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Article

Student Researchers Negotiating Consent in Northern Aboriginal Communities

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Abstract

In this article, the authors discuss what students are doing to reconcile the differences between institutional ethical review standards and the reality of community-based, qualitative research, particularly in northern Canada. They examine the experiences of 12 students who are currently undertaking or have recently completed qualitative research in the North. Students raised concerns about what informed consent really mean; the contentiousness of obtaining written consent, and modified consent forms and the flexibility of research ethics board (REB) standards. The authors demonstrate that significant judgment is required in the introduction of ethics procedures in northern Canadian research. More work is needed to guide novice researchers and help build their agency for making ethical judgments in the field.

Keywords: students, ethics, vulnerable populations, northern research, Aboriginal

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Introduction

It was a really tough day for me. I handed out my consent forms, explained them and ask the [research participants] to sign them. I knew that without the signed forms I wouldn't really be able to use the data (whatever that means) but it felt so difficult . . . so un-natural. We have been working together for this long and now because of the interviews they have to sign something? I

> am sure many agreed to sign just as a favor to me . . . I hope this doesn't affect the relationship I have built with them already.—Excerpt from a graduate student's field notes.

Community-based researchers are asked to adhere to various ethical standards. Obtaining approval from university research ethics boards (REBs) and other research institutes can be one of the most significant hurdles to overcome in planning and facilitating a research project, especially one to be undertaken in a northern Aboriginal community. Researchers working in the North are asked to obtain northern research licenses as well as university ethics approval. For graduate students, this system of prospective review is often daunting. Procedural requirements are heavy. Ethics boards have specific processes for obtaining informed consent from research participants. REB standards appear firm, regardless of the type of research proposed, the population with whom the research will be undertaken, or the location in which the research will be carried out. As the excerpt from the graduate student's field notes indicates, reconciling the differences between ethical review requirements, specifically around informed consent, and the realities of research in community settings is often challenging. This is especially true for research that happens in northern Canada, because researchers can be isolated from their home institutions and, when working with Aboriginal people, are required to follow protocols in addition to the norm in southern locales. This article is a discussion about what student researchers are doing to reconcile the differences between the ethical practices they are required to follow in Canada and the ethical situations they are faced with in the field.

The contentiousness of informed consent

Although it continues to grow, the body of literature discussing the issue of how researchers negotiate ethical review, particularly related to informed consent with Aboriginal communities, is relatively small, with that focusing on research in northern Canadian communities forming an even smaller subset. However, this literature clearly indicates that both researchers and community members have encountered a number of important ethical difficulties when trying to establish informed consent among research participants. The issues that have been faced tend to be focused on three main questions: What constitutes informed consent, how should consent be obtained, and from whom?

What constitutes informed consent, and how should it be obtained?

According to the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans (1998), free and informed consent refers to "the dialogue, information sharing, and general process through which prospective subjects choose to participate in research involving themselves" (p. 2.1). The same policy (which governs the vast majority of academic and government-sponsored research in Canada) also stipulates that informed consent "should ordinarily be obtained in writing" (p. 2.1).

Unfortunately, the application of this standard (the familiar consent form) has been seen as inappropriate, and even offensive, to members of some Aboriginal communities, for a number of reasons. First, long-established culturally acceptable protocols for obtaining informed consent, such as the giving of tobacco, might already be in place in some communities, making the need for a signed consent form in addition to such protocols puzzling and possibly insulting for community members (Ruttan, 2004). Second, as a physical document, the signed consent form indicates a participant's agreement to participate in a given research project at a given point in time (usually before the research has taken place). Using this single instance as assurance of consent conflicts with notion of informed consent as an ongoing and constantly renegotiated process (Kaufert & Kaufert, 1996; Piquemal, 2001; Weijer, Goldsand, & Emanuel, 1999). The question of when consent should be obtained is also troublesome. After completing a participatory study with Aboriginal women for example, Meadows, Lagendyk, Thurston, and Eisener (2004) raised a concern, asking, "what boundaries govern the researcher in community consultation prior to institutional ethical review?" (p. 20). They felt it appropriate to gauge community responsiveness, build relationships,

and assess the applicability of the research to the local context before beginning their work, but they did not have institutional ethical protocols to govern them during this phase.

There is some precedent for the use of modified consent forms in research with Aboriginal people. Meadows et al. (2004) explained that they acted on suggestions from their Aboriginal advisory committee and sought and received permission from a Conjoint Health Research Ethics Board to use a simplified one-page version of the generic consent form. They justified this approach saying that they had also used plain-language forms in other studies. They stated, "The oral traditions of aboriginal people and our aboriginal committee guided us to make the informed consent process as unobtrusive as possible" (p. 6).

Differing perceptions of the nature of informed consent between research participants and the institutions researchers must report to can create real ethical dilemmas as investigators strive to meaningfully "engage the realities of increasing self-determination" (Kaufert, Commanda, et al., 1999) of northern Aboriginal communities while meeting the required standards of their profession (or, in the case of students, the requirements of their academic program and institution).

Consent from whom?

Adding complexity to the navigation of ethical review and informed consent are issues concerning which members of communities might, or might not, be able to give informed consent. From a traditional Euro-Canadian standpoint, answering the question "Consent from whom?" might seem rather straightforward. According to the TCPS (1998), for example, informed consent must be given by "prospective subjects, or authorized third parties" (p. 2.1). This standard can be problematic in Aboriginal communities, however, as principles such as consent (Piquemal, 2001) and morality (Casteel, 1996) might be considered communal as well as individual, and "the rights of individuals and shared interest of the community might be weighted differently" (Kaufert, Commanda, et al., 1999, p. 140). As a result, several communities, institutions, and researchers have recommended that consent be obtained by community representatives in addition and/or prior to obtaining consent from individuals (Alaska Native Knowledge Network, 2001; Canada, 1993; Dene Cultural Institute, 1993; Kaufert, Commanda, et al., 1999; National Aboriginal Health Organization, 2002)—that is, from both individuals and "authorized third parties." Nowhere has this principle been more strictly enforced than in the Northwest Territories, the Yukon Territory, and Nunavut, where all persons conducting scientific research must, by law, consult with and obtain the consent of all appropriate community organizations prior to beginning any research. This process has not largely been adopted by REBs in Canada, but it is part of the process of obtaining a northern research license (Aurora Research Institute, 2004; Nunavut Research Institute, 2004; Yukon Heritage Branch, 2001).

Conflicts arise for researchers and community members alike in deciding just who constitute "appropriate community organizations" and whether their consent can meaningfully represent the wishes of the community at large. The Northern Canadian consultation process has been criticized by some community members, who have not seen it as effectively "ensuring community involvement in (or even awareness of) pending research or adherence to ethical guidelines" (Inuit Tapirisat of Canada, 1993, p. 4). Even when this awareness is widespread, moreover, ensuring adequate and equitable representation of community members can be difficult (Canada, 1993; Kaufert, 2001). In addition, challenges can arise from conflicts between individual rights and community interests (Community Information and Epidemiological Technologies Canada, 2003; Norton & Manson, 1996), although it can also be difficult even to determine "who is and who is not a member of the community" (Freeman, 1993, p. 192). After all, according to the Association of Canadian Universities for Northern Studies (1998),

> The word "community" is not restricted to a limited area of settlement. The surrounding land that supplies resources for the settlement and the people who live there are viewed as part of the

> community. In addition, there are communities of interest within geographical communities. These too, should be considered where research activities might affect them. (p. 7)

Negotiating cthical review

There is little to indicate that the process of ethical review will become any less controversial in the future. Researchers and ethicists have argued about the purpose and usefulness of current ethics review practices (Bosk & DeVries, 2004; Haggerty, 2004), the inadequacies of REB protocols for qualitative and collaborative research (Meadows et al., 2004), and the great contentiousness of REB standards for informed consent (Bhutta, 2004; Malone, 2003; Milton, 2000). Many researchers, particularly from the social sciences, are unhappy with current REB processes and are skeptical that these bureaucratic hurdles improve the ethics of research. Bosk and DeVries stated clearly, "Researchers have simply figured out what it is the [REBs] want to hear and found ways to say exactly that" (p. 254). Bosk (2004) expanded,

> Neither my graduate students nor I have ever experienced any problems from the Institutional Review Board (IRB) . . . meeting the requirements to pass IRB . . . seems to me a simple even if an unwelcome chore, a matter of knowing what the regulations require and then providing exactly that. If the requirements are burdensome it is only because compliance with them bears at best a mysterious relationship to the question of whether I will conduct my research in an ethical manner. (p. 417)

These authors have call for more research looking at how institutional ethics boards work, more diversity among REB members, better education of review board members and researchers, and a more speedy appeals process.

Haggerty (2004) has been troubled by the fact that many social science researchers consciously evade current ethics regulations. He is not worried about the impacts of these evasions on research practice (feeling they are largely unproblematic in this regard); rather, he has expressed concern that "violation of the rules" might become commonplace, and if at any point individuals are to be singled out and reprimanded for their lack of compliance, it will tend to be the "most vulnerable or marginal members of the academy" (p. 2) who will be identified. He believes this outcome is inevitable in systems where large numbers of people routinely ignore rules that they perceive to be illegitimate or unnecessary.

Meadows at al. have (2004) discussed the complexities they faced in their own research with Aboriginal women:

> Conflict was created within us as researchers as we attempted to balance seemingly competing tensions—our desire to work ethically and in a culturally sensitive manner with . . . an under-researched population, and our desire to produce excellent research in a timely fashion using sound methodology. (p. 6)

They noted that many ethical dilemmas faced by researchers have yet to be addressed by REB standard protocols and have called for further debate surrounding the creation of guidelines for researchers committed to ethical methodology in research with Aboriginal people specifically.

Unfortunately, there are few investigations of how all of these complex factors—at either the individual and communal levels—have been, or should be, effectively and ethically managed. In this article, we examine the experiences of student researchers negotiating ethical review and informed consent protocols for research in northern Canada. Through our examination of these experiences, the study contributes concrete and practical examples to help us understand the challenges faced by student researchers and

how they are managing in the face of these hurdles. The work adds a unique perspective to the ongoing debate on the issue of REB standards and their applicability to diverse research arenas.

Method

Twelve graduate students who were engaged in or had recently completed research in the North were asked to respond, in written form (via electronic mail) or orally, by telephone or in person, to the following questions:

1. Briefly explain your research.

2. Explain the consent process you are using (or used) in your research.

3. Did an ethics board approve your research? If so, which ones and did you have any problems or issues related to your proposed method of consent?

4. Did you use a consent form in your research? If so, did you modify the form? How?

5. How did research participants receive your method of consent?

6. Do you have any problems or concerns related to consent that you could share?

7. Would you use the same method of consent again? Why or why not?

The sample was purposive. Participants were selected because they were researchers working in the North, from diverse geographic and disciplinary backgrounds, and known by at least one of the authors. Researchers came from eight Canadian universities, and 11 ethics boards and/or territorial research institutes reviewed their work. The points made in this discussion are colored and strengthened by these case examples. This work was approved by the University of Calgary Conjoint Scientific and Ethical Review Board.

Findings

The student experiences bring to light a series of ethical and procedural dilemmas. The concerns have been grouped under three categories, related to what informed consent really means, obtaining written consent, and modified consent forms and the flexibility of REB standards.

What informed consent means

Concerns put forward by the students focused on the understanding of what informed consent actually means, and when it is, or is not, required. Research projects in the North can take many forms. Increasingly, research approaches are grounded in participatory, collaborative research methodology. This means that the researcher spends time negotiating a research relationship in the community, working with local people, building trust, and establishing a role for him- or herself in the community. When is it appropriate to obtain consent in this type of research? There are methodological issues surrounding informed consent and its place in studies that involve prolonged engagement in a community and ongoing observation:

> I was always observing while I was in the community and writing field notes on what I was seeing. This was explained in the consent form but I don't know if it was really taken in. I think

> with this type of research it is very difficult to separate the researcher from the researched since we are engaged in the process together.

Another concern about what consent means relates to the idea of confidentiality. REBs often require researchers to ensure that research participants remain anonymous and that the data collected remain confidential. This approach to anonymity and confidentiality is explained in the generic consent form; however, it is contentious for graduate students working in the North, because first, it is often difficult to promise anonymity in studies done in small communities, and second, in research involving Aboriginal people, it might not be respectful to be given knowledge and then not identify the person who shared it with you:

> The biggest issue was with anonymity/confidentiality versus giving appropriate credit for knowledge. The researcher must be confident the project is well understood before asking for consent.

Students were also concerned about the "blanket" nature of consent. Most commonly, the consent process involves informing the participants of the risks of the research, as well as ensuring that they know that they can withdraw at any time and can refuse to participate in any part of the work. The participants are also told why the information is being collected and how it might be used in the future. If the participant signed the form (or offered oral consent), the students wondered what that meant, technically and practically. Technically, it seemed to mean that the researcher could collect and use the data in the manner that was explained in the consent form (even though this is often a "best-guess" and might be vaguely explained). For example, a researcher might say, "Participants will remain anonymous, and the data may be used in future publications, conference presentations and academic reports." Students knew this should not be taken as carte blanche to cover all future use. Practically, obtaining consent did not eliminate the need to make future ethical judgments about the collection, publication, and use of the data. Essentially, passing an ethical review did not ensure ethical practice. This is something that many of the students came to understand:

> I am concerned with all the sensitive information that the women shared with me and I feel it may not be good for families if I publish [even though I have consent].

> I gave them a copy [of the consent form] and I kept a copy. A couple of times I found their copy was just left [behind], which made me wonder if the form was of any importance.

One student said it concisely:

> I think the integrity with which I carry out my work is very important to the ethical considerations of the project.

In addition to the concerns already mentioned, the role of the researcher in northern settings also contributed to the complexity and contentiousness of informed consent for students. However, research in the North is less frequently of the "fly-in and fly-out" variety that was more common in the past. Today, licensing boards require investigators to follow protocols, consult with communities, and ensure that research results are returned to the participants. In this context, the researcher (and particularly the student researcher) can take on many roles. Along with investigator, the researcher can also be thought of as a volunteer, coworker, trainee, outsider, expert, community member, university student, friend, youth, teacher, nurse, and so on. These diverse roles impact the meaning and process of obtaining consent from research participants. Students noted that in some cases they felt research participants felt obliged to take part in the study because the participants knew the student personally. In other cases, students noted that participants felt having to sign a consent form or provide explicit oral consent was redundant, after

obviously volunteering. It was a challenge for some students to communicate the "unnatural" messages about consent without adversely affecting the relationships they had already built in communities:

> I know the participants wanted [to be involved] because they asked . . . they called me on the telephone. I was there both as a support (this developed over time) and an observer . . . the [participants] began to see me as a friend and even started to call me friend. From an empiricist standpoint, this would be coercion but from my feminist and post-modern perspective this is reality and the lived experience of conducting research . . . in a small northern community.
>
> I wondered whether anyone would refuse consent considering I was thought of as one of their co-workers?

Obtaining written consent

The next group of concerns expressed by the students was centered on the use of written consent forms and the process of using a signature to mark and symbolize a consensual relationship. Participants felt that obtaining written consent in research with Aboriginal people might be inappropriate for a number of reasons. First, the use of a signature and the idea of signing a document are parallel to the signing of treaties between Aboriginal and non-Aboriginal people in earlier times. There might be a mistrust of forms that are used by "Western" people:

> [Aboriginal people] involved in the study may feel that the written forms are not culturally safe . . . written forms may not be culturally acceptable and could be perceived as a colonial construct.
>
> [The method of consent] was usually OK but sometimes people would prefer not to sign, they said (spoken) words should be enough. I would like to be able to simply document that consent was given instead of imposing a non-traditional method which may detract from trust and respect.

Second, Aboriginal languages have a long oral tradition; however, the writing of these languages is a relatively recent phenomenon. If consent forms are presented in English, and English is not the first language of the research participants, they might not fully understand the content of the form, and the approach might not be entirely respectful. However, if the text is translated into an Aboriginal language, there is no guarantee that the level of understanding or respect will be increased.1 One student discusses language concerns that she faced in her research:

> The translation was respectful but not particularly useful as only one of my participants indicated that she understood the written words, but even she said she read the English version . . . Many [participants] were pretty silent through the process, made very few comments but smiled at me and signed it. It was difficult to say whether they understood it or not.

The students also expressed concerns related to the awkward and formal nature of obtaining written consent:

> I am not sure if I would use the same form of consent again, it felt like an awkward formality. Could there be implied consent? I mean if they agree to talk to you after they know you are a researcher and about your research project doesn't this say something?
>
> Written consent would have been awkward, I was glad to be able to use oral consent for the interviews.

Half of the students from whom we collected experiences used an oral form of consent at least in part of their research, and it seems that a precedent is being built for this approach.

Modified forms and the flexibility of standards

In addition to concerns related to the textual nature of written consent forms, student experiences include concerns about the preset forms that are suggested for use by REBs and the relative flexibility of REB requirements in relation to them. Most often, the preset form requires signatures of the participant, the researcher, and a witness, and it contains, "standard verbatim clauses regarding injury and liability . . . raising issues such as harm from the research and costs of subsequent treatment" (Meadows et al., 2004, p. 5). In the health sciences especially, students felt these forms pertained more to clinical drug trials than they did to most qualitative and community-based collaborative research. Two narratives highlight concerns with generic forms:

> The biggest problem was the phrase, "are you aware of the risks involved in this project." Although I tried to explain it, people got confused and uncertain at this point . . . the Ethics Board required it, but I would have liked to make some modifications, like taking the risk phrase out.
>
> The participants often sought clarification about risk, what exactly does that mean and what exactly do we have to do? I would then convert it into plain language.

In response to the question regarding whether they would use the same method of informed consent again, one student commented:

> I would have no choice as rules for consent are dictated by the Faculty Ethics Board.

Of the 12 participants, 9 used written consent forms, and 7 of these were modified from the generic templates in some way. However, some graduate students who were faced with the generic forms of the University REBs were largely unaware that the wording of these forms and even the approach to obtaining consent can be flexible. Although REB standards appear to be firm, they will consider modified forms in many cases. The applicant must be aware that the regulations are flexible and make a successful request for modification. This being "in the know" was reflected in the narratives:

> I created my own form based on those used successfully by friends. [I had] no problems with the Board but I found the process intimidating. I sought advice prior to submission regarding potential problems and found this very helpful.

Students who were successful at getting a modified consent form approved by a REB have often "done their homework" and provided evidence to show where modified forms have been used elsewhere in similar research and/or have included explicit justification for each modification. In the case of 2 students who used the generic consent form, they commented that the form was not well received by study participants and that they wished they could have used some other way. Modifications made by other students included shortening the form (and omitting certain clauses), making the form more plain language, and structuring the form around a question-and-answer format. Four of the students translated their forms into other languages as well.

Six of the students from whom we collected information used some manner of oral consent. This meant that the student explained the project and any risks it might involve (in some way), and then the participants orally offered their consent to be involved. In three cases, oral consent was used exclusively, whereas in the other three cases it was combined with some form of written consent. In all but one case,

the students said they audiotaped or videorecorded the oral consent. Students made these specific adaptations and obtained approval from an REB for them in each case.

Discussion

The argument has been made that it is "the quality of the consent, not the format, that is relevant" (American Academy of Pediatrics, 2004, p. x), but in reality many researchers working with Aboriginal communities continue to face the difficult task of "navigat[ing] through conflicting agendas" (LaBoucane-Benson & Cardinal, 2004, p. viii) when it comes to gaining REB ethical approval and securing informed consent. The 12 experiences drawn on for this article revealed methodological and ethical concerns that were faced by graduate students engaged in projects in northern Canada. Arguably, these issues exist for other researchers in the North and for researchers in other settings as well. There are concerns related to what informed consent really means, obtaining written consent, and modified consent forms and the flexibility of REB standards.

Concepts like risk, vulnerability, empowerment, and care underlie ethics review processes and ethical research practice. It is the duty of REBs, and the obligation of the researcher, to ensure that the research participant is protected from harm, is made aware of any risks associated with the research, and has the power to make his or her own decisions about being involved. What has been less widely recognized, however, is that there are times in which the standards for protecting "vulnerable" research participants place student researchers in positions where they become a vulnerable group themselves. Graduate students entering into research projects, especially in northern Aboriginal communities, are in unique settings. They are asked to develop creative, cutting-edge projects that will be respectful to the research participants and the community in which they live and, on the other hand, fulfill the procedural and bureaucratic requirements of their academic programs and institutions. Students also have a distinct time line and supervisory structure to work under while doing research.

The experiences of some graduate students show that their own academic requirements can be at odds with the obligations and responsibilities they take on at the community level. For example, students in this study expressed frustration at having to use written consent forms where cultural practices did not condone their use. Others were not sure about promising anonymity when the research participants wished to be identified. There was a sense of having to negotiate between the procedural and the practical, the theoretical and the research reality. When conflicts arose, students found themselves in positions of vulnerability, limited by their need to complete their academic program, follow certain REB guidelines, and do everything within a strict timeline. Students' ability to make judgment calls "in vivo" were restricted by the ethical procedures they agreed to follow at the outset of their study. Some brought out complex forms, undertook lengthy descriptions of research risks, and imposed written consent in culturally sensitive situations because they felt obliged to do so. The comments related to wanting to do otherwise but feeling as if they were restricted by REB requirements indicate this. When the information was collected from students for this study, one potential participant offered responses to the questions and then gave a caveat, saying that his remarks should not be used in the study because he was afraid of what might happen to him if it were revealed that he was unable to follow the REB requirements to which he had originally agreed. He exists as one of the most vulnerable or marginal members of the academy, those most at risk as described by Haggerty (2002). Instead of being proud of the work he had completed, he felt a measure of guilt that he had not followed the rules.

In these cases, student researchers are robbed of any agency they might have to make sound ethical decisions as situations arise; they are unable to make judgments about being ethical within the unique and evolving research settings in which they find themselves. Students might not feel able to be honest about the challenges they are facing, as they are constrained by time and supervisory pressures. They might feel forced to cover up any modifications they make in the field or, in converse, they might feel unable to

make any modifications at all, regardless of what specific situations might call for. In essence, students are being constrained by standards and have to find ways to stumble through as best they can, especially when situations beyond their original plan arise.

Although this study helps us recognize that there are times when student researchers become vulnerable groups, it is not reasonable to recommend that students should not have to follow REB protocols at all. What the findings indicate is that negotiating between ethical procedures and ethical practice was more difficult for some students than for others, and there are ways to make this process easier to navigate and more effective at ensuring ethical practice in the field (which is, of course, our goal). There was evidence to indicate that not all students were placed at the same level of vulnerability in this process. Those students who had mentors or peers who were aware of the potential modifications that could be made to generic standards fared better than those who were isolated or did not have this kind of guidance. A number of students spoke about relationships they had with other researchers (both senior and junior) that made a difference in how they approached and negotiated REB protocols. One student talked about using a modified consent form that had already been developed by another member of a peer group; another mentioned that she knew to meet with a medical ethicist (from the REB) to get advice prior to submitting her proposal. This points to an avenue for assisting future students in this process by, first, ensuring that the fact that REB standards are somewhat negotiable is better known among graduate supervisors and members of supervisory committees and, second, ensuring that students are aware that they are able to question generic standards, particularly those related to the use of consent forms, and that they can meet with an ethicist for guidance prior to submitting their proposal. REBs could assist in this process by publicizing that modified forms and "custom" approaches may be considered depending on the research context. REBs could also ensure that examples of modifications that have been approved previously are made available so that new students faced with these concerns would not have to "reinvent the wheel" in each instance.

This article is unique, in that it reveals issues faced on the ground by investigators who are still learning the ropes in the research world. Even though there might have been some perceived risk in doing so, the student researchers openly discussed the hurdles and barriers they faced in gaining ethical approval and in making ethical protocols work in the field. Their comments indicate that it is, indeed, a challenge to take REB generic procedures and standards into research settings, particularly those of remote Aboriginal communities. We hope that sharing their experiences will contribute to the growing debate on the ethics and practice of community-based research as well as inform the work of other new (and even perhaps experienced) researchers. Ethical review should help researchers foresee and prepare for the dilemmas they will face, as well as ensure that the researcher is able to make judgments and gain support, when unique situations arise. Research participants must be given the utmost respect and care, yet the vulnerability of the researcher should not be forgotten in this process. In the end, ethics review should improve the quality of research in all regards, not exist as a procedural hurdle that is distanced from the reality of the research experience.

End Notes

1. Although a fifth of the nearly 1 million people who identified as North American Indian, Métis, or Inuit in the 2001 Canadian Census speak an Aboriginal language as their mother tongue, less than 10% of them report being able to read and write that language (Government of Canada, 1992; Statistics Canada, 2003).

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