

PROPERTY OF
P.A.R.C. LIBRARY
1107 SEYMOUR ST.
VANCOUVER, B.C. V6B 5S8
681-2122 LOCAL 294

Report on Research Ethics Review in Community-Based HIV/AIDS Research

Written by
Russel Ogden
for the Canadian HIV/AIDS Legal Network
under contract with AIDS Vancouver
July 1999

H
210
OGD
1999

AIDS Vancouver gratefully acknowledges the Canadian HIV/AIDS Legal Network for its financial administration of this project. Funding was provided by the Care, Treatment and Support Program of the HIV/AIDS Policy, Coordination and Programs Division of Health Canada, as an initiative of the Canadian AIDS Strategy on HIV/AIDS.

The views expressed in this document are those of the author and do not necessarily reflect the official views of Health Canada or the Canadian HIV/AIDS Legal Network.

Copyright © Russel Ogden 1999

Summary

This report addresses a programmatic concern arising from the Canadian Strategy on HIV/AIDS for community-based research. In order to benefit from the annual allocation of community-based research funds, eligible organisations must be in the position to administer a process for ethical review. Alternatively, ethical review of research projects must be obtained from traditional ethics committees at academic or clinical research institutions.

Most community-based organisations do not have mechanisms for research ethics review. Where ethics review has been required, it has usually been obtained through a partnership with an external ethics committee. This option is problematic for community-based researchers because, as a rule, academic and clinical institutions do not provide direct services to non-member researchers. Consequently, a systemic barrier exists for community-based researchers and community-based organisations seeking ethical review of research proposals and ongoing projects.

This report describes 21 interviews with a sample of Canadian AIDS service organisation leaders and community-based researchers. In general, community-based researchers experience difficulty in accessing ethical review. Moreover, ethical review by traditional academic and clinical committees cannot be said to be fully sensitive to the needs of community-based researchers, less traditional research methodology, and the ethical concerns of community-based populations of study. Traditional ethics committees are criticised for lengthy delay in the review process, a concern for liability and for imposing dominant scientific research values on community-based researchers.

It is proposed that community-based organisations resolve some of these systemic and institutionally bound barriers through the development of autonomous, informed, community-based research ethics committees. Such committees should function with due regard to established standards of ethical conduct *and* also provide a cooperative forum

for consultation with, and guidance to, community-based researchers. Community-based research ethics committees should ultimately promote independence among community organisations, support awareness of and sensitivity to ethical issues, and further the development of community-based research.

The development of an ethics review infrastructure for community-based organisations should be regarded as an opportunity to become more informed about research ethics and the protection of the interests of research participants. Additionally, an ethics infrastructure would assist community-based organisations to give a more informed and critical assessment of research proposals that academic and clinical researchers bring to them.

Introduction

Ethical conduct in research requires that the rights of research participants be considered and respected. A primary function of an ethics review committee is to ensure that researchers design studies that conform to recognised standards of ethical conduct in research. Traditionally, research ethics committees have been features of both academic and clinical research institutions and not community-based or grass roots organisations.

This report explores some emerging issues concerning access to ethical review for community-based researchers and community-based organisations. A component of the Canadian Strategy on HIV/AIDS (CSHA) includes a \$1,000,000 annual allocation for community-based research (CBR). The responsibility for the administration of these research funds rests with the National Health Research Development Program (NHRDP). The goal of the CBR programme is the promotion of community-based research and continued development of partnerships and relationships of trust which are fundamental to the positive use of knowledge and community development. A requirement for eligible organisations is that they be “capable of administering a process for ethics review and approval.”¹ This requirement has been identified by the NHRDP as a “programmatic concern” of the CBR HIV/AIDS program.²

¹ Canadian Strategy on HIV/AIDS: Request for proposals [<http://www.hc-sc.gc.ca/hppb/nhrdp/cbr.htm>] p. 2.

² See Agenda—Victoria consultation: NHRDP’s community-based research program. May 5th & 6th, 1999.

The Definition of Community

It has been suggested that the concept of “community” in modern society is as controversial as the notion of class.³ Popular academic usages of community range from physical and geographical characteristics to the nature and quality of social relationships sustained by communities, including community feeling or community spirit.

Notwithstanding the problems of definition, all communities exist within real or symbolic boundaries and these boundaries help to define social membership or social exclusion. In the context of HIV/AIDS, “community” is probably best understood symbolically as the network of interrelationships involving affected and infected persons. This network includes free persons and collectives that act as units within the community but also have other purposes and identities.⁴ Typically, these relationships can be characterised by conflict, mutuality and reciprocity.

³ Lowe, S. (1986). *Urban social movements: The city after Castells*. London: MacMillan.

⁴ Etzioni, A. (1996). The responsive community: a communitarian perspective. *American Sociological Review*, 61, 1-11.

Ethics Review Boards: The Systemic Barrier to CBR

The first problem encountered by community-based AIDS service organisations and community-based researchers is systemic. Ethics review boards are virtually non-existent in community-based organisations; hence, the ethics review criterion of the CSHA programme is difficult to achieve. To overcome this barrier, the current strategy of community-based researchers is to rely on partnerships with academic institutions. This report explores whether this strategy adequately serves the principle objectives of ethical community-based research and the needs of community-based HIV/AIDS organisations.

To gather knowledge about the recent experiences of AIDS service organisations (ASOs) vis-à-vis the CSHA community-based research initiative, telephone and face-to-face interviews were conducted nationally with ASO leaders and community researchers. Potential interviewees were selected from the organisations in the national membership list of the Canadian AIDS Society. Approximately two dozen ASOs were approached to make initial contacts with key informants in CBR. These initial contacts facilitated additional referrals to other key informants.

Altogether, 21 open-ended interviews were conducted. Interviews covered the experiences, if any, that informants had in applying for research ethics review, including where and how the application was made. Informants were asked how they felt about the need for ethical review and barriers in accessing research ethics board (REB) services. The interviews were framed in the context of the CSHA CBR program and the requirement for research ethics review.

An irony in this report is that no formal mechanism for ethical review was available during the design and implementation of this project. Although this inquiry was not originally conceived as one that would pose ethical concerns for informants, it bears mention that some informants did express concerns about their confidentiality. Moreover,

given the scope of informant experiences regarding ethics review and government funding, guidance from an ethics committee may have been useful in this instance. Notwithstanding formal ethics review, this project respected the general principles of ethical conduct in research.

The ultimate purpose of this report is to document the experiences of community-based researchers in accessing ethical review and to offer some solutions to improve the quality and nature of ethics review in CBR.

Overview of Community-Based Research

Since CBR means different things to different people, it is useful to begin with a broad description of community-based research. Community-based research is distinguished from traditional academic research in that it takes place in community settings and involves community members in the design and implementation of research projects. A defining characteristic of CBR is collaboration with grass roots organisations and groups that have minimal claim to expertise in the “science” of research. The community rather than researchers usually defines research questions.

Organisations and individuals engaged in CBR should place a premium on the nurturing of mutually respectful relationships between academic experts and community members. The School of Public Health and Community Medicine at the University of Washington has identified six principles for guiding the development of research projects and their collaboration between researchers and community members. These principles provide a useful point of reference for understanding the general concept of community-based research:

- “Community partners should be involved at the earliest stages of the project, helping to define research objectives and having input into how the project will be organised.
- Community partners should have real influence on project direction—that is, enough leverage to ensure that the original goals, mission, and methods of the project are adhered to.
- Research processes and outcomes should benefit the community. Community members should be hired and trained whenever possible and appropriate, and the research should help build and enhance community assets.
- Community members should be part of the analysis and interpretation of data and should have input into how the results are distributed. This does not imply

ensorship of data or of publication, but rather the opportunity to make clear the community's views about the interpretation prior to final publication.

- Productive partnerships between researchers and community members should be encouraged to last beyond the life of the project. This will make it more likely that research findings will be incorporated into ongoing community programs and therefore provide the greatest possible benefit to the community from research.
- Community members should be empowered to initiate their own research projects which address needs they identify themselves.”⁵

In the context of HIV/AIDS CBR, Trussler and Marchand have proposed 10 principles that capture similar themes to the above principles, but also specify community participation in the review of funding and publication of findings (Appendix).

Notwithstanding the above principles, there is a sense that community-based research and academic research are separate worlds, with each not fully understanding the other. In HIV/AIDS CBR, Trussler and Marchand identify “research rigour vs. agency life” as one of the tensions between academe and community.⁶ Sclove et al. observe that while “university administrators vary in their attitudes towards community-based research, indifference, scepticism, or even resistance appear to be fairly common” and community-based research is generally viewed as less rigorous than academic research.⁷ Although academic rigour may not be a dominant feature or goal of CBR, the methodologies, findings and results of CBR can have an important bearing on subsequent academic

⁵ School of Public Health and Community Medicine, University of Washington: *Principles of community-based research*. [<http://weber.u.washington.edu/~sphcm/academic/comrsch.html>]

⁶ Trussler, T. & Marchand, R. (1998). *Knowledge from action: Community-based research in Canada's HIV strategy*. Ottawa: AIDS Vancouver & Health Canada. (p. 23).

⁷ Sclove, R. E., Scammell, M. L., & Holland, B. (1998). *Community-based research in the United States: An introductory reconnaissance*. Amherst, MA: The Loka Institute. (p. vii).

study. Over time, grass roots issues often develop into the foci of mainstream academic research. In this regard, Allman et al. observe that in many Canadian HIV prevention initiatives the CBR approach “represents the evolution of an alternative paradigm for social science investigation.”⁸

**PROPERTY OF
P.A.R.C. LIBRARY
1107 SEYMOUR ST.
VANCOUVER, B.C. V6B 5S8
681-2122 LOCAL 294**

⁸ Allman, D., Myers, T., & Cockerill, R. (1997). *Concepts, definitions and models for community-based HIV prevention research in Canada*. Toronto: University of Toronto HIV Social, Behavioural and Epidemiological Studies Unit. (p. 21)

Research Ethics Review: The Tricouncil Policy Statement

In August 1998 the Tricouncil released its long awaited policy statement, *Ethical Conduct for Research Involving Humans*.⁹ The intent of the policy is to promote ethical research and to “define a common policy of ethical conduct for research involving human subjects.” The Tricouncil policy outlines the mandate of institutional Research Ethics Boards, including membership, duties and authority as well as financial and administrative independence. Implicit in the policy is that institutional REBs are legitimated by the institutions that create them and that the Tricouncil policy is the prime directive for ethical research.

In Canada, there are nearly 250 REBs currently listed with the National Council on Ethics in Human Research (NCEHR). None of these REBs is associated with what one might call a community-based organisation. It is fair to say that academic researchers derive much of their scientific legitimacy and prestige from their institutional affiliations and that these affiliations also afford a legitimacy and credibility to REBs.¹⁰ Although the Tricouncil does not have the mechanism to monitor the activities of institutional REBs,

⁹ The Tricouncil comprises the three main research councils of Canada mandated to promote and fund research: the Medical Research Council (MRC), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC). The full Tricouncil policy is available on the internet: [http://ncehr.medical.org/English/mstr_frm.html]

¹⁰ Institutional research ethics committees do not always conduct their affairs ethically. Professors John Lowman and Ted Palys have documented numerous instances where the Simon Fraser University Ethics Review Committee have disregarded standard ethical review procedures and engaged in institutional conflict of interest. See Lowman, J. & Palys T. (1998). *The History of limited confidentiality at SFU: A submission to the SFU Ethics Policy Revision Task Force*. [<http://www.sfu.ca/~palys/History.html>]
For a discussion of the objectives, interests and values of the university in promoting academic freedom and ethical conduct in research see the commissioned opinion of UBC law professors Michael Jackson and Marilyn MacCrimmon (1999) *Research confidentiality and academic privilege: Implications for the new ethics policy at SFU* [<http://www.sfu.ca/pres/researchconfidentiality.htm>]

its policy statement provides the national standards upon which complaints may be evaluated by the three individual councils.

The Tricouncil policy makes no direct reference to CBR, yet it is clear that virtually all research involving humans should receive ethical review by an institutional committee which must operate independently from the parent institution's administration. The common standards and principles that REBs are expected to observe are as follows:

- Respect for human dignity
- Respect for free and informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits
- Minimising harm
- Maximising benefit

Although the Tricouncil policy is in many respects dominated by a biomedical orientation, it also recognises that in “many areas of research, subjects are participants in the development of a research project and collaboration between them and the researcher in such circumstances is vital and requires nurturing” (section i.7). This statement is the closest that the Tricouncil comes to recognising the concept of community-based research. At the same time, however, the Tricouncil warns that a potential risk of researcher-community collaboration is that participants may be overly influenced by a trust in the researcher rather than by assessment of the pros and cons of participation through an informed consent process. One implication here is that the Tricouncil is concerned with the possibility that participant/stakeholder confidence in the researcher and the agenda for community development may run interference with ethics and scientific objectivity. Alternatively, the ethics of collaboration and co-operation in CBR

may herald a communitarian ethic where informed consent is less contractual in nature. Moreover, the potential risks in most CBR are relatively minimal (particularly compared with experimental biomedical studies) and the concern for scientific objectivity may take a back seat to an agenda for community development.

The legitimization of REBs through institutional affiliation poses a question for REBs located in community-based organisations: would the ethical review and judgement of a community REB be acceptable to the Tricouncil or NCEHR? Given the scarcity of CBR REBs, this is a topic for future discussion. Nevertheless, with the growth of community-based research and the Tricouncil expectation that the research it funds be subject to ethical review, one might anticipate that some community organisations will respond with new regulatory infrastructures for ethical oversight. In order to meet the interests of CBR research participants, such infrastructure should be characterised by an appropriate degree of competence and expertise in considering matters of ethics, as well as independence from potential conflicts of interest. Additionally, CBR ethics committees should be carefully conceived so that local politics does not override the agenda for research.

One possibility for the future of ethical review in Canadian CBR may mirror what has already happened in the area of biomedical research where there are now mechanisms for private ethics review. For example, *Institutional Review Board Services (IRBS)*¹¹ was created in 1993 because qualified investigators, particularly those not based in hospital or university settings, were encountering difficulties in accessing ethics review. IRBS advertises that it conforms to federal regulations and provides high quality reviews with a very quick turnaround time. However, IRBS does not normally consider “research projects involving prisoners, foetal or other controversial subjects.” Since many CBR projects involve inquiry into sensitive topics that embrace sexual behaviour, drug use, and imprisoned populations, it is unlikely that IRBS would be an appropriate resource for

¹¹ <http://www.digiserve.com/irbs/index.htm>

CBR. Additionally, IRBS charges approximately \$2,500 for its services—a significant overhead to typically low-budget community-based projects.

Capacity for CBR and Accessing CHSA Grants

In Ibanez-Carrasco's recent report of the *Community Practice Roundtable* at the XI BC AIDS Conference, the concept of CBR as the "intersection of science and community development" is a recurrent theme.¹² Ibanez-Carrasco demonstrates that some ASOs, particularly those that have been around for some time, have evolved to a point of developing a research consciousness. These ASOs have developed the capacities for programme and service evaluation and are in the position to use the knowledge generated from those evaluations to inform and service their communities. Therefore, particularly where an educational component is built in, CBR has long-term implications for a variety of areas in community development, including training, advocacy, and direct services.

Some key informants in this project indicated that CBR is unrealistic for many small organisations because they suffer from an "experience deficit." Moreover, it was suggested that many clients in the community have difficulty accepting the link between research and community service. For small and emerging community HIV/AIDS organisations, the demand for direct services to members overshadows any research capacity—CBR is a low priority and often perceived as unattainable because of lack of funds, time, and expertise. Ironically, if these organisations could marshal resources to promote CBR, the empowering potential of community development through research might help to resolve "experience deficit" issues and enhance direct services. In other words, these ASOs would have the potential to become more influential in the development, promotion, and dissemination of community research. Ultimately, they would be better positioned to service their members through direct services and advocacy.

¹² Ibanez-Carrasco, F. (1999). *Community Practice: What's theory got to do with it?: An ethnographic report of a roundtable at the XI BC AIDS Conference*. (November 21, 1998, St. Paul's Conference Centre).

The process of applying for CHSA funds was perceived to be a difficult one for ASOs. Most of the informants were aware of the CHSA funds for CBR but identified the application process as “too lengthy” and “overwhelming to a non-research organisation.” An ideal type response from one informant was: “The NHRDP application looks too complex and seems out of our league.” To be sure, when it comes to grantsmanship skills for research, community-based organisations lack the skills, experience and knowledge that is common to academic researchers. Indeed, the NHRDP application form reflects a format familiar to professional researchers and academics; consequently, it is intimidating to community organisations lacking the essential knowledge and experience to compete for research funds. Some informants felt that it was better not to submit proposals “for a shot at the money” for fear of losing credibility in future opportunities. At the same time, informants said they would welcome any resource that might assist them with proposal development.

**PROPERTY OF
P.A.R.C. LIBRARY
1107 SEYMOUR ST.
VANCOUVER, B.C. V6B 5S8
681-2122 LOCAL 294**

How Do Community-Based Organisations and Researchers Access Ethical Review?

As a matter of practice, institutional REBs review the ethical protocols of their own members and not those of non-affiliated researchers. In community partnership situations with an academic researcher the process of applying for ethical review usually is left to the dominion of the academic's institutional guidelines. Institutional guidelines and the members of academic REBs, however, may not be sensitive to ethical issues arising from CBR methodologies. For example, in AIDS prevention research there is often a very close relationship between the affected communities and behavioural researchers. These complex relationships present challenges for institutional guidelines which may not recognise research relationships that include collaboration and partnership. For that matter, members of institutional REBs are likely to come from research backgrounds that have placed them in control of the research process, because of scientific and funding criteria. In the context of CBR, REBs need to be sensitive to the distribution of power between community-based researchers and the organisations in which they work.

It is not surprising that the ASO informants in this project pointed out that non-academic community-based researchers lack access to the traditional REB. Institutional guidelines are institution-specific and usually do not provide instruction for the conduct of non-affiliated researchers. Moreover, the Community Research Initiative of Toronto (CRIT) was the sole community-based REB identified by key informants. Consistent with the institution-specific model found in university and clinical settings, the CRIT REB only reviews research projects done by CRIT staff or involving CRIT participants. CRIT REB members are volunteers and their services are provided on an *ad hoc* basis. It is not known if the jurisdiction and expertise of the CRIT REB would be recognised by the Tricouncil or NCEHR. The CRIT REB is not listed in the NCEHR's current roster of Canadian ethics committees.

Informants in this project offered a range of observations about the process of seeking ethical review. In research partnered with academic institutions, some ASO informants were happy to accede the REB process to the professional researcher. Ethics review was seen as a procedural inconvenience and odious bureaucratic “hoop jumping.” Therefore, it was viewed as a distinct advantage that the community-based organisation could avoid the burden of the ethics review process. The availability of the REB to the academic researcher signified one less consideration for the often over-taxed community-based organisation.

However, several informants noted a drawback with academic partnerships because issues of study design, analysis and dissemination often become the dominion of the academic researcher. Sometimes community partnerships are reduced to relationships of giving *access* to the researcher and fail to embrace the spirit of collaboration and participation that is intrinsic to CBR. The result is tokenism—the researcher determines the research questions instead of the community. In this regard, the lack of a community-based research ethics infrastructure is a contributing factor in ASOs’ inability to be full players in research.

Some informants lamented that the community-based researcher has no place to take ethical concerns. While general guidance can be taken from professional codes of ethics and university protocols, the barrier in accessing institutional REBs means that community-based researchers are disadvantaged by not having a core resource that already exists for academic researchers. Several informants echoed the sentiment that university REB committees and procedures are not specifically designed with community-based or wider participatory interests in mind and that liability concerns for CBR activities outweigh ethical considerations. The concern that ethics review requirements may impose legal, regulatory and financial inhibitions was also raised.¹³

¹³ See Sclove, R. E., Scammell, M. L., & Holland, B. (1998). *Community-based research in the United States: An introductory reconnaissance*. Amherst, MA: The Loka Institute. (p. vii).

The following are two examples where informants described how liability concerns with university REBs had negative effects on community-based research:

Case 1

The CBR project was partnered with a university and had been designed to include community-based researchers. The involvement of non-professional community researchers raised liability concerns for the university REB. Specifically, the REB was concerned about a lack of jurisdiction over those researchers. The outcome was a twelve-month delay in approving the project as well as fundamental modification of the data collection methods. Ultimately, one of the CBR objectives—to pass on skills and training to para-professional researchers in the community—had to be abandoned due to the liability concerns of the university.

Case 2

A researcher/university sessional instructor was awarded a grant for a community-based study. The researcher submitted a request for ethical review to the university REB, which then raised jurisdictional issues: the REB argued that since the university was not a beneficiary of the research grant and because the researcher was not a permanent employee, there was no obligation to give the project ethical review. The researcher countered that the university had agreed to review the project and, given its stated obligations to community partnerships, there was a responsibility to give the project ethical review. The ethics review process lasted over six months. The project eventually received, and passed, ethical review, but on the condition that the local AIDS organisation accept all potential legal liability arising from the research.

In effect, the self-determination of the community as it pertained to the research projects was subordinated to the university's privileged values. The above examples raise a number of issues salient to CBR. Why should an REB have the capacity to limit the work

of non-professional community-based researchers? Does this not represent a chilling of some types of research because of epistemological criteria rather than ethical criteria? Is the university REB the appropriate institution for the ethical review of CBR? Are these outcomes of REB review indicative of a power imbalance that places community partners at a disadvantage when it comes to achievement of project goals? The researcher in Case 1 felt that the costs to the community were too great and that the participatory interests of the project had been severely undermined. The researcher concluded: "We need an independent community committee consortium to put proposals through a process and to get guidance and ethical review."

Several informants questioned whether an institutional academic committee is the appropriate body for the ethical review of CBR. Some observed that the research questions posed by academics are often different from those of community-based organisations. Much CBR involves the evaluation of programmes and support services and there was a perception that academic researchers are often not very interested or experienced in those areas of science.

Additionally, informants perceived stylistic differences between academic standards and community-based standards. For example, one CBR project proposed an informed consent form written in the first person. When the project was submitted to the REB, it was required that the consent form be rewritten in third person language. Although this may appear to be a minor issue of semantics, it does imply a distancing between the researcher and participant that is perhaps less desirable in CBR than in academic research.

One informant described frustration in locating a forum for ethical review. The researcher, academically trained, felt ethically obliged to submit a project for ethical review. Since he was not affiliated to a university at the time, he decided to put the research ethics proposal before the board of directors of the organisation serving the population of study. The process was described as a farcical means to an end, which did little to resolve the researcher's need for ethics review:

“It was a sham. We got the approval quickly, but I don’t think the board was at all equipped to give scrutiny to the ethical considerations of the study. We received no ethical guidance and it seemed to me that the whole process was really just an exercise in ‘rubber-stamping.’ Nobody, including me, and particularly the prospective participants, (in the study) benefited. Looking back, it was a somewhat dishonest process.”

Another informant, a researcher who also sits on a university REB, felt that university ethics committees, through inexperience, are insensitive to the methodologies of CBR. The researcher planned to apply for federal CBR funding but indicated intent to search out a non-university ethical review in an effort to maintain community-based research principles and to avoid university-imposed restrictions on the proposed research design.

There also appear to be cracks in the system which allow some federal government funded projects to proceed without formal ethics review. One informant reported that substantial funding had been received recently from a federal source without any requirement for REB review regarding the use of human participants. Another informant reported receipt of federal funding for an ethnographic study even though there was no ethical review prior to the collection of the data.

The above examples demonstrate that formal REB review is not yet a national standard in Canada. Nevertheless, one must keep in mind that literally thousands of research projects are conducted in Canada every year and allegations of unethical conduct by researchers are very rare. Research into HIV/AIDS issues by community-based researchers frequently involves sensitive issues of fundamental social importance and the populations of interest continue to place a high degree of trust in researchers. It is fair to say that this trust probably exists because community-based researchers have taken pains to earn it.

Ethics committees tend to be born from conservative institutions, reflect conservative values, and often include members who are not directly involved in actual research with

human subjects. Therefore, it is not surprising that ethics committees are prone to rejecting research proposals concerning controversial and sensitive topics.¹⁴ This may explain why, as mentioned earlier, a community-based researcher who also sits on a university REB would want to take a prospective CBR project to a non-university committee. It could well be that the traditional university REB is so detached from community-based research questions that it cannot fully appreciate the potential benefits of research to local communities and the ethical issues that would arise if the research were not carried out at all.

¹⁴ Sieber, J. E., & Stanley, B. (1988). Ethical and professional dimensions of socially sensitive research. *American Psychologist*, 43, 49-55.

Conclusion

Community-based organisations and investigators recognise the need for ethical conduct in research. However, the documentation of these standards is relatively recent and CBR researchers often find that a mechanism for ethical review is unavailable at the community level. Obtaining ethical review from a university or hospital REB requires partnerships that are not always helpful to community research agendas and may even alter the design and process of community-based research. Additionally, most institutional REBs lack the community membership essential to the proper peer evaluation of community-based research projects. The problem of lengthy time delays in the approval process compounds the access barrier and general sense that traditional REBs are insensitive to, and inexperienced with, community-based research.

One way to resolve the current systemic barrier to ethical review for CBR is to establish competent and impartial REBs for community research. Guidance may be found in the Tricouncil policy which says that REBs should be “designed to ensure the expertise, multidisciplinary and independence essential to competent research ethics review.” The Tricouncil suggests the following composition for an REB: it should have at least five members, male and female; two persons with expertise in the methods and research being reviewed; at least one person with knowledge in ethics; a person knowledgeable in relevant law (especially for biomedical research); and at least one person who is drawn from the community served by the research institution but not affiliated with the institution. For a community-based REB it would probably be a good idea to have greater scope for community participation.

The general message is that an REB should be competent, experienced and independent. The committee should have the capacity to thoughtfully assess the merits of the proposals it receives and to share the knowledge from its experiences with the community. Finally, the inclusion of a community member facilitates accountability to local communities, provided that the community itself accepts that person as a member.

For larger ASOs, the internal expertise to create an ethics committee probably already exists. The subsequent challenge would be to create an infrastructure that would provide efficient, thoughtful, and competent ethics review services to *all* community-based researchers. A possible solution would be to assemble a consortium ethics committee, drawing from a national roster. Depending on the nature of individual research projects, reviewers would be selected on the basis of their particular expertise and knowledge. Additionally, to share on a broad scale its knowledge and experiences with community organisations and researchers, a community REB could produce and disseminate widely a detailed annual report summarising the scope of ethical issues arising in CBR and the strategies employed to safeguard the interests of research participants.

The establishment of an REB for community-based research should not be viewed as odious: it is a necessary step for the protection of research participants and the furtherance of CBR and community development. Indeed, a community-based REB offers a unique opportunity to promote independence among community organisations, improve community-based researchers' awareness of ethical issues, and further the development of CBR in general as well as the development of ethical theory. Specific benefits of CBR ethics committees are as follows:

- Community ownership of the ethics review process. On the one hand, this would promote independence in CBR; on the other hand, it would help to develop expertise essential to more balanced relationships with academic partners.
- Expedited ethics review at the community level would facilitate timely completion of research.
- Community-based ethics committees would provide direct guidance and consultation to community-based researchers and research populations.
- Increased peer involvement in the ethics review process should foster community members' receptivity of CBR.

- Autonomy of community-based ethics review would promote understanding of less traditional research methodologies. The ethics review process by community REBs can be expected to be less rigid and formulaic than academic or clinically based ethics committees.

**PROPERTY OF
P.A.R.C. LIBRARY
1107 SEYMOUR ST.
VANCOUVER, B.C. V6B 5S8
681-2122 LOCAL 294**

Recommendations

1. It is recommended that a community-based REB be established as quickly as possible to remove the systemic barrier facing community-based researchers. The REB should be recognised as having the authority to review, approve or reject research proposals as well as perform a positive function by providing ethical guidance to researchers and organisations.
2. It is recommended that a community REB promote principles of fairness and access, so that any CBR project in Canada could benefit from ethical review and guidance.
3. The existence of any community-based REB should be made known to researchers and community-based organisations. This could be achieved by including contact information in the NHRDP CBR grant applications.

Appendix

COMMUNITY-BASED RESEARCH: TEN PRINCIPLES¹⁵

1. PARTNERSHIP
 - Community/professional equity
2. INITIATION
 - Community initiated, earliest involvement
3. PEER REVIEW
 - Community participation in funding review and publication
4. COMMUNITY BENEFIT
 - Research should improve community conditions
5. CAPACITY BUILDING
 - Instruct and employ community members in research procedures
6. OWNERSHIP
 - Lived experience belongs to the community; right of refusal
7. INTERPRETATION
 - Community participation in analysis and interpretation of findings
8. DISSEMINATION
 - Community right of review prior to publication; accessible language

¹⁵ The Principles for CBR in HIV/AIDS were developed by Terry Trussler and Rick Marchand. The principles have been presented at several conferences and workshops and

9. IMPLEMENTATION

- Facilitate inclusion of findings into programs and messages

10. EMPOWERMENT

- Encourage community members to initiate own inquiries

are the subject of ongoing evaluation and review (R. Marchand, personal communication July 11, 1999).