CHAPTER

3

ETHICS IN SOCIAL RESEARCH

After some beginning lessons about "science" and "empiricism," followed by a discussion of the preliminary stages of conceptualizing research, we're almost ready to tackle the procedural aspects of gathering data. Our emphasis thus far has been on the *strategy* of investigation. But as Schatzman and Strauss (1973) remind us, the conscientious researcher "needs both strategy and morality. The first without the second is cruel; the second without the first is ineffectual" (146).

FORMALIZING CODES OF ETHICS

Biomedical Horror Stories

The contemporary formalization of principles of research ethics is most often traced to what was undoubtedly one of the most grotesque examples of experimentation with humans that history can offer: the Nazis and the medical research they performed on the Jews they had incarcerated in concentration camps during World War II. As the postwar Nuremberg trials revealed, the Nazis' "experiments" included such procedures as severing and exchanging limbs between live people, made all the more torturous by a lack of anaesthetic. Or, with clipboards and observational protocols in hand, the researchers would place their captives in ice baths and watch to see how long it took them to die from hypothermia.

The Nuremberg trials resulted in development of the "Nuremberg Code," which was the first contemporary statement of research ethics to articulate ethical standards for conducting biomedical research involving human participants. That code subsequently "became the foundation of the *Declaration of Helsinki*, adopted by the World Health Organization in 1964 and revised in 1975. It was also the basis for the 'Ethical Guidelines for Clinical Investigation' adopted by the American Medical Association in 1966" (Berg 2007: 55).

The Nazis were not the only biomedical researchers to give evil a face. For example, beginning in 1932 the United States Public Health Service (USPHS) undertook the Tuskegee syphilis study, which ended up being a 40-year **longitudinal** study of the consequences of untreated syphilis. The USPHS did not infect anyone with syphilis; rather, it identified a group of men who had contracted the disease and, without their consent, decided it would be useful to observe systematically their deterioration over time. When the study began, there was no known treatment for the disease. However, even after a cure was identified, the researchers made sure that the men in their sample—all of whom were African-American—received no treatment, since doing so would have "spoiled" the study.

Even if we were to assume that the Tuskegee syphilis study initially may have had legitimate aspirations for furthering scientific understanding of syphilis in the 1930s when no cure yet existed,[1] there is nothing that could justify continuation of the study—and simply watching the men degenerate and die—after a cure had been developed. The scientific gains were minimal while the human cost was huge. To continue the study was no less than a denial of the dignity of the participants as human beings, as U.S. President Bill Clinton

declared when he made a formal apology to the eight participants still alive in 1997 and the surviving families of the others.

Nor does the list of biomedical horrors perpetrated in the name of science end there. There are the two Brooklyn physicians who injected live-cancer cells into their unsuspecting geriatric subjects; the CIA-sponsored LSD/brainwashing experiments conducted on psychiatric patients in Montreal during the 1960s; Canadian and U.S. pharmaceutical researchers who used convicts as test subjects in risky drug trials; and the government and church authorities who saw Aboriginal children attending residential schools being used as subjects in a variety of experiments without their or their parents' consent. The stories seem to go on and on (e.g., Berg 2007; Bronskill & Blanchfield 1998; Collins 1988; "Native Kids Used for Experiments" 2000). All too often, overzealous researchers have mixed the "noble" motives of science with self-interest, an overblown sense of self-importance, and a dehumanization of their "subjects"—who all too commonly are members of socially vulnerable groups such as Jews, Blacks, Indigenous peoples, women, psychiatric patients, the poor, the drug addicted, the homeless, the elderly, and citizens of the Third World—and have forgotten about such fundamental ethical issues as consent and human rights. Clearly, in these cases, the research never should have been done in the first place; no gain in knowledge can justify the denial of human dignity that is involved when human beings are treated as no more than means to an end.

Complexities in the Social Sciences

In the social sciences, discussion about the formalization of ethics guidelines began in the late 1950s. Unlike the biomedical domain, it did not arise from horror stories of social science research, but from new sensibilities about the sorts of issues that social scientists were facing. Two issues in particular dominated the discussion. The first involved the complexities that were beginning to occur from the growing professionalization of social science fields of study. In his 1959 presidential address to the American Sociological Association, Talcott Parsons noted the burgeoning interest among sociologists in applied issues and, believing these would create new conflicts of interest, suggested that "perhaps a working code of relationships particularly needs to be worked out" (Parsons 1959: 558). In the 1960s Project Camelot—in which the CIA was surreptitiously funding research devoted to discovering how to generate insurgency that might topple Third World governments and showing they were willing to masquerade as anthropologists if it suited their purpose in foreign lands (Horowitz 1967)—left sociologists and anthropologists concerned about maintaining academic freedom and ensuring independence from government.

Sociology did not jump at the opportunity to develop a formalized code of ethics, however, which was seen as a double-edged sword. Most of the 1960s were spent debating whether or not developing a disciplinary code of ethics was desirable. Some members of the American Sociological Association argued that "ethics regulation" was best left in the hands of individual researchers who would remain accountable for their actions (e.g., Becker 1964; Freidson 1964; Roth 1969). Their worry was that the creation of an external standard—to the extent it took the locus of ethical decision making away from researchers and handed it to bureaucrats who might or might not understand the research process—would mark the beginning of the end of academic freedom both for individual researchers and the academic research enterprise as a whole.

Of particular concern was the impact such committees would have on the **sociology of knowledge**. Although the image people have in mind when generating protective codes of ethics is of the vulnerable welfare recipient, student or prison inmate, Galliher (1973) suggested the creation of codes with those persons in mind would instead make it even more difficult to do research with persons who are not so powerless, and who often have elaborate screening devices to keep researchers at bay until "appropriate" (i.e., often

self-serving) agreements for the conduct of research have been put in place:

> The irony of the attempt to protect human subjects through a Code of Ethics is that this very Code encourages an approach to data that can be used to legitimize a highly stratified society. Far from protecting those who are vulnerable, the Code serves to aid those least in need of our concern. (97)

Dorn and Long (1974) agreed, but suggested Galliher's "naive" understanding of the *Code* led him to overlook yet another group protected by its contents, i.e., "mainstream" sociologists and their professional organization, the ASA:

> As a product of professionalism, the *Code* appears to be based on the role of the sociologist as "bureaucratic social scientist." In other words, the *Code* not only proclaims the desirability of ethical conduct, it also proclaims the desirability of a particular kind of sociology and a particular role for the sociologist. The *Code* mainly addresses the problems and dilemmas associated with the "organizational or bureaucratic ethos," that is with the individual researcher who uses human subjects, works with collaborators, relies on grantsmanship and outside financial support, and who believes in a "value-free," objective neutral sociology. (34)

Galliher (1973) summed up the issue well when he cautioned,

> Even after giving due weight to all the likely costs and risks to the profession, the unavoidable question sociologists must answer is whether a sociology that only poses approved questions in an approved fashion is either empirically or morally sound. (99)

Others argued the opposite: far from *impeding* academic freedom, a formalized code of ethics would help *preserve* it by serving as a buffer against third-party intervention into the research process (Schuler 1967). For example, when and if a government were to point to this or that isolated example of an ethics violation and propose seizing control of the research-regulating apparatus that most codes of ethics represent, researchers could point to their disciplinary code and say, "Thanks, but no thanks; we are already regulating ourselves."

A Shifting Locus of Responsibility

THE RESEARCHER MUST JUDGE

If part of the intention of the development of formalized codes of ethics was that it would keep external efforts at regulation at bay, then the strategy in the long run has proven a colossal failure. In the 1970s, researchers were seen as an accountable group of individuals who were responsible for ensuring that no harm came to their participants. The idea that anyone but the researcher was driving the ethics bus was laughable. How could one possibly predict all the things that could possibly happen during a research project? Who but the researcher would have the knowledge and experience to make responsible ethical decisions as issues arose? How could academic freedom survive any other way?

These issues seemed self-evident when the initial social science codes were formulated. The American Psychological Association's statement of principles (APA 1973) reminded us there are few inherently right or wrong answers to ethical questions. Although each ethical principle is easy to recognize and agree to in isolation, in the real world multiple principles combine and interact, requiring trade-offs that must be decided upon with every choice involving both advantages *and* disadvantages. In the end, the APA recognized that each researcher must choose her/his own resolution to ethical questions. Their ethics "guidelines" were exactly that: advice for researchers to *consider* when designing their research. That they did not carry the force of "commandments" or "rules" was affirmed explicitly by noting that the choice of whether and how to do any given piece of research should reside with the "considered judgment" of the "individual social scientist." Investigators were obliged to take "personal responsibility" for ensuring that ethical issues

were considered, and the principles were offered as an ideal to which they should aspire. But the choice of what to do belonged ultimately to the researcher, whose job would be to consider how those principles played out in the specific context at hand.

Three decades later, much on the ethics landscape had changed. Canadian associations that once simply adopted the codes of their U.S.-based counterparts developed codes of their own (e.g., Canadian Psychological Association 1991, 2000; Canadian Sociology and Anthropology Association 1994; Sinclair et al. 1987). The new codes offered nothing original in their inventories of principles but departed significantly from previous efforts insofar as both the Canadian and U.S. associations (1) have (all but one) embraced a more centralized decision-making structure that assumes/gives the discipline/agency regulatory authority, and (2) have emphasized the creation of one-size-fits-all mega-codes that transcend boundaries within and between disciplines.

Also significant was how the disciplines attempted to remove boundaries between professional roles within disciplines. The American Psychological Association, for example, decided in 1997 to stop formulating unique sets of ethical principles for particular roles or settings (e.g., one set directed to researchers and another developed for therapists) and, instead, to generate one overarching set of principles to cover the whole range of roles that psychologists occupy. This obviously made for a lengthier list of principles (15 pages as opposed to 1) and a new order of complexity. A similar approach—essentially a photocopied APA code with few discipline-specific adaptations—was followed by the ASA (1997). Both disciplines moved in the direction of more centralized control—issuing "standards" instead of "guidelines" and soon viewed the respective associations instead of researchers as the final arbiters of ethical practice. And yet, the most recent revision of the Canadian Psychological Association *Code of Ethics* (2000) continues to assert a role for personal conscience, noting in section IV-17, for example, that psychologists should

> Familiarize themselves with the laws and regulations of the societies in which they work, especially those that are related to their activities as psychologists, and abide by them. If those laws or regulations seriously conflict with the ethical principles contained herein, psychologists would do whatever they could to uphold the ethical principles. If upholding the ethical principles could result in serious personal consequences (e.g., jail or physical harm), decision for final action would be considered a matter of personal conscience.

The American Anthropological Association (1996) is the only discipline to avoid rather than embrace a centralization of authority. Their *Statement on Ethics* emphasizes educating/sensitizing researchers about ethical issues and offers guidelines for the resolution of ethical dilemmas:

> Anthropological research, teaching, and application, like any human actions, pose choices for which anthropological researchers, teachers, or individuals applying anthropological techniques and knowledge individually and collectively bear ethical responsibility. Since anthropological researchers, teachers, and practitioners are members of a variety of groups and subject to a variety of ethical codes, choices must sometimes be made not only between the varied obligations presented in the code, but also between those of this code and those incurred in other statuses or roles. This statement does not dictate choice or propose sanctions. Rather, it is designed to promote discussion and provide general guidelines for ethically responsible decisions. (Sec. VI)

GOVERNMENTAL INTERVENTION

The idea of centralizing ethics regulation and placing government in a watchdog/overseer role seems to have originated in the wake of the Tuskegee scandal at the U.S. Department of Health and Human Services with the establishment of the Office for Protection from Research Risk, which

more recently became the Office for Human Research Protections. The Canadian government's formal entry into the ethics regulation business came in the mid-1990s with the development of the *Tri-Council Policy Statement* (TCPS) on ethics in research regarding human participants, which all universities that wish to receive funding from the federal granting agencies are required to follow (see CIHR *et al*. 1998).

It is clear that much of the concern that gave rise to the *Tri-Council Policy Statement* arose in relation to biomedical research and the conflicts of interest that were beginning to arise in an era when money-hungry university administrations were being asked to engage in ethics review of proposals by private benefactors with very deep pockets. In particular, the prospect of big money from pharmaceutical windfalls, genome patents, and the like (large grants to the faculty; large overhead for the university) gave rise to concern about the extent to which universities and university researchers caught up in an entrepreneurial spirit might be tempted to forget their ethical responsibilities to society in general and to their research subjects in particular. In this regard, Michael McDonald, director of the University of British Columbia Centre for Applied Ethics and a member of the Tri-Council Working Group that created the early drafts of what eventually became the TCPS, offered the following reflections:

> In constructing the *Code,* our concern was to address central features of Canadian research involving humans, including:
>
> - Increasing private sector dollars pouring particularly into medical research, much of this in the private sector
>
> - Attendant pressures on REBs [Research Ethics Boards] to issue quick and favourable verdicts on research proposals (McDonald 1998)

Another objective of the federal government presumably was to generate a code of ethics relevant to all researchers in Canada who engage in research with human participants. Citing a growing trend toward multi-disciplinary and multi-site research, which was said to create an inconsistent patchwork of ethics decision making across various institutions using various codes, the interest was in creating a harmonized ethics code that emphasized common ethical principles and to which all researchers in all disciplines in all institutional contexts could be held accountable. Clearly this approach represented a significant departure from a more discipline-driven, localized process of ethics review, replacing it with a more centralized process using a "one-size-fits-all" model to which, presumably, all researchers can and must subscribe.

Unfortunately, there was little effort to accommodate the diversity of methodologies and perspectives that characterize humanities, health, and social sciences. The "one size" that was supposed to fit all reflected a biomedical, experimentalist, quantitative model, with little attention or concern over how these principles would translate into other epistemologies and approaches (e.g., Palys 1996a). Tellingly, there was little or no complaint from researchers who primarily undertook quantitative and experimentalist projects who "saw" themselves in the regulations and found categories and approaches that made sense to them. Others, and especially those who specialized in qualitatively oriented research who engage in field research that takes a more collaborative and inductive approach, expressed grave concern (e.g., see Haggerty 2004; van den Hoonaard 2002). The Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC), a committee established to assess how implementation of the TCPS was affecting the social sciences and humanities and to advise on future developments in the TCPS, consulted with Canada's social science and humanities research communities and found there was good reason for this concern. SSHWC (2004) concluded:

> If there is a fundamental problem we can identify, it is that the granting agencies' desire to create a regulatory structure to deal with the

> stereotypical clinical trial has resulted in a document and set of structures that assume different modes of research involving different relationships and different concerns than most social science and humanities researchers seek and encounter. Stated simply, the TCPS does not "speak" to their experience, leaving REBs that may lack appropriate breadth of expertise free to impose default assumptions that threaten free inquiry for no ethical gain. The further one's research gets from the paradigmatic/positivist/experimentalist assumptions and understandings that permeate the TCPS, the more ill-fitting the TCPS's application becomes. As this implies, although the deleterious effects of the TCPS have been felt across the social sciences and humanities, it is the more collaborative, inductive, field- and text-based research traditions that have been the most adversely affected. (10)

These problems with the TCPS and the regulatory system it invokes are not unique to Canada. The centralization of authority in government and federal agencies that the Canadian system involves parallels those taking place in other countries. Not surprisingly, the problems identified by SSHWC in Canada are echoed by researchers from the United States (e.g., see Adler & Adler 2002; Christians 2000; Hamburger 2005), Australia (e.g., Israel 2004a, b), and Great Britain (e.g., Pearce 2002), all of which have similar regulatory systems in place.

More recently, the granting agencies have produced a revised second edition of the TCPS (CIHR et al. 2010) that ostensibly benefited from a decade of experience with the first TCPS, the input of many different committees (such as SSHWC) who consulted with the research community and offered advice to the granting agencies on the problems that had been experienced and made suggestions about how to proceed, and direct consultation with Canada's research community. Many issues remain that we consider later in this chapter but, for now, we discuss some of the core principles of research ethics one must consider when undertaking social and health science research.

ETHICS PRINCIPLES

Is The Research Worth Doing?

The choice at the beginning of any research project involving human research participants is whether to do the research at all. This "basic ethical dilemma" sees the researcher balancing two important and sometimes conflicting obligations: to science and to participants. The first is a *scientific obligation* to *do* research in the *best* way we know how. Being a social scientist involves a commitment to the value of knowledge and understanding. Our social mandate is to understand all aspects of society not only as an end in itself, but also thereby to contribute to the development of rational social policy. Since much of our research involves human participants we also have a *humanistic obligation* to treat people with dignity and to safeguard their interests. When participants are volunteers who are participating only because we enter their lives and ask them to do so, for little or no direct gain to themselves,[2] our obligation only increases to ensure that no harm comes to them. That responsibility rises exponentially when the participants do not even know they are participating in a piece of research, as often occurs, for example, when we do observational research in public settings, in archives, or perhaps even after a person's death.

We have already noted some of the biomedical research that clearly involved greater cost to participants than was justified by the research. Research is not without risks—and some research can pose considerable risk, particularly in relation to maintaining confidentiality—but in the social and health sciences we do not kill people. The more typical situation arises with those studies that challenge us to consider where exactly we should draw the line between ethical and unethical.

Stanley Milgram's obedience research (e.g., Milgram 1963, 1974) is often discussed in this regard. His research dealt with an important social behaviour: blind obedience to a presumably

legitimate authority figure. However, to obtain his data Milgram deceived his participants by telling them his experiment was about the effects of punishment on learning, when "really" (from Milgram's perspective) it was about how obedient ordinary people would be when ordered to deliver what they believed were real and painful electric shocks of increasing severity to another human being every time they made a mistake in a learning task.[3]

Many were surprised and disturbed that 65 percent of Milgram's participants were completely obedient to the end, even when every indication was that they had certainly hurt, and may even have killed, the other participant. Perhaps even more disturbing were their rationalizations for doing so, along the lines of "I was only following orders" and "It was not *my* responsibility to decide," which were chillingly reminiscent of the rationalizations of the Nazis charged and tried at Nuremberg following World War II, and of U.S. Lieutenant Calley after his murder of innocent civilians in Vietnam. The guilt and stress that participants felt during their participation was considerable. You get a feeling for what it must have been like for the participants when you read Milgram's (1963) original account of how "real" the situation was for the participants.[4] His general characterization of the atmosphere created is as follows:

> In a large number of cases the degree of tension reached extremes that are rarely seen in socio-psychological laboratory studies. Subjects were observed to sweat, tremble, stutter, bite their lips, groan, and dig their fingernails into their flesh. These were characteristic rather than exceptional responses to the experiment … Full-blown, uncontrollable seizures were observed for 3 subjects. On one occasion we observed a seizure so violently convulsive that it was necessary to call a halt to the experiment. (375)

Milgram presents evidence from the debriefings that always followed participation that his research subjects accepted the deceit and felt they had learned from the experience. But *was* the infliction of deception and stress he routinely induced warranted? Milgram argued that it was and received various awards for his research from such prestigious authorities as the American Association for the Advancement of Science; others (e.g., Baumrind 1964) believed what he had done was despicable and that his research would sully our reputation for many years to come.

Informed Consent

One core ethical principle is that of **informed consent,** that is, the notion that it is important for researchers to get consent from people before involving them in research, and that their consent, when and if they give it, should be based on honest and complete information regarding what their participation will involve. This particular principle is typically highest on the list for those who do biomedical research where the question—when, for example, a patient with a certain disease is given the opportunity to take part in a trial for a new drug or receive some experimental procedure —is whether the patient understands the risks, and is willing to participate nonetheless.

In the biomedical realm, this most often involves a written agreement in the form of a contract that the research participant is expected to sign in order to participate, which is consistent with the accounting culture that exists in the medical community and the highly regulated process of clinical trials necessary to develop and distribute new drugs and treatments. In the social sciences and humanities, and especially with more qualitative forms of research, the process of informing the prospective participant and obtaining consent is more likely to be done orally—which is consistent with the emphasis on establishing a mutually trusting relationship and not on legal contracts—although many researchers often will give a written **information sheet** that outlines what the nature of the participant's contribution would be, any risks involved, and explains any promises and safeguards the researcher offers. The idea is to inform prospective participants, in language they understand,

about any considerations a reasonable person would want to know before deciding whether to participate. The researcher should be both clear and realistic about what is being offered, making neither grandiose claims about the prospective utility of the research nor any promises that s/he is not prepared to keep.

But informed consent is not always required in social science research. For example, when observational research is done in public places, the participants might never even know that they were part of a study. Of course, this begs the question of where "public" ends and "private" begins. Consider, for example, the covert participant-observation research Lofland and Lejeune (1960) conducted at Alcoholics Anonymous, where researchers actually joined a group and surreptitiously kept notes of the group's activities and dynamics. Is an AA meeting "public" because anyone can walk in and participate? Or is it "private" because the people who go there for help have an expectation of privacy once they have taken the bold step of sitting down and seeking help for a serious problem? Similarly, is an Internet chat site "public" because anyone can enter? Or "private" because of some tacit social expectation that only those who are serious about the topic will join? Does it make it any more ethically acceptable in either case if the researchers ensure that no one is ever named or otherwise identified?

Perhaps the most famous and controversial study of this type was Laud Humphreys's (1970) *Tearoom Trade,* in which Humphreys played the role of a "watch queen" in order to observe intimate homosexual encounters in public washrooms. Although this choice in itself gave some observers cause for pause because of the intimacy of the behaviour, notwithstanding that it was happening in a "public" place, greater controversy surrounded Humphreys's research when he surreptitiously took down licence plate numbers, found out where the men lived, and then (in disguise) interviewed them in their homes to discover more about who they were in their lives away from the tearooms. Was the lack of consent justified by the knowledge that was produced and/or the confidentiality that was maintained? Would it make any difference to you to discover that homosexuality was illegal in most of North America at the time, and that Humphreys's research went a long way to dispelling many of the homophobic stereotypes that were prevalent?

Even when a researcher *does* set out to secure informed consent, it is sometimes easier said than done. Myriad prospective difficulties present themselves. One worry is that there may be reason to believe that telling participants about the study's objectives may influence the very phenomenon one is trying to observe. For example, in a study commissioned by a federal government committee looking into issues regarding pornography and prostitution (Palys 1986), Ted was interested in ascertaining the social (and particularly the sexual, aggressive, and sexually violent) content of video pornography available in neighbourhood video establishments. Should he have approached video outlet proprietors and told them that he was (in part) interested in determining whether videos involving sexual violence were as pervasive as the media suggested?

Ted felt that if proprietors did indeed have an array of sexually violent material, and if they came to realize that their offerings were under systematic scrutiny, they might withdraw some of their more questionable videos for the duration of the study and thereby invalidate the results. He also reasoned that, in this instance, the videos were "public" materials and that this was a straight economic exchange in which his only obligations were to pay the required fee and return the tapes in good condition. That he and his assistants took the tapes home to code their content was their choice. At the same time, because the proprietors did not know of the study, Ted felt obliged to ensure confidentiality and thus never referred to any particular establishment by name. A record of the establishments was in a file of which only he knew the location, and was destroyed after the study was completed.

Pragmatic problems also may arise in securing informed consent. The information to be conveyed might be too technical or esoteric for prospective participants to appreciate fully, or some attribute

of them might virtually preclude the assurance of communication (e.g., in the study of young children or some psychiatric patients). The researcher nonetheless should attempt to communicate those aspects of the study that might reasonably affect willingness to participate and, in the latter case, normally would contact guardians or other advocates of the prospective participant(s).

Further, securing informed consent is sometimes impossible or highly impractical. When coding archival records or photographs of crowds, for example, it may not be possible to identify or contact all the people involved. Lack of identification may not be a problem since it implies anonymity, although one also would want to ensure that subsequent accounts avoid inadvertently providing identifying information through other clues (e.g., personal characteristics, place of work). When people can be identified but not contacted, precautions normally should be taken to ensure confidentiality (e.g., by blurring or pixelating faces if pictures are used).

And finally, although consent is normally discussed and agreed upon before beginning one's research, research that involves more than a one-shot/single-session encounter has the advantage of allowing the development of greater comfort and rapport between researcher and participants, assuming that all is going well and the researcher is treating participants with care. But consent in such research should be seen as more of an ongoing agreement that can be re-negotiated when and if circumstances change. That is what Nancy Olivieri, a medical researcher affiliated with Toronto Sick Children's Hospital and the University of Toronto, intended during a multi-site clinical trial she undertook for a drug that was being developed by multinational pharmaceutical company Apotex. If successful, the drug would have allowed children who otherwise had to stay in hospital and endure frequent and painful blood transfusions to live a more normal and pain-free life. A small preliminary trial showed promising results and Dr. Olivieri signed on to the larger project and began recruiting participants from among her patients. Part of the informed consent process involved telling them that while the preliminary results were not conclusive, they were at least promising and that the drug was basically safe.

Once the clinical trial actually began, however, problems with the drug started to show up, and there were indications that patients needed to be more closely monitored than was originally expected, with death now a possible "side effect" of the drug. Dr. Olivieri felt obliged to bring these facts to the attention of her patients and their parents—feeling that this was a substantive change that warranted a re-visiting of the information on which their consent had been based—as well as to other researchers in the medical community who were involved in similar trials with this drug. Although such a response would appear to be an ethical no-brainer, given our obligations to participants, the response by the funder and Olivieri's institutional employers was harsh and swift. Apotex threatened to sue Olivieri for breeching the confidentiality agreement she had signed, and the University of Toronto, who had been looking forward to the multimillion dollar donations that Apotex had been prepared to offer the university and Sick Children's Hospital, wilted under the pressure and failed to live up to their responsibilities to ensure that research participants were adequately informed and protected.[5]

Confidentiality

While informed consent is often touted as the primary ethical principle in the biomedical community, **confidentiality** is the principle with more consistent relevance in the social sciences and humanities. People have a right to keep information about themselves private or to share it only with those whom they trust to safeguard it. When we approach people and ask them to divulge information about themselves, and especially when that information could cause them embarrassment or harm if it were to be released, it is incumbent on researchers to take every precaution to ensure that confidentiality as to the source of the information

is respected.[6] In order to provide that protection, however, it is important to consider where and how threats to confidentiality might arise and, hence, what we are protecting ourselves and our participants against.

LOOSE LIPS SINK SHIPS

By far the most pervasive threats to confidentiality are those that come from our interactions with people in the milieu we are researching. These are what you might call relatively "low-grade" threats because they disappear most times with a simple "no," but they occur frequently and must be prevented. They arise most commonly when multiple people are being interviewed in one setting—a given organization, community, or family, for example. Some of the participants inevitably will be curious about what another research participant said. It may be quite well-meaning: a concerned parent might fish for hints about what her/his uncommunicative son or daughter divulged to the researcher about illicit drug use or something as apparently innocuous as what they said about their career plans. Or it may be more maliciously motivated: a respondent might give the impression that s/he is an "insider" on some issue and look for confirmation from you that another person divulged a particular opinion, allegiance, or point of view as a way of justifying a vendetta or other campaign of action against the person.

Researchers must be very careful not to say anything to any one person that another person told them, or in many situations even whether some specific other person participated (or did not). This may sound very simple, but guarding against it requires considerable vigilance. The problem arises because we want to appear competent, intelligent, and "in the know" so that people will respect us as interviewers and feel confident giving us information. But if we start sharing what others have told us, even if the information seems innocuous, we begin to tread on very dangerous ground. Our typical status as "outsiders" to the setting means we are less likely to know enough about the internal dynamics of the setting to make good choices about what is safe to share and what is not. Things that to us seem innocent may have significant consequences within the setting we are researching. The best way to inspire confidence in research participants is to show them how vigilant you are in safeguarding the information that others give you; it tells them that you will show the same vigilance with their information and that they really can trust you. Conversely, if you are sloppy with others' confidences, why would they believe you will be careful with theirs?

LEGAL THREATS

Far less common are more formal efforts by third parties to acquire information from confidential research sources through legal means such as subpoenas. In the litigation-happy United States the literature contains a few dozen examples of legal threats to confidentiality that have arisen in the last 30 years out of what is no doubt hundreds of thousands of research projects that have been carried out in that time (see Cecil & Wetherington 1996 and Lowman & Palys 2001a for a sample of U.S. cases).

In the late 1960s and 1970s these cases most often involved legal authorities (police, grand juries, prosecutors) trying to acquire confidential research information from researchers in order to prosecute the research participant or someone known to the research participant for violations of law. The U.S. federal government recognized the threat this posed to research participants, and ultimately to research itself, and developed statute-based protections known as **Confidentiality Certificates** (for health research)[7] and **Privacy Certificates** (for justice research)[8] that create absolute protections for the confidentiality of identifiable information from being used in any legal proceeding without the permission of the participant. Accordingly, such threats have all but disappeared. When they do appear in court, judges have for the most part been very respectful of the privacy of research participants (see Lowman & Palys 2001a). Since the 1980s and 1990s the more common scenario is for subpoenas to occur in the context of civil litigation, i.e., where one group of people is suing a multinational

pharmaceutical, tobacco, oil, or computer company, citing an independent researcher's work in their statement of claim and the company then subpoenas the researcher in order to try to enlist or discredit her/him as part of its legal defence.

RUSSEL OGDEN AND SIMON FRASER UNIVERSITY

In Canada, only one researcher has ever been subpoenaed and asked to divulge information that would identify particular participants, and that is Russel Ogden. Ogden was a criminology graduate student who, for his M.A. thesis, interviewed people who had assisted in the suicides and euthanasia of people with HIV/AIDS. His ground-breaking research illuminated a highly controversial practice to which no one other than the participants would normally ever be exposed. Knowing something about this niche of life—the circumstances of its occurrence and the perspectives of those who engage in it—provides important information that enriches the quality of public debate and our understanding of law in context. Such research is impossible without the assurances of confidentiality, privacy, and anonymity provided for by research ethics policies and the trust that participants have in researchers' and the university's adherence to those principles. Because the very freedom of research participants is at stake, the ethical burden on researchers who undertake such research is high.

All research undertaken at Canadian universities involving human participants requires ethics review, and Russel Ogden's was no exception. Regarding informed consent, Ogden proposed to tell participants there was no obligation for them to disclose identifying information, that there was a small chance he might be subpoenaed, and that he would protect the confidentiality of his sources in any event. Because this research could not be done without a meaningful assurance of confidentiality, Ogden made it clear to the SFU Ethics Committee that he would offer "absolute confidentiality" to his research participants. The committee approved his proposal.

Although few people were interested in the topic of Ogden's research when he was beginning it, it was national news by the time he was completing it two years later because of a woman named Sue Rodriguez. Ms. Rodriguez had a degenerative neurological condition commonly known as Lou Gehrig's disease, and, in anticipation of the day when she would be unable to act, she began petitioning the Parliament of Canada for legislation that would enable her to have an assisted suicide. Media outlets across the country—and a Senate committee established on the topic—looked for an expert in the area of assisted suicide. Russel Ogden was that person. Simon Fraser University bathed in the media spotlight, and the university's media relations department helped him manage the dozens of requests for interviews that were arriving. Ogden's research was a perfect example of the role that university research can fulfill by offering information about certain niches of life to those charged with developing social policy, such as members of Parliament and senators.

All went well until the Vancouver coroner read an article about Ogden's thesis and decided that the information Ogden had gathered might be helpful to him in investigating a death that had come to his attention. Information contained in a newspaper article suggested to him that the death might have been an assisted suicide. But who was she? How exactly had she died? The coroner wondered whether one or two of Ogden's research participants might have attended her death. He asked to see a copy of Ogden's M.A. thesis and subsequently subpoenaed Ogden to give evidence at the inquest.

Ogden appeared and answered all the more general questions that the coroner asked him regarding assisted suicide among people with HIV/AIDS—in the belief we share that part of the role of academics is to share their expert knowledge with the courts when it will assist them in their decision-making—but he refused to answer any questions that would have allowed for any of his research participants to be identified. He then became the first researcher in Canada ever to be threatened with a charge of contempt of court if he did not reveal confidential research information. Ogden claimed **researcher–participant privilege** and again refused.

We will discuss the notion of "**privilege**" in greater detail below, but suffice it to say for now that, to say that some relationship is "privileged" means that persons in that relationship are exempt from the normal requirement that all of us have to testify when asked to do so in a court of law when and if information discussed in the context of that relationship becomes of interest to the court. The lawyer-client relationship is protected by a privilege, for example, so that you can go and talk freely to your lawyer and seek legal advice without fearing that s/he will get subpoenaed and be on the witness stand the next day giving evidence against you. Because privileges can interfere with the court's search for truth—evidence that might otherwise be useful to a court adjudication is not available—privileges are very rarely granted. However, it is recognized that certain socially valued relationships simply could not exist without the confidence that what is said in the context of that relationship will remain confidential. Some of these are recognized in statute; any others have to be asserted in court.

There is no privilege based in statute for researchers in Canada—except for Statistics Canada researchers whose participants are protected through the *Statistics Act*—but one *can* claim privilege on a case-by-case basis in the **common law**. Because the circumstances had never arisen in Canada for such a claim to be tested prior to Ogden, his case was a historic opportunity for SFU to come to Ogden's aid to defend academic freedom and assert researcher–participant privilege for the benefit of research participants and the research community as well. Instead, the university administration dropped him like a hot potato. No one from the university administration or Research Ethics Committee ever testified on his behalf or offered to explain the importance of confidentiality to his research. The university administration also refused initially to assist in any way with his legal fees, but, after pressure by his supervisor, then-president John Stubbs agreed to offer $2,000 on "compassionate grounds" toward legal fees that ultimately mounted to more than $11,000. Fortunately, Ogden understood his ethical obligations and defended his research participants nonetheless, arguing that his research was done in accordance with the highest ethical standards of his discipline and could not be done without a guarantee of confidentiality, which he was now honour-bound to uphold. After hearing Ogden's evidence in relation to the **Wigmore criteria** (see below), the coroner agreed that Ogden and his participants deserved recognition of a public-interest privilege and "release[d] him from any stain or suggestion of contempt" (*Inquest of Unknown Female* 1994: 10).[9]

The struggle to have the university recognize the error of its decision not to defend Ogden would go on for several years, with the university lambasted along the way by a provincial court judge when Ogden later sued the university for breach of contract. Ogden argued that he was required to do original research as part of the requirements for his M.A. degree, that he did so in a manner that followed SFU's research policies and the highest ethical standards of his discipline, and hence that there was an implicit contract obliging the university to support him in court when the guarantee of confidentiality he made—which the university research ethics committee had approved—was challenged.

There are several respects in which this case is noteworthy, not the least of which is that it allowed Ogden to subpoena then-president John Stubbs as well as Bruce Clayman (a physicist who at that time simultaneously occupied the roles of dean of Graduate Studies, vice-president of Research, and chair of the University Ethics Committee) and require them to explain the basis of their decision to refuse to support Ogden's principled defence of his participants, research confidentiality, and academic freedom. Their testimony revealed the decision had nothing to do with ethics; the primary concerns of the president and vice-presidents who advised him were liability considerations and "image." In the end, Judge Steinberg sided with the university as a matter of contract law—it was up to the university to decide which cases it would litigate and which it

would not—but with Ogden on the moral issues that permeated the case:

> The vague statements of personal support as expressed by the president of the University, Dr. Stubbs, and the dean of Graduate Studies, Dr. Clayman, sound hollow and timid when compared with the opportunity they had as leaders of the University, to promote the demonstrated value of academic freedom and academic privilege as evidenced in this case. To set aside this opportunity because of fear that if they were to financially support Ogden by paying his legal fees in this context, some people might misapprehend that they were in favour of euthanasia, demonstrates a surprising lack of courage. (*Russel Ogden* v. *Simon Fraser University* 1998: 68)

An independent review of the university's decision making conducted by SFU professors Nick Blomley (geography) and Steven Davis (philosophy) followed and was consistent with the tenor of Judge Steinberg's decision. Blomley and Davis concluded that the university administration had erred in its decision and should (1) send a letter of apology to Ogden; (2) reimburse Ogden for his legal fees; and (3) guarantee that, in future, any graduate student whose academic freedom was challenged by a third party in the way that Ogden's was would receive legal help. Then-president Blaney accepted all three recommendations (see Lowman & Palys 2000; Palys & Lowman in preparation). Although the episode began as a low point in the university's history, in the end SFU's graduate students went from individuals the university would allow to swing in the wind, to students who probably have the best legal guarantees in the world that such a debacle will not happen again.

Although Simon Fraser University and many other universities in the country started acting as if subpoenas would rain down on researchers thereafter, the fact of the matter is that now, almost 20 years later, Ogden is still the only researcher in the country who has ever been subpoenaed. As this suggests, the likelihood of you or any other researcher being subpoenaed, particularly in Canada, where litigation happens less frequently and where grand juries (the biggest source of subpoenas in the United States in criminal cases) do not exist, is about equal to the likelihood of you being hit by a bolt of lightning on your birthday—theoretically possible but highly unlikely. Nonetheless, since your ethical obligation is to protect your research participants and because in general it is so easy to build some degree of protection into your research, you should do so simply because that is what we do. There are two primary ways to maximize such protection to participants: procedurally and through law.

PROCEDURAL PROTECTIONS

The easiest way to protect the confidentiality of respondents is simply never to obtain or record participants' names in the first place, that is, to safeguard their confidentiality by providing them with anonymity from the moment you begin gathering data. There are many kinds of research—particularly more structured kinds of research such as survey, interview, and questionnaire-based studies in which numerous respondents are all being asked roughly the same questions—where this is the easiest rule to follow. If you have never gathered identifying information in the first place, and if the information you gather is not sufficient to identify specific individuals indirectly, then there is no threat to worry about, and you can simply guarantee confidentiality to your participants when you inform them prior to asking them for their consent to participate.

In situations where you must obtain people's names, either because you need them ahead of time in order to know whom to approach or because the circumstances of the situation lead you to obtain that information, you should **anonymize** your records at the first opportunity and then destroy your original digital recordings or records[10] (or give them to your participants if that is what you promised to do). Sometimes you may need to keep some form of identifier that allows you to distinguish between respondents; in that situation use **pseudonyms,** that is, invented

names that are used consistently through your notes so that you can keep together all the quotations from the person you'll call "Kim" and be able to differentiate "Kim" from "Pat." Should your notes ever inadvertently fall into the wrong hands, no one but you will know who "Kim" and "Pat" "really" are, and with the passage of time, your memory of who was assigned what pseudonym will no doubt fade as well.

In the event you are generating more quantified and structured data that are maintained in digital files, your options are simply to delete any identifying information from the file as soon as is practical or to keep identifying information in a separate file, preferably in a different order than exists in the "content" file, but linkable through some designator included in each file that only you know about.[11] In some cases—and the more sensitive the data the more you are advised to do this—researchers save their data in files using encryption programs such as PGP (Pretty Good Privacy) or TrueCrypt, which gives as good an assurance as one can get that no one else will be able to make use of the data to identify particular respondents.[12] Other strategies for anonymizing, encrypting, and hiding computerized data are given by Boruch and Cecil (1979); although the specific technologies they describe are in many cases obsolete, the conceptual guidelines they provide for devising anonymizing strategies are as relevant today as they were at the time that book was written.

Although high-tech, computer-based approaches can create a challenge to third parties who might be interested in your data, another line of defence is offered by going precisely in the opposite direction, that is, the "old school" low-tech solution of using a notebook of sorts (especially for non-quantitative field note data), which can be hidden more easily than your computer's hard drive. The thing to do here is to seek and pursue approaches that are appropriate for the kinds of data you are compiling. The greater the harm that can come to participants if the data were to be revealed, the greater the level of protection you should seek.

LEGAL MECHANISMS FOR PROTECTING RESEARCH CONFIDENTIALITY

Recall that Russel Ogden invoked a researcher–participant privilege when he was subpoenaed. Generally speaking, there are three sources of privilege. The first is statute-based, i.e., where the protections that exist are actually written into law. In Canada, the only research participants whose information enjoys **statute-based protection** are those who participate in research conducted by Statistics Canada. The *Statistics Act* gives Statistics Canada employees a privilege to ensure that identifiable information unearthed by research by one portion of government (Statistics Canada) cannot be used by any other branch of government or in any court or other proceedings in a manner that would violate the confidence of any individual respondent. Researchers in Canada who are not employees or "deemed employees" of Statistics Canada[13] are not so fortunate; they do not have the *guaranteed* privilege that exists via the *Statistics Act*, but in the end may be no less protected because of the possibility for recognition of privilege through the common law (Palys & Lowman 2000).

The two types of privilege that are generated through the common law are known as "class" and "case-by-case" privileges, which differ in how well-established they are and where the onus of proof lies when a challenge arises. An example of a **class privilege** is the lawyer–client privilege that has been recognized by courts in Canada and other countries for a very long time. To say it is a "class" privilege means that the court is prepared to assume it exists without the need for every lawyer and client to prove they deserve it every time their confidences are challenged. Accordingly, if anyone were to argue that any given communication between a lawyer and her/his client should be revealed, the onus of proof would be on the challenger to demonstrate what compelling reasons exist in this case for the privilege to be set aside.

In the event that privilege has not yet been established for a particular relationship either in statute or as a class privilege in the common law, anyone can nonetheless ask the court to recognize

a public-interest privilege *in that particular case*. In Canada and the United States, researchers will have the best chance of making a claim of **case-by-case privilege** recognized in common law by designing their research to anticipate the requirements of the Wigmore criteria or Wigmore test, a set of four criteria that the Supreme Court of Canada has stated it will use to adjudicate whether a privilege should be recognized given the circumstances in the case at hand (Palys & Lowman 2000), and that also has been recognized as appropriate for this purpose by the U.S. Supreme Court (Palys & Lowman 2002). The criteria specify that

> (1) The communications must originate in a *confidence* that they will not be disclosed;
> (2) This element of *confidentiality must be essential* to the full and satisfactory maintenance of the relation between the parties;
> (3) The *relation* must be one which in the opinion of the community ought to be sedulously *fostered;* and
> (4) The *injury* that would inure to the relation by the disclosure of the communications must be *greater than the benefit* thereby gained for the correct disposal of litigation.* (Wigmore 1905: 3185; italics in original)

A successful claim of privilege requires evidence that speaks to all four requirements (e.g., Crabb 1996; Daisley 1994; Jackson & MacCrimmon 1999; O'Neil 1996; *R.* v. *Gruenke* 1991; Traynor 1996; Wiggins & McKenna 1996). That is exactly what Russel Ogden did when he was subpoenaed by the coroner, and his research stands as a legacy for researchers dealing with sensitive topics on how to do it right (see especially Jackson & MacCrimmon 1999; Palys & Lowman 2000, 2002; in preparation).

DESIGNING RESEARCH TO ASSERT RESEARCH–PARTICIPANT PRIVILEGE

When engineers learn to design a bridge, they are taught to neither under-build nor over-build. This requires them to have a good understanding of the place the bridge will go—how solid is the ground underneath? what range of weather conditions will it have to endure? how high do the winds ever get? how much traffic does it need to hold at peak time?—and then to design something that is safe within that context. If they under-build they run the risk of the bridge falling down and killing those who are on it. If they over-build they end up spending tens of millions of your taxpayer dollars for nothing.

Researchers face an analogous challenge when it comes to confidentiality protections. The trick is to be thoughtful and careful and to know enough about what you are getting yourself and your research participants into so that you understand the risks without getting hysterical and seeing potential threats in every shadowy corner. When the data are gathered anonymously or anonymized very soon after collection, there is little danger to participants for a violation of confidentiality and hence the researcher should simply guarantee to her/his participants that their identities will be kept "strictly confidential." However, if the source of the information is identifiable and a disclosure would bring harm to the participant, then that is when you need to build a stronger bridge and "Wigmorize" your research. Doing so involves anticipating the requirements of the court, as Russel Ogden did when he was gathering the data for his master's thesis. We outline some of the issues to consider below.[14]

CRITERION 1: ESTABLISHING A SHARED EXPECTATION OF CONFIDENTIALITY The first criterion tells us that a prerequisite for claiming privilege is that the two or more people involved in the relation must have a shared understanding that their communication was, in fact, confidential. As Wigmore (1905) wrote, "The moment confidence ceases, privilege ceases" (3233). In practical terms, this means researchers should ensure there is a clear "expectation of confidentiality" that is shared by researcher and participant and that the research record includes evidence that speaks to that understanding.

In the few U.S. cases where things have gone badly for researchers (e.g., see Lowman & Palys

* Palys, T. S., & Lowman, J. (2002). Anticipating law: Research methods, ethics and the common law of privilege. *Sociological Methodology*, 32, 1–17.

2001a; Palys & Lowman 2002), it is noteworthy that none had evidence regarding this first element. For example, neither Mario Brajuha[15] (Brajuha & Hallowell 1986) nor Richard Scarce[16] (Scarce 1994, 1999) had clearly established that their interactions were part of a researcher–participant relationship; neither had completed a formal research proposal, and, consequently, neither had subjected his proposed research to ethics review. No record existed of the pledge they had made to participants, nor was there any formal indication or approval that showed they were engaged in an activity that was university-approved and being executed in accordance with the canons of their discipline. Nor had either of the two kept records of their and the participants' understanding regarding confidentiality in field notes. Brajuha, for example, could say only that he had guaranteed confidentiality to some but not all participants and could not recall to whom he had guaranteed confidentiality and to whom he had not (Brajuha & Hallowell 1986; O'Neil 1996).

In cases where a researcher–participant privilege *was* recognized, the opposite held true. For example, when the Vancouver coroner subpoenaed Russel Ogden (see *Inquest of Unknown Female* 1994; Lowman & Palys 2000) and asked him to identify research participants who may have witnessed the death, Ogden presented evidence showing that he had completed a proposal and undergone a research ethics review, and he produced copies of the pledge of confidentiality he had made to prospective participants. This established that Ogden was indeed engaged in "research," that appropriate officials at the university believed his plan reflected the highest ethical standards of his discipline, and that he and his participants shared the understanding that their interactions were completely confidential. Although no legal authority in Canada had ever subpoenaed a researcher and asked him or her to reveal confidential information, Ogden and his supervisor correctly anticipated that if anyone were to challenge the confidentiality of their information it was likely to be the coroner. Ogden's pledge meant he would refuse to divulge identifying information even if threatened with contempt of court.

A matter of no small legal importance with respect to Ogden's pledge was that it was unequivocal. Although one does not have to guarantee "absolute" confidentiality as Ogden did—and we would actually advise instead that one's promise should state any communications will be "strictly confidential"[17]—anything less runs the risk of being treated as a "waiver of privilege" by the courts. For example, in *Atlantic Sugar* v. *United States* (1980), corporate respondents to an International Trade Commission questionnaire were told that the information they provided would not be disclosed "except as required by law." A U.S. Customs Court later used this exception to justify its order of disclosure of research information from researchers, saying they were the law and "required" the information. The lesson here is that researchers should (1) be prepared to discuss confidentiality issues with participants; (2) make that discussion part of the research record; (3) be clear on what they are prepared to guarantee; and (4) live up to that pledge.

CRITERION 2: ESTABLISHING THAT CONFIDENTIALITY IS ESSENTIAL Because claims of research–participant privilege are decided on a case-by-case basis, general claims about the importance of confidentiality to research are not enough. Researchers also should be ready to demonstrate that confidentiality was crucial to their specific research project (Daisley 1994; Jackson & MacCrimmon 1999; Palys & Lowman 2000, 2002). Traynor (1996) suggests that the necessity of confidentiality should be addressed in research proposals, thereby showing that confidentiality was part of a considered plan and neither capricious nor rote. For example, Ogden's research proposal explained why he believed it would be impossible to gather reliable and valid data and to meet the ethical standards of his discipline unless he offered complete confidentiality to participants.

Claims that confidentiality was "essential" can be weakened by behaviour that is inconsistent with such claims. For example, in the *Scarce* case, the courts seemed skeptical about the researcher's claim

of privilege when it became known that he and the research participant who was the prime suspect in the case were friends outside the research context. Was the researcher truly claiming privilege because of the research relationship? Or was he using it out of convenience and his allegiance to a friend? The claim of privilege was undermined further when it became evident the researcher's wife was at a key meeting where a confession may have been made, when the wife had not been shown in evidence to be part of the research team (*In re Grand Jury Proceedings: James Richard Scarce* 1993; O'Neil 1996; Scarce 1994, 1999). If confidentiality is important, then your actions should be consistent with that claim, and "confidential" conversations do not happen when people who are not part of the research team are present.

In contrast, Russel Ogden only strengthened his claim for privilege by asking participants directly—and recording their answers—how important the provision of confidentiality was to their participation. All participants who had witnessed or participated in an assisted suicide or euthanasia stated that confidentiality was vital to their participation. They would divulge information to Ogden *only* if he promised to maintain their anonymity. The coroner found this evidence persuasive, recognizing that the information he sought never would have existed in the first place had it not been for Ogden's guarantee, which he now was obliged ethically to honour (*Inquest of Unknown Female* 1994).

CRITERION 3: ESTABLISHING THAT THE COMMUNITY VALUES THE RELATIONSHIP The third criterion asks whether the relationship under scrutiny is so socially valued that "the community" believes it should be protected. Various "communities" can be considered here, such as the research community; the community of which participants in the research at hand are members; those who engage in policy formulation and implementation and who value independent research that contributes to that task; and the broader citizenry, who benefit from the knowledge created through research. Much of this information would come from expert testimony when and if the researcher is subpoenaed. However, there is also evidence that can be gathered and material that should be retained as one goes through the process of preparing for and executing the research.

For example, any research that has satisfied peer review, secured funding, and/or undergone ethics review must clearly be valued by the research community. Court decisions, too, often make reference to and reflect the high value that society places on academic research (e.g., *Dow Chemical* v. *Allen* 1982; *In re: Michael A. Cusumano and David B. Yoffie* 1998; *Richards of Rockford* v. *Pacific Gas and Electric Co*. 1976). In Russel Ogden's trial, an internationally renowned criminologist testified about the importance of confidentiality to research such as Ogden's. A nurse who had worked with Vancouver's HIV/AIDS community for years also testified about how important confidentiality was within that community, especially given the hysteria about HIV/AIDS at that time, when a positive test affected one's employability and insurability and made one a social pariah.

CRITERION 4: A BALANCING OF INTERESTS Any well-designed social or health science research on a sensitive topic that anticipates the evidentiary requirements of the Wigmore test should satisfy the first three criteria easily. The fourth criterion sees the court balance the social values upheld in the researcher–participant relationship against the costs that would be incurred by withholding relevant evidence in the case at hand. In Ogden's case, this came down to Ogden's need to maintain his ethical pledge to participants and the impact a disclosure would have on the research enterprise if Ogden complied *versus* the coroner's need for the evidence to make an accurate determination of the Unknown Female's identity and cause of death in the inquest at hand.

But note the asymmetry here: until a "class" privilege is recognized, researchers have to make their decisions ahead of time and can only hope they are correct in their speculation of the range of circumstances that might arise, while the courts

make their decisions after the fact on the basis of the concrete facts that are presented to them. The U.S. Supreme Court recognized this paradox in a case involving a claim of therapist–client privilege (*Jaffee* v. *Redmond* 1996):

> We part company with the Court of Appeals on a separate point. We reject the balancing component of the privilege implemented by that court and a small number of States. Making the promise of confidentiality contingent upon a trial judge's later evaluation of the relative importance of the patient's interest in privacy and the evidentiary need for disclosure would eviscerate the effectiveness of the privilege. As we explained in *Upjohn,* if the purpose of the privilege is to be served, the participants in the confidential conversation "must be able to predict with some degree of certainty whether particular discussions will be protected. An uncertain privilege, or one which purports to be certain but results in widely varying applications by the courts, is little better than no privilege at all."

Researchers face exactly this dilemma. We can see what decisions the courts have made and feel some degree of confidence that research can meet the Wigmore criteria and that the judiciary has been very respectful of the rights of research participants, but with the case-by-case analysis that is involved in the Wigmore test, all we really know in advance is that the law will be made after the fact on the basis of a situation we can only guess at. However, researchers must make their decisions ahead of time. One would hope that Canada's ethics powers (see below) will seek to rectify this problem in the manner that it has been done with Statistics Canada's research participants via the *Statistics Act* and in the United States for some kinds of research through Confidentiality Certificates and Privacy Certificates, but as of this writing there has been no visible movement on this issue.

The ideal course of action for any researcher is to do their best to be ethical *and* legal—as the Wigmore criteria allow and as Russel Ogden demonstrated is possible—but the lack of statute-based protection in Canada and the fact that the law is effectively made up after one's research is over creates the possibility that the "ethical" thing to do—to protect one's research participants and their right to confidentiality—may conflict with the "legal" thing to do—to give identifying information to a court when a legal order is given and all legal means of resistance have been exhausted. Because of this, researchers who want to gather sensitive information from participants must decide ahead of time what they will do if, in that last instant, law and ethics point in different directions. Those who would limit their allegiance to the participant by law and would comply with a legal order to disclose information that would be harmful to participants' interests must inform potential participants of that fact when securing consent.

In our view, the question we need to ask ourselves for any piece of research we do is whether we believe the rights of our participants and the knowledge we are gaining outweigh any other foreseeable concerns or interests that might arise in the research. If the answer to that question is yes, then one proper ethical course is to give an unqualified pledge of confidentiality, and, having made that decision and the promise that goes with it, we are ethically obliged to keep it. If the answer is no, then in our view the proper course of action is to not do the research because you would have to limit confidentiality, and that would be placing research participants at risk—albeit a very small risk because no researcher has ever been ordered to divulge confidential research information to a Canadian court—for your benefit.

If we look to the United States, where there have been more cases and where in at least three instances researchers *have* been ordered to divulge information that would violate particular research participants' confidentiality,[18] a search of the literature that describes the subpoenaing of researchers has yet to reveal a case where we believe violating a research confidence would have been the ethical thing to do. Accordingly, we will continue to ask ourselves the balancing question before we engage

in any piece of research and, where the answer is yes, will continue to offer an unqualified guarantee of confidentiality to the participants in our research.

OTHER CONFIDENTIALITY CONSIDERATIONS

THE INTERSECTION OF ETHICS AND LAW The debate about ethics and law with respect to research confidentiality arose in the wake of the Ogden subpoena, ostensibly because his subpoena took something that had, until then, been nothing more than an abstract threat, and made it real. In response, the then-vice-president of Research at SFU, a physicist who chose to be chair of the SFU ethics committee at a time when SFU's ethics policy allowed that, introduced a policy of "**limited confidentiality**" that would be imposed on all researchers who were gathering information that might involve revelations of criminal activity. John Lowman and Ted Palys and most of their colleagues in Criminology rejected this idea, seeing it as a violation of their academic freedom and inconsistent with the ethical standards of their discipline. Criminology as a discipline would not be possible unless researchers were prepared to take a non-judgmental approach to many of the people they study, and the same is true of many other disciplines. How can epidemiologists understand the spread of disease if persons who have them are unwilling to talk to researchers because they will be reported if they admit exposure? How can political scientists understand the development of political attitudes and social policies if members of oppositional groups see the researcher as a prospective agent of the state? If we believe that studying these difficult and controversial areas is a prerequisite to the positive, rational, and humane development of law and policy, ensuring research participant confidentiality is safeguarded so that they do not pay a price for their altruism and our benefit is a fundamental ethical requirement; to do any less seems exploitative.

This stance is reflected in the draft *Code of Ethics* of the Academy of Criminal Justice Sciences, which states,

> Confidential information provided by research participants should be treated as such by members of the Academy, even when this information enjoys no legal protection or privilege and legal force is applied. The obligation to respect confidentiality also applies to members of research organizations (interviewers, coders, clerical staff, etc.) who have access to the information. It is the responsibility of administrators and chief investigators to instruct staff members on this point and to make every effort to insure that access to confidential information is restricted.[19]

Other disciplines say much the same thing. For example:

> Informants have a right to remain anonymous. This right should be respected both where it has been promised explicitly and where no clear understanding to the contrary has been reached. These strictures apply to the collection of data by means of cameras, tape recorders, and other data-gathering devices, as well as to data collected in face-to-face interviews or in participant observation. (American Anthropological Association *Statement on Ethics* 1986, principle 1c)[20]

> [S]cholars also have a professional duty not to divulge the identity of confidential sources of information or data developed in the course of research, whether to governmental or non-governmental officials or bodies, even though in the present state of American law they run the risk of suffering an applicable penalty. (American Political Science Association *Guide to Professional Ethics in Political Science* [2nd ed.] 2008)[21]

> Sociologists have an obligation to ensure that confidential information is protected. They do so to ensure the integrity of research and the open communication with research participants and to protect sensitive information obtained in research, teaching, practice, and service.…

> Confidential information provided by research participants, students, employees, clients, or others is treated as such by sociologists even if there is no legal protection or privilege to do so. Sociologists have an obligation to protect confidential information and not allow information gained in confidence from being used in ways that would unfairly compromise research participants, students, employees, clients, or others. (American Sociological Association [ASA] *Code of Ethics* 1999; reprinted 2008)[22]

However, all these codes also enjoin researchers to understand the law as it relates to their work, to consider possible limitations to confidentiality that may arise from either legal and/or ethical considerations, to make an ethical choice about how these will or will not affect their work, and to be honest and forthcoming to research participants about these choices.

AVOIDING CAVEAT EMPTOR ETHICS People who choose to limit confidentiality have the obligation to tell prospective participants about these limits because in many cases these will affect the willingness of participants to take part in the research. Also, limiting confidentiality is unethical when it involves no more than the researcher downloading risk to the research participant, as well as the responsibility of deciding what is or is not legally appropriate to say. This would make research participation an unfair and exploitative exchange: the researcher takes no risk but gets all the gains in information and whatever else accrues from it (royalties, patents, publications); the volunteer research participant takes all the risks and, if trouble should ever arise, is greeted by a researcher who says, "Gee, that's too bad, but I told you that might happen." This sort of **caveat emptor ethic**, which we see lampooned in Figure 3.1, is beneath the "highest ethical standards" to which members of the academy are supposed to aspire. Our ethical obligation is to protect our research participants, not to protect ourselves *from* participants by using an ostensibly "ethical" approach that, in our view, is no more than liability management and exploitation in ethics clothing.

Limiting confidentiality does not limit one's ethical obligations. First and foremost is the ethical obligation to ensure research participants know the researcher's commitment to confidentiality is limited, but to do so without causing them to waive any rights they may have, such as their right to assert privilege through the Wigmore criteria. In part, this may involve being crystal clear

Figure 3.1: Caveat emptor ethics

about what unique set of circumstances might lead to disclosure—so that the courts cannot see the limitation as a general waiver of privilege—and do everything possible otherwise to ensure that the research participant is protected, including exhausting all legal avenues.

For example, in one Canadian case involving a claim of therapist–client privilege, where both the therapist and her client considered the fact that a court might subpoena the therapy records (*M. [A.]* v. *Ryan* [1997] 1 S.C.R. 157), the therapist promised to do "everything possible" to defend the confidentiality of the records. She then put this into practice by being vigilant in the way records were maintained so that nothing appeared in the records that would cause the patient harm if they were disclosed in court, not including some information in records in the first place when the therapist and her client agreed that some information was best not recorded, and living up to the promise by defending the privilege all the way to the Supreme Court of Canada.

(UN)ANTICIPATED THIRD PARTY HARM A more difficult issue involves the scenario where a researcher learns of some dastardly harm that will befall some innocent third party. In this case, a researcher might wish to consider violating confidentiality not because of some legal imposition but for ethical reasons. The key thing to consider here is whether or not such revelations of prospective harm are anticipated (e.g., Palys & Lowman 2000). If they are *not* anticipated, then it makes little sense to refer to them in informed consent statements. For example, it would be a tad absurd and somewhat offensive to start off interviews with parents by saying something like, "These interviews about your children's teachers are completely confidential unless you tell me that you are going to kill one of them." We assume the best of our interviewees unless there is reason to believe otherwise, and a pledge of confidentiality about their views of teachers is exactly that, a pledge about their provision of that information. Any plot to kill the principal would be beyond the realm of the research, and the researcher would have to figure out some ethical way to try and prevent that harm without denying the rights of the participant s/he is still obliged to protect.

The decision making becomes a bit more dicey in situations where we might well *anticipate* getting information involving harm to third parties. For example, in the literature on prisons there has been an ongoing debate regarding the effects of solitary confinement on prisoners. One set of researchers argued that there is really no problematic effect to solitary confinement per se, while another group of researchers argued that the effects of solitary confinement can be very debilitating, and in particular may lead prisoners to become more violent to themselves (i.e., suicidal, self-mutilating) and/or others (i.e., assaultive).

If we wanted to do research in which we assessed what happens to prisoners who are placed in solitary confinement, it seems unlikely that prisoners would tell us about these tendencies if they knew we would inform authorities about anything unseemly they disclose. Imagine you are a prisoner placed in solitary confinement, whereupon a researcher comes up to you and says, "I really want to find out the effects of solitary confinement. I would particularly like to hear whether you have any intention to harm yourself or others. However, I should warn you that if you tell me anything along those lines, I'll be obliged to tell prison authorities."

If you were a prisoner who was planning on doing harm to yourself or someone else, would you tell the researcher about those desires, knowing that the researcher would then go and tell prison authorities? We suspect not. And yet that is exactly the position in which Ivan Zinger and his colleagues (Zinger 1999; Zinger, Wichmann, & Andrews 2001) placed their participants in research conducted in three of Canada's maximum security prisons concerning the effects of solitary confinement on prisoners. In the end, Zinger found that prisoners in solitary confinement were no more likely than inmates in the general prison population to report a desire to harm themselves or others

and, because of that, sided with researchers who had argued that there are no terrible effects to solitary confinement. Given that Zinger was at that time an employee of Corrections Canada and that his results place a stamp of approval on Corrections Canada policies—"Problems with the use of solitary confinement? What problems?"—we can only see the limitation of confidentiality in this case as an exercise in self-interest (see Lowman & Palys 2001b; Palys & Lowman 2001).

To the extent that other researchers follow Zinger's lead and routinely limit confidentiality, one can envision a huge credibility gap arising in situations where self-interest leads a variety of authorities to want to find nothing, that is, to do research "with eyes wide shut." Imagine wanting to study police interrogations in order to determine whether and how frequently they violate the rights of accused, and limiting confidentiality by telling officers that any violations will be reported to superiors. Or imagine studying the ways that forestry and mining companies circumvent environmental regulations and telling employees that anything they tell you might be subject to subpoena. We can imagine the headlines now: "Police Always Follow Procedure, Says Study." "Study Finds Resource Companies Always Respect Environmental Regulations." How comforting.

We don't mean to minimize the difficulties and ethical soul-searching that can characterize such situations, but remember again that there are two things we need to consider whenever we undertake a piece of research. One is what it takes to ensure that the data we end up with are valid and reliable—the scientific obligation. If we end up with data whose validity is questionable, then we have wasted everyone's time and perhaps placed people at risk for nothing. Indeed, that is our biggest concern with Zinger's research regarding the effects of solitary confinement; however important the question he addressed and however thoughtful other elements of his research design may have been, his decision to limit confidentiality made the value of the information he gathered questionable. So why gather it in the first place?

The second part of the equation involves the humane considerations that we have for our research participants and those around us. And on that score we have to consider whether hearing about some things and gaining some kinds of knowledge are worth it. Zinger began his research by noting that 19 prisoners died in custody in Canadian prisons from suicide or homicide in the year preceding his research. To what extent did solitary confinement contribute to that number? Could more humane policies or procedures or the simple banishment of forced solitary confinement reduce that number? Do we want to know or don't we? By limiting confidentiality, Zinger will never know. Is the long-term benefit of potentially saving 19 lives per year worth going into this research with an unqualified guarantee of confidentiality? In our view, that is exactly the question that has to be answered. Because the validity of the data depends on the guarantee of confidentiality, the choice is between deciding that the benefits are worth it and doing the research with full confidentiality, or deciding that it is not and withdrawing from the research. This does not prevent the researcher from taking actions designed to try to avoid the harm that would otherwise result, but s/he must do so in a way that respects the rights of the informant as well.

But what happens if we are simply moving along in our research with the parents of children playing Little League baseball, asking them about the role that organized sports plays in their children's lives, when we come across some piece of disturbing information that might involve harm to a third party that we had not anticipated at the outset of the study? Should we tell someone about it or not?

The answer, we suggest, is "it depends." If we believe confidentiality is a core ethical principle, and that we have a duty to our research participants that is akin to the duty that a lawyer has to their client or that a priest has for the information he hears in the confessional, then it should be only in the rarest and most extreme situations that we should consider violating our promise of confidentiality. But where should the bar be set? One legal

case heard at the Supreme Court that addressed these issues in relation to the lawyer–client relationship was *Smith* v. *Jones* (1999).

Briefly, Mr. Jones (a pseudonym) was charged with assaulting a prostitute in Vancouver's Downtown Eastside (DTES). He was intending to plead guilty and his lawyer sent him to a psychiatrist for an evaluation that, it was hoped, would be helpful when it came time for Jones to be sentenced. Because the assessment was being done as part of a legal defence, the communications between psychiatrist Smith (also a pseudonym) and defendant Jones was considered subject to lawyer–client privilege. Perhaps because of this protection, Mr. Jones was very open with Dr. Smith, and started telling him that he had actually developed a plan to kidnap, detain, assault, and kill prostitutes on the DTES and that the assault he was charged with was actually just a "trial run" to see whether he had it in him to kill someone. The plan was already being implemented not only in terms of the trial run, but he had also renovated his apartment—changing locks and doors and such—in a manner that would allow him to imprison women there with no risk of them escaping. Dr. Smith was shocked by these revelations and the potential trail of death that lay ahead if Mr. Jones were let loose, and he let Jones's lawyer know that he wanted to share these details with the court at sentencing. The lawyer balked at this possibility, seeing that such revelations would be contrary to his client's interest, but psychiatrist Smith insisted and the matter went to court. Given that lawyer–client privilege is a class privilege, the onus was on Dr. Smith to show why his concerns were so compelling that the privilege should be set aside and his information be allowed in court.

The case is an important one because it dealt with the very issue we are discussing, i.e., where the bar should be set in order before a violation of confidentiality might be considered permissible given the duty of confidentiality that is reflected in the existence of a lawyer–client privilege. It is relevant to the research enterprise because, as the justices explained,

> [Solicitor–client privilege] is the highest privilege recognized by the courts. By necessary implication, if a public safety exception applies to solicitor–client privilege, it applies to all classifications of privileges and duties of confidentiality. (at 44)

In the end, the Supreme Court said that three criteria must be met before it might be considered *permissible* for someone who has a duty of confidentiality to violate that confidence: (a) there must be a clear danger to an identifiable target; (b) the prospective harm must involve serious bodily harm or death; and (c) the danger is imminent. Because all three were present in this case—(a) Jones was targeting prostitutes in a specific area of Vancouver's DTES; (b) he was planning on killing them; and (c) the plan was already in motion and being implemented—the Supreme Court decided that it was indeed permissible for Dr. Smith to set aside the privilege and violate the confidence given this set of facts.

Three further observations of the Court are noteworthy. First, the justices made clear they were not setting out any kind of *requirement* for disclosure in such an instance, but rather simply setting out minimal criteria beyond which a disclosure might be permissible. Second, the Court also made clear that it had no rigid formula to offer as to when a decision for disclosure should be made, and that every case must to be considered on a case-by-case basis. How this is done would depend on the time available: if the harm were about to happen, the decision would have to be made then and there; if there was more time before the intended event, as was the case in *Smith* v. *Jones*, then consultation with trusted others (or taking the matter to court, as Dr. Smith did) should occur. And finally, the Court also reminded lawyers (and all others with a duty of confidentiality) that, in the event circumstances such as those described in *Smith* v. *Jones* were to happen and a decision for disclosure made, there are many different ways the situation can be dealt with and the harm prevented—dialing 911 is not the only alternative—and that one's responsibility

to the client (or research participant, in our case) does not end with a decision to disclose. Any disclosure must be the minimal possible disclosure needed to effect an outcome, with the rights of the client (or research participant) transgressed as little as possible.

Conflicts of Interest

RESEARCHER CONFLICT OF INTEREST

Being "ethical" as a researcher means that you have a primary obligation to consider things from research participants' perspectives and to ensure participants' rights are safeguarded. In many cases the interests of researcher and participant coincide. Researchers become researchers for many different reasons, but two we frequently hear include the desire to understand something deeply and well for its own sake (whether as a general motive or to understand some specific domain) and to generate knowledge that will help produce some social good. Research participants are also typically altruistic; none of them gets any direct or large reward for participating. So in that sense, both researchers and participants often share the belief that something is important, and both hope their actions will produce knowledge that will benefit the greater good.

However, it would be naive of us to assume that the interests of researchers and research participants always coincide. Occasions may arise when it is in the researcher's self-interest to gloss over the details in order to ensure a ready supply of research participants from whom one can gather information. And these days many university researchers are engaged in entrepreneurial interests in addition to their university "day job": consulting; creating standardized tests that are used in schools, hospitals, prisons, and other institutions; and other product development such as pharmaceuticals, software, and educational materials. Concern arises over the conflicts of interest these activities may bring to the underlying research, for example, where development of a particular product can result in considerable wealth being generated from patents, royalties, fees, and commissions, or where a favourable evaluation may result in an increase in share value. In these situations the university researcher is no longer an "independent" researcher who is simply following knowledge for its own sake with no stake in the outcome.

This conflict of interest is particularly problematic when the researcher is in a position of power relative to the research participant—or when the **gatekeeper** who has allowed the researcher access to the participants is in a position of power over the participants[23]—and is especially worrisome in the case of captive audiences who depend on the researcher for other rewards. For example, it used to be that many psychology departments would require students—especially the hundreds or even thousands who take Introductory Psychology at some universities—to participate in research in return for partial course credit, in part because it gives students the experience of what it is like to be a research participant but also to keep up the supply of bodies required for faculty member and graduate student research. The practice still continues in many places, but there is now more effort made to ensure that students have reasonable options if they would prefer to decline the opportunity.

Of course, many of those studies entail little or no risk whatsoever; the major one is probably the possibility of dying of boredom. However, other "captive" situations are far more problematic, as the following incident reveals:

> We used prison inmates in a number of research projects and always asked for their consent. However, in retrospect, it seems to me that since I also sat on boards that made recommendations for parole and had other important influences on their prison lives, it might be questioned whether they really felt free to refuse in view of their high need in these areas. (APA 1973: 47)

Ethics problems arise when the power differential between researcher and participant is considerable. They are exacerbated when the prospective risk to participants or the possible cost to them if they refuse to participate is high, for example, where the

researcher is also the teacher who hands out grades, the physician who is also responsible for treatment, or the prison authority who is also responsible for maintaining discipline or making recommendations for positive rewards like day passes or parole. From an ethical perspective, it is incumbent on the researcher to seek out independent advice on how best to deal with any appearance of conflict of interest—conflict that would be evident to any neutral third party looking at the situation. The most common ways of doing so are taking steps to alleviate the conflict—for example, by divesting oneself from one side or the other of the conflict, such as by divesting oneself of shares in the company, or getting an independent decision-maker involved who has no vested interest in the outcome and is not in any way dependent on or related to the researcher.

CONFLICTS OF ROLE

A woman was sitting on a riverbank one day, soaking up the sun, when suddenly she saw a man in the river in danger of drowning, calling for help.[24] She bravely jumped into the water, swam over to the man, dragged him out, and saved him by giving him artificial resuscitation. But no sooner had she sat down to catch her breath when another body appeared in the water, and she jumped in again and saved that person as well. Both were thanking her profusely when suddenly a third body appeared and in she jumped again. But no sooner than she had finished saving that person, yet another appeared in the water! However, this time, instead of jumping into the water, she began to walk upstream.

"Hey!" called someone who had been watching all of this unfold. "Aren't you going to save that guy as well?"

"Hell, no!" she replied. I'm going to go upstream to find out how all these people are ending up in the river in the first place!

It is difficult to be in two places at once, as is the case with the woman in our story. She can be the front-line person who jumps in and saves people, or she can don a researcher's cap and head upstream to find out what is causing the situation, but she cannot be in both places at the same time. An analogous situation arises when the individual doing the research occupies two different roles with respect to the participant where the duties associated with the two roles come into conflict.

We have already described how the primary ethical duty of the researcher is to protect her/his research participants. With respect to confidentiality, this typically means putting one's judgmental hat aside and listening to whatever it is that the participant wants to share with you, and sometimes what people tell you is not pretty. This is especially true in regards to many of the social and health problem areas that are most important to understand—poverty, addiction, disease, abuse, oppression, exploitation, bullying, prejudice and discrimination, corruption. As the preceding section on the *Smith* v. *Jones* case showed, when one has a duty of confidentiality, the bar that might justify a disclosure is set very high.

However, there are now many professionals—including, for example, social workers, physicians, teachers, nurses and counsellors—whose professional codes of ethics call on them to report certain kinds of behaviour to authorities, with far lower triggers for disclosure than were outlined in *Smith* v. *Jones* (1999). These often are "helping" professionals whose inclination and obligation, going back to our allegory of bodies in the river, is to jump in the river and save whoever is floating downstream. There are many situations where their professional codes of ethics do not clash with codes of research ethics, but many others where they will, and confidentiality is one of those areas. On this point the original federal ethics policy, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al. 1998) stated that

> To preserve and not abuse the trust on which many professional relations reside, researchers should separate their role as researcher from their roles as therapists, caregivers, teachers, advisors, consultants, supervisors, students or employers and the like. If a researcher is acting in dual roles, this fact must always be disclosed to

> the subject. Researchers should disassociate their role as researcher from other roles, in the recruitment process and throughout the project. (2.8)

The newest edition of the TCPS (CIHR et al. 2010) also recognizes the problem but is less prescriptive:

> Researchers and research students hold trust relationships, either directly or indirectly, with participants, research sponsors, institutions, their professional bodies and society. These trust relationships can be put at risk by conflicts of interest that may compromise independence, objectivity or ethical duties of loyalty. Although the potential for such conflicts has always existed, pressures on researchers (e.g., to delay or withhold dissemination of research outcomes or to use inappropriate recruitment strategies) heighten concerns that conflicts of interest may affect ethical behaviour.
>
> …Conflicts may arise from an individual's involvement in dual and multiple roles within or outside an institution. While it may not be possible to eliminate all conflicts of interest, researchers are expected to identify, minimize or otherwise manage their individual conflicts in a manner that is satisfactory to the REB.*

If left unmanaged, the main problem with these role conflicts is that they can put the researcher in a policing role—as was the case with Ivan Zinger in his study of the effects of solitary confinement—instead of simply trying to understand the situation, thereby violating the following principle:

> Researchers shall avoid being put in a position of becoming informants for authorities or leaders of organizations. For example, when records of prisoners, employees, students or others are used for research purposes, the researcher shall not provide authorities with results that could identify individuals unless the prior written consent of the participants has been given. Researchers may, however, provide administrative bodies with aggregated data that cannot be linked to individuals for purposes such as policy-making or program evaluation. When seeking consent, researchers shall advise prospective participants if aggregated data from a project may be disclosed, particularly where such disclosure may pose a risk to the participants. For example, aggregate data provided to authorities about research on illicit drug use in a penitentiary may pose risks of reprisal to the prisoners, even though they are not identified individually.† (CIHR et al. 2010, see discussion regarding Article 5.2)

Balancing and Combining Ethical Principles

Although not exhaustive, the list above describes some of the major principles that should be considered prior to undertaking one's research. The role of the researcher is to treat research participants with care. A general rule we always try to apply is to ask what standard we would expect a researcher to follow if the participant was our mother, son, or a close friend.

And of course there are many issues we haven't discussed in this relatively introductory treatise: situations that arise in particular research contexts that pose unique dilemmas and have been the subject of considerable debate. Where does

* Excerpt from TCPS 22nd edition of *Tri-Council Policy Statement: 2010*. Pages 59-60 and 91. MR21-18/2010E-PDF http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010. Reproduced with the permission of the Minister of Public Works and Government Services, 2012.

† Excerpt from TCPS 22nd edition of *Tri-Council Policy Statement: 2010.* Pages 59-60 and 91. MR21-18/2010E-PDF http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010. Reproduced with the permission of the Minister of Public Works and Government Services, 2012.

"encouragement to participate" end and "coercion" begin? What ethical safeguards should researchers practise when they are dealing with cultures and groups other than their own? Is concern about privacy outmoded when tens of millions of people put the intimate details of their lives on Facebook and line up to participate in reality TV shows that leave nothing of their personal lives to the imagination?

Our main intention in this chapter thus far has been to try and convey something about some of the main ethical principles that researchers bring to their work. But if "being ethical" involved no more than following a bunch of principles in relatively predictable scenarios, then everything would be easy. We're all intelligent people; we all want to be ethical; we all have a sense of right and wrong. However, problems arise for at least four main reasons, all of which suggest that it's not as easy as it looks.

First is that the very nature of research involves some degree of unpredictability. If we know exactly what is going to happen, there is no need to do the research. The implication is that, instead of relatively *certain* costs and benefits, we are often weighing our best *guesses* of costs and benefits.

Second is that the environment in which we operate is to some degree uncertain, particularly when it comes to the intersection of our research activities and the rights of our research participants with other activities and the rights of other people in society. One area this is particularly true is where issues of ethics intersect with issues of law. We want to be ethical, and of course we want to be legal, and the Wigmore criteria—in relation to confidentiality—give us our best shot at being both ethical *and* legal. But what do we do when and if one of those rare occasions arises when "being legal" points in one direction and "being ethical" points in another? Do you believe it is more important to be ethical? or legal?

A third source of difficulty is that ethical principles do not exist in isolation. All of them operate in any given situation and sometimes they conflict. "Being ethical" thus involves not simply following a set of rules but trying to find a way to resolve competing demands, balancing and trading off different "goods," and making decisions based on the perspective and best interests of our research participants.

An implication of the above is the fourth difficulty, that there are rarely any clear-cut "right" and "wrong" ethical answers. Add to this the fact that researchers and participants are individual human beings who differ from one another, have different belief systems, and value ethical principles differently—because of the value systems they bring to the research—and part of the "problem" is to recognize that there are potentially different ways to deal with situations, more than one of which can be ethically "correct."

Indeed, far too much time is spent by would-be ethicists arguing about what the "right answers" are, as if these were things that could be determined absolutely once and for all, when (arguably) the more important issue is whether the *process* of ethics consideration engaged in by the researcher has adequately taken into account the perspective of participants and the specifics of the case as they are known. At bottom is the question of whether the research can survive mechanisms of accountability that revere two core principles: whether we adequately consider and protect the rights of the research participant, whose dignity we value and without whose participation the research enterprise would not exist, and whether it is respectful of the academic freedom of the researcher, which is a cornerstone of the research enterprise and without which the social value of research would be undermined.

Beyond some reading that discusses ethics issues and some of the more contentious debates that have raged in the social and health sciences on these issues, your ethics education will come in large part from a front-line involvement with research where you meet real people and, we hope, take the time to know your research participants as people. And notwithstanding the general principles that books like this espouse, ethics considerations always come down to case-by-case considerations that involve a unique mix of the people who are your participants, the specific issue you are researching, your own perspective and interests, the norms and standards of your discipline, the social and legal context in which you are operating, and on and on. There are few simple answers, and

you owe it to yourselves and your participants to give these matters deep consideration.

Implications for the Sociology of Knowledge

We continue to be concerned about the regulatory process for ethics that exists in Canada notwithstanding recent efforts to improve the TCPS, particularly because of the impact this highly bureaucratic scheme appears to have had on the sociology of knowledge for reasons that have nothing to do with ethics per se. A recent book by sociologist and University of New Brunswick Professor Emeritus Will van den Hoonaard (2011) adds to the evidence accumulated by others (e.g., SSHWC 2004) that affirm the legitimacy of these concerns. Van den Hoonaard's book documents the changing face of the research enterprise in Canada since the advent of the TCPS. Although it is difficult to disentangle the impacts of the TCPS per se from other changes in the academy, interviews with researchers and REB members across the country reveal REB censorship and, more disturbingly, a growing researcher propensity for *self*-censorship in the wake of REB control. Through archival analysis of master's theses in anthropology and research presentations at conferences that focus on qualitative research methods, van den Hoonaard (2011) revealed that more intensive and involving field research methods such as participant observation and ethnography are done far less frequently since the advent of the TCPS, while studies based solely on interviewing—which was always integral to field methods but often only one element of an inherently multi-method perspective—have increased in frequency.

Other sources make the same observation in Canada and other countries that have seen their governments develop and implement federal codes of ethics (e.g., Fitzgerald 2004; Katz 2007; Shea 2000; SSHWC 2004).[25] While many U.S. authors have emphasized the censorship aspects of ethics regulation (e.g., Hamburger 2005), few have considered the repercussions that contemporary ethics regulation has had for whose voices are being heard and whose are missing in the great social discussion to which researchers are supposed to contribute. Social groups that are most likely to be affected are the socially marginalized and vulnerable who have shown for decades their willingness to speak to social and health scientists who want to learn about their niche of life and point of view as long as their conversations are confidential, but who would be most concerned about prosecution, suppression, and stigmatization if they were to be identified. This includes not just those who have broken or who are breaking the law that criminologists often talk to, but also those who walk in the shadow between illegal and legal, or who are the whistleblowers that help shed light on injustice or the illegal behaviour of those for whom they work, or who are harassed by legal authorities who themselves are treading the boundary between legal and illegal, or who suffer from health conditions that would affect their reputation, employability, or insurance benefits.

British author Robert Dingwall (2008) draws attention to the role of independent observer that the university has occupied, and the perspectives that would be lost if researchers were to become simple agents of the state:

> In the contemporary world, citizens depend upon a great deal of expert knowledge in order to make good judgments about each other and about the social institutions that they encounter. The quality of that knowledge depends crucially on free competition between information providers. If what has traditionally been the most disinterested source of information, the universities, becomes systematically handicapped in that competition, then all citizens lose out. When we give up doing participant observation with vulnerable or socially marginal groups because of the regulatory obstacles, then a society becomes less well-informed about the condition of those who it excludes and more susceptible to their explosions of discontent. How helpful is it when the only ethnographers of Islamic youth in the UK are undercover police or security service agents? (10)

He also reminds us of some of the functions of deviance, whether with a lower case or capital "d."

> The great English sociologist, Herbert Spencer, drew an important contrast between industrial and militant societies. The latter type, which are well-exemplified by the former Soviet Union and its East European satellites, were, he argued, doomed to lose out in global competition because their authoritarian structures blocked diversity and innovation. Both socially and economically, they were frozen by their command systems. IRBs and other forms of pre-emptive ethical regulation begin to look like the precursors of the surveillance states that are being increasingly entrenched in the US and the UK. Their incursions into liberty are justified in the name of security, but may well have unanticipated consequences in terms of prosperity. Wherever dissident voices are silenced, innovation eventually dies. (10)

The result is a shallower research enterprise relying more and more on existing public data sets that have been prepared by institutional authorities to serve their own ends, and a progressively greater denial of voice to those most affected by what those institutions do.

SUMMING UP AND LOOKING AHEAD

In this chapter we have attempted to convey some of the many complexities that must be faced whenever one does research with human participants. If there is a central point to this chapter, it is to think about the relations you allow to exist between researcher and researched.

Research participants are a crucial resource to science disciplines that attempt to understand human action, and, particularly when we are in a more privileged position than our research participants, and especially when we are in a position of power over participants, we must live up to our obligation to maintain their dignity and treat them with care. In this regard, several major ethics principles that transcend disciplinary boundaries were introduced. These include the balancing of scientific and human considerations that influence whether we engage the research in the first place, the principles of informed consent and the maintenance of confidentiality, and issues of researcher, REB, and institutional conflict of interest.

A separate focus of the chapter involved examination of the regulation of ethics by third parties: disciplines, universities, granting agencies, and the federal government. It was argued there has been a trend toward more extensive and more centralized ethics regulation over time. Although general support was expressed for the idea of ethics review because of the opportunity this allows for an independent look at the proposed research by a third party, concerns arise to the extent these third parties are themselves involved in conflicts of interest that lead them to advance views and interests that can be at odds with the rights and interests of research participants and the ethical obligations and academic freedom interests of researchers.

Special heed was taken of the *Tri-Council Policy Statement* (TCPS) on ethics for research involving human participants, now in its second edition (CIHR et al. 2010), that governs all research done in universities across Canada. Some possible strengths of this intervention were noted, as well as possible deleterious effects on research participant rights and the academic freedom of researchers. Particularly worrisome is the negative effect of the biomedically and experiment-driven research mentality that frames the TCPS on other research perspectives, particularly on more qualitative field-based research traditions and more critically oriented research that speaks to some of society's most pressing problems and seeks to give voice to marginalized and stigmatized members of society in order to ensure the broadest possible participation in democratic discussion and debate. Readers of this book are encouraged to keep themselves informed on these matters as the TCPS continues to be implemented and Canada's ethics bureaucracy grows.

STUDY QUESTIONS

1. According to the chapter, what is the "basic ethical dilemma"? Why is it a dilemma?
2. What does each of the following concepts mean, and how can you ensure that they are implemented in your research: informed consent, confidentiality, anonymity.
3. Look up a recent issue of a journal in your area of study, pick an article that interests you, and evaluate it in terms of the ethical principles outlined in this chapter.
4. Is an AA meeting "public" because anyone can walk in and participate? Or is it "private" because the people who go there for help have an expectation of privacy once they have taken the bold step of sitting down and seeking help for a serious problem? Does it make it any more acceptable if the researchers ensure that no one is ever named or otherwise identified? If so, can researchers go anywhere and watch anything as long as no participant is ever identified?
5. Seek out the ethical guidelines of the discipline or career for which you are studying. Are the principles discussed in this chapter included among the guidelines of your discipline? What new issues arise that are not dealt with here?
6. What is the difference between anonymity and confidentiality? What procedures can you follow to ensure confidentiality? What legal mechanisms exist for the protection of the confidentiality of research participants?
7. What are the three sources of privilege? How do they differ?
8. What are the Wigmore criteria, and why is it beneficial to know them? Give some concrete suggestions on how you can integrate your knowledge of the Wigmore criteria into your research.
9. Describe some of the ways ethics regulation has changed over the last 30 years.
10. Go to your university's website and read the university's ethics policy. What does your university do to ensure there is no institutional conflict of interest?
11. How many REBs are there at your university or college? Who are the members of the REB that you would be applying to? Do they represent the full range of research done at your institution? Are there committee representatives who have expertise in both qualitative and quantitative research traditions?
12. The TCPS requires research ethics boards to have at least one "community member" on the board. Who is/are the community member(s) at your institution? In what way might the presence of this/those person(s) be beneficial for researchers and research participants? In what ways might it be detrimental?
13. Discuss the question of the rights of researchers in relation to the rights of participants, and generate your own criteria for how conflicting interests might be resolved (a) when the researcher is in a position of power over participants and (b) when the researcher is dependent on an agency and/or participants for continued funding and access.
14. This chapter has argued that, while researchers should make every effort to be both "ethical" and "legal," situations might arise where those two are placed in conflict, that is, you must choose between acting ethically but in violation of a particular law (e.g., you can live up to your ethical obligation to protect the rights of your research participants only by defying a court order to disclose confidential research information) or to act legally but in violation of an ethical obligation (e.g., follow a court order to disclose confidential research information even though this brings harm to your participant). Put yourself in these situations. Which do you believe is more important?
15. In the 1950s and 1960s when formalized codes of ethics were first being developed in the social sciences, some researchers opined

that formalizing a code of ethics was the best thing a discipline could do because it would protect academic freedom and keep third parties who would undermine discipline-based control at bay. Others argued the opposite, i.e., that it was a slippery slope that would ultimately undermine academic freedom and end up with nothing better than socially approved questions being asked in socially approved ways to the benefit of no one. We now have the benefit of hindsight. Sixty years later, who do you think was right?

16. You are undertaking a study in a psychiatric clinic for which you have signed an agreement guaranteeing confidentiality to the caregivers you are observing. You soon begin to notice cases where patients are apparently being denied their rights to refuse treatment, and you see two instances of what you perceive as physical abuse. Revealing this information to another authority would be a violation of the confidentiality you guaranteed. What would you do in this situation?

NOTES

1. Even this assumption is tenuous, since there is nothing in the facts of this research that would have precluded the researchers ensuring that the men who participated in the study were made aware of the risks and consented freely.
2. While it is deemed acceptable to pay participants with a small honorarium or gift, these are not supposed to go beyond a token thank you or to defray expenses. This is done in order to ensure that the choice to participate is made freely and not solely because of the incentive.
3. Unbeknownst to the "real" subject in the experiment, the "victim" was actually a confederate of the experimenter's—an actor—and never actually received any shocks.
4. Milgram continued doing research along these lines for many years and eventually published a book (Milgram 1974) summarizing his contributions. Since our interest here is not in his substantive findings but in the ethical issues involved in doing such research, we find it most informative to use his earliest reports. These were written with the enthusiasm of someone who felt he had overcome the reputed artificiality of laboratory settings to discover something important and before controversy broke out.
5. The Olivieri case has received considerable attention and been the subject of a detailed investigation coordinated by the Canadian Association of University Teachers (CAUT). See Thompson, Baird, & Downie (2001).
6. We refer to confidentiality of the *source* because the information itself is not confidential; we set out from the start telling people that the research will be written up in articles and books.
7. For information regarding Confidentiality Certificates, see http://grants.nih.gov/grants/policy/coc/
8. See http://www.nij.gov/funding/humansubjects/privacy-certificate-guidance.htm for information regarding Privacy Certificates.
9. Readers who would like to know more about the *Ogden* case and its repercussions can peruse a Webpage Ted set up that goes through some of the debates that happened at the university and many key documents. It is located at http://www.sfu.ca/~palys/OgdenPge.htm. A key source is the *Russel Ogden Decision Review* by Blomley & Davis (1998), located at http://www.sfu.ca/~palys/ogden.htm. Ted Palys and John Lowman are also now in the process of writing a book about the Ogden case and the ripples it sent through the research community. Tentatively entitled *Going the Distance: The Law and Ethics of Research Confidentiality*, it should be available by 2013.

10. You should specify you are doing this, and the reasons for doing this, in your proposal, and it should be done as soon as possible during the data gathering process. In the United States, most subpoenas have arisen well after the research is done, by which point any identifying information should have been destroyed with only anonymized information remaining. Once a subpoena arrives, if it ever does, it is too late to destroy the original notes or tape, as any destruction at that point likely would be considered destruction of "evidence," which would leave you open to charges of obstruction of justice or contempt of court.
11. Simply deleting a file from your computer does not actually remove it from your hard drive; it simply removes it from view. Deleted files often can be recovered from hard drives even five years after they have been deleted using file recovery software or hardware.
12. TrueCrypt is free "open source" software, which means that the software is available for free to anyone wishing to modify or use for non-commercial purposes (but it can also be bought in for-profit situations). While PGP was originally distributed as "freeware" by the Michigan Institute of Technology (MIT), it is now only available commercially through the Symantec website (http://www.symantec.com) or directly from the program creator Philip Zimmermann (http://www.philzimmermann.com). At the time of this writing TrueCrypt can be downloaded for free from the organization website (http://www.truecrypt.org/).
13. Section 6 is entitled "Oath of Office." It asserts that "The Chief Statistician and every person employed or deemed to be employed pursuant to this Act shall, before entering on his duties, take and subscribe the following oath or solemn affirmation: 'I, …, do solemnly swear (*or* affirm) that I will faithfully and honestly fulfil my duties as an employee of Statistics Canada in conformity with the requirements of the *Statistics Act*, and of all rules and instructions thereunder and that I will not without due authority in that behalf disclose or make known any matter or thing that comes to my knowledge by reason of my employment.'"
14. This is a good time to remind you that we are social scientists, not lawyers, and while the suggestions we offer here have undergone peer review (e.g., see Palys & Lowman 2000, 2002), it is intended only as general advice and should not be construed as specific legal advice. Researchers who are dealing with sensitive information where the possibility of subpoena is legitimate should consult competent legal help; we emphasize "competent" because we have found there are actually very few lawyers who are up-to-date with the law of privilege *and* who understand the academic enterprise and its ethical requirements.
15. Brajuha was a graduate student doing participant observation at a restaurant where he worked as a waiter while doing an M.A. thesis on the sociology of the American restaurant. One day the restaurant burned to the ground under mysterious circumstances that looked like arson. When the grand jury looking into the matter heard that a researcher was on site and had been maintaining something called "field notes," the grand jury subpoenaed the field notes in the hope they might contain clues on the cause and perpetrator of the fire. Brajuha claimed privilege and refused to share his field notes with the grand jury. In the end, his claim for privilege was not accepted—the Court of Appeal said that while a privilege *might* exist, Brajuha had failed to make the case—but he was allowed to anonymize his field notes before submitting them.
16. Richard Scarce was a graduate student doing research with members of the Animal Liberation Front (ALF), a radical animal rights group that occasionally engaged in "direct action." When Scarce and his family went on vacation one year, a member of ALF

took care of his house. On returning from the trip, Scarce discovered that the university's animal care facility had been vandalized extensively and that the ALF member who had house-sat for him was the prime suspect. The grand jury looking into the matter subpoenaed Scarce. Scarce became only the second researcher ever to be jailed (for 159 days) for contempt of court.

17. The word "absolute" is something of a red herring. While it may well reflect the researcher's intention, and may well make sense within the specific context of the research being envisioned, when taken out of context it begs the question of whether anything in life is absolute, which is a tough argument to make. "Strict confidentiality" is similarly strong but without the hook that "absolute" brings.
18. Two of these cases involved subpoenas from grand juries; grand juries do not exist in Canada. The third case was the *Atlantic Sugar* case cited above, where the researchers limited confidentiality, and the court treated the limitation as a waiver of privilege.
19. Online at http://www.acjs.org/pubs/167_671_2922.cfm
20. Online at http://www.aaanet.org/stmts/ethstmnt.htm
21. Online at http://www.apsanet.org/content_9350.cfm
22. Online at http://www.asanet.org/about/ethics.cfm
23. We are thinking here of situations where, for example, the administrators in an organization give access to their employees, or prison officials are the ones giving access to the inmates, or teachers are the ones giving access to their students. Such research often originates with the organization's or institution's needs in mind, which raises the issue of how the interests of prospective research participants are being addressed and/or are in conflict with the desires of the organization.
24. We first came across this story in Stan Cohen's (1985) *Visions of Social Control*. He attributes it to social activist Saul Alinsky. We offer our own version of it here.
25. See also the collection of papers presented at a 2006 Symposium on Censorship and Institutional Review Boards that were later compiled in the *Northwestern Law Review* at http://www.law.northwestern.edu/journals/lawreview/issues/101.2.html. The international scope of the problem is evident when one notes that Katz's and Shea's articles focus primarily on the United States, Fitzgerald's article focuses on the "commonwealth countries" of Britain, Canada, Australia, and New Zealand, and SSHWC's monograph refers primarily to Canada.