

# What Are They Worried About? A Case Study of an Ethics-Review Process

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## Abstract

This is an account of the ethics-review of a project on the ethics-review process. It uses a detailed case account as a way to explore the ethics-review process and how the issues that arose raised questions about how some core concepts, in particular confidentiality and anonymity, are understood and used in the context of the ethics-review process. It explores how the concept of confidentiality was used as explanation and excuse in relation to allowing the observation of ethics committees in the process of deliberation. It suggests the need for everyone involved in the ethics-review process to engage in “deep listening” of the kind common to anthropological and ethnographic research to better understand what they are doing and how they are using concepts that are the corner stones of the discourse on research ethics and the ethics-review process.

## Introduction

In recent years researchers have been writing about their experiences with research ethics committees (Lincoln & Tierney, 2004). In many cases the purpose of these case accounts is to highlight issues related to the review process, such as the time and expense involved, particularly with multisite research (e.g., Flynn, Dixon, Amos, & Appleby, 2000; Tully, Ninis, Booy, & Viner, 2000; Wald, 2004; Whiteman, Webb, Purdie, & Green, 2003), that the current review process is inappropriate for some kinds of research because it is seen as based on a “medical model” (e.g., Bosk, 2004; Ramcharan & Cutcliffe, 2001; van den Hoonaard, 2002b), or that the expectations of the committee, in particular expectations related to informed consent, are inappropriate for particular populations (e.g., Barrett & Parker, 2003; Duncombe & Jessop, 2002; Marshall, 2006; Thompson, 2002). Most of these papers are critical of the process and primarily descriptive in nature. They form an important body of literature that encourages consideration and possible reform of the process to address common problems. There are some, however, who suggest that what we see in the literature is not exemplars of the common case, but the words of a disgruntled few (Pattison & Stacey, 2004). In addition to this body of literature there are several reports that do not focus on particular cases, but bring together a body of opinion that supports the arguments presented in the case accounts (e.g., American Association of University Professors, 2001; Haggerty, 2004; Interagency Advisory Panel on Research Ethics Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC), 2004; Israel, 2004). This latter body of literature bolsters the argument that there are problems with the review process, especially in relation to research from the social sciences and humanities, and the case accounts reflect particular instances or examples of such problems and issues.

Thus, there is a growing body of literature on the review process from an experiential point of view. Often it is dismissed in everyday discourse as merely anecdotal,<sup>1</sup> but as a body of literature it provides a data set, a body of narratives (a legitimate form of data for social scientists), that indicate some important issues related to the research ethics review process. As case studies they are legitimate foci for analysis. This paper adds to this body of literature, but attempts to move the account beyond description and uses an ethnographic approach to try to understand these experiences from a deeper analytical perspective. It suggests that the issues involved are not only structural and procedural (e.g., Nowak, Bankert, & Nelson, 2006), but are even more fundamental and need to be understood as reflecting deeper issues, such as common understandings of key concepts and principles and the role of committees. Thus the problems identified in the literature, as a body of data,

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<sup>1</sup> The idea that such accounts are considered anecdotal, and thus lack legitimacy, came out in some of the interviews/discussions associated with this project, but I did not recognize the importance of this perspective until it came out in a discussion at an international bioethics conference.

suggest that more complex solutions are required to ameliorate some of the frustrations researchers have come to associate with the ethics review process.

The case reported here echoes many of the issues raised in the aforementioned literature. However, it has a few unique aspects. First, it is about a project to study the ethics review process, and second, it used an ethnographic approach to try to develop a more analytical perspective. Perhaps more importantly, in this case ethics committees and observations of them in the process of deliberation were part of the study. One result is that when ethics committees were approached about allowing me and/or my assistant to observe the committee it was considering a request in which the committee meeting would be the object of study, rather than some particular people or some anonymous “other.” It reinforces the point made by people like De Vries (De Vries, DeBruin, & Goodgame, 2004) that obtaining permission to study ethics committees can be difficult and this has an impact on understanding the real issues involved in the ethics-review process and, in particular, the concerns raised by researchers from some fields, for example the social sciences.

A review of the case presented below in some detail raises a number of questions and suggests possible explanations for why some committees had problems with the project and the request to observe. They include role confusion, discomfort with being the object of study, and, perhaps, confusion over the meaning of some core concepts and their application in this case. Although the explanation of the responses of the committees approached to be involved in this study requires consideration of several complex components, some of them seem more critical than others. This paper looks at just a few.

### **Background**

The impetus for the project that is the focus of this paper came from the experiences of the author and her students and colleagues with the ethics-review process and a growing body of literature on the process that indicated it presented particular problems for certain kinds of research, specifically that related to non-medical research that involved methodologies and topics of interest more common to the social sciences and humanities and those associated with potentially vulnerable populations. The first stage of the project was undertaken as part of period of study leave from my institution. Once the study leave application had been submitted I refined and expanded the proposal and submitted it for funding. It was awarded funding for three years as an ARC (Australian Research Council) Discovery Grant. The purpose of the project, as presented in the grant application, is as follows:

This project, an ethnography of the ethical review process for research involving humans, involves an anthropological analysis of research ethics and the ethical review process as culture and cultural process. It does this through document reviews, case studies, key informant interviews, and observations of the ethical review process. One of its purposes is to better understand why some kinds of research, namely research involving alternative paradigms and that associated with sensitive populations, seem to present particular difficulties for ethical review committees, research gatekeepers, and the researchers involved. This research might help us better address the issues involved and allow the development of research and ethics programs, policies, applications, and educational efforts that are less problematic for all parties concerned. It is not about whether or not research and the ethical review process are ethical, but what are the cultural factors that influence ideas about ethics and the ethical assessment of research and how they may impact on contemporary research.

As is common with ethnographic research, data collection has involved many processes, including all the processes proposed in the application — and more. More than 200 people

participated in one or more formal interview/discussions. In addition, data collection has included informal interviews with a wide range of people, attendance at meetings dealing with research ethics and the ethics review process and, in some cases, the presentation of papers and discussion of the presentations, the review of websites related to committees associated with the observations and those of the institutions of people formally involved in the project, and key informant and colleague responses to draft papers related to the project. Document review has included the published literature and policy documents from the five countries involved (Australia, Canada, New Zealand, the UK, and the USA). Of particular importance in this case is that it also includes data collection and analysis in relation to my own experiences with the ethics review process, particularly in relation to this project, but including others submitted during this research.

In the countries involved there is the general expectation, and in four of the countries a requirement, that all research conducted in institutions that received federal funding will undergo the ethics review process. This is the case in Australia, the home base for this project. Thus, an ethics application was submitted prior to beginning the period of study leave that would become the first stage of the project. It is at this point that the case study begins.

### **An ethics review story**

At the time of writing, this project has undergone: one formal, full committee application review; one exempt review; five additional reviews of the original application (up to 3 years after initial submission); and “reviews” based primarily on multiple question/answer emails following receipt of a request to observe a committee. The key contacts, and often all members of committees, were provided with a copy of the “approved” information sheet and background information on the project and me. The idea for including the latter followed a request by one committee Chair. The Chair had agreed to the observation, but asked for some information so I could be properly introduced to the committee at the time of the meeting. In 2004 a website on the project was launched and thereafter potential interview/discussion participants and committees received a copy of the information sheet and the address for the website (<http://www.ethicsproject.com/>) for the additional background information. The background information on the site is based on the kinds of information provided to committees over the course of the research.

In a few cases committees were approached by an intermediary, someone from that institution, but most were “cold call” contacts by either me or a project assistant. Analyses of the acceptances and declinations indicate that using an intermediary or contact by an assistant had no relationship to the final decision of the committee or the complexity of the process.

Many committees agreed to be observed based solely on the information sheet and some information on me. With the exception of the first full, formal committee review (described in detail below), negotiations with committees took from a few minutes to three months. At the end of this period most committees agreed to allow the observation, but not all of them, even after months of discussion and negotiation. In ethnography it is often the “negative” case that leads to a deeper level of understanding of a particular phenomenon. It is for this reason that I focus on those committees that did not allow an observation and the explanations provided for why a committee made this decision and the questions raised in the negotiation of observations for those situations that involved more than the initially provided information.

At least 50 committees<sup>2</sup> were formally contacted to request the opportunity to observe. This resulted in 29 observations. Seven committees agreed to an observation but were not observed for various reasons: some logistical, some related to meetings not being held for one reason or another (e.g., not enough applications to hold a meeting, a need to reschedule a meeting for some reason). One committee was observed twice: once by me and about a year later by an assistant. Some of the observed committees were part of a system of committees, for example the committees in the UK are part of a centralised system and the national office coordinated the observations, but not all committees contacted by the office allowed an observation and we were not able to attend a couple of meetings for logistical reasons.

### The full committee review

Table 1 outlines the key stages of the first, primary and full committee review process. This process took ten months. The application was submitted in October, eight months before my leave was initially scheduled to begin. I received a written response from the committee two months later that included three parts dealing with 1) confidentiality, 2) number of participants, and 3) data storage (Table 2). I responded to the letter two weeks later after taking time to develop a response supported by references to the literature, the national policy document, and my professional code of ethics. I included an invitation to the committee to participate in the study, but noted that I would understand if they decided to not participate. This was intentionally included as an attempt to make it clear that approval of the application and permission to observe were separate issues. In other words, I was trying to make it clear that they could approve the application even if they did not want me to observe the committee. As noted above, committee observations were only one part of the study and this was clearly presented as the case in the ethics application.

**Table 1. The First Review Process**

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- 7 Oct 2001 – Initial submission
  - 6 Dec 2001 – Response from Committee
  - 20 Dec 2001 – Response to response
  - 13 Feb 2002 – The ambiguous letter
  - Feb-July – Sought advice on meaning of letter and what to do, continued to approach committees overseas, prepared for study leave
  - 8 Aug 2002 – Met with Chair of Committee
  - 22 Aug 2002 – Received unambiguous letter of approval
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In February, four months after the initial submission, I received what I call the “ambiguous letter” (Table 3). It contained two core paragraphs. The first one reiterates the “excuse” or “way out” I offered them in my letter in relation to observing that committee. However, it was unclear whether or not the letter was rejecting the study as a whole, including interviews with key informants and the collection of instrumental cases, and if the committee actually meant that I would have to submit a full application for review of the entire study to any other committees that might be involved. I had never had any doubt that each committee

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<sup>2</sup> A number of committees were approached informally in various ways, mainly through intermediaries in opportunistic situations, such as during an informal discussion in an unrelated context. In the contact list we have included only those committees where there was some form of formal contact.

would be approached and allowed to make its own decision about the request and an outline of the process for contacting committees was in the application.<sup>3</sup> One of the purposes of an information sheet is to provide information to potential participants and provide an opportunity to ask questions so they can make an informed decision.

**Table 2. Questions/Comments from Ethics Committee Dated 7 October 2001**

1. The Committee noted the response to Q3.4\* regarding the issue of confidentiality. The Committee was of the opinion that although the researcher was not interested in the actual applications but in the deliberations of the Committee, these deliberations are conducted on the understanding that they are confidential. Further, whether the researcher is interested in the actual applications or not, access is provided to documents which would otherwise be considered confidential. There is a compromise in the confidentiality of both the Committee members and applicants. The committee will reconsider this protocol when this important issue is addressed. **(Confidentiality)**
2. In addition, the Committee requested an indication of the number of professional colleagues, experts, key informers [sic] and HEC's [sic] the researcher will interview/discuss/observe (Q5.1(a)). **(Numbers)**
3. The response to Q6.4(c) should specify that data would be stored at a secure University site. **(Storage)**

\* Reference to the number of the item on the application form.  
Words in **bold** are my categorisation label for the content.

**Table 3. Core of Response from the Committee 13 February 2002**

- The Committee discussed your response regarding the issue of confidentiality at length. Although you state that you are interested in the review process rather than the content of applications the Committee considers these issues inherently inseparable. Further, the Committee feels that it would be inappropriate for you to observe the deliberations on confidential ethics applications submitted by your ... colleagues, particularly without their specific consent for you to do so. **(Confidentiality/Consent)**
- Based on the above considerations the Committee is unable to approve your protocol to observe this HREC. **(Refusal)** Should you wish to proceed with this study at other institutions please apply to their HREC directly. **(Confusing – No approval for any part of study? Must go through application process for all committees?)**

Words in **bold** are my categorisation label for or comment on the content.

<sup>3</sup> “Observations of ethical review panels in the process of deliberation and review of resulting documentation will contextualising data from other aspects of the study. The focus will be on the deliberations and the nature of the deliberations or discourse involved, not particular applications. Thus there is no need to breach confidentiality. As this is potentially a very sensitive area, I will contact Chairs and Secretaries of ethics committees, discuss my project with them, provided them with copies of the attached information sheet, and ask them to introduce the project to members of the panel and obtain their permission to observe and review appropriate documents.”

Many committee members interviewed in the study report that delays in the review process are often because of the researcher, who may not respond to the committee in a timely fashion. In this case I take responsibility for some of the delay. The delay was generated in part by the “ambiguous” letter (Table 3) and the time it took me to obtain advice from others. Some participants in the project report similar situations where there was a delay in responding to the committee because it took time to construct what they hoped was an appropriate response. One reason for the time period in my case is that there were some delays in meeting with one of the people from whom I wanted advice.

The obvious question at this point is: Why did I not approach the committee to obtain clarification? Advice I would normally give to others. There were several reasons. First, this committee has had a history of being a “closed” committee (Fitzgerald & Yule, 2004), where researchers were not allowed to know who sat on the committee and were discouraged in many implicit and explicit ways to not contact the committee directly. Second, I had had previous unpleasant experiences in trying to approach this committee. Third, and most important, I did not want to get the committee “off side,” a reason later articulated by some participants in the project for why they do not contact their committees — and there is some evidence from the study that in some cases this concern is justified. As the final arbitrators of whether or not a researcher can conduct a project, committees have immense power and researchers, particularly researchers who are relatively powerless and of low status, are often cautious in approaching a committee. Finally, given the content of the letter (Table 2), I was not quite sure what to ask or how to ask it, and not put the person I contacted on the defensive or “off side.”

I dealt with the quandary of what to do about the ambiguous letter by using an ethnographic approach. I showed the letter (the data) to several colleagues (key informants) and asked for their interpretation. All agreed that it was at best ambiguous. Many thought it meant I would have to go through the full ethics review process with all potential committees I would want to observe. Some asked: What are they afraid of? This is a question that was to be asked again later when I talked to various informants about committees not allowing observations (see below).

I had the unique opportunity during this time to meet a highly respected scholar in the area and postponed further action until I could meet with him and discuss the situation and get his advice. His advice was to go to a higher authority. But who? At this time the only available route to an appeal was to this committee or to the university, although I did not know who in the university I would contact. Even if another form of an appeals process had been available, I was not sure it would have been the best thing to do. Again, this is an issue of not getting the committee “off side” and the potential long term implications of doing so.

During this period I also continued to negotiate with committees overseas and obtained permission to observe some committees. One in the US put my request through as an “exempt review” and another based its acceptance on my formal letter of request and a copy of the proposed information sheet. Another committee said it had no problem with me observing as long as I had ethics approval from my home institution, but at this point it was not clear if I had it and if I did not, then the whole thing was going to get very complicated and time consuming. It would potentially mean asking other committees to take on a task most participants in research are not asked to do: undertake a review of the ethics application form. This would be adding an extra burden by asking them to engage in work they should not be required to do if they chose to participate. I could foresee this as becoming a barrier for conducting the research, particularly as some committees seemed willing to have me observe as long as it required nothing more of them than providing access to the meeting.

In July, as the revised date for my leave drew near (I had revised it after getting the ambiguous letter because I realised the situation was not likely to be resolved quickly), I approached a chair of a committee I was using as an advisor and asked his advice. He said I needed to approach the chair to ask: “What do I need to do to get approval?”

For reasons similar to those outlined above about not getting the committee (or anyone involved with it) “off-side,” I decided not to approach the Chair directly initially. First I tried to contact the ethics office by telephone and email. After five days without a response I looked up the Chair’s email address and sent an email asking if I could talk to him about what I needed to do to get approval. Although he replied the same day, I did not pick up the message until the following day. In his email he asked me to make an appointment through the ethics office, that he was in the office two days each week. I called the ethics office that day and the next and left messages that the Chair had asked me to make an appointment. Two days later (8 August) I received a call at 12.30 pm asking me to be at the office to meet with the Chair at 2 pm. Fortunately I was home and already on study leave so I was able to get to the office, which is (if the traffic is with you) about a 30 minute drive from my home and my office.

I arrived about five minutes early. After a twenty minute wait I was finally taken in to see the Chair. I described my dilemma, that I was not sure how to understand the letter or what I needed to do to obtain approval — and that I was already on study leave, but obviously could not begin some of the work on the project until I had clear approval, and that I had applied for a national grant and the reviewers’ reports suggested that I might get the grant. He did not have a copy of the project file and asked if I had a copy of the letter the committee sent to me. I had copies of everything with me. He took the letter and began to read. Shortly after he began to read he looked up at me and said: “This is a terrible letter. I can see why you are confused.” He gave me a very sincere apology and told me that I had only received part of the letter. He said the committee had approved the project months ago, but after a long discussion, one of the longest he could remember, the committee decided that I should not observe the committee. He apologised again and said that he would prepare a new letter that would make it clear that the project had the committee’s approval and would send it out to me that day — or did I want him to fax it to me? I did not have a fax machine at home so I suggested that it be mailed to my home. I received the new letter two weeks later.<sup>4</sup>

If I left the story here, it could easily be seen as another story about problems with the structure and process of the review, and these certainly are issues in this case. It might also be seen as “bashing” a particular committee. However, as the story unfolds further it should become clear that this is about more than structure and process issues, or issues related to one committee. There are more fundamental issues involved.

### The story continues

As noted earlier I had already begun to contact committees while I was going through the initial approval process. This was necessary so I could arrange my travel schedule to be able to attend meetings at the various sites. Not having unequivocal formal approval delayed final arrangements in some cases, but with the final letter the study could begin in earnest. Over the next few years my project assistants and I formally contacted many committees. As noted earlier, these requests were accompanied by the project information sheet and some background information on me. It became clear that committees or the gatekeeper involved needed to know something about me. There are indicators in our data that suggest that the fact that I was a mature person with an extensive research background and a health

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<sup>4</sup> Normally “snail” mail takes 1-3 days to be delivered within metropolitan areas in Australia.

professional who already possessed a PhD in anthropology were important factors. I had credibility. When the ARC funding came through, this enhanced the validity of the project. Once a number of observations had been conducted this seemed to make people more comfortable about agreeing to an observation. In some conversations and emails we discussed the fact that the more committees observed the easier it was to maintain anonymity.

In most cases initial contact was by email to the contact address on the committee's website. This was generally the ethics officer. Some committees also include the name and email contact of the Chair of the committee. When this information was available the message was sent simultaneously to the Chair and the ethics officer. A few contacts were made by telephone, particularly if time was a factor, and some were made through an intermediary. All contacts in the UK were made through COREC (Central Office for Research Ethics Committee).

Reactions of the committees fall into several categories:

1. No problem. The request was followed by an invitation to attend a meeting and information on the date, time and site provided.
2. We need more information. The ethics officer or Chair asked for additional information by email or in a couple of cases a telephone conversation. This was generally a list of questions, sometimes a series of questions that spanned multiple emails, most dealing with confidentiality of the proceedings and/or the applications.
3. We need more information and we want to see your original application. This included five committees; not all of these committees agreed to an observation even after seeing the application. The request could also include a request to see all correspondence with the primary committee.

In some cases other members of the committee were clearly consulted before a final decision was made. They were contacted by email, in person, or the request was considered at a committee meeting. In others, the decision was made by the Chair. This was mainly for committees that regularly have observers, but it also happened with other committees. In one situation the contact person explained that there was not enough time before the meeting to contact the members so the Chair made the decision that I would not be allowed to observe. In a couple of cases the applicants were contacted to notify them of my request to observe and to ask their permission.

Only one of these applicants asked that we not be present, but no reason was given. A key informant suggested that the reason was unrelated to the request to observe, but no other explanation was offered. (We left the room when this application was reviewed.) A second applicant contacted me directly to ask why I felt there was a need to ask for the applicant's permission as the applicant did not think this was necessary. This applicant later participated in a formal interview in which this was only one of several issues discussed. In many of the meetings where applicants attended they were told either before they came into the meeting or when they first came in that we were there as observers. In some cases they were told that we would leave if they wanted us to, but no one indicated in any way that they wanted us to leave or were uncomfortable with our presence. In fact, quite the opposite. Some seemed pleased that we were there and welcomed us.

Requests to see the original application were interesting because in no other project that I have conducted or have information for has a potential participant in a project asked to see the original ethics application.<sup>5</sup> It seems apparent that participants in the projects approved by ethics committees are generally expected to make their decisions based on the information provided during the consent process, generally the written information sheet, but some committees seemed to have a different expectation when they became the focus of the research. This is consistent with other data from the project and in the literature in that committees do not always accept the decisions of other committees. This most often occurs in relation to multisite reviews. There were also discussions in some committee meetings and in interviews where people were critical of decisions of other committees, even when they had not been involved in the review of a project that was the subject of discussion.

On the other hand, as a couple of key informants suggested, this could be simply a matter that committee members, unlike many research participants, know that there are documents beyond the information sheet and, unlike many research participants, they feel “empowered” to ask for the materials. Such comments remind us that this research involved “studying up” (Nader, 1972). It looked at “institutions, organizations, bureaucracies that have broad public impact” (Nader, 1972, p. 305). Many people involved as individual key informants and members of committees are social elites in superordinate positions. Nader, along with Rainwater and Pittman (1967), Galliher (1980) and others, suggest that researchers have the right and, perhaps, the obligation to study publicly accountable behaviour, to make transparent the behaviour and decision-making processes of those who function in the public interest. However, this position is not necessarily shared by all the people involved in the ethics-review process, even in those situations where ethics committee meetings are considered “open” to non-members (Fitzgerald & Yule, 2004). Perhaps, for these people, one way to deal with researchers like me is to play the “confidentiality card.” In doing so these people use a concept salient to the process under inquiry to deal with their personal and possibly their professional concerns about observations.

The request to see the original application raised some minor concerns for me given that the application had been written long before these committees asked to see it. As would be expected, the project, and my knowledge of the topic, had matured considerably in the meantime. Nothing of substance had changed in terms of purpose or methodology, but my thinking was more mature and refined than it was before the project began. If asked to write the application again, I might be able to write a better and stronger application, although after re-reading the application as I prepared this paper I am not sure that is the case. I might be able to write one that more strongly and specifically addressed the kinds of concerns that arose in this project. On the other hand, most of these concerns were addressed in the application, but obviously not strongly or clearly enough to allay some people’s concerns, if this was a concern rather than an excuse.

### **What are they worried about?**

Key informants in relation to the first category listed above explained that they had no problem with me being present as they regularly had observers. Some committees saw a need for the deliberations to be open and transparent and allowed, sometimes even encouraged, observers, particularly new researchers who might learn something from the observation that would help raise their ethical consciousness. Some had no problem because they considered my research to be important and that the observations were essential to the study. Some members said they were happy they were participating because they hoped to

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<sup>5</sup> During some presentations on the project I asked the audience if anyone had ever had a participant ask to see the original application. In one meeting two people raised their hands. Unfortunately I did not have the opportunity to talk to them to obtain any details.

learn something for themselves out of the research. In New Zealand observations are allowed for regional committees in the national guidelines. The application form includes a question about whether the applicant wants the review to be considered in a closed meeting and, if so, to provide a reason. None of the applications reviewed at the regional meetings we observed had requested a closed review.

In an attempt to understand the reactions of the committees in the second and third category I asked the contact person or other key informants, particularly for those that decided to not allow an observation, if they would mind explaining why they had made that decision. These explanations, and often questions voiced in the negotiation process, focused on the issue of “confidentiality.” In interview/discussions with general key informants I asked for their ideas. Many of the people initially responded with: “What are they worried about?”

These responses resulted in several questions and hypotheses, all addressing the question: What are they worried about?

- Were, as some key informants suggested, members of the committees just exercising their right to say no?
  - Were members, like some other potential participants in observational studies, simply not comfortable about being observed for all the various reasons people have for not wanting to participate in studies where their behaviour will be observed?
  - Given their elite status and insider knowledge in relation to the review process, did they feel more empowered than others who might be asked to participate in research to say no?
  - Or, had I gotten caught up in the internal politics of the committee, which can happen in other situations that involves working with organised groups who use access to them as a way to play out internal issues?
- Was this simply a case of poor communication on my part so that some committees did not understand their role as participants in the research?
  - Did they not understand that it was the nature of the deliberations that was the object of interest, not particular committees, people, or applications?
  - Did they not understand that I was only asking for permission to observe, not asking them to conduct a separate, new site ethics review, particularly when the information sheet made it clear that the project had already undergone review and had been approved? The information that the project had several forms of approval was offered to some committees in the series of emails that became part of the process of negotiating an observation.
  - Despite the explanations did they still think of this project as an evaluation? Do the responses reflect committee members’ anxieties about the quality of their ethics committee work? In part was this a concern about identity management of the committee as a whole and of individual members?

- Was this *really* a concern about confidentiality (the most often stated concern) and, if so, why?
  - The 1999 version of the Australia *National Statement*, which was in effect at the time, states: “Institutions and organisations and their HRECs must establish working procedures concerning ... confidentiality of the content of protocols and of committee proceedings” (Commonwealth of Australia, 1999, p. 17). In the Handbook developed to supplement the *National Statement* it states in relation to Section 2.18 on inviting researchers to attend meetings and “confidentiality of protocols and proceedings” that material submitted to it for review should only be used for that purpose and be treated as confidential. That entry ends with: “These strategies [consent of the parties involved or omitting potentially identifying information] could also be applied when inviting interested researchers and others to attend committee meetings” (National Health and Medical Research Council, 2002, p. C29). These statements suggest that non-members can be invited to attend as long as the committee establishes some kind of procedure for dealing with the confidentiality issue. Thus, was the response of some committees an interpretation that this statement precluded all non-members from having access to the meetings, rather than a more liberal interpretation that the committee needed to have a policy in relation to the protocols and proceedings to deal with confidentiality (e.g., the signing of a confidentiality agreement or acceptance of the assurances in the information sheet), but they did not have one?
  - Given that the word confidentiality was not used in the information sheet, did they assume it did not apply? Do committee members really understand the concept of confidentiality and all its complexity? What is more important: a description of realistic intent or using expected words, even if they cannot be guaranteed?
  - Was the concern confidentiality, anonymity, or privacy? Were people confounding the terms?
- Was the focus on confidentiality really reflecting other concerns related to the review process or something about the cultural context in which it occurs?
  - In particular, does it reflect issues of trust — or more specifically a lack of trust of researchers? Did they really think that I would use the information inappropriately, for example, that I would “steal” the ideas presented in the applications or tell the researchers what the committee said about them and their projects? (These were some of the explanations given for why the applications and the deliberations had to be confidential.)
  - Does all this reflect concerns related to privacy that are so paramount in other areas of contemporary life?
  - Does this reflect liability concerns or a fear about having a witness to decisions that might eventually come up for scrutiny, such as the

actions taken against some committees in the U.S. in the late 1990s, where I might not legally be able to withhold information contained in my notes?

- Is there a double standard? Committees regularly approve research that deals with very intimate aspects of people's lives, but do they have a different standard when something related to them becomes the object of study? For example, participants in research they approve make decisions based on information sheets and answers to questions provided by the researcher, but are there other, higher expectations in relation to the committees?

The issue here is not that committees (or at least some members of the committees) declined to participate, that was their right.<sup>6</sup> The issue here is trying to make sense of why they declined to participate as a committee and how to interpret the explanations offered. If we understand the issues involved, we might be able to better address them.

Committee and key informant explanations fell primarily into two of the domains suggested in the list above. First, some thought that the committees might think that the purpose of the project was really to evaluate the committee rather than being an attempt to understand this critical aspect of the ethics-review process by peeking into what is for many a "black box" (De Vries & Forsberg, 2002; Fitzgerald & Yule, 2003). One informant suggested we should tell committees that we were not the "ethics police." Comments from some committees and some members suggest that this may have been an issue for some. For example, at the end of some meetings I was asked: "So how do we compare to other committees?" Given the context in which this question was asked, in most cases this was not really a serious question, but some did seem to want an answer. Sometimes I used it to open a discussion about their committee and sometimes I sort of avoided the question by making a clear joke about how we were comparing the committees in terms of the food or snacks they offered or noting that if I could manipulate the accents of the people around the table no one would know where this committee was located. Nevertheless, it was clear that some members thought we were evaluating them and, based on even just the explicit responses, it was clear that after-meeting discussions often helped them better understand what kinds of things I was observing and trying to understand.

One key informant suggested that for some committees and some members of committees, the request resulted in role confusion. Over the course of the study it became clear that while the committees were being approached to be participants in the study, some confused this with their role as reviewers of research proposals, even though steps were taken to make it clear that the two roles were separate, even in the initial review where the committee did have two types of decisions to make: 1) whether to approve the research and 2) whether or not to participate in the research. In at least one situation this role confusion was at the heart of the problem of obtaining permission to observe the committee, but this confusion does not explain why the request to observe presented a concern. Role confusion may help explain why some committees requested a copy of the initial ethics application, but does not seem to get at the heart of the issue.

All of the above potential explanations are probably relevant and help explain the responses of some committees. However, a review of the data and participant observation in a number of contexts (e.g., student seminars on research ethics, participation in workshops on research

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<sup>6</sup> In at least one case the decision about whether or not we would be allowed to observe revolved around one member. In this case I was told that all members would be contacted to obtain their consent and all would have to agree. The invitation to attend had been extended when all but this one member had responded.

ethics and the review process, attendance at presentations on research ethics and the ethics-review process) suggest that a lack of understanding of some key concepts, like confidentiality and anonymity, or the confounding of such concepts, may be particularly important.

As noted earlier, the explicit reason given by some committees as being the problem that had to be resolved revolved around the concept of “confidentiality,” as either explanation or excuse. Some committees resolved the issue and some, but not all, asked that a confidentiality agreement be signed. Some decided in the end that I did not really need to sign an agreement, that they would accept my word that the information would be treated as confidential. Others simply decided to deny the request to observe. Whether or not permission to observe was eventually granted, it was clear that this request produced considerable angst for some committees. On the other hand, there were committees that had no problem with the request and permission was readily forthcoming. One analysis of these experiences eventually led to the idea of open and closed committees where openness in terms of allowing observations by non-members was one element (Fitzgerald & Yule, 2004).

### **Core concepts**

The analyses of this case and questions like those posed above raised consideration of committee members’ understandings of some core concepts, in particular research, human research, anonymity, confidentiality, privacy, and subject (or whatever label is appropriate in a particular instance). This material and other information collected during this project suggest a lack of understanding of the nature of ethnography, but I will leave that discussion for another paper.

The literature on these core concepts makes it clear that none of them are easily defined in a way that is satisfying for all kinds of research. The 1999 version of the Australian *National Statement* (Commonwealth of Australia, 1999, p. 6) explicitly makes the point that the concept of research is difficult to define. In relation to privacy and confidentiality, Forster (2002, p. 169) states that “both privacy and confidentiality are complex concepts with a multitude of facets and potential definitions.” These two concepts are often confounded with anonymity. Forster uses the 1993 OPRR Guidebook as the basis for presenting definitions of privacy and confidentiality.

*Privacy* can be defined in terms of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviourally, or intellectually) with others. *Confidentiality* pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission. (Forster, 2002, p. 169)

The Australian *National Statement* states:

Confidentiality refers to the legal and ethical obligation that arises from a relationship in which a person receives information from or about another. The recipient has an obligation not to use that information for any purpose other than that for which it was given. (Commonwealth of Australia, 1999, p. 52)

Tolich (2001, p. 78) notes that researchers (and I would add ethics committee members and others, including some policy developers) “often conflate the terms *anonymity* and *confidentiality* when these terms should not be used together.”

The Canadian *Tri-Council Policy Statement* states that “the best protection of the confidentiality of personal information and records will be achieved through anonymity (Tri-Council, 1998, p. 3.3). This statement seems to get at a core issue. The issue is that information presented in reports of research cannot be connected to a particular person, even if the person’s identity is known, which seems to me to be anonymity, not confidentiality.

Ethics committees often based their understandings of and the use of these terms in relation to the law and rights to maintain them as they apply to particular professions (e.g., doctors, lawyers) (van den Hoonaard, 2002a). As van den Hoonaard and others (e.g., Lowman & Palys, 2000; O’Neill, 2002) highlight, this right or privilege does not extend to many other researchers, like social scientists. The codes of ethics of each of these professions may make explicit that these concepts apply to their research, but the ability to maintain confidentiality and anonymity is not guaranteed under the law of most countries, although the Wigmore criteria may be applicable (O’Neill, 2002).<sup>7</sup> Furthermore, there are also other types of research where assurances of confidentiality and anonymity often cannot be made. This includes, for example, studies that involve readily identifiable people, especially public figures, and studies that involve “studying up” (Nader, 1972), where the focus is on powerful or semi-powerful elite groups or individuals who may often be easily identified in any material produced in relation to those people. On the other hand, it is often possible to present information from all kinds of respondents in a way that does not allow them to be identified or connected to the information presented. When data are drawn from a pool of people where many said the same thing, it is often not necessary to identify specific respondents; although every respondent who made such a comment might be convinced they are being quoted.

Understandings of and the use of these concepts are likely to become even more complex when there is ambiguity in what constitutes “human research” and the role of the humans involved. For example, the use of the term “subject” implies that the investigation focuses on particular individuals and that the research is on them. The assumption is that the humans will be providing information on themselves or allowing access to information on them as an individual. However, many kinds of research, including this research, are not actually on humans, but human organisations and institutions (like ethics committees). In this kind of research, the people involved in interview/discussions provide information about the organisation or institution rather than providing personal information about themselves. Granted, they are presenting their perspective and opinions, but these are not in relation to them as the object of the research. This research, for example, was not specifically about people’s attitudes towards or opinions about ethics committees even though these were often offered. It was about understanding the ethics-review process. People did share information on their attitudes and opinions, but that information, when offered, was used to gain insight into the process not to develop a report on individual attitudes and opinions. Thus, does research become human research just because humans are involved in providing information or access to information? If this is the case, and clearly it is not, then almost all research is human research. Data collected in relation to this project indicates that making the distinction between humans as the providers of information about a phenomenon and providing information on themselves as the object of the research is difficult.

Research like this adds another layer of complexity. Intellectual property rights of participants are now well recognised as an important issue in many kinds of research. Studying up, particularly when key informants are in positions where they may have publicly

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<sup>7</sup> The Wigmore criteria were named for the jurist who outlined them in 1909. They may be evoked to enable researchers to maintain confidentiality under specific circumstances (O’Neill, 2002).

authored material and concepts, complicates the situation. It raises ethical dilemmas such as whether people will be or should be identified because of their intellectual property rights or the fact that it may be difficult to maintain anonymity if specific information is used. There is also a question about whether or not people who are in positions of public trust in democratic or liberal societies have the right to not provide particular kinds of information. Some key informants made it clear that they had agreed to talk to me because they felt that they had an obligation to because of their professional role. Some of these people stayed in the role throughout the interview, but more often they moved into a form of discussion where they were inserting their personal perspective. Sometimes they clearly identified this switch by saying something like “this is just my personal point of view” or “this is what I think.”

I have introduced these particular concepts from the many that are potentially relevant because I think they may help explain some of the responses and events that were involved in this particular case. I have focused in particular on anonymity and confidentiality because in the course of this research I have come to question how these terms are used and what they really mean.

### **Anonymity, Confidentiality and This Project**

Confidentiality, the focus of much of the discussion in relation to this project, seemed like a spurious argument for several reasons. First, in relation to the observations we explicitly stated that we were not collecting or recording information on particular individuals or individual applications — and we did not. We were observing a naturally occurring group (with a public responsibility) involved in their normal activities. Second, we gave assurances in various ways that we would keep details of the deliberations anonymous and confidential, that we would not be collecting any identifying information on any of the applications. In fact, in most cases we would not see the applications (unless the committee decided we could or should have access to them) nor were we likely to know any of the researchers involved. In some cases we were asked to sign confidentiality agreements and we did so. In some cases it was clear that the committee was concerned that others would be able to identify the committee in any product from the research. To address this latter concern, a concern about anonymity (and perhaps a concern about how the committee might be judged), not confidentiality, even if it was expressed within a discourse of confidentiality, was addressed by noting that no committee would be identified, nor would any information be presented in a way that would allow an observed committee to be identified,<sup>8</sup> and that the more committees we observed the easier it would be to keep them anonymous.

On the other hand, the information sheet does not include the word confidentiality or any of its variants. This was done intentionally as my reading of the literature prior to preparing the application made it clear that I could not assure absolute confidentiality, that legally I could not do so. In addition, some of the people I expected to interview would be high profile people and it might not be possible or appropriate to maintain full anonymity. As noted earlier, some of these people have intellectual property rights in relation to some ideas and terms and might want to be identified. Therefore I did not want to promise something I knew I could not absolutely guarantee. I thought it would be unethical to do so. Instead, the final two core paragraphs (presented below) deal with the core issues, but this is done without actually using the word confidentiality and, I thought, better reflected what I could offer.

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<sup>8</sup> In some circumstances, like this one, for obvious reasons the only committee that could not be kept totally anonymous was the one associated with the primary review. However, we did not observe this committee, but if we had it could have been anonymously included in the data set as we did observe other university committees. The data used here (e.g., quotes from letters to me or from me) in relation to this committee are mine to use.

Should you agree to participate you may do so anonymously. No identifying information will be collected or used without your explicit permission. You may withdraw from this study at any time without prejudice.

Observations of the ethical review process by ethics committees will focus on the deliberations and the topics discussed, not specific applications. No identifying information on any applicants or information that will allow the identification of specific applications or projects will be recorded or used in any way.

This raises the question of whether the issue was one of “disconfirmed expectancies” (Brislin, Cushner, Cherrie, & Yong, 1986; Fitzgerald, 2004b; Mullavey-O'Byrne, 1994). Committees often explicitly require researchers to include a comment on confidentiality, using the word confidentiality, in their information sheets. When committee members or gate keepers did not find the word in my information sheet was their expectation not met and, thus, they then assumed that it was not being offered? Or is it that they do not understand the meaning and intent of the term and thus cannot see it unless it is explicitly labelled? Was it a concern about being identifiable and they did not want any information about their decision in relation to any particular application made public? Or, were they confounding the concept with anonymity — or privacy, which, given the information shared, is what I think was the real concern.

### **Conclusion**

Any ethics story is more complex than it initially seems. Weaved into it are human understandings of ethics, research methods, core concepts and processes, and individual issues. The case account presented here raises many questions about what happens within the ethics-review process in general and in particular cases. In this case, because the project was ethnographic in nature and design, and dealt specifically with the ethics-review process, the issues may have become more complex. However, an attempt to reflect on the issue of why some committees seemed to experience some difficulty with this research led to identifying some core issues that may be applicable to other cases. Most importantly, it revealed some important issues related to the ethics-review process and why it has come to be viewed by many as problematic, particularly for research using alternative paradigms. Whether or not the explanations presented here are a true reflection of the issues at play, they highlight that the ethics-review process is not simply the application of rules or guidelines. It is a very human process that involves everyday interpretations of particular circumstances. It indicates that when researchers are confronted with the seemingly inexplicable response from a committee that the researcher needs to think beyond superficial explanations to get at the heart of the problem. Things are not always what they at first seem. This case highlights the need for communication between all the parties involved to be honest, but that in order for this to be the case, everyone involved will have to be able to engage in a kind of deep reflection on what is really going on. I think that what too often occurs is that people involved in these situations are not really able to articulate their real concerns and so they fall back on “pat answers” and standard phrases. They use the discourse of ethics (e.g., confidentiality) as a way to explain something they cannot or do not want to explain. However, such often superficial explanations can result in more misunderstandings and the implementation of simplistic rules to deal with complex human dilemmas.

The original version of this paper was presented at an international bioethics meeting where the theme was “deep listening” (Fitzgerald, 2004a). In that paper I made a point that ethnography is a form of deep listening and its use in relation to trying to understand what happened in this case was the application of ethnographic deep listening. In this paper I

have tried to apply this idea to develop potential interpretations of this situation as a way to both better understand and respond to the situation and to share the process and interpretations with others. All aspects of the ethics-review process require deep listening if we are to come to reasonable and satisfying situations that allow the ethical development of new knowledge that will help us better understand humans and the human condition, and will help us understand human ethics in a broader sense. The latter part I will leave to the philosophers, but in the meantime we can all apply a deep reflective “listening” to the dilemmas that the ethics-review process presents and, in the process, attempt to make it a process that allows us to engage in, but not create unnecessary barriers for, research.

The simply answer in this case might be that some committees felt threatened by this research and chose to not participate. Another answer, at least in terms of Australia, is a simplistic interpretation of a statement in the national guidelines. Both of these probably address the issue to some degree, but the situation seems far more complex. In trying to deal with the complexity, I have raised a number of issues that are worthy of further consideration. I have also suggested an approach that can be used to try to get past superficial explanations so that we can begin to address some of the deeper issues involved. I think the kind of deep listening and the open-mindedness and willingness to see everything as data that is characteristic of ethnographic research can be used to advantage in understanding the ethics-review process as a human and cultural process. It provides a foundation for what we might call the ethnography of ethics and the ethics-review process.

This form of deep listening and the use of ethnographic reflexivity have raised for me questions about the applicability of the concept of confidentiality in research and the ethics-review process. In some definitions of confidentiality, if the information is used in the way intended and complies with what the person agreed to then the test of confidentiality has been met. But, if confidentiality is defined as keeping secret that which has been offered in confidence, once we have used the information in an explicit way it is no longer confidential. If, as many social scientists do, we use a quote from someone or tell their story, technically we breach confidentiality. If there is no information offered that would allow the identification of the person who offered the information then it is anonymous, not confidential. The only data that is confidential is that which we do not explicitly use. In this and other research, people have told me things that will never appear in any explicit way in my reports. Such information often influences my thinking about an issue, but used in this way it does not breach confidentiality. Anthropologists commonly use information in this way when they study human phenomena. The information from several people are synthesised; there is often no one-to-one reporting as is often found in other kinds of research. Thus, I think that in many instances where people use the term confidentiality they really mean anonymity, or, perhaps, privacy. As a result of the analytical process I applied to this case I now believe that throughout my research career I have unwittingly breached confidentiality in the way I have presented data. However, I do not think I have breached the intent of the consent I received from people; they knew I would use material, including quotes, from interviews in my work and I have respected their privacy and kept them anonymous.

I think confidentiality is a topic that deserves more deep listening. I think we need to listen to how the term is used and applied and then decide if it is being used appropriately. At the very least, we might use the concept of confidentiality as the focus of deep listening exercises that can provide the model for exercises in relation to other concepts and how they apply to various kinds of research. This is obviously already happening, but maybe it just needs to be more explicit in some cases. The hope is that in doing so we can address some of the issues that make the ethics-review process so frustrating for some and so seemingly off the topic for others.

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