

Negotiating Partnership and Ownership in Community-Based Research: Lessons from a Needle Exchange in Montréal

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ABSTRACT

The field of community-based research (CBR) maintains that members of a research population are to be actively involved in the generation and interpretation of data which concerns them. This paper examines a process for negotiating partnership between a needle exchange programme and institutional researchers in Montréal. The paper outlines some of the reasons why this agency needed to develop guidelines related to partnership and the ownership of research results. The lessons learned can be applied and adapted to different settings, and provide a model for Aboriginal communities to negotiate formal agreements with institutional researchers from universities or public health departments.

BACKGROUND

Historically, the relation between Indigenous people and scientific researchers has been complex and complicated. Scientific research was an integral part of the work of colonization, as demonstrated by Aboriginal scholars (Smith, 1999). These critics clearly show the ways in which the practice of colonialism was often justified in and through ‘scientific’ theories – the argument that a particular people was uncivilized provided an alibi to conquer them, dispossess them of their lands, language and traditions, and even to kill them outright. Given such a history, then, the stakes are quite high when it comes to doing research on questions related to Aboriginal people.

The complex relations Aboriginal communities have to research itself have been underlined in recent years with controversies related to genetic research and Indigenous knowledge. The initiative Human Genome Diversity Project, for example, seeks to obtain genetic information from Indigenous people all over the globe. Aboriginal people object that the process has in no way involved Indigenous people, and that it further represents a research initiative destined to benefit the interests of pharmaceutical companies, who will profit from the patents obtained on such genetic material (Lone Dog, 1999). Indigenous people will, once again, be mere objects of knowledge. In a similar vein, Indigenous peoples object to researchers using their traditional knowledge of different plants to develop scientific and pharmaceutical remedies whose profits will not benefit the particular Indigenous community from which the knowledge was obtained (Zerda-Sarmiento & Forero-Pineda, 2002). Questions about genetic research and indigenous knowledge, then, are two current examples which illustrate the unequal power relations between scientific researchers and Aboriginal communities.

THE RELEVANCE OF COMMUNITY BASED RESEARCH

Within such a general context in which scientists exploit and objectify Indigenous peoples, the idea and practice of community based research (CBR) is refreshing. CBR refers to a research process in which members of a target population are actively involved, from the development and conception of the research question, to the collection of data, to the interpretation of results, to the dissemination of research findings. CBR can be conducted by academic and institutional researchers if they are committed to a research process which is truly community-based. CBR can also be conducted by a community organization.

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Terry Trussler and Rick Marchand (2000) have outlined ten guiding principles of CBR. These are:

Partnership Initiative	(Equality between the community and professionals)
Peer Review	(Involvement of the population from the beginning)
Community Benefit	(Involvement of the population in the grant review)
Capacity Building	(The research must improve the conditions of the community)
Ownership	(CBR helps people learn how to do research)
Interpretation	(Lived experience belongs to the community. Members have the right to refuse the research results.)
Distribution	(The involvement of the population in the analysis and interpretation of the results.)
Implementation	(The right of the population to revise before publication and to ensure the research is presented in an accessible language.)
Empowerment	(The research should facilitate program delivery and be able to be integrated into services.)
	(CBR should encourage members to initiate their own research projects.)

(p. 38).

Drawing on the framework outlined by Trussler and Marchand, this paper recounts some lessons learned at a needle-exchange in Montréal, CACTUS (Centre d'Action Communautaire auprès des Toxicomanes Utilisateurs de Seringues). The lessons are especially concerned with the principles of *ownership*, *interpretation*, and *distribution*. We begin with a description of different institutional research projects at CACTUS and examine some of the salient issues in terms of CBR. We then outline the steps taken by CACTUS to ensure its equal partnership with institutional researchers. It is hoped that the lessons learned will be relevant to different Aboriginal communities in negotiating partnership with institutional researchers from local universities and/or departments of public health.

It is important to specify that this paper concerns the elaboration of an equal partnership between a community-based organization and institutional researchers. This is a situation somewhat different from one in which a community based organization initiates and conducts a research project on its own. Nevertheless, it raises fundamental questions about the process of conducting research, most particularly with regards to the validation of research results. Furthermore, we underline here that this paper reflects the particular view of its authors. Both authors were staff members of CACTUS-Montréal in 2000, although they have both since moved on to work elsewhere. The statements and interpretations made here do not reflect the official position of CACTUS-Montréal, the individual researchers, the team of researchers discussed in the different examples, nor the Department of Public Health of Montréal. To be consistent with CBR principles, a copy of this article was shared with CACTUS with an opportunity for comment prior to submission for publication.

THREE EXAMPLES OF INSTITUTIONAL RESEARCH AT CACTUS: KNOWLEDGE FOR WHOM?

CACTUS was founded in 1989, the first needle exchange in Canada. The agency was established by concerned individuals working in public health. In recent years, the actions of certain researchers working 'in partnership' with CACTUS have forced some members of the organization to question its involvement in research, and to develop mechanisms to ensure that the perspectives of both the agency and its clients are adequately represented in research findings. Three different instances explain how some workers at CACTUS came to be suspicious of institutional researchers.

The first example is well known. In the fall of 1997, researchers in the field of HIV and intravenous drug use released the results of a cohort study on IDUs in Montréal (Bruneau et al., 1997). The findings revealed that amongst the clientele of CACTUS, there were more seropositive IDUs compared with IDUs who did not use the services of a needle exchange. The researchers maintained that the results of this study raised serious questions

about the universal benefits of needle exchange programs (NEPs): “We believe caution is warranted before accepting NEPs as uniformly beneficial in any setting.” (Bruneau cited in Loconte, 1998). The results and interpretation of the study took many people in the field of HIV and addictions by surprise; workers at CACTUS, other researchers, and even the Department of Public Health. The ‘surprise’ element was augmented by the fact that the researcher had not contacted CACTUS before releasing the results of her study at a press conference. In practical terms, this meant that the agency was in a position of reaction to the media. The Executive Director of CACTUS had to field questions from the media which called into question the very justification and relevance of the program, the Department of Public Health had to rationalize its funding, and workers of the needle exchange had to answer questions from the clientele. The severity of the situation was perhaps most apparent to frontline workers, for example when, one client asked a worker if the media reports meant that CACTUS was giving out dirty needles.

The situation illustrates well how this institutional researcher did not follow the principles of CBR outlined by Trussler and Marchand (2000). In this case, it is clear that CACTUS was not involved as an equal partner in the research process. Indeed, CACTUS offered its own interpretation of the data; if more seropositive people were amongst the clientele of CACTUS than IDUs who did not go to needle exchanges, this could be explained by the fact that CACTUS often served as a bridge to the health care network for IDUs, people who were deeply mistrustful of health services given the discrimination they faced as drug users. In this regard, it is especially important to fund programs like CACTUS precisely because they establish contact and meaningful relationships with the most marginal of seropositive people, and work to hook them up to the existing health care and social services network.³

This experience further demonstrates the importance of involving the community not only in the interpretation of the results, but also in their dissemination. The situation demanded that CACTUS, public health, and everyday IDUs react to this information. This process did not involve members of the population (the principle of *initiative*). Furthermore, subsequent to this event, CACTUS raised an important ethical issue: the release of the research results without consulting CACTUS and IDUs created a context in which confusing or contradictory messages were disseminated in the general public through the mass media. This confusion was most apparent in the question posed to the needle exchange by a user: “Are you giving out dirty needles?” In this regard, the lack of involvement of CACTUS and IDUs in the dissemination of the research damaged the reputation of the organization in the milieu of intravenous drug users. It is important to underline that such credibility is tenuous at the best of times, given the criminalization of drug use in Canada and the subsequent discrimination IDUs experience in health care, housing, and employment. Damaged credibility with this population, then, can easily reinforce a perception of CACTUS as an agency ‘like all the others’, where drug users are not respected and where their involvement is not encouraged or welcome. While the researcher did not have to negotiate this issue in the long term, it remained a central aspect of the everyday work CACTUS could do with IDUs in Montréal.

The second example of institutional research with CACTUS also raises fundamental questions with respect to the credibility of the organization among intravenous drug users. The project in question was a qualitative study of the different kinds of IDUs who use the services of CACTUS, in order to develop appropriate programs of HIV prevention for the population. The researchers conducted interviews with IDUs, as well as engaging in participant observation in both the fixed site needle exchange and on the street with outreach workers.

³ Bruneau’s research has been used in an attempt to oppose needle exchange programs in the United States, and she wrote an editorial in the New York Times which countered the mis-use of her research. See Julie Bruneau and Martin Schechter, “The Politics of Needles and AIDS”, The New York Times, April 9, 1998. Available online at www.mapinc.org/newsesdp/v98/a05.html. Also note Bruneau’s more recent comment that “in the vast majority of cases needle exchange programs drive HIV incidence lower.” The Washington Post February 27, 2005 : B06.

While there has clearly been an attempt to misuse the results of Bruneau’s research, the point we wish to underline here is that, in our view, there was a lack of equal collaboration and participation between the research team and front line workers in the needle exchange.

While CACTUS supports the relevance of qualitative research methods for furthering an understanding of IDUs, the authors of this paper objected to the relationship established between the researchers and the community based organization. One street outreach worker, for instance, stated that he felt he had no choice but to allow the researchers to accompany him during his outreach, since the research protocol had outlined this approach. He felt uneasy in doing so, however, since the presence of a researcher who did not know either the individual clients or the culture of the street in Montréal could damage his credibility amongst IDUs. This outreach worker was thinking through the long-term effects of ‘collaboration’ in the research study. Would participation ultimately impede relations of trust between him and the clients? In a similar vein, some staff members at the fixed site objected to the presence of a researcher who was disrespectful of how space was managed by the staff of the agency. Although the researcher was ostensibly in the fixed site only to observe, staff at the needle exchange cited several instances in which the individual initiated conversations with IDUs.

From the perspective of these authors, this approach did not respect the non-invasive nature of participant observation which the research team had assured the agency prior to beginning the study. From the perspective of research methods, this approach also raises a host of ethical and methodological problems, notably the difficulties in adequately observing a milieu when one is directly involved in it (Kirby et al., 2006). The CACTUS team made efforts to broach these issues with the researchers, and stated their clear objections to the presence of this individual in the fixed site. The individual remained on staff, however. CACTUS raised an important question in this regard; although the agency was a partner in the research, it had no say in the hiring or firing of the staff, despite the fact that these staff members were temporary guests in the work space of the agency.

Like the first example, this situation raises questions about the definition and nature of ‘collaboration’ between institutional researchers and community based organizations. Is ‘collaboration’ to be understood as merely offering a letter of support for the purposes of funding, with no further voice as to the way in which the research is conducted and its consequences for the staff and clients of the agency? This example also addresses the complicated issue of credibility with the clientele. As a community based organization, CACTUS must consider the extent to which the process of doing research impedes or facilitates contact and confidence with IDUs. Some members of CACTUS felt that these considerations were not reflected in the manner in which the research team conducted their study.

The third example builds on the previous two, and illustrates the efforts of CACTUS to learn from its previous history with community-based researchers. An outreach worker of the agency was approached by an institutional researcher. The researcher was interested in conducting a preliminary qualitative study on the relationship between street outreach and the prevention of HIV. It was the hypothesis of the study that it is necessary to create meaningful links with IDUs in and through street outreach, and that the work of HIV prevention can only be effective when this climate of confidence has been established. In principle, the outreach worker and other staff members of CACTUS recognized the tremendous impact and value of such a study; indeed, it could help justify funding street outreach through HIV/AIDS programs, without demanding an exclusively quantitative, statistical justification of the work carried out (i.e., the number of needles distributed in the course of street outreach).

There was an important procedural error on the part of the research team however; they approached the outreach worker directly, without contacting the Executive Director of the organization. Despite the fact that the outreach worker referred the researchers to the agency in order to obtain authorization for participation in the study, this official contact was not initiated by the researchers. When the outreach worker brought the matter to the team, there was general support for participation in the study. However, the team also decided that it was important to ensure that the interviewee and the CACTUS team would have an opportunity to validate the interpretation of the research results before their dissemination. This was a clear effort on the part of the agency to learn from its previous history with institutional researchers. The research team offered verbal assurance that validation of the results was possible. Based on such a guarantee, as well as a promise that it would be put in writing, the street outreach worker made an appointment to be interviewed by the research team.

The research team had not prepared a written agreement as to the validation of the research results when the designated time for the interview arrived, despite the fact that it was a clear condition of the participation of the agency in the project. With good will, the outreach worker granted the interview and referred the research team to the Executive Director of the agency. He reiterated that he was participating as a member of CACTUS, not as an individual, and that the research team therefore needed to enter into a formal written agreement with the agency. The outreach worker suggested that a delay of one week was appropriate for the preparation of these documents. One week later, CACTUS had not received the required documents. The outreach worker phoned the research team and requested that the documents arrive before the next team meeting, scheduled 10 working days after the date the interview had been granted. The worker was assured that these documents would be forthcoming by that date. The worker also clarified that if they were not received, CACTUS would make a decision about participating in the research project.

The documents were not sent by the time of the team meeting. CACTUS thus decided to withdraw from the research project until such time as a written agreement could be established. In discussions with the outreach worker, it was learned that the researchers had not signed a consent form with the interviewee, and that informed consent was not discussed orally at the beginning of the interview.

The agency sent two representatives to meet with the Department of Public Health research team representatives and to demand the cassette of the interview as well as any transcription documents which had taken place. Given the absence of any signed consent form or verbal consent, CACTUS and the outreach worker clarified that the researchers did not have authorization to use the data from the interview, nor any notes or reflections based on conversations with the outreach worker. CACTUS reiterated its motivation to participate in the research, but only if the organization could be assured of the right to refuse the results of the project.

The research team responded that it could not return the cassette to the agency due to confidentiality. They maintained that the interview was with an individual, not with the team of CACTUS. They did remit the cassette to the outreach worker, who accepted it with the clarification that he granted the interview as an official representative of CACTUS, and not as an individual. The research team also made the decision to not use the data collected from the outreach worker. The researchers expressed their regret that a good working relationship could not be established, and hoped that CACTUS could be involved in a larger research project on this subject matter. The research team was at that time preparing a grant application in this regard, to be submitted in the fall of 2000. CACTUS was not included as a partner agency in this grant application.

A VALIDATION AGREEMENT BETWEEN THE AGENCY AND INSTITUTIONAL RESEARCHERS: ENSURING THE PERSPECTIVE OF THE COMMUNITY IS REPRESENTED

The team of CACTUS responded to this situation by requesting a meeting with the research team and reiterating a motivation to participate. CACTUS had also prepared a 'Validation Agreement' to be signed between the agency and the researchers. As authors of this paper, we met on several occasions to write the text of this Validation Agreement. This was a pro-active move on the part of the organization, interested in clearly defining the terms of participation necessary for the agency to be involved in the research. The full text of the Validation Agreement is presented as an Appendix to this article.

The Validation Agreement contained several different elements as conditions for the organization's participation: clear, accessible language; length of the final report; timelines and delays for both the researchers and the agency to offer comments on the data; the agency's right of refusal of the results; and the responsibility of the researchers to represent the position of the agency, as well as the position of IDUs, in all public presentations of the research. CACTUS used the Validation Agreement as a way to negotiate clear definitions of roles and responsibilities for both the agency and the research team. It was designed to help learn from past experience with researchers. Several aspects of the Agreement illustrate this learning process.

The provisions around clear, accessible language were stipulated to ensure that the final report would be easily understood. Members of the agency had difficulty in the past reading reports with excessively technical language and academic jargon. The length of the final report was noted as a criterion because many front-line workers could not find the time to read a 100-page report in order to offer their comments. In this regard, the agency requested that any report exceeding 30 pages contain an Executive Summary. The section on timelines made clear provisions for appropriate delays amongst both the research team and the agency to offer their comments and provide feedback on preliminary drafts of the report. This section demanded recognition of the nature of community work, and sought to avoid a situation in which individuals would have to provide feedback on a report within a week or a few days in order to respond to the deadlines of institutional researchers. The agency's right of refusal of the research results was central to CACTUS and its participation. Importantly, the agency also stipulated that the research team needed to validate the findings with IDUs. Staff did not want to presume that their opinions represented those of IDUs. Furthermore, staff were interested in learning from the research process, if they held a different interpretation of the results than IDUs, that was an important lesson. Finally, the Validation Agreement outlined that the research team had to represent the perspective of the agency, as well as IDUs, in any and all public presentations of the research. This provision sought to avoid the type of situation CACTUS had previously experienced with a researcher who released the results with no consultation with the agency or its clients. If such an Agreement were in place in the context of the first situation described above, the researcher would have had to present the interpretation of the data to the agency and IDUs. The media reports on the subject would have been substantially different, and the agency and the Department of Public Health would not have been placed into a position of re-action subsequent to the press conference.

The research team refused to sign the Validation Agreement, with the justification that the timelines specified in the document would prevent them from completing their final report according to schedule. Although CACTUS offered to meet with them to negotiate the timelines in accord with their deadline, the offer was declined.

This refusal was significant, especially considering an invocation of 'timelines'. Since the agency had been involved in previous research projects, it was familiar with the fact that delays were often common in the preparation of a final report. More important, however, was the actual timing of the deadline. The communications between the researchers and the agency took place in the beginning of August 2000. The researchers wanted to complete their final report by the end of August. The authors of this paper believe that this 'deadline' was a function of grant applications to a large provincial granting institution (the grants being due in September). The research team had already been quite clear that they were planning to conduct a much larger study on this question, and that the current project was only a pilot investigation. In this regard, they had a marked interest in completing the final report for the pilot study in order to include it with their grant application. We feel that this criterion illustrates well how research was conducted first and foremost for the needs of the research team. The needs of a community-based agency and of the clients it serves could not be addressed in this framework. Full, equal participation in the interpretation and dissemination of the research results were sacrificed so that the researchers could apply for additional funds to embark on a larger project on the same theme.

CONCLUSION

As a community-based needle exchange, CACTUS is often approached by researchers to participate in various research projects. Numerous experiences with institutional researchers, however, have raised important questions about the implications of research, the definition of partnership between a community agency and institutional researchers, and the ownership of the data collected in a particular study.

These issues are at the forefront of the field of Community Based Research. It is generally recognized that CBR requires that organizations develop the capacities and skills needed to conduct a research project. As a preliminary first step, CACTUS developed a Validation Agreement to clarify the roles and obligations of both researchers and the community agency. This document outlines the conditions required for CACTUS to enter into an equal partnership with researchers.

The first time the agency proposed this Agreement to a research team, an understanding could not be reached between the agency and the researchers. Although no formal partnership was established, the authors of this paper do not view this in any way as a failure. On the contrary, in our view CACTUS sent a clear message to the researchers that partnership for the agency involves more than providing a letter of support for the purposes of funding agencies and unconditional access to the field. Equal participation means ensuring that the perspectives of the agency and its clients are represented in all public discussions of the research.

CACTUS has also been active in helping other community organizations learn from its experience. A workshop highlighting these examples was presented at the 2001 Canadian Skills Building Conference in Montréal (July 2001) to share the lessons learned at CACTUS. Similar agencies were encouraged to use the Validation Agreement as a model; they could modify it to suit their purposes, for instance, by demanding that the agency would have final say in the hiring and firing of research staff. The information presented here can also be useful for different Aboriginal communities and groups to think about how to negotiate the terms of partnership with institutional researchers. Readers especially interested in these issues may also be interested in examining some of the resources listed at the end of this article. They present some of the different agreements and principles of research necessary for a particular Aboriginal community to agree to work in collaboration with (outside) researchers.

The development of a Validation Agreement allowed CACTUS to be pro-active in its demand for inclusion in all aspects of the research process. This demand for inclusion -- for appropriate consultation throughout the research process and for ensuring that the interpretation of data included the perspective of the community agency and of IDUs – was one of the most important lessons learned. In our view, a strategy which demands full consultation and involvement in the interpretation and dissemination of results is fundamental to the realization of Community Based Research.

SOME USEFUL RESOURCES RELATED TO NEGOTIATING PARTNERSHIP

AIATIS (The Australian Institute of Aboriginal and Torres Strait Islander Studies.) *Guidelines for Ethical Research in Indigenous Studies*. May 2000. Available online at www.aiatsis.gov.au

HCPO Policy and Research. *Protocol for Research, Publications and Recordings: motion, visual, sound, multimedia and other mechanical devices*. The Hopi Tribe. Available online at www.nau.edu/hcpo

Dene Cultural Institute. *Dene Cultural Institute Guidelines. (Guidelines for the conduct of participatory community research to document traditional ecological knowledge for the purpose of environmental assessment and environmental management.)* Available online at http://www.idrc.ca/en/ev-28709-201-1-DO_TOPIC.html

University of Victoria, Indigenous Governance. *Protocols and Principles for Conducting Research in an Indigenous Context*. Available online at http://web.uvic.ca/igov/programs/masters/igov_598/protocol.pdf .

REFERENCES

- Bruneau, J., Lamothe, F., Franco, E., Lachance, N., Désy, M., Soto, J., & Vincelette, J. (1997) High rates of HIV Infection among Injection Drug Users Participating in Needle Exchange Programs in Montréal: Results of a Cohort Study. *American Journal of Epidemiology*, 146.12 (Dec 15).
- Goyette, G., & Lessard-Hébert, M. (1987) *La Recherche-Action : ses fonctions, ses fondements, et son instrumentation*. Sillery, Québec: Presses de l'Université du Québec.
- Hankins, C., Gendron, S., & Tran, T. (1995) *CACTUS-Montréal : Profil comportemental de la clientèle et prévalence de l'infection par le VIH, 1^{er} octobre 1994 – 7 février 1995. Rapport numéro 6*. Montréal: Direction de la santé publique.
- Kirby, S., Greaves, L., & Reid, C. (2006) *Experience, Research, Social Change : Methods beyond the Mainstream. Second Edition*. Toronto: Garamond.
- Laconte, J., Killing Them Softly. Policy Review No. 90 (July-August 1998). Available online at www.policyreview.org/jul98/needles.html.
- Lamoureux, H., Mayer, R., & Panet-Raymond, J. (1984) *L'Intervention communautaire* Montréal: Éditions Saint-Martin.
- Lone Dog, L. (1999) 'Whose Genes Are They? The Human Genome Diversity Project.' *Journal of Health and Social Policy* 10.4 : 51–66.
- Smith, L.T. (1999) *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.
- Trussler, T., Marchand, R. (2000) Avec la collaboration de Yves Jalbert, Craig McClure, Darien Taylor. *Générer des connaissances pour l'action. Évaluation d'un atelier national sur la recherche communautaire*. Ottawa: Société canadienne du Sida.
- Zerda-Sarmiento, A., & Forero-Pineda, C. (2002) 'Intellectual property rights over ethnic communities' knowledge.' *International social science journal* 51.1 (171) : 99-114.

APPENDIX A – VALIDATION AGREEMENT

This agreement outlines the rights and obligations of CACTUS-Montréal and the research team for the project _____ with respect to the process for validating the results of the research project.

The team of researchers is comprised of _____

This agreement is drawn up to ensure that the perspective of CACTUS is represented in the final report of the project. It is also part of the development of an active collaboration between researchers and community based organizations.

To this end, following the data analysis, the researchers agree to present these results to CACTUS, in written form, in order to receive feedback from the agency. A draft of the final report is considered acceptable.

The researchers commit themselves to writing the final report and the preliminary results of the research in a language which is clear, accessible, and easily understood. Excessive jargon and verbosity is to be avoided, and *all* scientific terms and concepts introduced in the documents will be clearly explained.

In the case of a preliminary report exceeding 30 pages (excluding references), the researchers will provide a summary of the project and its results in a document not exceeding 20 pages (excluding references). In any case, the preliminary results will present all the elements of the project: its history, theoretical and methodological framework, the interpretation of the data, the action identified as required, as well as any proposed recommendations.

CACTUS agrees to provide its comments and feedback within a period of 15 working days following the reception of these preliminary results. The researchers may consider the absence of any formal response in this time period as an acceptance of the data analysis, except in the case of a written communication (letter, email or fax) to the research team requesting an extension of the time for an agency response. Any prolongation of the time is not to exceed 15 working days. Such a prolongation for the official response of the agency can only occur one time.

According to its abilities, CACTUS will offer its comments in written form. In the event that the members of CACTUS are more at ease in giving their comments in an oral format, the organization will communicate with the Principal Investigator to formalize such an arrangement. It is understood that the same delays and timelines apply, and that the organization needs to organize itself to offer all of its comments at one time. In this case, one person will provide all of the comments of CACTUS to the research team.

The response of CACTUS will identify the main points of the organization. These elements will be those most important for the agency. CACTUS may also identify additional elements which are less crucial but still pertinent. CACTUS will also provide its comments concerning the relevance of this research for its daily work.

The researchers agree to integrate the responses of CACTUS in the final report. All of the major elements of CACTUS's response will be included therein. The position of the agency as to the relevance of the research for its daily work will also be transmitted in the final report.

Following the incorporation of the comments of CACTUS, the researchers will present a draft of the final report to the agency. (This may be a second draft, if the research team previously presented a preliminary version of the research to the agency.) CACTUS will provide its comments concerning this version of the report within a period of 15 working days.

There may exist a gap between the position of the research team and that of CACTUS-Montréal with respect to the interpretation of the results. In this case, the gap will be noted in the final report, as well as justification of the

two positions (or several positions, in the event that this is the situation). If the response of the agency does not offer a justification for its position, the research team will solicit this essential information from the agency.

Aside from the positions of the research team and CACTUS, the researchers agree to validate the results with intravenous drug users. Any differences in the interpretation of the results with this group from either the research team or the agency CACTUS will be noted.

As to the interpretation of the results, when there exists a gap between the position of the researchers and that of the agency, or that of intravenous drug users, the researchers agree to represent this gap, as well as the reasons which underlie it, in any public diffusion of the research results (press conference, final report, executive summary, article, book, or other form of diffusion).

I, the undersigned, have read the agreement and agree to respect it. I am authorized to sign this agreement for my entire team.

Signature for the researchers

Signature for the agency

Date

Date