



## Short report

## Institutional ethical review and ethnographic research involving injection drug users: A case study

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## ABSTRACT

Ethnographic research among people who inject drugs (PWID) involves complex ethical issues. While ethical review frameworks have been critiqued by social scientists, there is a lack of social science research examining institutional ethical review processes, particularly in relation to ethnographic work. This case study describes the institutional ethical review of an ethnographic research project using observational fieldwork and in-depth interviews to examine injection drug use. The review process and the salient concerns of the review committee are recounted, and the investigators' responses to the committee's concerns and requests are described to illustrate how key issues were resolved. The review committee expressed concerns regarding researcher safety when conducting fieldwork, and the investigators were asked to liaise with the police regarding the proposed research. An ongoing dialogue with the institutional review committee regarding researcher safety and autonomy from police involvement, as well as formal consultation with a local drug user group and solicitation of opinions from external experts, helped to resolve these issues. This case study suggests that ethical review processes can be particularly challenging for ethnographic projects focused on illegal behaviours, and that while some challenges could be mediated by modifying existing ethical review procedures, there is a need for legislation that provides legal protection of research data and participant confidentiality.

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## Introduction

Over the past 40 years, ethnographic research on drug use has helped advance scientific understandings of drug use (Moore, 2005) and identify shortcomings of public health responses targeting injection drug use, including needle exchange programs and overdose prevention campaigns (Bourgois, 1998; Moore, 2004). This body of drug use research is distinguished from other modes of enquiry by its methodology, which relies upon direct interaction with drug users, largely within the natural settings of “drug scenes” (Agar, 1997; Moore, 2005). Ethnographic researchers conventionally immerse themselves in the everyday activities of the group being studied in order to describe the social contexts relevant to the topics under consideration (Hammersley & Atkinson, 2006). This is termed “participant-observation” and is considered to be a fundamental component of ethnographic enquiry.

Conducting ethnographic research with drug users often involves complex ethical issues (Bourgois, 1998; Maher, 2000), and numerous legal issues related to the conduct of ethnographic work among individuals engaged in illegal activities have been examined in the literature (Carey, 1972; Librett & Perrone, 2010; Weppner, 1973). Being present within drug scenes may lead ethnographers to have interactions with the police, face the possibility of arrest, or encounter threats to their own safety in the field (Librett & Perrone, 2010; Williams, Dunlap, Johnson, & Hamid, 1992). Taken collectively, “being there” in drug scenes may represent a significant legal risk for ethnographers conducting research involving drug users (Carey, 1972).

The ability to conduct ethnographic fieldwork with drug users is predicated upon the understanding that the researcher will protect the anonymity of participants and the confidentiality of information obtained (Fitzgerald & Hamilton, 1997; Israel, 2004). However, the ability of researchers to maintain the confidentiality of sensitive information regarding drug use and other illegal acts is often limited by regulatory frameworks governing research ethics. These frameworks typically compel researchers to break confidentiality to report child abuse or to warn a third party of imminent harm, but

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researchers may also be compelled to breach confidentiality if police were to subpoena their fieldnotes or project data (Israel, 2004; Wiggins & McKenna, 1996). The presence of an ethnographer may expose research participants to legal risks if sensitive information regarding criminal acts were to be disclosed.

#### *Ethnographic research and institutional ethics review*

Ethnographic methods seek to investigate social processes and activities *in situ*. In most ethnographic research, the risks to participants are largely similar to those arising from their “everyday activities” (American Anthropological Association, 2004; Canadian Institutes of Health Research, 2009). However, institutional ethics review boards may have difficulty conceptualizing the risks related to ethnographic projects, partially due to the predominance of the biomedical research model within review frameworks (Bosk & DeVries, 2004; Buchanan et al., 2002; Fitch, 2005). While critiques of how ethical review boards assess non-biomedical research have been articulated (Atkinson, 2009; Librett & Perrone, 2010), there is a lack of social science research examining institutional ethical review processes (Anderson & DuBois, 2007). In particular, the review of actual ethnographic research projects has rarely been documented, although such an examination could illustrate key ethical issues and potential solutions to these issues (Bosk & DeVries, 2004).

However, additional ethical considerations exist in relation to ethnographic research focused on illegal activities due to the fact that such research may expose participants to risks that are fundamentally different than those encountered through everyday activities. The presence of a researcher as participants engage in illegal activities carries particular risks for research participants, which do not exist in relation to ethnographic work focused on communities that are not under surveillance by law enforcement. In these instances, if confidentiality of research data is not maintained, the disclosure of sensitive information could be very damaging for participants, potentially incriminating them or exposing them to criminal prosecution related to engagement in illegal acts (Stiles & Petrila, 2011). These dynamics are of great concern from the perspective of ethics review committees and therefore necessitate the examination of many complex ethical issues that are not common to all ethnographic research. Therefore, there is a need to better understand the nature of these risks and potential strategies to manage them.

There have been calls for case studies to document the ethical review processes for ethnographic research (Bosk & DeVries, 2004; Buchanan et al., 2002), in order to address the lack of empirical information regarding the institutional management of ethnographic research. In addition, there is also a need to better understand institutional review processes in relation to ethnographic research with drug users and other individuals involved in illegal activities. Such accounts may serve to equip ethnographers with potential solutions that could be put forward to research ethics boards to help navigate common concerns regarding ethnographic projects focused on illegal activities, and help institutional review boards better manage such research. This report aims to provide an account of the institutional review process for an ethnographic research project focused on people who inject drugs (PWID), document the key ethical issues that emerged through the review process, and describe how these were resolved.

#### **Methods**

We utilize an intrinsic case study methodology (Stake, 1988) to describe the institutional ethics review process for our ethnographic research focused on the health harms related to injection

drug use in Vancouver, Canada. The case study presents our experiences regarding the adjudication of a research protocol we developed as it underwent institutional review. The authors of this manuscript are referred to as “the investigators” within the case study. We reviewed all written documentation regarding the application and correspondence between the review board and the investigators to identify the most significant concerns related to the proposal. We summarize the review process, requests made by the review board, and our responses, in order to illustrate how salient concerns were navigated. In addition, we present expert opinions obtained through the review process to explore how the most significant issues raised by the review board were perceived by experts external to the institution, and to describe how key issues were eventually resolved. In order to minimize bias in the case study reporting on our protocol and experiences, we have attempted to recount events and occurrences by relying on the record of official communications when reporting the case.

#### **Case study: the institutional review process**

##### *Background*

In Canada, the Tri-Council Policy Statement (TCPS) provides the framework for all research ethics reviews and outlines the responsibilities of institutional review boards, termed review ethics boards (REBs) (Canadian Institutes of Health Research, 2009). Unlike the United States, in Canada statutory mechanisms or legislation designed to protect the confidentiality of sensitive study data (e.g., Certificates of Confidentiality) do not exist, which means that individual REBs must manage these concerns on a case-by-case basis. While Canadian courts have protected the confidentiality of research data in noteworthy instances (Stiles & Petrila, 2011), these decisions have been based upon the specifics of the particular case rather than statutory or legislative protection of research (Palys & Lowman, 2000).

##### *The application and proposed approaches to consent*

The application did not seek approval under the minimal risk category, due to the focus on marginalized drug users. The objectives of the research focused on blood-borne virus transmission, HIV prevention, and HIV treatment among PWID in Vancouver. Research activities included ethnographic fieldwork with an emphasis on observational activities in public injection settings and the local supervised injection facility (SIF), as well as in-depth interviews with PWID. The research sought to increase understanding of the influence of drug use settings on drug-related harm among PWID in Vancouver, in order to inform policy responses and public health interventions. Qualitative interviews, involving one-to-one conversations in a private setting within a storefront research office, would be audio-recorded, then subsequently transcribed and analysed. Written informed consent would be obtained for office-based interviews and participants would receive \$20 CDN honoraria.

Observational activities involved visiting settings where PWID consume drugs, including public injection settings (i.e., streets, alleys, parks) and the SIF. During observational work, the research would be explained to potential participants using a verbal script of introduction, and oral informed consent would be obtained. Fieldnotes detailing observations and conversations would be generated subsequently, and these notes would employ arbitrary code names and description of demographic characteristics (age, ethnicity, and gender) in reference to participants encountered during observational work. These methods sought to protect the anonymity of individuals participating in observational research, by rendering them unidentifiable. No monetary compensation would

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