

Institutional regulation of research on families and legal status:
Negotiating competing notions of risk in a Canadian University context

Julie E.E. Young

York University

Judith K. Bernhard

Ryerson University

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Abstract

Little information is known about various segments of the population. This paper deals with the difficulties of conducting academic research with one such group, namely those with uncertain legal status. University-based researchers willing to contribute their time and resources to this area are hampered by tensions between legal frameworks and the academic ethics system. The authors' experience of proposing a longitudinal, mixed-methods study of life without full legal status is used as a case study on how competing notions of risk assessment frustrate efforts of data collection needed to provide accurate information on this group. We have drawn attention to a) the negotiations with the university ethics review board that severely curtailed the possibilities of conducting multiple interviews with this population and shaped the methodological decisions and outcomes of the research, b) the impact of the local context of heightened focus on immigration enforcement on decision-making, and c) how having to give participants a promise of *confidentiality to the extent bound by law*, meant, in effect, no real confidentiality at all. In general we found what Haggerty referred to as 'ethics creep,' ethics review boards placing increasingly restrictive demands upon researchers based on purely hypothetical assessments of risk. We raised questions about how understandings of risk and vulnerability are negotiated in the context of academic research and the implications of risk mitigation methods for the integrity of such research. Based on our own experiences, we suggest that a number of researchers working with marginal populations are being adversely affected and we consider what practical remedies are desirable. New paradigms and protocols are needed to find ways of meeting reasonable protective requirements without hamstringing investigators.

(250 words)

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Researchers, secure in their own unquestioned legal status, might assume that the main challenges in carrying out a project with people living with precarious legal status will be gaining the trust of people who wish to stay below the radar of immigration enforcement authorities. What we discovered through our work in Toronto was that many of the challenges involved in such research occur before one ever ‘enters the field’ to conduct surveys, interviews, or focus groups. In our negotiations with the ethics review board (ERB) at our institution, we were confronted with a system of ethical governance adapted from medical models that were inappropriate for working with those with precarious legal status. In this paper we reflect on how different notions of risk and confidentiality led us to make ethical, legal, and methodological decisions that shaped the outcomes of the research. Following a brief review of the need for research on this population and our proposed research contributions, we elaborate on how notions of risk and vulnerability are negotiated in the context of academic research.

Researching the lives of Canadian residents without full legal status has sparked the interest of several groups over the last decade. Some of the simplest questions such as ‘how many?’ are without answers. Estimates ranging from 40,000 to 600,000 individuals (Jimenez, 2003; Robertson, 2005) are based on newspaper articles and have no proper basis. There are wide areas of their lives for which almost no data exist, particularly regarding people’s daily, lived experiences of precarious status.

Canadian citizens, service providers, government bodies, and immigrants are thus currently encumbered by a major blind spot and lack of properly founded policies. This

handicap is further complicated by the large-scale ignorance and misconceptions that exist surrounding this issue. In the absence of information, misconceptions abound (Berinstein, McDonald, Nyers, Wright, & Zerehi, 2006; Berk & Schur, 2001; Lessard & Ku, 2003; Schwenken 2003; Yau 1995).

While actual numbers of people living with precarious status are unknown and difficult to document, it is known that numbers are expected to increase as the Canadian government relies more heavily on temporary migration to address labour market needs at the same time as it makes it more difficult to enter the country on a permanent basis (Goldring, Berinstein and Bernhard, 2009; Office of the Auditor General, 2009).

The significant and growing population of people with precarious status in the country calls out for academic research to document their situations. Yet much of the university-based research that has been done to date is comprised of small-scale needs assessments by and for service providers. Thus the project was envisioned as a large-scale survey to be followed up by interviews with a sample of participants over several years. The longitudinal, qualitative interviewing method was an essential aspect of the project we proposed because it would allow us to establish trust with participants over time so they would feel comfortable disclosing their experiences and struggles.

It was this longitudinal interviewing component that raised concerns for the ethics review board. Our ability to carry out multiple interviews with participants over several years would require us to collect and store their contact information. The ERB believed that having this personal information in our files risked drawing the interest of immigration enforcement officers who might subpoena our documents, placing research participants at risk of detention and deportation and researchers at risk of litigation and

even jail. It was difficult to assess the extent of these risks. On the one hand we knew that the chances of a researcher having files subpoenaed by immigration authorities was low. On the other hand, the political climate in Toronto gave board members and researchers pause, as there had been some high profile immigration raids and arrests throughout the city during that year. We return to this issue in more detail below.

Negotiations about risk and vulnerability of research participants are influenced by the multiple ways and locations where the state intervenes in the research process: in our case, this included the funding structure, the legal system, and the immigration enforcement regime. The ERB, researchers, and research subjects have different and at times competing notions of risk and trust, in terms of both risk to participants and risk to researchers (of being subpoenaed, going to jail, etc.). It is these competing notions that we were negotiating in a particular political context; working in 2005 in Toronto contributed to how we conceptualized and addressed risk in our research.

Our team was struggling with three competing imperatives: a) our commitment to the subject of precarious status and the academic quality of our work, in terms of concerns with depth and authenticity, b) the moral and ethical obligations to our participants, and c) our obligations to the Canadian legal system. Nonetheless, the many important insights gained from our research only indicated further the need for more extensive work of this kind. Although small in scale, the two projects we undertook offered insights into what it is like to live in Toronto with precarious legal status.

‘The political moment’: Precarious status and Toronto, Canada, circa 2005

Of particular focus in the present chapter are the situations of people with precarious

legal status who are residing in Canada. As Goldring, Berinstein and Bernhard (2009) argue, legal status in Canada is not clear cut but rather exists in gradations. Many people enter the country with official status, for example by making a refugee claim or travelling on a work or visitors visa, and are known to authorities; however, the outcome of their claim or the duration of their stay is uncertain and their relationship to state entitlements and support is precarious. As a result, in Canada it is difficult to claim that people living with precarious status are invisible to the authorities, in the sense of not having documents and being in hiding. In the majority of Canadian cases, they are hyper-visible to the state in that their presence and identities are known, although their whereabouts may not be. In other cases, however, people have entered the country undetected and are unknown, in an administrative sense, to state officials. It is important to understand the range of status situations that exists in Canada in order to engage with notions of risk and vulnerability that attach to particular individuals.

Services to this group – that likely numbers in the hundreds of thousands – are absent, provided unofficially, or administered in an *ad hoc* fashion, and research into their experiences is limited. A few studies have outlined the challenges faced by people living with precarious legal status in accessing healthcare and other social services (Access Alliance Multicultural Community Health Clinic 2005; Bannerman et al. 2003; Berinstein et al. 2006; Committee for Accessible AIDS Treatment 2001) but these have focused mostly on the perspectives of service providers rather than the people affected.

Research into the lives of these residents is relevant to all Canadian citizens because no resident exists in a vacuum – the lives of people in a community are inter-related. It is important to consider the impact of policies on individual and collective

wellbeing. Several studies have found that people living with precarious status in Canada are hesitant to seek out medical attention unless in emergency or acute situations; as a result, these residents do not benefit from preventative healthcare (AAMCHC 2005; Bannerman et al. 2003; CAAT 2001). Moreover, living with a sense of exclusion is detrimental to people's health (Hall and Lamont 2009). Different kinds of research projects are needed to understand the significance of precarious status, including studies of migration patterns, economic mobility, political engagement, and educational and employment outcomes. Knowledge generated in these areas would benefit community health centres, schools, social workers, planners, and policymakers at a number of levels.

The dearth of academic research into the situations of people living in Canada with precarious status is not for lack of interest on the part of researchers. Though people may be interested in contributing their time and resources towards researching the lives of residents with precarious legal status, a series of factors discourages them from engaging in this important area. In particular, research is limited by tensions between the legal framework and the academic ethics system over the issue of maintaining participant confidentiality. This tension, which frustrates efforts at data collection, is related to the conceptualization and assessment of risk. We use our experience of proposing a project that was severely curtailed as a case study for why there is so little research with this population, focusing in particular on the role of the ethics review board in this process. Our familiarity with these matters derives from our experiences of carrying out two research projects in Toronto involving participants with precarious statusⁱ. We met a great deal of resistance from various actors throughout the process – from the government funder to the university ethics review board. We focus in particular on the

ethical, legal, and methodological issues we encountered in relation to research into the situations of people whose whereabouts are of interest to the state and its immigration enforcement officials.

Our project was the first of its kind at our university and as a result, the first that raised these questions for the ERB. We were negotiating the notion of risk and the boundaries of confidentiality along with our Board since the potential risks facing our participants were of concern to all of us. The ethical issues our research engaged were complicated by the fact that the research population we were working with was not homogeneous; rather, we were seeking to establish trust with people whose situations ranged from hidden to hyper-visible. Although confidentiality is crucial in many research contexts, and particularly in ours, the challenge we sought to address was establishing trust with people who were in a variety of relations to the state and facing different kinds of vulnerabilities. Our desire was not to place them at more risk than they already faced in their daily lives, which varied because our participants included people who wanted to remain hidden and people who depended for their livelihoods on having their temporary work permit renewed. Throughout the ethics review process we were balancing out different notions of risk from the perspectives of the ERB, potential participants, and the research team, which included academic and community-based researchers. As researchers, our understanding of risk at the time of the project was related to the political moment.

Our sense that we might be putting our participants at increased risk was related to the political moment. A number of immigration raids that had taken place at a downtown mall in the spring of 2005 as well as the arrest on our university campus of a

non-status woman who had been volunteering at an International Woman's Day event in early March (Rebick 2005). She was initially detained by campus security, which is run by a private security company, and then arrested by Toronto Police. In this sense, immigration enforcement practices were not a distant possibility but a local, albeit unpredictable, reality. It is unclear whether the risk of participating in our research projects was greater than the risks people faced in their day-to-day lives in the city, except that more people would be aware of their status. We were making decisions around the research process in the context of a heightened focus on immigration enforcement in the city. We attempted to balance a desire to do justice to the research as originally conceptualized, since we felt that carrying out multiple interviews with participants was a more comprehensive way to approach it, with the desire not to put people at greater risk than what they already faced on a daily basis due to their status.

The Ethics Review Board and the negotiation of risk

The crux of the challenges we faced in getting our projects underway revolved around our negotiations with the ethics review board at our institution. Our university, like those in the rest of Canada and the US, is charged with developing an ethics review process in compliance with a statement developed by the federal government (for the UK situation see Dyer & Dermitt, 2009). In Canada, the *Tri-Council Policy Statement (TCPS)*ⁱⁱ sets the protocols and requirements for evaluating proposed research projects involving human subjects. Deriving from their concern with protecting research participants (and their medical-model mentality), this board had the authority to alter our project or even prevent it altogether. In most cases projects considered by the ERB are approved, often

with some adjustments to wording of informed consent documents or recruiting procedures. In our case, the key – and related – issues that arose in the ethics review process concerned the evaluation and mitigation of potential risks to individuals who agreed to participate in the research, and the extent to which we could promise to maintain their confidentiality. Before reviewing in detail our engagements with the ethics review process, we provide an analysis of the function and role of ERBs in Canada.

The ERB was institutionalized because of highly unethical practices of researchers in various settings, especially in the areas of medical and psychological researchⁱⁱⁱ. In Canada, ethical guidelines were systematized in 1976 (Fitzgerald 2004). Ethics review boards hold researchers accountable for the content of their research and their treatment of participants. They also function as gatekeepers around disciplines to secure the integrity of the social sciences, preventing them from being tainted by scandals: they are “the final arbitrators of whether or not a research project can be conducted” (Fitzgerald 2004, p. 318). The ERB has a dual role that complicates its relationship to researchers whose work is subject to evaluation and approval: it is charged with protecting the rights of ‘human subjects’ involved in research projects and it is subject to the state’s control, which establishes the Board’s terms of reference and standards of practice.

The ethics review process is based on a scientific (medical) model of research in which procedures and protocols are much more standardized than they need to be in social science research. A standard application form, modelled after biomedical research designs, is used to evaluate all projects, whether they are based in the sciences, social sciences, or humanities. A number of researchers have argued that the some of the

assumptions underlying the ethics review process pose an epistemological challenge to qualitative research, especially for projects in which it is necessary to build trust with participants. This has led some researchers to suggest that the reach of the ERB has become unwieldy as the ethics protocol is not well suited to projects in the social sciences and humanities (Bledsoe et al. 2007; Dyer and Demeritt 2009; Greyson and Miles 2005; Sikes and Piper 2008; Stark 2006). Dyer and Demeritt, writing in the UK, went so far as to suggest that asking gang members or illegal workers to sign a consent form is ridiculous. As Greyson and Miles (2005) pointed out, the formal written consent requirement causes an interaction to become formal in the first minute, and, in the eyes of participants, raises threatening possibilities. This makes qualitative research quite difficult as researchers rely on making connections with participants in order to carry out studies.

A number of researchers have referred to the ERB as an inappropriate regulatory system for surveillance and oversight of the work of researchers. Inspired by Foucault's work (1987), the workings of the ERB are seen as an illustration of disciplinary power that is exercised through its invisibility. Koro-Ljungberg et al. (2007) suggested that in obtaining approval from the ethics board, "researchers are constrained and continuously 'produced' through normalization" (p. 1076). Haggerty (2004) argued that ERBs have expanded their purview and created tighter, more detailed regulations in all areas; he refers to this trend as 'ethics creep.' Board requirements structure all interactions with participants and, in some cases, preclude unplanned interactions and formalize those that do occur (Alcadipani and Hodgson 2009; Haggerty 2004).

Other authors have suggested that seemingly inflexible ethics protocols might

lead researchers to simply fill out the required forms and get through the ethics review process, without sufficiently engaging with difficult ethical questions raised by the research but not addressed in the formal review process (Allen 2008; Halse and Honey, 2005; Koro-Ljungberg et al. 2010). Moreover, they argued researchers' assurances on the ethics application that they will follow particular protocols may not be followed in the research process. Dyer and Demeritt (2009) opined that "ethical frameworks applied by formal ethical review processes ignore...wider normative and political concerns at best, and at worst actively subvert ongoing efforts to infuse [research] practice with an ethical sensibility"(p. 48). In other words, standardized applications and required wording in informed consent documents risks making ethics review a mere step to check off prior to beginning research rather than a reflective process in which potential risks and challenges are seriously confronted by researchers.

Haggerty (2004) claimed that ERBs focus on risk without evaluating the empirical likelihood that potential risks might materialize. Board members "generally do not know the empirical likelihood of the potential untoward outcomes that they try to regulate" (p. 402; see also Lowman and Palys 2007). The area of risk to participants is extensively covered by Haggerty who suggests, "the range of potential research related harms envisioned by ERBs at times seems to be limited only by the imagination of the reviewers" (p. 400). By focusing on worst-case scenarios in proposed research projects, the ERB affects the topics and questions on which researchers are able to focus. Indeed, Bledsoe and colleagues (2007) argued the ethics review system 'regulates creativity':

Facing demands that spiral to the level of sheer impracticality, faculty and students at many institutions face a stark choice: to conduct innovative research in

their fields or to meet the requirements of their institutions' IRBs [Institutional Review Boards].... This strikes to the core of the research enterprise (pp. 594-596).

Haggerty (2004) reported the case of an American researcher named Wax who was unable to carry out a study on the phenomenon of teenagers who sniffed glue. The ERB denied Wax's application because he did not include "provisions for securing parental consent – an impracticality given the nature of the topic being studied. Enforcing this rule for such research bears little relationship to the aim of protecting research subjects from harm" (p. 410).

In their examination of the fallout from a case at Simon Fraser University (SFU) in Vancouver, Canada, Lowman and Palys (2000, 2007) challenged ERB protocols that place *a priori* limits on participant confidentiality. In 1994 Russel Ogden, a masters student in criminology at SFU, was subpoenaed by the Vancouver Coroner and asked to reveal two of his confidential sources. Part of Ogden's research was with people who had witnessed an assisted suicide within the HIV/AIDS community. Ogden invoked the Wigmore criteria (to be examined in further detail below), arguing the public interest in the research outweighed the court's desire to know the identity of his participants, which was accepted by the Coroner. Despite Ogden's vindication and the upholding of participant confidentiality in this case, Lowman and Palys (2000) indicate that SFU's Vice President of Research quickly:

Put limitations to confidentiality on the Ethics Committee's agenda: 'It was agreed that in cases where it can be foreseen that the researchers may not legally be in a position to ensure confidentiality to their subjects, these researchers must

be required to provide only limited confidentiality in the wording of the consent form' (p. 250).

Most ERBs in Canada require researchers to indicate in informed consent documents that participants' confidentiality will be protected 'to the extent permitted by law,' effectively limiting confidentiality before research has even taken place. Lowman and Palys (2007) argue that requiring the *a priori* limitation of confidentiality amounts to a 'buyer-beware' approach to ethics, absolving "researchers and universities of the responsibility of spending the time and resources necessary to even assert research-participant privilege" (p. 173). Limiting confidentiality removes the responsibility from researchers to protect participants and "is likely to facilitate 'liability management' by universities: 'we warned you that confidentiality is limited, so do not complain to us if the information you gave us falls into the hands of the courts or police'" (p. 171). Lowman and Palys ask, "Is this how universities should 'respect' the 'human dignity' of research participants" (p. 171)? They argue that research that aims to protect "health, safety and human life" and advance the public interest requires confidentiality (p. 169).

It is in relation to this kind of balancing act, in which maintaining participant confidentiality allows for research that is in the public interest to take place, that the option of the so-called 'Wigmore criteria' is important. The definitive decision-making apparatus around such questions in the US is what is called *The Wigmore Test* (Lempert and Saltzburg 1982; Lindgreen 2002; Lowman and Palys 2001). This procedure, now followed in Canadian courts as well, allows researchers to protect the confidentiality of their sources (Wigmore 1905). The researcher must be able to demonstrate that the results of the research and the interests of the participants are of greater importance than

resolving a legal matter. The Wigmore test does not contest the law, but claims that the litigant's research would benefit the community to the extent that it ought to be made an exception. In order to successfully meet the Wigmore test, researchers must show that the community can benefit from the research *only* if researchers are able to protect the confidentiality of participants.

The decision by SFU officials to mandate 'limited confidentiality' in cases where the ERB felt there was potential risk of subpoena had an impact on the kinds of research that were subsequently carried out at the university. The Research Ethics Policy Revision Task Force, appointed at the school in 1998, found that "sociologists, criminologists, and others – particularly graduate students working with time restrictions – began to avoid field and interview research" (Lowman and Palys 2000, p. 253). In our situation we felt that requiring limitations to promises of confidentiality would have a chilling effect on our ability to carry out our research with people living in Toronto with precarious status.

Negotiating 'risk' through the ethics review process

The key aspects of the ethics review process that our proposals engaged were notions of risk and the issue of confidentiality; the latter was paramount but inseparable from the calculation of risk, in the sense that participants, due to their status, faced risks in their everyday lives^{iv}. Our proposed project highlighted the importance of studying precarious status and called for a large-scale, longitudinal, mixed-methods study. The study would include 1,700 surveys and 250 in-depth interviews with both individuals living with precarious status and the 'institutional actors' – such as service providers, religious leaders, union organizers, and teachers – with whom they came into contact in four

southwestern Ontario cities. Before carrying out this large-scale, multi-year project, however, we received funding to do a pilot study in which we would interview people living with precarious status in Toronto. At the same time, a Master's student who became affiliated with the research team developed a project that would use semi-structured, open-ended interviews to focus on how youth experience living with precarious status in Toronto (Young 2005).

While we were not aware of the Ogden case as we began our discussions with the ERB, concerns about potential risks facing participants and protecting participant confidentiality became central to these negotiations. The main issue revolved around our plan to carry out multiple interviews with people living with precarious status. In order to do this, we would need to collect and retain participants' contact information. The Ethics Board worried that our files might be subpoenaed by immigration enforcement officials and recommended that we follow one of two options: 1) not to pursue more than one interview with each participant, or 2) to clearly indicate in the informed consent documents that we were only able to promise confidentiality 'to the extent permitted by law.' Both options presented serious limitations to our methods and to the proposed research. A longitudinal study comprised of multiple interviews over time would allow us to establish trust with participants before delving into their experiences of living with precarious status.

The research team was aware that people who fear detention or deportation would need time to determine who can be trusted. We anticipated that people would be hesitant to participate or reluctant to answer questions when the immediate benefit to themselves was unclear. As a result, we planned to make extensive efforts to foster the kind of

continuity and sensitivity in researcher-participant relations that was seen as crucial to good data collection (Cornelius 1982). In order to do that we felt the research would require more than one interview with each participant. The focus of the first two sessions would be on asking the participants questions about their migration experiences. For example, we planned on asking how they decided when and where to migrate. Was there someone in their family that had moved abroad before? We also planned to talk about their networks – who were the significant people in their lives? Where did they live? Were these ties weakened by immigration or maintained? In this manner, the questions about hardships could be saved until the third or fourth interview session when a degree of trust had been established. This aspect of the research design meant that we would need to collect participants' contact information in order to be able to follow up with them. It was this confidential information – and the matter of the extent to which we would be able to protect it if challenged – that formed the crux of our negotiations with the ethics review board.

The main concern of board members was that if the researchers were in possession of the participants' contact information, there was a risk their information could be traced back to their identities. Even if pseudonyms and code numbers were used, having a list of participants' phone numbers put them at risk as researchers' records might be subpoenaed and the researchers ordered to disclose contact information to the Canada Border Services Agency (CBSA), the federal immigration enforcement agency. The possible risk of having our files subpoenaed was seen as so dangerous that we were directed not to pursue any follow-up interviews. We learned that researchers in a number of areas in the US had been subpoenaed to produce their field notes in order to identify

participants. For example, in 1971 a researcher was subpoenaed for his study about whether participants had collected welfare while receiving income maintenance in the US. Another of the cases that gave us pause was that of Samuel Popkin, a Harvard professor who was jailed for eight days in 1972 for refusing to reveal the identities of the people he interviewed for a secret war study (Lowman and Palys 2001). In 1973 the US Federal Bureau of Investigation threatened to subpoena the research records of the Kinsey Institute's work on human sexuality. We discovered that in some cases, upon failure to produce field notes, researchers had been jailed for several months at a time (Carroll and Knerr 1975; Lowman and Palys 2001). Most surprising to us were the cases where universities had not supported their researchers, allowing them to be sued and even to go to jail in spite of conducting the research as part of the terms of their employment. Although Lowman and Palys (2007) report that asking a researcher to hand over their files has only happened on a single occasion in Canadian history and furthermore that the researcher was not in the end forced to hand over his files (the Ogden case discussed in the previous section), we felt the risk of having our files subpoenaed was plausible given the political climate around immigration enforcement in the city at the time.

The ERB and our group discussed options such as keeping the contact information in a separate location from the surveys or converting it into digital data. Given the sensitive nature of our topic, no one contested that confidentiality was essential or that our duty in conducting such research included the ability to provide research participants with such an assurance. The ERB insisted that we could not promise complete confidentiality, only confidentiality permitted by law. It appeared that if we went ahead with multiple interviews, which would require that we collect and store

contact information, the ERB would require us to *a priori* limit participant confidentiality by indicating in informed consent documents that, ‘Confidentiality will be provided to the fullest extent possible by law.’ We felt this coy turn of phrase would mislead study participants into a false sense of security. This ‘myth of confidentiality’, a promise of confidentiality to the extent bound by law, meant, in effect, no real confidentiality at all.

We approached a Toronto law firm for advice. Lawyers there insisted we should anticipate a Wigmore defence from the beginning of the research process and indicate that the research could not go ahead unless we were able to promise confidentiality. They suggested, for example, that when starting the interview, the researcher should discuss confidentiality with the participants and specifically ask them, ‘If there was no promise of confidentiality, would you be willing to talk to me about this matter?’ We were advised that recording in field notes that the promise of confidentiality was absolutely essential is good preparation for the Wigmore test.

We sought further advice directly from Ted Palys, a colleague who had written extensively about the Wigmore defence. In response to our question about how to conduct research with participants whose legal status makes them vulnerable to detention and deportation, Palys (2005) agreed with the lawyers that we should be “anticipating Wigmore from the start” and that taking actions like meeting with the full ERB, obtaining legal counsel, or consulting with him would be well regarded by a court as it showed that we had always acted as though confidentiality was essential:

Basically you should be thinking of ‘evidence’ and the creation of a record showing how much you are concerned about your participants, which you obviously are, and of the steps you are taking to ensure that your interactions with

them are as bulletproof as you can make them. This interchange between you and I [the email exchange] is similarly important insofar as it shows you are going as far as seeking expert advice on what to do. You should also make it clear in your interactions with the ERBs. Bottom line here is that it is pretty clear that everyone you are contacting recognizes that confidentiality is essential to gathering valid data and protecting the research participants, and that the project cannot happen, and the data will not exist for anyone's use (i.e., yours OR the court's) without it (Palys 2005).

As a final step before making our decision around the ethics protocols, and at the suggestion of a former Immigration Minister who was a visiting scholar at our institution at the time, we contacted the Canadian Border Services Agency (CBSA) asking for a letter undertaking to respect the confidentiality that we would be promising our participants. We argued that although it was clear that the proposed research was for the public good, in order to conduct the study, we had to be able to assure participants that their responses were confidential and that their participation in this study would in no way trigger enforcement to investigate or deport them. The response that we received was that the agency was “mandated to remove inadmissible persons from Canada as soon as is practical. Therefore, it would be contrary to the CBSA’s legislative obligations to entertain the request not to pursue enforcement action of the study participants” (Doiron 2005). Given that the CBSA’s response was to state their mandate and indicate they could not assure us they would not seek to pursue participants, it was even more important to maintain their confidentiality and not collect personal data. They had to remain anonymous to the researchers in order for us not to be in a position of having

personal contact information in our possession.

Despite our prior deliberations in developing the research proposal, we decided to reconsider our plan to engage in multiple interviews with people whose status was precarious. After extensive consultations with the ERB, lawyers, and colleagues, we elected to carry out a single interview with participants in order not to have to collect contact information. Understanding that this project focused on a vulnerable population, our main concern was to ensure that these individuals not be placed at any more risk than they already faced on a daily basis due to their precarious legal status. We scaled back our research plans and in 2005, conducted a study that surveyed 18 individuals living with precarious status recruited through ten entry points. The survey consisted of short-answer, closed questions and was administered by the research team in the language with which the participant was most comfortable. The interview protocol concluded with four open-ended questions to draw out further stories and details. The youth study, which had a shorter timeframe for completion, involved open-ended, semi-structured interviews with six participants recruited through four entry points.

The most significant compromise we made for both projects was not to collect or store participants' names or contact information so that these details would not appear in our files. This meant that we had to abandon the idea of multi-interview research. Because we could not record contact information, even if this was in code, we could only have one meeting with each participant. As a result, we had to delve into challenging and confidential matters at our first meeting and were unable to clarify details or follow up about particular questions. While we still considered that the project would provide invaluable insight into what it is like to live in Canada with precarious status, we felt that

a door had been shut. The ethics review process raised obstacles preventing us from carrying out what would have been an innovative study. The ERB requirement to either not pursue multiple interviews or limit confidentiality from the outset meant that we could not test our proposed research design (i.e. longitudinal interviewing).

This inability to conduct a follow-up interview is one of our major concerns with the legal restrictions on being able to promise complete confidentiality to participants. It goes without saying that data regarding precarious situations are rendered incomplete and superficial unless people are willing to tell their stories and share troubling personal experiences. Regardless of legal restrictions, the simple fact remains that people are not willing to share such personal information unless trust is established in a normative manner. This includes a comfortable relationship established over the course of multiple meetings. Our inability to engage in multiple meetings with participants was a limitation to both projects; however, overlooking this was a decision we made in order to protect our participants from the risk that we would be forced to disclose their identities to authorities.

Concluding thoughts: On risk, vulnerability, and immigration status

While the obstacles raised by our institution's ERB affected our subsequent decisions about the project, we do not want to overstate the role of the ERB in policing knowledge production in our case. We agreed with Board members that the risks of detection, detention, and deportation are and were real for people living with precarious status. The ERB's response to our application and its cautious approach to the issues of risk and confidentiality contributed to our methodological decisions that were perhaps overly

cautious, in the sense of erring on the side of caution at the expense of doing a comprehensive study. As both Haggerty (2004) and Lowman and Palys (2007) suggest, limited and compromised research can be the result when ERBs focus on risk without evaluating the empirical likelihood that potential risks might materialize. It bears repeating, however, that the local context was a factor in our decisions, since we felt that the risk of being subpoenaed was not negligible given recent immigration raids in public spaces, including the arrest of a non-status woman on our campus a few months earlier. As Haggerty (2004) contends, “While academics have only rarely been asked to reveal their sources, because research is not a statutorily protected form of communication researchers can be faced with difficult decisions about whether they are willing to go to jail rather than reveal their sources” (p. 407).

Academic researchers facing such options are in an untenable position. On the one hand, they face the threat of being served with a subpoena to disclose the names and phone numbers of those interviewed and being responsible for a person’s life falling apart because of detention or deportation. On the other hand, researchers face the moral, academic, and professional dilemmas inherent in being unable to do an individual’s experiences justice because she or he may be safely interviewed once and only once. The *Tri-Council Policy Statement* indicates that ““Researchers should avoid being put in a position of becoming informants for authorities”” (Lowman and Palys 2007, p.170). In our case, our research engaged two faces of the state: its research arm (through SSHRC, which funded our pilot study, and the TCPS, which governs the ethics review process) and its immigration enforcement arm (in the form of the Canada Border Services Agency, which polices immigration violations and which we did not want to assist by collecting

information of interest). The Canadian government oversees both SSHRC and CBSA; although they are separate departments, they function within the same broad context of governance and oversight.

While this paper focuses on our experiences of negotiating the conflicting imperatives of our research agenda, the ethics review process, and the Canadian legal framework, there is no question in our minds that the difficulties we confronted around questions of risk and confidentiality were connected to the larger environment of knowledge production. We decided not to put a Wigmore defense to the test but agreed to reconsider it if the long-term project was funded. The fact that the larger version of the project was not funded by the federal research council suggested to us that there were additional factors at play in preventing researchers from asking certain questions and engaging with particular populations. This raises a host of further questions about what research is considered important, what gets funded, and what is seen as too controversial.^v Despite taking note of the importance of the topic and providing a developmental grant that allowed us to carry out the pilot study, the funding body twice refused to support a more thorough investigation of precarious legal status in Canada.

The limited amount of information available about living with precarious status in Canada is unfortunate. Further knowledge about the significant and growing segment of the population that lives in grey areas of legal status could educate the public as well as inform political mobilization and policymaking. The challenges we encountered in our research with people living with precarious immigration status can be compared to those faced by researchers working with drug addicts, individuals who provide assisted suicide, and interventions aimed at male clients of prostitutes, the so called ‘john’ schools, whose

research participants might be of interest to various authorities. In these sensitive cases, the protection of the researchers' sources is paramount to thorough data collection.

Questions of risk and confidentiality must be balanced against the potential benefits to be derived from carrying out research with 'vulnerable' populations. Risk is a social construct; however, it has material implications and must be understood in context.

In this paper we have illustrated how the ethics review board at one university tried to support what it categorized as 'risky' research while prioritizing the protection of participants who are in a vulnerable position in relation to the state and whose whereabouts are of interest to particular authorities. Due to concerns about potential risks faced by participants and researchers as well as different perspectives on the limits of confidentiality, the voices of those who are marginalized due to their immigration status were not adequately heard. New paradigms and protocols are required in order that this and other vital areas of research with marginalized populations may flourish. We believe it is in the interest of all Canadians that this happen. Ethics review boards must devise appropriate protocols in order for immigration researchers to be able to recruit people in settings where they are likely to be living with precarious legal status.

Before committing to a research project in the area, researchers have to know what to expect in terms of timelines, requirements, risk mitigation methods, and legal protection if given a subpoena to appear in court. In our case, the focus on potential risks prevented an innovative study from taking place and the phenomenon of how people experience living with precarious status remains under-researched and difficult to study. As a result, the many individuals who live in Canada long-term without having access to the privileges and protections that come with permanent legal status remain marginalized,

although we recognize that in practice many citizens and permanent residents are neither privileged nor protected. The limited research into precarious legal status does not provide greater protection for people living with such status – and likely further stigmatizes them.

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ⁱ In this paper we report on our negotiation of the ethics review process; for discussion of our findings, please see Bernhard et al. (2007) and Young (2005).

ⁱⁱ The Tri-Council consists of the Social Sciences and Humanities Research Council (SSHRC), the Natural Sciences and Engineering Research Council (NSERC), and the Canadian Institutes of Health Research (CIHR), which are the three major funding bodies for research in Canada.

ⁱⁱⁱ For a history of the development of institutional ERBs see Alcadipani and Hodgson (2009).

^{iv} A more detailed account of our experiences with the ethics review process is recorded in Bernhard and Young (2009).

^v For an elaboration of how ethics boards and funders influence such decisions, see Sikes and Piper (2008)