each encounter was centred on a specific objective: 1) to generate a fuller acknowledgment of knowledge generated by community actors in relation to HIV/AIDS in the Abitibi-Témiscamingue region, 2) to select the research themes and target group, and 3) to validate the research protocol in concert with community actors. The aim of common reflection among community actors and institutional researchers on the region's HIV/AIDS research needs became one of the project's main strengths, providing participating community actors with an opportunity to consolidate common motivations and aims (Girard, 2016), as well as centering the focus of research needs on their concerns (McIntyre et al., 2007).

Towards a fuller acknowledgment of knowledge generated by community actors

The first discussion session aimed to set in motion a process of reflection among the various actors participating in the research collective on CBPR needs in the Abitibi-Témiscamingue region in relation to men at risk

of HIV/AIDS infection. First, this initial session allowed participants to become acquainted both with one another and with the expectations of each in relation to their participation in the project. Furthermore, in order to pre-empt the common CBPR obstacle of a lack of clearly defined roles (Flicker, 2008), the research collective, approved by community actors and researchers, devoted particular attention to the distribution of tasks among participants. Second, the collective took time to define community-based research in order to ensure that all participants understood and agreed on the core principles of egalitarian relations among members (Demange et al., 2012). Third, in order to specify the research project’s target group, the research collective elaborated a topic tree drawn from participating members’ accounts of their professional experiences (see Diagram 1).

Diagram 1–*Topic tree of participants’ professional experiences*



Source: Compiled by authors

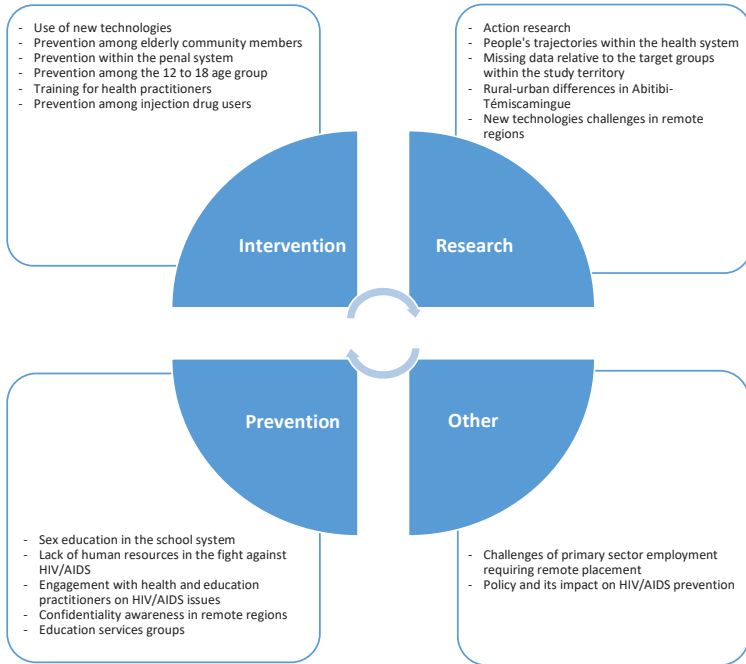
Two observations followed from this exercise. The first concerned the use of the term “**behaviour**” in formulating project objectives; at stake was whether to employ the term “**life conditions**” instead in order for the project to remain relevant to the target group and inclusive of potential

future objectives. For example, an individual's lack of information on HIV/AIDS is not a function of behaviour. The second major observation was that of a lack of consensus among participants as to the life conditions of at-risk individuals in the Abitibi-Témiscamingue region. The following is an excerpt of a community actor's testimony of participation in the reflective process:

Discussions in the course of the HIV/AIDS research project helped me to realize that, despite the social importance and impact of the disease, there is still a dearth of knowledge on the perception of the disease within certain social groups, specifically among men, signifying a need for further research that will allow us to deepen our understanding of the subject. (General practitioner, CISSAT, translation from French)

Participants expressed generally positive assessments of this first session, citing, in particular, the collective's multidisciplinary and plurality of knowledge as positive factors stimulating their willingness to engage in continued contributions within the project. Participants also cited emergent networking possibilities as a highly positive aspect of their participation. Paralleling developments in other community-based research experiences, the process of discussion among community actors and researchers led participants to formulate new observations on regional HIV/AIDS concerns. This proved a highly fertile process, particularly in terms of the diversity of proposed analytical avenues that were integrated into the study's subsequent stages. This approach, in addition, was successful in raising community actors' motivation concerning and engagement with the project, paralleling what Wallerstein and Duran (2008) have described as the role of empowerment in inciting community actors to engage more actively in the fight against HIV/AIDS at the local level.

The collective's second meeting had the pragmatic aims of determining research themes and delineating the target group. First, a workshop activity enabled the group to define the needs of the participating organizations and, consequently, to decide on common objectives. This consisted of participants forming three-person discussion groups focused on defining the needs of participating organizations and formulating collective objectives; each group presented its results to the collective. The workshop resulted in an examination of a broad diversity of existing needs in such spheres as raising awareness, intervention, and research (see Diagram 2).

Diagram 2—CBPR needs of research collective members collective members

Source: Compiled by authors

Second, the exercise led to discussions focused on common research objectives. The collective opted for an action research approach with the objectives of identifying protective factors of prevention and education within groups at risk of HIV/AIDS infection in Abitibi-Témiscamingue and of operationalizing an intervention program based on the factors identified. Based on the model elaborated by Tremblay and Bonneli (2007), participants formulated objectives in relation to the successive stages of the selected action research approach.

The community actors and institutional researchers participating in the research collective were convinced to adopt an action research approach for the purposes of the study because of two core elements—one related to the target population, the other to methodology: 1) the dearth of existing knowledge on men's practices in relation to HIV/AIDS in remote regions, and 2) the fact that action research is methodologically flexible and adaptable to specific objects of study.

The second session resulted in the identification of the study's target population—that is, men in the Abitibi-Témiscamingue region—as well

as an optimal methodological approach: the participating community actors concluded that action research was the approach best suited to the project's objectives, mostly because it would elicit greater participant engagement. Moreover, the approach engendered a reciprocal learning environment (O'Fallon and Dearth, 2002) within the research collective while also strengthening the bonds of trust between community actors and researchers.

The third and final session was devoted chiefly to the presentation and discussion of the research protocol among all members of the research collective. In addition, the session served to familiarize participating research assistants with data collected since the launch of the project, as well as the study's general aims, target group, and methodology. The session was an opportunity for mutual exchange: community actors questioned and made proposals to fine-tune the study question, objectives, and methodology elaborated by the participating researchers. A participating community actor describes the session's positive outcomes:

Participating in the research protocol presentation was an occasion to discuss the study's implications with other participants. Differing points of view enrich this type of project and provide a platform for the recognition of the diverse realities of groups affected by study objectives. (Representative of Coalition d'aide à la diversité sexuelle de l'Abitibi-Témiscamingue, translation from French)

It is important to underline that the participants identified in Table 1 were fully engaged in the collaborative process throughout the course of the study.

A grant application based in the expertise and knowledge of community actors

The data discussed in the present study are the result of a nearly year-long collaborative process to establish local HIV/AIDS research priorities involving community actors and institutional researchers. The collected data were coded by a working group comprising a cross-section of participants. The working group set out to formulate an application for a research grant from CIHR based largely on the collective's discussions of the action research methodology and participants' consolidation and harmonization of objectives during the first two sessions, described above. The draft grant application was validated by the working group with the approval of the research collective overall. The following sections outline the planned stages of the project, as described in the application.

Definition of the research problem and context

The first phase of the project will aim to assess conditions relative to project themes in Abitibi-Témiscamingue with the following primary

objective: to identify groups of men at risk of HIV/AIDS infection through a region-wide survey. The survey will allow the research collective to evaluate the state of knowledge on HIV/AIDS among men in a remote region and will document prevention practices in order to define the research problem. Both participating community actors and institutional researchers will play key roles in this process.

Testing of objectives

The second phase will begin with analyses of the available relevant literature and the multifaceted professional experiences of the research collective's members, particularly those of the participating actors-researchers. The phase will aim to achieve three objectives: 1) formulate working objectives that will be tested and assessed, 2) modify the intervention based on the comparative analysis of conceptual and practical knowledge, and (3) co-construct an education and prevention intervention initiative for use by practitioners in the Abitibi-Témiscamingue region.

Adjustment of objectives

The third phase will involve the application of the intervention initiative elaborated in the testing phase. Specifically, the two objectives of this phase are: 1) to launch and evaluate the prevention and education initiative in the five regional municipalities of Abitibi-Témiscamingue, taking into account the responses of health and community workers and the target group, and 2) to identify practices favouring prevention among men at risk of HIV/AIDS infection.

Adjustment of action planning

The final phase, that of action planning, will aim to create lasting changes resulting in improved HIV/AIDS prevention and improved men's health conditions, as well as the joint creation of knowledge on practices favouring prevention among men at risk of HIV/AIDS infection in Abitibi-Témiscamingue.

Local results

Within the scope of the study described above, this encounter took the form of a research collective comprising community actors and researchers investigating various factors affecting men at risk of HIV/AIDS infection in the Abitibi-Témiscamingue region. Following a nearly 12-month-long period of joint intersectoral reflection, we are convinced that the initial phase described above has laid the foundations of a robust collective action research process by producing five local results:

1) *Development of local research capacities and of the potential for collective action among researchers and practitioners*: the reflection and discussion process described above established new communication lines between researchers and community actors, whose worlds remain generally disconnected, to the detriment of knowledge creation. The project brought together representatives of the two domains within a joint work initiative in order to explore and elaborate new paths for community research at the regional level into HIV/AIDS issues in the context of remote communities. The process was founded on a principle of fomenting a reciprocal learning environment among community actors and institutional researchers, as put forward by O'Fallon and Dearry (2002).

2) *Valorization of community actors' contributions*: as a result of the process of reflection on HIV/AIDS issues in a regional context in which community actors played a key role, the institutional researchers guiding the nearly year-long process have been able to affirm local knowledge and make it accessible within the framework of a community-based research project funding application.

3) *Establishment of regional research priorities*: the discussion process engendered within the project led participants to delineate potential research goals connected to the theme of men at risk of HIV/AIDS infection in the Abitibi-Témiscamingue region. In addition, the discussion process uncovered common points of interest among the participating community actors, which guided the participating researchers' re-evaluation of initially postulated research priorities. Overall, this process was an important step in validating the project among community actors; it was also highly illuminative for the participating researchers, who were confronted with the realization that their initial conceptualizations of HIV/AIDS research needs in the region did not concord with the field experiences, expertise, and knowledge of community actors. From this realization, however, emerged new knowledge, which has underpinned all subsequent stages of the project.

4) *Legitimizing the exchange of discourses among community-based actors-researchers as a process of knowledge-creating inquiry*: within the scope of the project, discussions among actors-researchers and institutional researchers took place both in common plenary sessions and in smaller sub-groups, but always within an approach focused on egalitarian reciprocity and empowerment (Wallerstein & Duran, 2008). The participating institutional researchers adopted a relationship-building approach that was epistemologically grounded both in the acknowledgment of one another's experiences and in the negation of academic claims to a monopoly on knowledge and truth. The resulting discussions, therefore, fully acknowledged the expertise of practitioners in relation to men's health and HIV/AIDS in the region.

5) *Valorization of community-based participatory research*: the choice of the action-research approach emerged from among the participating community actors, whose initiatives compelled the research collective to consider it as a potential methodology in formulating the research protocol. The participating institutional researchers, moreover, consider that this was a signal of the motivation and interest of community actors to continue their engagement in forthcoming project phases and validated the importance of the joint work of researchers and community actors in defining research priorities.

Analysis and conclusion

The objective of the present article is to underscore the fundamental importance of a collective approach that brings together community actors and institutional researchers within a process aiming to identify research needs and priorities at the regional and local levels. Local results described above serve as a summary of the joint work undertaken by a research collective of institutional researchers and community actors reflecting on issues surrounding HIV/AIDS and men's health in a remote regional context. In this process, the core elements of generated knowledge on HIV/AIDS conditions and realities in the Abitibi-Témiscamingue region emerged from initiatives put forward by community actors in the course of discussion sessions conducted within a balanced partnership (Guta et al., 2013) between community actors and institutional researchers.

It is essential to underline that the role of community actors engaged in the project involves the co-creation of knowledge and goes far beyond straightforward participation. In particular, the participating community actors formed a working group whose responsibilities included planning, organizing, and chairing the collective's activities, as well as putting forward recommendations following progress reports on the draft grant application. As a result, community actors were not merely consultants, advisors, or information providers: they took on a leading role in guiding the community-based research partnership.

The community-based participatory research approach adopted for the purposes of the project was developed with relevant actors, rather than for them. Community actors constituted a fount of knowledge that guided discussions, generated solutions in complex situations, defined research priorities, and contributed a diversity of reflexive perspectives (Absolon & Dion, 2017; Demange et al., 2012). We believe that, by prioritizing the concerns of community actors (McIntyre et al., 2007), recognizing their knowledge and expertise (Bernier et al., 2015), as well as gaining their trust and stoking their desire to collaborate (Girard, 2016), the collective was able to build a robust dialogue that can serve as the foundation of future collaborations.

In contrast with traditional research methodologies, the power balance within the collaborative process described above was weighted towards community actors: they decided on the initiatives that would be best suited to local needs in HIV/AIDS research. The collective thus grounded its work in the principle that community-based research is defined and directed by community actors (O'Fallon & Dearry, 2002), thus generating their empowerment (Cargo & Mercer, 2008; Belone et al., 2016; Berkowitz, 2001; Cacari-Stone et al., 2014; Khodyakov et al., 2013; Wallerstein et al., 2018). The participating community actors have undertaken to work towards the social transformation of their communities through HIV/AIDS research.

In terms of project ethics, therefore, the participating actors' choices and actions were not subject to the participating institutional researchers' control or to any other authority. They acted freely in accordance with their judgment of what they considered best for HIV/AIDS research in the region; community actors took on a leading role in guiding the project (O'Fallon and Dearry, 2002). The research collective's aim to develop a participatory research project investigating HIV/AIDS realities in the Abitibi-Témiscamingue region is founded in a shared conviction that innovative research approaches can drive real change, in which the participating community actors and institutional researchers all wish to play an active part. The approach generated a reflexive process that allowed for the integration of knowledge that otherwise would have remained outside the research domain (Demange et al., 2012).

It is important, moreover, to note the participation of First Nations representatives within the research collective. It has been well documented that cultural insecurity, discrimination, racism, and the misapprehension of local realities on the part of health institutions and professionals impact negatively on the use of health and social services by First Nations community members (Boksa et al., 2015; Goodman et al., 2017; Jacklin et al., 2017). Their participation was therefore essential to a comprehensive discussion of HIV/AIDS needs in the Abitibi-Témiscamingue region. Indeed, the project allowed participating researchers and First Nations community members to establish new bonds based on an emerging mutual familiarity and in shared concerns. These bonds will be fundamental in engaging the Lac Simon, Pikogan, and Kitchisakik communities in future community-based research endeavors. Indeed, the current study has already served as a launchpad for a forthcoming project focused on HIV/AIDS issues involving the Pikogan community.

An additional element that bears discussion is the aspect of time investment in this type of project, which has been discussed as an obstacle by Flicker (2008) and noted by some of the project's participants. First, it is necessary to take account of the time required to send initial invitations, receive answers, and confirm the presence (or absence) of participants; indeed, it was sometimes necessary to postpone meetings to a later

occasion because community actors could not attend on a particular date. Overall, the project has served to underline and validate the benefits and contributions of community-based research in the production of knowledge (Israel et al., 2013; Israel et al., 2017). As noted above, and as is evident from the testimonies of participating community actors, the project not only engendered a harmonization of institutional and community viewpoints, challenges, and concerns, but also established a pioneering community-based HIV/AIDS regional research network.

The project brought together two worlds that seldom meet: that of institutional researchers and that of community actors. The collaboration successfully attained three stated objectives, which were to: 1) develop local research and social action capacities, 2) stimulate institutional-community partnerships, and 3) contribute to the production of community-based research knowledge.

Ultimately, the engagement of community actors throughout the development the regional community-based participatory research project democratized the process (Guta et al., 2013) of knowledge production. The approach to HIV/AIDS research, previously untried in the Abitibi-Témiscamingue region, favoured the development of partnerships among a variety of community actors and institutional researchers in order to address issues of concern for the community. This experience in joint work and learning was an opportunity for community actors to not only understand the research process more fully, but also take a leading role in elaborating a research protocol that reflected local needs. Importantly, the project sought to democratize relational processes and eschew an implementation of bureaucratic obstacles that may have otherwise hindered further engagement in community-based research.

It is important to note, however, that partnerships of this type can present limitations. First, the initial groundwork of stoking the interest of community actors to attend joint meetings was a lengthy process. Second, it proved difficult at first to identify community actor representatives who were both qualified and available (MacQueen et al., 2001) to attend meetings. This was a source of preoccupation for the institutional researchers, since community representatives frequently changed from one meeting to the next, owing to a range factors, such as busy work schedules, personnel changes in the workplace, vacations, and various unforeseeable events. Other limitations have been noted in the relevant literature, including internal conflicts between researchers and community actors, communication issues, and ethical concerns surrounding the dissemination of data (Brugge & Kole 2003, Guta et al., 2013; Minkler et al., 2002; O'Toole et al., 2003). Although these latter complications did not arise during the 12-month collaborative process described above, the research network put in place in the

Abitibi-Témiscamingue region may yet be susceptible to such difficulties. We will remain alert to their potential occurrence and work to counter obstacles in collaboration with our community partners.

NOTES

1. We would like to thank Mireille Hubert, Catherine Jutras, and Suzanne Paré for their participation and contribution to this project and article.

REFERENCES

- Absolon, K., & Dion, S. (2017). Doing Indigenous community-university research partnerships: A cautionary tale. *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning*, 3(2), 81–98.
- Beaulé, G. (2012). *La situation sur les infections transmissibles sexuellement et par le sang en Abitibi-Témiscamingue*. Agence de la santé et des services sociaux de l'Abitibi-Témiscamingue. http://www.cisss-at.gouv.qc.ca/wp-content/uploads/2018/03/2012-01_situation-ITSS.pdf
- Beaulieu, M., & Adrien, A. (2011). *Attitudes de la population québécoise envers les personnes vivant avec le VIH*. Agence de la santé et des services sociaux de Montréal. <https://www.cocqsida.com/assets/files/mediatheque/SONDAGE%20attitudes%202010.pdf>
- Belone, L., Lucero, J. E., Duran, B., Tafoya, G., Baker, E. A., Chan, D., Chang, C., Greene-Moton, E., Kelley, M. A., & Wallerstein, N. (2016). Community-based participatory research conceptual model: Community partner consultation and face validity. *Qualitative Health Research*, 26(1), 117–135.
- Berkowitz, B. (2001). Studying the outcomes of community-based coalitions. *American Journal of Community Psychology*, 29(2), 213–227.
- Bernier, M., Amirault, M., Migliardi, P., Andersen, F., Howard, T. R., Shafiq, F., & Cameron, R. (2015). Du facilitateur de la recherche au centre de collaboration : Soutenir le renforcement des capacités de recherche sur le VIH/sida dans les communautés au Canada. In J. Otis, M. Bernier, & J. J. Lévy (Eds.), *La recherche communautaire VIH/sida: Des savoirs engagés*. Presses de l'Université du Québec.
- Blouin, K., Venne, S., & Lambert, G. (2017). *Portrait des infections transmissibles sexuellement et par le sang (ITSS) au Québec: année 2016 et projections 2017*. Institut national de santé publique du Québec. <https://www.inspq.qc.ca/publications/2324>
- Boksa, P., Joobar, R., & Kirmayer, L. J. (2015). Mental wellness in Canada's Aboriginal communities: Striving toward reconciliation. *Journal of Psychiatry & Neuroscience*, 40(6), 363–365.
- Brugge, D. & Kole, A. (2003). A case study of community-based participatory research ethics: The healthy public housing initiative. *Science and Engineering Ethics*, 9(4), 485–501.
- Cacari-Stone, L., Wallerstein, N., Garcia, A. P., & Minkler, M. (2014). The promise of community-based participatory research for health equity: A conceptual model for bridging evidence with policy. *American Journal of Public Health* 104(9), 1615–1623.

- Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annual Review of Public Health, 29*, 325–350.
- Colvin, C. J. (2011). HIV/AIDS, chronic diseases and globalisation. *Globalization and health, 7*(1), 1–6.
- Demange, E., Henry, E., & Préau, M. (2012). *De la recherche en collaboration à la recherche communautaire : Un guide méthodologique*. ANRS/Coalition Plus, coll. Sciences sociales et sida.
- Dumas, J., Lévy, J. J., Ryan, B., & Thoër, C. (2011). Internet et la santé des minorités sexuelles : enjeux théoriques et empiriques. In J. J. Lévy, J. Dumas, B. Ryan, & C. Thoër (Eds.), *Minorités sexuelles, internet et santé* (pp. 17–38). Presses de l'Université du Québec.
- Flicker, S. (2008). Who benefits from community-based participatory research? A case study of the Positive Youth Project. *Health Education and Behavior, 35*(1), 70–86.
- Girard, G. (2016). Les réseaux mis en contexte : une perspective comparative sur la prise en charge du VIH en France et au Québec. In B. Brossard & D. White (Eds.), *La santé en réseaux : explorations des approches relationnelles dans la recherche sociale au Québec* (pp. 169–190). Presses de l'Université du Québec.
- Goodman, A., Fleming, K., Markwick, N., Morrison, T., Lagimodiere, L., Kerr, T., & Society, W. A. H. R. (2017). They treated me like crap and I know it was because I was Native: The healthcare experiences of Aboriginal peoples living in Vancouver's inner city. *Social Science & Medicine, 178*, 87–94.
- Guta, A., Flicker, S., & Roche, B. (2013). Governing through community allegiance: a qualitative examination of peer research in community-based participatory research. *Critical Public Health, 23*(4), 432–451.
- Institut de la statistique du Québec. (2016). *Répartition de la population de 25 à 64 ans selon le plus haut niveau de scolarité atteint, la région administrative, l'âge et le sexe, Québec, 1990 à 2019*. <http://www.stat.gouv.qc.ca/docs-hmi/statistiques/education/niveau-scolaire/repartition-scol-ra-sexe-age.html>
- Israel, B. A., Enge, E., Schulz, A. J., & Parker, E. A. (2013). *Methods in community-based participatory research for health*. (2nd ed.). Jossey-Bass.
- Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., Guzman, J. R., & Lichtenstein, R. (2017). Critical issues in developing and following CBPR principles. In N. Wallerstein, B. Duran, J. G. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health: Advancing social and health equity* (3rd ed., pp. 31–46). Jossey-Bass.
- Khodyakov, D., Stockdale, S., Jones, A., Mango, J., Jones, F., & Lizaola, E. (2013). On measuring community participation in research. *Health Education and Behavior, 40*(3), 346–354.
- Jacklin, K. M., Henderson, R. I., Green, M. E., Walker, L. M., Calam, B., & Crowshoe, L. J. (2017). Health care experiences of Indigenous people living with type 2 diabetes in Canada. *Canadian Medical Association Journal, 189*(3), E106–E112.
- LeBlanc, P. (2013). *La ruralité en Abitibi-Témiscamingue : Visions multiples*. Chaire Desjardins en développement des petites collectivités.

- MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, R., Blanchard, L. and Trotter, R. T. (2001). What is community? An evidence-based definition for participatory public health. *American Journal of Public Health, 91*(12), 1929–1938.
- McGrath, J. W., Winchester, M. S., Kaawa-Mafigiri, D., Walakira, E., Namutiibwa, F., Birungi, J., Ssendegye, G., Nalwoga, A., Kyarikunda, E., & Kisakyie, S. (2014). Challenging the paradigm: anthropological perspectives on HIV as a chronic disease. *Medical Anthropology, 33*(4), 303–317.
- McIntyre, A. (2007). *Participatory action research*. SAGE.
- McIntyre, A., Chatzopoulos, N., Politi, A., & Roz, J. (2007). Participatory action research: Collective reflections on gender, culture, and language. *Teaching and Teacher Education, 23*(5), 748–756.
- Minkler, M., & Wallerstein, N. (2011). *Community-based participatory research for health: from process to outcomes* (2nd ed.). Jossey-Bass.
- Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L., & Rogers, J. (2002). Ethical dilemmas in participatory action research: A case study from the disability community. *Health Education & Behavior, 29*(1), 14–29.
- O'Fallon, L. R., & Dearry, A. (2002). Community-based participatory research as a tool to advance environmental health sciences. *Environmental Health Perspectives, 110*(Suppl 2), 155–159.
- Otis, J. (2015). Parcours de recherches participatives avec la communauté gaie au Québec : engagement et doutes. In J. Otis, M. Bernier, & J. J. Lévy (Eds.), *La recherche communautaire VIH/sida: Des savoirs engagés*. Presses de l'Université du Québec.
- O'Toole, T. P., Aaron, K. F., Chin, M. H., Horowitz, C., & Tyson, F. (2003). Community-based participatory research: Opportunities, challenges, and the need for a common language. *Journal of General Internal Medicine, 18*(7), 592–594.
- Riffin, C., Kenien, C., Ghesquiere, A., Dorime, A., Villanueva, C., Gardner, D., Callahan, J., Capezuti, E., & Reid, M. C. (2016). Community-based participatory research: Understanding a promising approach to addressing knowledge gaps in palliative care. *Annals of Palliative Medicine, 5*(3), 218–224.
- Sutton, M., Anthony, M. N., Vila, C., McLellan Lemal, E., & Weidle, P. J. (2010). HIV testing and HIV/AIDS treatment services in rural counties in 10 southern states: Service provider perspectives. *The Journal of Rural Health, 26*(3), 240–247.
- Tremblay, G. et Bonnelly, H. (2007). La recherche-action comme moyen pour favoriser la réussite scolaire des garçons aux études collégiales. *Éducation et francophonie, 35*(2), 62-77.
- Veinot, T., Harris, R., Bella, L., Rootman, I., & Krajnak, J. (2006). HIV/AIDS information exchange in rural communities: Preliminary findings from a three province study. *The Canadian Journal of Information and Library Science, 30*(314), 271–290.
- Veinot, T. C., & Harris, R. (2011). Talking about, knowing about HIV/AIDS in Canada: A rural–urban comparison. *The Journal of Rural Health, 27*(3), 310–318.

- Wallerstein, N., & Duran, B. (2008). The conceptual, historical, and practice roots of community based participatory research and related participatory traditions. In M. Minkler & N. Wallerstein (Eds.), *Community-Based Participatory Research for Health* (2nd ed., pp. 25–39). Jossey-Bass.
- Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (2018). *Community-Based Participatory Research for Health: Advancing Social and Health Equity* (3rd ed.). Jossey-Bass.