

**ETHICS AND SOCIAL SCIENCE RESEARCH:  
A Survey of Social Science Researchers' Experiences of  
Ethically Challenging Incidents and Ethics Review**

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## Abstract

This study aimed to profile social science researchers' experiences of ethically challenging incidents and ethics review and to consider these experiences in terms of the two institutions from which participants were selected. Data was gathered by means of an email survey sent to social science researchers working in both a university and a research organisation. The findings reveal that ethically challenging incidents involving privacy, confidentiality and anonymity, harm, beneficence, poor science, role conflict, informed consent, recruitment of participants and publication were encountered frequently by social science researchers. While respondents reported both positive and negative experiences of ethics review, researchers at the university reported significantly more ethically challenging incidents and negative experiences of ethics review than did researchers from the research organisation.

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## Frequently Used Abbreviations

REC	Research Ethics Committee
IRB	Institutional Review Board
IEC	Independent Ethics Committee

It has long been recognised that biomedical research involving human participants has an ethical dimension. Efforts to ensure the ethical conduct of biomedical research include the establishment of ethical principles, codes and guidelines. More recently, efforts include the institutionalisation of ethics review, in which a research ethics committee (REC) is charged with the responsibility of reviewing the ethical dimensions of research proposals before they are implemented.

The realisation that consideration of ethical issues is as pertinent in social science research as it is in biomedical research has arisen more recently. As such, the majority of universal ethical codes and guidelines are designed for biomedical research and while compulsory ethics review has existed in biomedical research since the 1960s it has only recently been made compulsory in the social sciences. Subsequently ethics review and research ethics in general have been the focus of much recent critical debate in the social sciences. There is, however, a clear lack of empirical studies in the area of social science research ethics, particularly where researchers' everyday experiences with ethically challenging incidents and ethics review are concerned.

This study attempts to make a contribution to this lack of data by surveying social science researchers' experiences of ethically challenging incidents and ethics review. The first part of this thesis, Chapter 2, reviews the existing literature on research ethics and ethics



review with a particular focus on social science research. The aims and methods of this study are outlined in Chapters 3 and 4 respectively. Chapter 5 provides an overview of the sample characteristics. The results of this study and the discussion of these results are integrated in Chapters 6 and 7. The descriptive and exploratory nature of this study necessitated that many thematic areas be identified rather than an in depth analysis of the main themes. The wide range of thematic areas covered lends itself to the integrated presentation and discussion of results, as separate presentation would have required a re-presentation of most of the results in the discussion chapter, resulting in unnecessary repetition. Finally, Chapter 8 provides a summary of the main findings, a discussion of the limitations of the study and recommendations for future research.

## 2.1 An Overview of Research Ethics

“Ethics (from the Greek ethos, “character”) is the systematic study of value concepts ‘good’, ‘bad’, ‘right’, ‘wrong’ and the general principles that justify applying these concepts” (Sieber, 1992, p.3). While ethics is the subject matter of many diverse disciplines and numerous areas of inquiry, this discussion will be limited to the field of research ethics. Research ethics refers to a branch of applied ethics which seeks to prevent research misconduct and protect the welfare of research participants (Schüklenk, 2005; Wassenaar, 2006). Two dimensions of research ethics have been identified. The first is ‘procedural ethics’, which usually involves following the ethical guidelines of the researcher’s home institution/organisation and seeking approval from a REC to undertake research involving human subjects (Guillemin & Gillam, 2004). The second dimension is ‘ethics in practice’. This refers to the everyday ethical issues that arise when doing research (Guillemin & Gillam, 2004). The study of research ethics may enable researchers to better understand their ethical responsibilities, may enable researchers to learn how to best prevent research abuses and make research beneficial for all involved (Kimmel, 1996; Sieber, 1992). Furthermore, ethically informed and aware researchers should be better equipped to avoid ethically challenging incidents and to cope and resolve them if they do occur (Kimmel, 1996).

### 2.1.1 Brief History of Research Ethics and Ethics Review

Research that is unethical does not only have the potential to cause harm to the research participants but may produce invalid data and lead to ineffective interventions. It may ultimately result in people becoming progressively more reluctant to participate in legitimate research (Extended Background and Rationale, n.d.). In South Africa, as in many other developing countries, the risk of research being conducted unethically is high as there are many vulnerable groups of poor or previously disadvantaged people who are more vulnerable to exploitation (Dhai, 2005).

Until the end of the twentieth century the ethical conduct of research in the humanities and social sciences was the responsibility of individual researchers and was, at best, informally policed by fellow researchers and the wider research community (Cribb, 2004). Today however, ethical review is becoming increasingly obligatory for social science research around the world (Wassenaar, 2006). The majority of South African universities and research institutions stipulate that all social science research involving human participants be reviewed by an independent REC prior to data collection.

Likewise, many leading international and local social science journals request authors to submit proof of ethical clearance before the article can be considered for publication (Wassenaar, 2006).

The current emphasis on research ethics and ethical reviews is largely a result of a number of biomedical investigations that blatantly violated the most basic ethical

standards (Oakes, 2002). The most notorious of which is thought to be the Tuskegee syphilis study, the longest non-therapeutic experiment to be conducted in medical history (Kimmel, 1996). The Tuskegee syphilis study, which was funded by the United States public health service, ran from 1932 until it was publicly exposed in 1972 and subsequently stopped due to public outrage (Kimmel, 1996). The subjects in the study were 399 poor black men diagnosed with syphilis. In 1947 penicillin was found to be an effective treatment for syphilis yet participants were purposefully denied treatment so that researchers could document the natural history of the disease. The participants in the study did not give informed consent and were unaware that they were being denied treatment, which resulted in the death of many (Oakes, 2002; Wassenaar, 2006).

The rise of research ethics, however, is most notably attributed to the horrific experiments conducted on prisoners in Nazi concentration camps by Nazi doctors and medical researchers during the Second World War (Oakes, 2002; Schüklenk, 2005). Experiments included healthy prisoners' reactions to various diseases, poisons, and extreme temperatures (Kimmel, 1996). These atrocities were revealed and documented in the Nuremberg trials, which ended in August 1947. The most important outcome of the Nuremberg trials was the development of the Nuremberg code in 1948 which aimed to outline permissible limits for human experimentation in an attempt to prevent future atrocities such as those perpetuated in Nazi concentration camps (Kimmel, 1996).

The ten-point Nuremburg code stipulates that voluntary informed consent of all human participants is essential, that human experiments should produce useful results unobtainable by other methods and that animal experimentation should be conducted prior to human experimentation (Kimmel, 1996). It also stipulates that experimentation should avoid unnecessary harm to participants, that no experiment should be conducted if there is a priori reason to believe that serious injury may result and that the degree of risk should not exceed the importance of the problem under study (Kimmel, 1996).

Furthermore, in terms of the Nuremburg code, measures must be put in place to protect participants from any and all possible injury, the experiment should be conducted by suitably qualified persons, the human participants should have the right to withdraw at any stage and the researcher should be able to terminate the experiment at any stage if it is believed that harm may befall the participants. The Nuremburg code was superseded in 1964 by the World Medical Association's Declaration of Helsinki, which has undergone numerous revisions, the most recent of which was approved in 2000 (Dhai, 2005).

In 1974 the National Research Act was signed into law in the United States of America and the National Commission for the protection of human subjects of biomedical and behavioral research was created (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The commission's deliberations culminated in the Belmont Report of 1979. The objective of the Belmont Report was to provide a framework for the resolution of ethical problems in research on human participants (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The report identifies the three basic ethical principles



(respect for persons, beneficence and justice) that should inform the conduct of ethical research involving human participants and outlines the guidelines (informed consent, risk/benefit assessment and fair subject selection) which should be followed if research is to be in line with these ethical principles (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Recent revisions of the Declaration of Helsinki (in 1983, 1989, 1996, 2000) have incorporated the Belmont Report, making the Declaration of Helsinki the most widely accepted guide worldwide on medical research involving human participants (Christie, 2000). The Declaration of Helsinki is important in the history of research as it set the stage for the implementation of the Institutional Review Board (IRB) and Independent Ethics Committee (IEC) process in a number of countries (Christie, 2000; Dhali, 2005).

Concerns regarding research ethics in the social sciences were similarly driven by public outrage at certain studies. One such study was Milgram's (1974) obedience experiment, in which participants were deceived into believing that they were administering lethal electric shocks to other people. The study was criticised for the excessive psychological stress it placed on some subjects and that, as deception was involved, true informed consent was not obtained (Dunn & Chadwick, 2001). Much social science research, especially psychology, engaged in experimentation with human participants has been subject to guidance documents and formal ethical review since the mid 1960s in the United States and the United Kingdom (Wassenaar, 2006). Although problematic social

science research contributed to the need for ethical review, ethics committees did not develop specific guidelines or procedures for social science proposals (Wassenaar & Corbella, 2007).

In South Africa the University of Witwatersrand formed a committee for medical research on human subjects in 1966. In 1998 the South African National Department of Health began to develop guidelines for the ethical conduct of clinical trials, which cumulated in the Clinical Trials Guidelines being published in 2000 (Dhai, 2005). The South African Health Act 61 of 2003 ch9, s 71 requires that an independent accredited REC approve all health research with human subjects (Wassenaar, 2006). In 2003 the Human Sciences Research Council introduced compulsory ethics review for all research (including social science research) and at present most South African Universities and research institutions require all research involving human participants (both social scientific and biomedical) to be reviewed by an REC (Wassenaar, 2006). The National Health Research Ethics Council was appointed in 2006 to register, accredit and audit all RECs in South Africa (Republic of South Africa, Department of Health, 2004).

Cribb (2004) attributes the extension of ethical guidelines and reviews from the medical and behavioural sciences to the humanities and social sciences to a fundamental change in the way research was perceived. Research of any sort began to be seen as disempowering and potentially dehumanising. Subsequently the focus of research ethics shifted from the prevention of physical and psychological harm to a focus on maintaining the subject's dignity. This line of reasoning was also followed by a move away from the term 'research subject' to 'research participant', emphasising the active contributions of

research volunteers (Cribb, 2004). The term 'research participant' will therefore also be applied in the present work.

### 2.1.2 A Framework of Moral Principles

Numerous moral theories (such as utilitarianism, kantianism, liberal individualism, communitarianism, and ethics of care (cf., Beauchamp & Childress, 2001)) have been transformed and organised into prescriptive rules that regulate behaviour and guide decision-making in human interactions (Slack, 1997). As a discussion of the value and contribution of all the abovementioned moral theories to the field of research ethics is beyond the scope of this thesis, the discussion will be limited to the Beauchamp and Childress (2001) framework of moral principles. This framework comprises four clusters of principles; respect for autonomy, non-maleficence, beneficence, and justice. These principles were first documented in the 1979 Belmont report. They can be found in most moral theories, have been used to inform numerous ethical guidelines, and can be applied in various ways to determine whether research is ethical (Beauchamp & Childress, 2001).

Autonomy refers to an individual's personal freedom of thought and action (Slack, 1997). The principle of autonomy is concerned with respect for the dignity of research participants and is achieved by respecting the decision-making capabilities of autonomous persons (Beauchamp & Childress, 2001). The principle of autonomy also states that persons with diminished autonomy have the right to be protected (Beauchamp & Childress, 2001). This principle is operationalised by obtaining voluntary informed



consent from all participants and ensuring that confidentiality is respected (Sieber, 1992; Wassenaar, 2006).

The principle of non-maleficence requires the researcher to ensure that participants are not harmed or wronged in any way during the research process (Wassenaar, 2006).

Non-maleficence is generally considered to be a stronger requirement than the third principle of beneficence. However, as beneficence requires the researcher to attempt to maximise the benefits that the participants obtain from the research while preventing harm, it is further-reaching than the principle of non-maleficence (Sieber, 1992; Slack, 1997; Wassenaar, 2006).

The principle of justice requires that researchers treat participants with equity and fairness (Sieber, 1992; Wassenaar, 2006). An injustice is said to occur when a benefit to which a person is entitled is denied without reason or when a burden is unduly imposed (Beauchamp & Childress, 2001). The researcher is, for example, obliged to show fairness in the selection of participants and in the distribution of risks and benefits (National Research Council, 2003).

While these four philosophical principles are almost universally accepted, critics argue that they are unsuitable for practical decision making as they lack hierarchical order which renders their application arbitrary and therefore they fail to guide and justify researchers' actions (Schüklenk, 2005). In response to the limitations of these ethical principles there have been numerous attempts to pragmatically delineate the ethical

obligations of researchers. Emanuel, Wendler, Killen and Grady's (2004) ethical framework provides one useful way of doing so (Wassenaar, 2006).

### 2.1.3 A Recommended Framework for Ethical Research in the Social Sciences

Emanuel et al.'s (2004) framework<sup>1</sup>, which is structured to match the process of research design, implementation and reporting, embodies the four philosophical principles as well as their operational implications and synthesises traditional codes, guidelines and literature on the ethics of researching human participants. Unlike previous documents, Emanuel et al.'s (2004) framework is not a response to a particular incident and therefore does not focus on specific instigating events at the expense of others (Emanuel, Wendler & Grady, 2000). While this widely accepted framework was developed in relation to clinical research in developing countries, it has recently been described as a useful approach to the ethical dimensions of conducting research in the social sciences (cf., Wassenaar, 2006; Wassenaar & Corbella, 2007). Social science has been defined by *The Columbia Encyclopedia* (2001) as a term for any or all of the branches of study that deal with humans in their social relations. This definition was selected for its broad and generic nature as the social sciences span a wide range of disciplines, many of which have disparate methodological and epistemological stand points.

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<sup>1</sup> Emanuel, Wendler, Killen and Grady's (2004) framework of what makes clinical research ethical is an extension of Emanuel, Wendler and Grady's (2000) framework applied to research in developing countries and includes an eighth principle of Collaborative Partnership.

Emanuel et al. (2004) advocate that ethical research should involve a collaborative partnership with the host community, be of value to the research community or society at large, be scientifically valid, ensure the fair selection of participants, have a favourable risk-benefit ratio, be subject to review by an independent REC, ensure informed consent is maintained and show respect for recruited participants and study communities (these principles will be elaborated on in Section 2.2 below). According to Emanuel et al. (2004) consideration of these eight principles should ensure that the research conducted is ethical and that participants are not harmed. Emanuel et al. (2004) argue that through an application of these eight principles and accompanying benchmarks (that operationally delineate practical measures to determine the extent to which the research satisfies the principles) research can be conducted in an ethical manner and exploitation can be minimised.

Although Emanuel et al.'s (2004) framework has been described as the most appropriate approach to the moral dimensions of conducting research in the social sciences (Wassenaar, 2006; Wassenaar & Corbella, 2007), a number of authors (cf., Mattingly, 2005; Riessman, 2005) have argued that predetermined ethical frameworks are not always applicable to social science research, primarily because the ethical dilemmas that arise in social research are context specific. Frameworks, such as the above, are argued to be based on the inherent assumption that it is possible for a contract (guided by universal, context-free ethical norms) to be established between the researcher and the researched, that if adhered to, will ensure the researcher's ethical behaviour (Mattingly, 2005). In place of existing rigid, universally applicable guidelines, i.e., informed consent and

confidentiality, some authors (cf., Mattingly, 2005; Riessman, 2005) have suggested that an ethics-in-context approach be adopted. The ethics-in-context approach rejects the application of a set of principles or benchmarks and instead encourages consideration of the unique circumstances that make up an individual research context and encourages decision making based on that context (Boser, 2006). The ethics-in-context approach claims to speak to the spirit of ethical research and allows for the modification of ethical and moral principles in different contexts (Riessman, 2005). Conversely, Wiles, Heath, Crow and Charles (2004) explain that existing ethical guidelines and frameworks for social research are broad and intentionally vague allowing researchers to adopt a 'situational relativist' approach in which guidelines can be interpreted to suit the needs of specific research and allow ethical decisions to be made on the basis of issues applicable to the specific research context.

While Emanuel et al.'s (2004) framework is intended to be universal, the authors acknowledge that the principles require practical interpretation that is context and culture specific. They argue that context and culture specific interpretation does not undermine the framework's universality nor does it constitute a form of moral relativism. Rather, the authors recognise that while the ethical principles embody universal values, applying these values depends on the particular context in which the research is conducted (Emanuel et al., 2000). For example, local contextual traditions and community structures will influence how informed consent can be negotiated.

## 2.2 Ethical Issues in Social Science Research

While Emanuel et al.'s (2004) framework provides a good indication of the issues that need to be considered in order to conduct ethical research, it is common that uncertainty arises over how to balance competing values in a given instance. Such situations have been described by Smith (1985 in Kimmel, 1996) as ethical dilemmas. "An ethical dilemma is apparent in research situations in which two or more desirable values present themselves in a seemingly mutually exclusive way, with each value suggesting a different course of action that cannot be maximised simultaneously" (Kimmel, 1996. p.7).

Guillemin and Gillam (2004) extend the definition to include 'ethically important moments'. These are instances in which it is fairly clear how the researcher should respond, and yet there is still something ethically important at stake where the approach taken or the decision made has further ethical ramifications. While ethical dilemmas and/or ethically important moments can arise through a blatant disregard of ethical principles or guidelines, most often they occur unexpectedly when intentions of the researcher are misunderstood or 'imported' procedures to ensure participants' protection are inadequate (Reissman, 2005). Moreover, ethical dilemmas and/or ethically important moments often concern insidious ethical issues that arise in the course of doing research (Guillemin & Gillam, 2004). The term 'ethically challenging incidents' will be used from here on to synthesise the terms 'ethical dilemma' and 'ethically important moments' as they are defined above.

The eight principles of Emanuel et al.'s (2004) framework outlined in Section 2.1.3 will be used to illustrate the broad areas in which ethically challenging incidents may occur. When applicable, documented examples of ethically challenging incidents will be discussed. This discussion will be limited to the application of the framework and discussion of ethically challenging incidents in social science research only.

### 2.2.1 Collaborative Partnership

Firstly, according to Emanuel et al. (2004) in order for research to be ethical it should involve a collaborative partnership between the researcher and the community being researched. Collaborative partnership requires researchers to conduct research that has been developed in co-operation with the community being researched (Emanuel et al., 2004). The research should have value to the community and respect the culture, traditions and practices of the community. Ideally, the researcher should strive to involve the community in as much of the research process as possible and the community should be able to share the benefits of the research (Emanuel et al., 2004). Emanuel et al. (2004) acknowledge that forming collaborative partnerships with the host community is not necessary or pertinent in all types of research. For example, research on destructive processes, such as racist practices would make community collaboration inappropriate (Wassenaar & Corbella, 2007).



### 2.2.2 Social Value

The second dimension of ethical research is social value. For research to be ethical it should address issues and generate knowledge or interventions that are of value to the community being researched or to society at large (Emanuel et al., 2004). The research should acknowledge who the beneficiaries will be and in what ways they might benefit. Furthermore, research where results are not disseminated or in which interventions cannot be practically implemented is not valuable (Emanuel et al., 2004).

### 2.2.3 Scientific Validity

According to Emanuel et al. (2004), scientific validity is another dimension that needs to be fulfilled if research is to be ethical. The research design, methodology and data collection and analysis should be rigorous, valid and feasible (Emanuel et al., 2004). Poor science can be equated with poor ethics because participants would be exposed to unnecessary risks and limited resources would be wasted on research that produces results that are invalid and consequently unusable (Dhai, 2005; Wassenaar, 2006).

Ethical issues that arise regarding scientific validity may take the form of scientific misconduct. Scientific misconduct has been defined by Schneider and Schüklenk (2005, p. 92) as “fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or reporting research findings”. This definition has recently been extended to include deviations from approved proposals without permission, failure to obtain

informed consent, breeches of confidentiality, undertaking research without REC approval, and any other deviation from accepted ethical standards (Schneider & Schüklenk, 2005).

#### 2.2.4 Fair Selection of Participants

The fourth dimension, fair selection of participants, is met when participant selection is conducted impartially and is based on the purpose of the research. For example, populations should not be used solely because they are easily accessible (Wassenaar & Corbella, 2007). In addition, no person should be denied the opportunity to participate without justification, and if appropriate participants should be selected in such a manner that the results are generalisable to the entire research population (Emanuel et al., 2004).

For selection of participants to be fair, it should be free from coercion and undue inducement. According to Emanuel, Currie and Herman (2005, p. 337) coercion involves “threats that make a person choose an option that necessarily makes him or her worse off and that he or she does not want to do”. While undue inducements involve an “offer of a desirable good in excess such that it comprises judgment and leads to serious risks that threaten fundamental interests” (Emanuel et al., 2005, p. 337). An ethically challenging incident that is frequently reported in the literature on research in developing countries is that inducements that are ordinarily acceptable may become undue inducements if participants are especially vulnerable due to poverty or historical disadvantage (cf., National Bioethics Advisory Commission, 2001). Emanuel et al. (2005) however argue



that poverty or unfortunate circumstances are not enough to create an undue inducement. Inducements only become undue when a person's unfortunate circumstances are combined with compromised judgement and accepting a seriously unfavourable risk benefit ratio that threatens their fundamental interests (Emanuel et al., 2005). Emanuel et al. (2005) therefore suggest that the dilemma of offering undue inducements can only be resolved by readjusting the risk benefit ratio by offering more benefits not less monetary incentives. Furthermore, according to Emanuel et al. (2005), many concerns about undue inducements are really misguided concerns that RECs are ineffectively assessing the risks and benefits of research.

#### 2.2.5 Favourable Risk/Benefit Ratio

Favourable risk/benefit ratio is the fifth dimension in Emanuel et al.'s (2004) framework. In order for research to be ethical, those who bear the risks and burdens of the research should also ultimately benefit from it (Emanuel et al., 2004). Ethical research should ensure that potential risks to the research participants are minimised and that potential benefits are maximised (Emanuel et al., 2004). Furthermore, the potential benefits to the participants and society should be relative to, or outweigh the risks (Emanuel et al., 2004).

Kelman (1982) identifies three possible harms that may arise from social research; injury, stress and indignation and diffuse harm. Participation in social research may cause physical injury in the form of violence among participants or violence directed at

participants as a result of participation when there is a breach of confidentiality (Kelman, 1982). Psychological injuries such as anxiety or painful self discoveries, however, are more common in social research, as is the possibility of material harm befalling participants. Material harm can include loss of resources or opportunities as a result of participation in research (Kelman, 1982). Stress and indignation may also occur during the research process, as may diffuse harm that may be damaging to society at large (Kelman, 1982). According to Macklin (2002) consideration of possible harms that may occur should include wrongs. A participant may not be harmed during research but may be wronged<sup>2</sup>. Ethical research should therefore attempt to minimise harm and avoid wrongs (Macklin, 2002). While some harms can be offset by benefits, wrongs cannot (Wassenaar & Corbella, 2007).

Benefits in social science research include benefits to subjects, to communities, scientific knowledge, the research institution and society at large (Sieber, 1992). Sieber (1992) cautions that most social science research is unlikely to lead to obvious improvements or contributions to society and/or science. It has similarly been argued that the benefit of most social science research is the career advancement of the researcher rather than participants or society at large (Wassenaar & Corbella, 2007).

The ethical requirement of protecting participants from harm has been problematised by Lofman, Pelkonen and Pietila (2004) in relation to participatory action research. As change and empowerment are central aims of this approach, the notion of harm needs to

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<sup>2</sup> For example, if a researcher were to covertly observe someone's private behaviour and never disclose any details to the observed person, the person would not be harmed but they would nevertheless be wronged (Wassenaar & Corbella, 2007).

be reconceptualised to include the emotional, physical and social demands that research related changes may have on those involved. In participatory action research then, protecting participants from harm requires that all changes are carried out slowly and are seen as necessary and valuable to all participants (Lofman et al., 2004).

#### 2.2.6 Independent Ethical Review

The need for ethical review by an independent REC is the sixth dimension of ethical research. By reviewing the research design and methodology a competent REC should both protect the participants from harm and enhance the quality of the research (Emanuel et al., 2004). REC's (particularly those in developing countries) may find it difficult to maintain independence because of power inequalities between RECs and sponsors or government (Milford, Wassenaar & Slack, 2006). Power inequalities may make it difficult for RECs to challenge authority and debate complex issues. Furthermore money, custom, prestige or ignorance may influence ethical review thereby compromising REC's independence (Milford et al., 2006). A study conducted by Milford et al. (2006) found that perceived challenges to the independence of RECs in African countries included pressure from sponsors, pressure from political powers, biased committee members, lack of transparency, bribery and unequal treatment of applicants under review. Studies such as this reveal the need for more resources and training to be made available so that RECs in developing countries may become better equipped to manage pressure from sponsors and government and root out bribery, bias and preferential treatment.

### 2.2.7 Informed Consent

Informed consent, the seventh dimension of Emanuel et al.'s (2004) framework, ensures that individuals have control over whether or not they part take in research and that they only participate when the research is in line with their values and interests (Emanuel et al., 2004). Informed consent involves four components a) provision of appropriate information, b) participants' competence and understanding, c) voluntary participation and the freedom to withdraw at any stage, and d) consent being formalised in writing (Emanuel et al., 2004).

Firstly, the researcher is required to provide potential participants with appropriate information so that an informed decision can be made about whether to participate or not (Wiles, Heath, Crow & Charles, 2004). The information provided to participants should include the aims and implications of the research, possible outcomes and benefits, as well as any additional factors that might influence participants' willingness to participate. The manner and context in which the information is provided is as important as the information itself (Flory & Emanuel, 2004). The provision of information must be in line with the participants' capacity to understand. Researchers should assess whether participants have comprehended the information provided (Wiles et al., 2004). Furthermore, special provisions need to be made when participants' comprehension is limited, such as in the case of children or mentally ill people. Assent to participate should be obtained from such persons to the extent to which they are able and third party consent should also be obtained in order to protect these participants from harm (Wiles et al.,

2004). In addition, informed consent is only valid if it is voluntary given. For consent to be voluntary it must be free from coercion and undue inducement. Although consent may be obtained verbally, in some situations written consent is required. Informed consent does not end with the signing of the consent form, rather consent should be conceptualised as an ongoing process whereby the researcher maintains open communication with the participants at all times and willingly answers any questions participants may have (Sieber, 1992).

The importance of informed consent in research ethics is especially problematic and contested in qualitative research, giving rise to numerous ethically challenging incidents. In most types of action research, for example, it is often not possible for participants to give informed consent in advance as not all the research activities are determined in advance by one person (Boser, 2006). The research activities are instead negotiated by all participants at each stage in the research process and participants can only decide whether to participate or not as the process develops (Boser, 2006). The dynamic and flexible nature of these types of qualitative research makes the possibility of obtaining informed consent problematic, and often requires participants to give consent to the unknown (Lofman et al., 2004). A more practical solution to this problem is for informed consent to be phased. This would require consent to be obtained as each new research activity is negotiated.

Moreover, obtaining written informed consent in marginalised societies is difficult because of illiteracy (van den Hoonaard, 2001) and suspicion of official forms

particularly in post-colonial contexts (Reissman, 2005). For example, in her work with infertile women in South India, Reissman (2005) found that a significant number refused or were reluctant to sign their name on the informed consent form. While for researchers the informed consent form functions to ensure that participation is voluntary and well understood, to establish ownership of the gathered information, and to release the funding organisations from liability, the act of signing such a form in a post-colonial context is often very different from this protective western understanding and may arouse fear and suspicion (Reissman, 2005). The imposing nature of many informed consent forms, written formally on official university letterheads, has received much criticism, as has the individualistic assumptions implicit in such forms (van den Hoonaard, 2001). Seeking individual informed consent is often not appropriate or possible in collective cultures (van den Hoonaard, 2001; Whittaker, 2005). In response to such ethical challenges Emanuel et al. (2000) specifically highlight that principles such as informed consent should have different operational applications in different cultures. Informed consent is put in place to ensure participants are treated with respect, but what constitute respect may differ from culture to culture. It may for example be more appropriate, and equally acceptable, to elicit consent from tribal leaders before approaching individuals in the community.

Another ethical challenge voiced by qualitative researchers is that the insistence on acquiring a name and signature on an informed consent form destroys full anonymity and makes research with certain groups, for example those engaged in illegal activities, even more difficult (van den Hoonaard, 2001). In some cases, a signed consent document is



clearly inappropriate. According to the National Institutes of Health (2002) an ethics committee may waive written informed consent if there is a confidentiality risk, and the only link between the participant and the research would be the consent document.

Written informed consent may only be waived if the research presents a minimal risk of harm and involves no procedures that normally require informed consent outside of research (National Institutes of Health, 2002).

More generally, it has been argued that the possibility of ever being able to achieve fully informed consent is unlikely as there is no way to judge whether the research has been fully explained or fully comprehended by the participants. Furthermore, there is no way of knowing all the possible consequences for each participant in a study (Wiles et al., 2004). For example, Estroff (1995) faced an unexpected ethical dilemma when she gave her research participants her book, the final product of her ethnographic research among a group of chronic mental patients. One of the women in her study recognised herself and was severely distressed by her representation - she felt 'exploited', 'misunderstood' and 'unmasked' (Estroff, 1995). This incident prompted Estroff (1995) to question the ethics of asking a person to consent to a process whose end product they cannot envision.

Nowadays it is common practice to include some form of comprehension assessment in the informed consent process, to conceptualise informed consent as a process allowing for the modification of the forms and agreements as new situations arise or as the research unfolds. Lastly in response to Estroff's (1995) remarks it might be argued that this ethically challenging situation reflects the shortcomings of the researcher and/or REC who may not have properly anticipated all the possible outcomes or risks of the research.

Furthermore, 'chronic mental patients' constitute a vulnerable population. As they are likely to display questionable capacity to consent, they may give their assent but 'permission' to participate in research should be given by a legally authorised representative who is independent of the researcher (Wiles et al., 2004).

In addition, Homan (1991) points out that the ongoing tension between the researchers' desire to achieve a good response rate and the participants' right to refuse to participate may prompt researchers to provide less than full information to potential participants in order to encourage participation.

#### 2.2.8 Ongoing Respect for the Participants and the Study Communities

Lastly, according to Emanuel et al. (2004), ethical research requires ongoing respect for participants and study communities. Such respect entails; a) allowing participants to withdraw from the research at any stage, b) providing participants with any new information obtained during the research, and c) monitoring participants' wellbeing throughout the research. While it is possible that ethical issues arise in all of the above, most documented ethical issues in maintaining ongoing respect arise while attempting to d) respect participants' privacy by maintaining confidentiality and anonymity.

Privacy, confidentiality and anonymity are three interrelated factors that require consideration when planning ethically responsible research as they affect potential participants' willingness to participate in research and to give honest responses (Sieber.



1992). Privacy refers to participants' desire to control the access others have to them and to information about them (Sieber, 1992). Confidentiality is an extension of this concept but it refers specifically to research data and how that data should be handled in order to maintain the privacy of participants (Sieber, 1992). Anonymity, on the other hand, means that identifying information will not be linked to the data and/or known to the researcher (Sieber, 1992). A confidentiality agreement should be reached while informed consent is being negotiated. The terms of the agreement need to be adapted to the particular research process and the nature of the data being collected (Sieber, 1992). As is the case with informed consent, ensuring confidentiality can be problematic in certain instances. For example, assumptions of privacy and confidentiality may not be understood in certain communities, certain methodologies are not conducive to protecting the privacy of participants, and the need for information may conflict with the participants' desire to release the information (Kimmel, 1996).

An ethical challenge Reissman (2005) faced during research on infertility in India, for example, concerned her quest for privacy, a condition required for confidentiality. Reissman's (2005) expectations of private interviews were a 'foreign import', a western assumption which was not possible due to limited space in the respondent's dwelling and the cultural belief that infertility is a family and community issue, which resulted in family members and neighbours crowding around the interviewee and interrupting and adding to her responses.

Participatory activities and focus groups, commonly used in qualitative social science research, also present complications concerning confidentiality, as the researcher cannot guarantee that all participants will keep the information released by other participants confidential (Lofman et al., 2004; Wassenaar, 2006). In such research particular attention should be given to confidentiality issues and the participants should be fully informed about confidentiality risks prior to participation (Wassenaar, 2006). Ideally, research on sensitive topics and/or research that may have severe negative consequences for participants as a result of breaches of confidentiality should not be conducted using such methodology.

The last aspect of Emanuel et al.'s (2004) principle of maintaining ongoing respect entails making final research findings available to the participants. As participants have voluntarily taken part in the research and assumed the risk, the host community and the participants have a right to know, in a suitable form, what was found and the possible implications of the findings (Emanuel et al., 2004). Making findings available to participants in social science research can prove ethically problematic. The small number of participants involved in most qualitative research may result in participants recognising themselves in the findings. This has prompted Lofman et al. (2004) to question how researchers should deal with situations where participants become distressed by the researcher's presentation and interpretation of their views or actions.

As is evident from the discussion in Section 2.2, existing literature on ethically challenging incidents is predominantly based on the personal experiences and reflections

of researchers as there have been few empirical studies which systematically document the ethical challenges faced by social scientists in their work as researchers.

Pope and Vetter's (1992) national survey of the ethical dilemmas encountered by members of the American Psychological Association (APA) is one of the few that provide some insight into the type of ethical issues encountered during research. The authors developed a survey which invited APA members to provide ethical dilemmas they faced in their work. Of the 703 ethically troubling incidents the authors received, the sixth most troubling incident (n=29) concerned research. Twelve of these dilemmas involved pressures and/or tendencies to misrepresent research procedures and/or findings. A further eight dilemmas reflected concerns about the rights of research participants. The remainder involved diverse topics such as mistreatment of animals, established researchers overriding new research, inadequate resources, and the difficulties of conducting research for large organisations in which many employees exert influence over how the research should be carried out (Pope & Vetter, 1992).

In contrast, similar studies conducted in South Africa found that ethical challenges in psychological research were seldom reported (cf., Slack, 1997; Wassenaar, 2002).

Pettifor and Sawchuk's (2006) comparison of several studies conducted in different countries using the Pope and Vetter (1992) model found that ethically challenging incidents involving research made up 23% of all the ethically challenging incidents encountered by psychologists in Mexico<sup>3</sup>, 10% in the British study, 6% in the Canadian study, 4% in the American study, 2.5% in the New Zealand study, 2% in studies

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<sup>3</sup> The Mexican study did not distinguish between dilemmas in research and academic settings.

conducted in both Sweden and Norway, only 1% in the study conducted in Finland (Pettifor & Sawchuk, 2006). The study also revealed that ethically challenging incidents involving research did not even feature in the equivalent South African studies (Pettifor & Sawchuk, 2006).

## 2.3 Ethics Review in Social Science Research

### 2.3.1 The Ethics Review Process

At present many South African universities and research institutions stipulate that all social science research involving human participants be reviewed by an independent REC prior to data collection (Wassenaar, 2006). An REC is a formally established committee which functions to review the ethical aspects of research proposals in order to ensure the wellbeing of potential human participants (Schüklenk, 2005; Wassenaar, 2006). An REC has the responsibility to review each research proposal within a reasonable period of time and decide whether the proposal be approved, modified before approval, disapproved or whether prior approval should be ceased or suspended (Dhai, 2005). In order to approve a proposal an REC should be satisfied that any risks to participants are minimised through the use of a sound research design that does not unnecessarily expose participants to risk and that all risks to participants are relative to or outweighed by the benefits to participants, science or society (National Institutes of Health, 2002). The REC also has a responsibility to ensure participant selection is fair in relation to the purpose and context of the research and that potential risks and benefits are equally distributed among

participants (National Institutes of Health, 2002). Furthermore, RECs should ensure that informed consent is sought, obtained and documented and that adequate provisions are made to protect the privacy of participants and to maintain the confidentiality of data (National Institutes of Health, 2002).

### 2.3.2 Resistance to Ethics Review

While the protection of human research subjects should be a goal strived towards by both RECs and researchers alike, the relationship between the two is not without complications. Critical debate currently surrounds the ethics review process which is at best seen as an ethical safeguard which contributes to well designed research, and at worst an unnecessary bureaucracy which is both interfering and obstructive (Wassenaar, 2006).

Although several studies have documented researchers positive attitudes towards ethics review (cf., Keith-Spiegel, Koocher & Tabachnick, 2006; Mc Neill, Berglund & Webster, 1992), in general literature on ethics reviews in the social sciences casts the relationship between researchers and RECs in a particularly negative light by focusing on researchers' frustrations with, and objections to ethics review. Such literature, however, is predominantly based on the personal experiences and reflections of researchers and members of RECs. To date few attempts have been made to systematically document social science researchers' actual experiences of ethics reviews. As such most empirical studies discussed below refer to researchers' attitudes towards and experience of ethics

reviews in biomedical and health research. It is important to note that objections and resistance to ethics review is by no means unique to the social sciences. There was, and to a certain extent still is, similar resistance to ethics review in biomedical research (Wassenaar, 2006).

An examination of researchers' resistances to ethics review is important as Keith-Spiegel et al. (2006) suggest that the ethical behaviour of researchers is closely tied to their perceptions of and experiences with RECs. Drawing on organisational justice research, Keith-Spiegel et al. (2006) asked 886 biomedical, social and behavioural researchers to rate 25 descriptors of REC functions and actions in terms of their importance. The authors found that researchers place high value on fairness and respectful consideration by their REC and that researchers' who have negative perceptions and who feel victimised by their REC are more likely to behave in a unethical manner in order to level the playing field. Such behaviour is detrimental to the REC, the institution, the researcher and their scientific work (Keith-Spiegel et al., 2006).

Researchers' resistance and frustrations to the ethics review process can be separated into principled and pragmatic objections (Wassenaar, 2006). The main principled objection comes from those who argue that ethical considerations restrict academic freedom (Oakes, 2002; Wassenaar, 2006). Many researchers believe that they have an inalienable right to research and that ethics review restricts that right (Oakes, 2002). This is, however, an erroneous argument as academic freedom asserts the freedom of intellectual



inquiry but not the unrestricted use of methodologies that may have negative consequences for research participants (Wassenaar, 2006).

The issue of trust is also often cited by those who query the need for ethics review (Whittaker, 2005). Such critics argue that there is an inherent integrity and trustworthiness in researchers that makes ethics review unnecessary and offensive. This trust is likened to the trust endowed to university faculty who are expected to be fair in their dealings with students, in setting exams and the like. It is argued that such trust should also be bestowed upon faculty in relation to their research pursuits (Whittaker, 2005). This is again an erroneous argument, if university faculty really were endowed with the kind of trust Whittaker (2005) refers to, there would be no external examiners and faculty reviews. These regulatory bodies in academia are analogous to RECs in research and are designed to benefit both researchers and participants. As even the best intentioned research can still unintentionally harm research participants, and while ethics reviews are put in place to prevent this, they also function to protect the researcher and their affiliated institution against lawsuits and information being subpoenaed (Illinois White Paper, 2003).

Another principled objection is that ethics review is irrelevant to social science research, as, in general, social science research carries far lower risks to research participants than biomedical research (Cribb, 2004; Oakes, 2002). While social science research is unlikely to cause direct physical harm to participants the risks of invasion of privacy, loss of confidentiality, psychological trauma, embarrassment, deception, stigma and

stereotyping, are risks nonetheless (Dhai, 2005). Moreover, as social science research has been argued to generate fewer direct benefits for research participants and society than biomedical research (cf., Macklin, 1982), Wassenaar and Corbella (2007) argue that the risk/benefit analysis of social science research should in fact be subject to much greater ethical scrutiny.

Several authors (cf., Mattingly, 2005; Reissman, 2005) object to the ethical universalism promoted by ethics review. According to Redwood and Todres (2006) the fundamental principles of biomedical research - beneficence, non-maleficence, autonomy and justice, have been translated into the practical guidelines of risk/benefit analysis, informed consent and confidentiality and are assumed to be context free and universal. Such ethical universalism is problematic because ethical guidelines and procedures that have been constructed in one context are exported to other, particularly developing world, contexts without modification (Mattingly, 2005; Reissman, 2005). The concern is that such a standardised approach to research ethics may not always correspond to the actual ethical issues that arise during research. This concern is shared by Hyder, Wali, Khan, Teoh, Kass and Dawson (2004) who found that 83% of the researchers they surveyed from developing countries felt that United States IRB regulations were insensitive to local cultures. Imported ethical procedures and guidelines that are insensitive to local cultures are likely to be misunderstood or simply insufficient (Mattingly, 2005).

Pragmatic objections to ethics review include the issue of time delays as most RECs only meet once a month and approximately half of all research proposals are returned for



amendments (cf., Wassenaar, 2006). Such frustrations can however be reduced if researchers factor the ethics review process into their research schedules (Wassenaar, 2006). In a review of the decisions made by the University of Cape Towns REC, Jelsma and Singh (2005) found that of the 189 proposals they reviewed 173 were approved, however 50% of those required resubmission with amendments. Ultimately, the average turn around time from submission to final approval was found to be 2 months (Jelsma & Singh, 2005). The authors found that more than one ethical problem was identified per proposal. Incorrect submissions resulted in 11% of the proposals being returned for amendment, 22% of the proposals required amendments involving scientific validity, 20% involved informed consent, 22% involved beneficence and well being of participants, 12% involved issues of justice and 13% of proposals were returned for amendment because of confidentiality or autonomy issues (Jelsma & Singh, 2005).

In a study of attitudes towards IRBs (in which over 2000 researchers, including 800 IRB members, from 61 institutions were surveyed) Gray and Cooke (1980) found that approximately half of all researchers surveyed felt that their research had been hindered in a way that was not countered by the benefits of the review process. Similarly, Mc Neill et al. (1992) conducted a study which sought researchers' views on the ethics of research practices and the Australian system of review of research proposals by RECs. Despite general support for the ethics review process, the authors found the researchers' experiences of ethics review to be slow and taxing. It was also found that researchers who had their proposals rejected or were required to make modifications prior to approval were more likely to view ethical review as an impediment to research. It has been argued

that most of the frustrations with ethics reviews arise from the poor ethical training social scientists receive and that if the researchers themselves were more competent in the ethical aspects of research their proposals would be less likely to be disapproved (Sieber, 1992).

Another commonly voiced pragmatic objection to ethics review is that RECs are not competent in their review of both the technical and ethical aspects of studies as biomedically focused RECs are often not familiar with social science methodology (Oakes, 2002; Wassenaar, 2006; Whittaker, 2005). Ethics committees were primarily established to review biomedical research. Over the years, however, their function has expanded to include a host of additional fields and methodologies including the social sciences (Illinois White Paper, 2003). As this occurred, their functions, responsibilities, and terminologies, which were clearly defined and appropriate for biomedical research, have become strained and ambiguous when applied to other contexts, such as the social sciences (Illinois White Paper, 2003). This has not only resulted in an increased regulatory burden but also imprecision and inappropriate restriction of social science research. RECs are accused of not being able to competently address issues unique to the social sciences and therefore, instead of adding value to research as is intended, they obstruct the progress of innovative research with irrelevant biomedical inquiries (Oakes, 2002). The complaint that social science research is often judged by the same standards as biomedical research prompted Keith-Spiegel et al. (2006) to hypothesise that, in their study on researchers' ratings of RECs actions and functions, biomedical researchers

would rate their RECs more favourably than would social and behavioural researchers. The findings however revealed that this was not the case.

The reliability of the ethics review process has also been questioned repeatedly (Ceci, Peters & Plotkin, 1985). Authors such as Eaton (1983) highlight that the reliability of ethics reviews should not be taken for granted. Eaton (1983) analysed 111 research proposals that were reviewed (in relation to their treatment of research subjects) by experienced reviewers over a period of ten months and found that reviewers were only in agreement eight percent of the time. Ceci et al. (1985) found similar inconsistencies in the decisions made by reviewers. Their study revealed that similar proposals were often approved at one institution and not at another even when the two institutions were situated in the same community and/or had shared institutional laws, standards and restrictions (Ceci et al., 1985). A more recent study conducted by Angell, Sutton, Windridge and Dixon-Woods (2006) found similar inconsistencies. Of the 18 applications reviewed by three RECs over a 12 month period, 11 received consistent decisions from all three RECs (Angell et al., 2006). Of the seven applications that received inconsistent decisions, six received consistent decisions from two RECs and one application received inconsistent decisions from all three RECs (Angell et al., 2006). Ultimately, over a third of the sample received inconsistent decisions. Statistical analysis led the authors to describe the level of agreement as 'slight'.

Further research is needed in order to determine whether documented inconsistencies are due to disparities in moral judgments, inadequate or incompetent review, or conflicts of

interest. Other authors (cf., Doob, 1983 cited in Ceci et al., 1985), however, argue that consistency among REC members' decisions is not necessarily desirable. Rather, REC members should represent diverse opinions and values in order to cater for and address a wide array of research proposals effectively.

RECs have also been criticised for being biased against certain types of research. Gaining ethics approval has, to a limited extent, been attributed to the luck of the draw (Ceci et al., 1985; Kimmel, 1996). That is, it has been suggested that proposals are more likely to be approved if the researcher is 'lucky' enough to get an REC who is sympathetic to their theoretical orientations and methodologies (Kimmel, 1996). Related to the issue of luck and bias, but far more concerning is the criticism that RECs allow their sociopolitical values and ideologies to influence their review of research proposals (Ceci et al., 1985). A study conducted by Ceci et al. (1985) found that socially sensitive proposals designed to document discrimination or reverse discrimination in relation to race and sex in corporate hiring practices were twice as likely to be rejected by reviewers than non sensitive proposals that aimed to document discrimination on the basis of height and weight (regardless of the presence or absence of ethical problems). Furthermore, analysis of the narratives accompanying the reviewers' decisions revealed that the main reason controversial proposals were rejected was the potential sociopolitical impact of the findings (especially when no ethical problems could be identified).

Several authors (Ceci et al., 1985; Haggerty, 2004) object to the overly conservative approach adopted by RECs in judging risks to research participants. Haggerty (2004)

criticises RECs for making decisions in order to appear consistent and for operating on an overly precautionary, 'just in case', 'worst case scenario' mentality instead of looking at each situation as unique, and considering what is most ethical in that situation. Haggerty (2004) argues that the tendency of ethics committees to be conservative, in order to minimise potential risk, and therefore not approve controversial yet well designed studies, can probably also be partially attributed to ethics committees' lack of training and confidence. This illustrates the responsibility RECs have to be well trained and competent (Wassenaar, 2006). In a study on the resources and needs of RECs in Africa, emphasising preparations for HIV vaccine trials, Milford et al. (2006) found that only 40% (n=49) of all REC members in the study received ethics training prior to joining their REC, while 52% (n=69) received training after assuming their position on the REC. The findings also revealed that 87% (n=26) of the RECs in the study agreed that their lack of training in health research ethics presented challenges in their review of protocols (Milford et al., 2006). Similarly, in a review of 12 health RECs in South Africa, Moodley and Myer (2007) found only two in which all members had received training in research ethics.

Moreover, Haggerty (2004) argues that RECs' conservative approach risks homogenising research activities as researchers begin "to follow what they perceive to be the path of least institutional resistance" (Haggerty, 2004, p. 412), rather than deal with the delays and ambiguity associated with ethics review of qualitative, nontraditional research. Similarly, Ceci et al. (1985) point out that the increasing realisation that ethics committees allow their social and political values to influence their decision making may

begin to affect social scientists' selection of research topics in a way that is counterproductive to the advancement of the social sciences. There is however no evidence that this has happened in biomedical research, where RECs have had to review proposals dealing with many controversial technological advancements, epidemics, and multifaceted interventions (Wassenaar & Corbella, 2007).

A further frustration is that once a study has received ethical clearance from an REC, the majority of committees do not have the resources and competencies to monitor ethics throughout the study, resulting in ethical compliance being left up to the researcher (Keith-Spiegel et al., 2006; Wassenaar, 2006). A study on the needs and resources of RECs in Africa conducted by Milford et al. (2006) found that 80% (n=25) of REC in the study agreed that they had inadequate ability to monitor approved protocols. Lack of post-approval monitoring can also be seen as an inherent contradiction in ethics committees' function. Researchers are trusted to act ethically after the approval of their study, yet part of the reason ethics review is necessary is that researchers are felt to have intrinsic conflicts of interest and other external influences that imply that they cannot be trusted to conduct ethical research without guidance and oversight (Ceci et al., 1985). Sieber (personal communication, cited in Ceci et al., 1985) explains that because of its dynamic nature, the research process may be experienced and carried out very differently to what was described in the proposal, even when there is no intent by the researcher to deceive the REC or deviate from the proposal.



Similarly, issues of interpretation and analysis of data are often not addressed by RECs. Once a proposal has been approved the researcher has complete freedom in the interpretive process. They can impose on the collected data any theoretical perspective about which the participants or the REC are unlikely to have any knowledge (Whittaker, 2005). Likewise, RECs have no way to monitor the more serious ethical transgression in data analysis such as the analysis of fabricated data and the dropping ('cleaning') of data that contradicts the data analyst's theory (Rosenthal, 1994). Mc Neill et al. (1992) found that 14 % of participants in their study admitted that they themselves had deviated from their approved proposals without obtaining approval for those deviations by an REC. As such the authors advocate that RECs adopt a more active role in monitoring the progress of research in order to limit unethical research practices. In a similar study, Allen and Waters (1983) administered questionnaires on attitudes towards the functions of RECs to members of selected RECs and a number of controls. Almost all respondents (97.7%) were found to support the ethical review process, and 47 % thought that monitoring procedures should be adopted (Allen & Waters, 1983).

Ethical guidelines and reviews have increasingly been criticised for not sufficiently addressing the ethical issues unique to qualitative research. A number of authors (cf., Redwood & Todres, 2006; van den Hoonaard, 2001) have questioned the appropriateness of reviewing the ethics of qualitative research using guidelines based on quantitative or biomedical research. Some even call for a complete change in the way that ethics are thought and spoken about because the current ways of doing so are dominated by quantitative and biomedical vocabulary (Redwood & Todres, 2006). Many guidelines, for



example, make reference to 'research protocols' and 'research subjects', terms which are foreign to qualitative researchers who see their research as a collaboration between themselves and the participants (van den Hoonaard, 2001). More serious, however, is the allegation that current ethical guidelines and reviews see quantitative research as the most valid form of knowledge production and consequently act as a gatekeeper to qualitative research (Redwood & Todres, 2006; van den Hoonaard, 2001). Similarly, Haggerty (2004) argues that the bureaucracy of ethics review is beginning to pose a threat to the ability to conduct scholarly research and expresses concern that in time the ever increasing expansion and formalisation of ethics review procedures will complicate, hinder or prohibit many forms of unconventional and qualitative social science research.

The act of submitting a full and detailed proposal for ethics review prior to the commencement of research is itself problematic in qualitative research (van den Hoonaard, 2001). The collaborative nature of qualitative, particularly participatory, research makes it difficult to specify the exact focus of research, as the research is constantly transformed through the collaborative relationship between the researcher and the participants (van den Hoonaard, 2001). As such research is continuously changing and unpredictable, Redwood and Todres (2006) question whether it is possible to consider ethical issues prior to the research as is required for ethics review. It is often not possible to determine a precise research question, let alone the potential risks and benefits of the research in advance (van den Hoonaard, 2001).

The reportedly increasing bureaucratic nature of most ethics committees has also been seen by some as a cause for concern (cf., Haggerty, 2004; Gunsalus, Bruner, Burbulers, Dash, Finkin, Goldberg, Greenough, Miller & Pratt, 2006; Illinois White Paper, 2003). Haggerty (2004) suggests that systems of ethical review are experiencing a 'creep', characteristic of most bureaucracies. Haggerty (2004) uses the term 'ethics creep' to refer to the "dual process whereby the ethics bureaucracy is expanding outwards to incorporate a host of new activities and institutions, while at the same time intensifying the regulation of activities deemed to fall within its ambit" (Haggerty, 2004, p. 391). As ethics committees are expected to do more and more they are becoming less and less effective: the primary function of RECs was to protect the research participants from harm, but at present many RECs find themselves acting as gatekeepers for responsible research, ensuring the scientific merit and methodological appropriateness of a study, and dealing with the ever-increasing burden of completing regulatory paperwork (Gunsalus et al., 2006; Illinois White Paper, 2003). Haggerty (2004) attributes the tendencies of ethics committees to interpret ethics guidelines in a way that widens and intensifies their regulatory structure to first, the open-ended nature of the formal ethics guidelines which unavoidably makes the process of applying broad ethical concepts to particular situations subjective and interpretive. Second, the culture of RECs tends to be precautionary and while this is both unavoidable and desirable it does not leave much to constrain the possible harms that can be imagined, resulting in the introduction of ever increasing regulations to manage a number of potential harms, whose probability of ever actually occurring is unknown (Haggerty, 2004). It is precisely because it is impossible to predict the risk of harm that following ethical principles and guidelines is so important. The

point, however, is surely not to prohibit research because of the ever increasing array of potential harms RECs can imagine, but to ensure that the benefits outweigh the risks or that participants are fully debriefed (Haggerty, 2004).

Despite resistance to the ethics review process, it remains a necessary and potentially beneficial process that can add value to a proposed study and reduce harm to the participants and protect the researcher from undesirable consequences (Wassenaar & Corbella, 2007). Competent RECs should promote the ethical conduct of research through a quick yet thorough review of the proposed study, by persons trained in research ethics and familiar with a range of social science disciplines and methodologies (Wassenaar & Corbella, 2007).

#### 2.4 Summary

This chapter has attempted to review the existing literature on research ethics, ethically challenging incidents encountered by social science researchers, ethics review and researchers' experiences and attitudes towards ethics review. While these topics have been the focus of many recent debates in the social sciences, a review of the literature reveals a clear lack of empirical studies in the area of social science research ethics, particularly where researchers' everyday experiences with ethically challenging incidents and ethics review are concerned. This study therefore aims to make a contribution to this lack of data.

### Chapter 3: AIMS

The objective of this study was twofold:

The first objective was to identify and describe social science researchers' experiences of ethically challenging incidents. More specifically, in terms of this first objective the primary aim was to elicit a profile of the ethically challenging incidents social scientists face in their work as researchers. An additional minor aim of this research was to establish whether the number of ethically challenging incidents respondents' reported could be associated with the institution at which the respondents are employed.

The second objective of this study was to identify and describe social science researchers' experiences of ethics review. In terms of this objective the primary aim was to profile social science researchers' experiences with ethics review. An additional minor aim of this research was to establish whether the respondents' experiences of ethics review could be associated with the institution at which they are employed.

The purpose of this chapter is to outline the methods used in this study. This will be achieved through a description of the research strategy, design and method, the data collection procedures, the coding and analysis of the data, the reliability and validity of the study and an outline of the ethical issues relevant to this study. The response rate to the questionnaire will be described and will be compared to that of similar studies.

#### 4.1    Research Strategy, Design and Method

A review of the literature reveals a clear lack of empirical studies in the area of social science research ethics, particularly where researchers' everyday experiences with ethically challenging incidents and ethics review are concerned. Subsequently, there is also a lack of clear theory and empirical data on which hypothesis-driven research could be based. This study is therefore predominantly descriptive and exploratory in nature as it attempts to identify and describe social science researchers' experience of ethically challenging incidents and ethics reviews. Despite the lack of a hypothesis, this research makes use of a deductive research strategy as the relevant background literature prompted the focus of the study and acted as a proxy for theory (Bryman, 2004). The purpose of this study is to add to the existing literature and body of knowledge on research ethics in the social sciences and to provide a platform from which identified issues and experiences can be investigated further and for which more appropriate guidelines, procedures and frameworks might be established. Moreover, Emanuel et al.'s (2004)

framework of ethical principles was used to structure the conceptualisation and discussion of ethical issues and challenges. In doing so the framework's relevance and usefulness for dealing with social science research was indirectly assessed. A cross-sectional research design was adopted in this study. This has been defined by Bryman (2004) as the collection of data from a number of cases at a single point in time in order to determine patterns of association. The research method adopted in this study was a self-completion email survey, which will be described in greater detail in Section 4.2 below.

## 4.2 Data Collection

In South Africa there are two sites in which social science research is primarily conducted; research organisations and universities. The participants in this study were thus obtained from both a large social scientific research organisation and a university, both of which have established RECs to which it is compulsory to submit research proposals for approval before research can commence. First, a comprehensive electronic list of all members from each research population was obtained. In the case of the research organisation a comprehensive email list of all research staff was obtained from the organisation's website. In the case of the university, the 2006 university handbook was used to identify all the academic staff in Faculty of Humanities, Development and Social Science. Email addresses were then obtained from the university's internal email system. From both research populations a total of 513 valid email addresses were obtained, to each of which a questionnaire was sent.



The questionnaire contained a cover letter and three sections. The cover letter informed the potential respondents of the nature and purposes of the study and assured confidentiality (see Appendix One). Section A of the questionnaire requested some demographic details of the respondents. Section B requested a description of an ethically challenging situation, and Section C requested a description of the respondents' experience of ethics review (see Appendix Two).

#### 4.3 Data Coding and Analysis

This study made use of both qualitative and quantitative methods of analysis. Qualitative analysis in the form of thematic analysis was used to profile researchers' experiences of ethically challenging incidents and ethics review. In terms of the quantitative analysis conducted, descriptive statistics were used to provide an overview of the sample characteristics and frequency counts were used to determine the strength of the themes identified in the thematic analysis. Lastly, chi square analysis was conducted to determine the association between the number of ethically challenging incidents reported per respondent and the institution at which they work and to determine the association between respondents' experiences of ethics review and the institution at which they work.

##### 4.3.1 Thematic Analysis

The responses in Section B and Section C of the questionnaire were coded and analysed separately. The responses from both Section B and Section C of the questionnaire were



first analysed using Ulin, Robinson, Tolley and McNeill's (2002) approach to thematic analysis.

Ulin et al. (2002) outline five precise analytical steps that should be used in the process of analysis. The first step is reading. This involves 'data immersion', reading and re-reading each set of responses until the researcher is very familiar with the content of the documents. After one has become familiar with the texts, one can move to the second analytic step, coding, in which information is assembled under various codes (labels for assigning units of meaning) in a continuous manner. Codes are then sorted into broader themes. Coding was conducted using QSR NVIVO. The third step identified by Ulin et al. (2002) is displaying. Once all the information has been combined and themes and codes have been arranged, the researcher can then examine the themes more closely. Displaying the data enables the researcher to examine the evidence that supports each theme and to illustrate the strength of each theme across all questionnaires. The fourth step is reducing (Ulin et al., 2002). This involves reducing the information to make the most essential concepts and relationships visible. The reduction process usually occurs once all the data is in, and the researcher is familiar with the content. The goal is to get an overall sense of the data and to distinguish overarching and secondary themes. This step involved reading and re-reading the responses, to develop and redefine codes, while noting the detail of themes and ideas. The last step involves interpreting the data, showing how thematic areas relate to one another and how concepts respond to the research question (Ulin et al., 2002). In this study an attempt was made to interpret the

data and analyse themes in relation to the selected theoretical frameworks and available literature.

While the responses for Section B of the questionnaire were coded inductively, the responses to Section C were first coded as being a positive experience, a negative experience or both. Next, a comprehensive list of codes identifying what it is that made respondents' experiences either positive or negative were identified. This list was then grouped into a number of broad themes. In addition a number of other codes were allowed to inductively emerge.

#### 4.3.2 Descriptive Statistics and Frequency Counts

Descriptive statistics were produced for all the data, using SPSS. The descriptive statistics were primarily used to provide an overview of the sample characteristics. Frequency counts were conducted to determine the strength of each theme in both Section B and C of the questionnaire. The results of the frequency counts also determined the prominence given to some themes over others in the presentation and discussion of results.

#### 4.3.3 Chi Square Analysis

The chi square test of independence is used to test the independence of two categorical variables (Larson & Faber, 2003). There are two assumptions that should be met before a

chi square analysis can be conducted. The first assumption concerns the size of the expected frequency: if the number of values in a sample is too small the assumption of normality may be violated (Howell, 2002). The expected frequency should not be less than 5 in at least 80% of the expected values if the chi square distribution is to provide an accurate approximation of the statistic (Howell, 2002; Lachenicht, 2002). The second and most important assumption is that of independence which requires each member of the population be assigned to only one category and that no member of the population remains unclassified (Lachenicht, 2002).

In this study the chi square test of independence was used to determine whether the occurrence of one variable affected the probability of another variable occurring. First, the number of ethically challenging incidents described per respondent was established and a chi square analysis was conducted to determine the association between the number of ethically challenging incidents reported per respondent and the institution at which they work. Second, a chi square analysis was conducted to determine the association between respondents' experiences of ethics review and the institution at which they work.

#### 4.4 Reliability and Validity

Despite the use of frequency counts and chi square analyses, this study is considered to be primarily qualitative in nature. Silverman (2005) suggests several methods for increasing the validity of qualitative data analysis. Validity refers to the extent to which an account accurately represents the social phenomena to which it refers (Silverman,

2005). Qualitative research is often criticised for being based on subjectively selected examples and extracts that happen to fit the researchers' analytic argument (Silverman, 2005). In this study anecdotalism was combated through comprehensive data treatment. Silverman (2005) uses the term comprehensive data treatment to refer to the process of incorporating all responses into the analysis. In this study the results of the thematic analysis reflect all the ethically challenging incidents and all the experiences of ethics review reported by all respondents. Comprehensive data treatment also involves actively seeking out and addressing all deviant cases (Silverman, 2005). Such deviant case analysis was made possible by the use of frequency counts, which not only enabled the strength of each theme to be determined, but allowed the themes that were only applicable to one respondent to be identified.

Reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions (Silverman, 2005). In this study the questionnaire was emailed to the identified sample on three separate occasions at approximately three week intervals. Potential respondents were requested to only complete the second or third questionnaire if they had not already completed one previously. While the purpose of this was to increase response rates it also provided an opportunity to test the reliability of the codes. The codes developed in the analysis of the first set of responses were applied to the second set and modified where appropriate. This was repeated with the third set of responses resulting in a comprehensive set of codes that can hopefully be applied to the analysis of future ethically challenging incidents and reported experiences of ethics review.

#### 4.5 Ethical Considerations

Permission for the study was obtained from both research sites through the submission of a proposal to the REC of both sites. Approval was obtained from both RECs prior to data collection. In addition, this was a low risk study as it was of an exploratory nature and it was not possible for the participants to be harmed in any way, other than through breach of confidentiality. As this study made use of an email survey, once each participant had responded, the completed survey (which did not contain any identifying information) was printed and the original electronic version deleted immediately so that the respondents could not be identified or traced. In other words, the completed questionnaire was permanently unlinked from the email.

#### 4.6 Response Rate

The first emailing of 513 questionnaires yielded 23 replies (4.5% response rate). This was followed by a second invitation to participate which yielded a further 17 replies resulting in a total of 40 replies (7.8% response rate). The third and final emailing of the questionnaire yielded a further 13 replies. The three emails inviting researchers to participate were emailed at approximately three week intervals. Of the total 53 responses received, one was incorrectly filled in and had to be excluded from the sample, leaving 52 completed questionnaires. A disappointing final response rate of 10.1% was therefore achieved. Of the 52 respondents, four (7.7%) reported that they had not yet experienced

an ethically challenging situation while five (9.6%) respondents reported having no experience of ethics review.

A number of recommended methods were employed to maximise response rates, namely multiple follow ups including replacement questionnaires, university affiliation, and a short questionnaire of less than one page (de Baux, n.d; Shehaan, 2001). The response rate was comparable with some surveys sent via email to university faculty using a similar sample size. For example, an email survey of administrative and teaching staff at the University of Hong Kong, Tse (1995, cited in Schonlau, Fricker & Elliott, 2002) achieved a 7% response rate with a sample size of 500 randomly selected participants. On the whole, however, the response rate was considerably lower than expected, as other comparable email surveys of university staff conducted by Schult and Totten (1994), Jones and Pitt (1999) and Schaefer and Dillman (1998) (all cited in Schonlau et al., 2002) yielded 19%, 34% and 53% return rates respectively.

The low response rate may be attributed to the decision to use an attached questionnaire as opposed to an embedded one (in which the questions are found in the body of the email) (Bryman, 2004). The advantage of an embedded questionnaire is that it is easier for respondents to return. However, limited formatting is possible with embedded questionnaires and the alignment of questions and answers is often lost (Bryman, 2004). It was decided to use an attached questionnaire so that a university letterhead and clear formatting could be included. However, limited knowledge of how to read and return an attachment as well as refusal to open the attachment out of concern that it may contain a

virus may also have negatively affected response rates (Bryman, 2004). Furthermore, the large amount of spam junk mail received via email may have caused respondents to ignore the survey. The decision to not offer incentives may also have negatively affected response rates as previous studies have found incentives to significantly increase the number of responses received (cf., Schonlau et al., 2002).



This chapter will detail the characteristics of the sample as obtained from Section A: Demographic Information of the questionnaire. The characteristics of the sample will be described and the main differences between institutions will be highlighted.

### 5.1 Sample Characteristics

Table 1 provides an overview of the sample characteristics, while Table 2 details the sample characteristics by institution. The sample comprised of respondents employed at both a university (55.8%) and a research organisation (44.2%). The mean number of years respondents were employed at their current institution was 8.4. The majority of respondents had PhDs (55.8%), 42.3% had Masters Degrees and one respondent had an Honours Degree. The mean age of respondents was 43.9 years. Male respondents made up 55.8% of the sample and females 44.2%. The mean years of experience as a researcher was 15.6. On average respondents had submitted 6.3 proposals for ethics review and had had 16.7 articles peer reviewed articles published. The majority of the sample conducted both qualitative and quantitative research (51.9%), while 19.2% reported only using quantitative methods and 28.8% reported only using qualitative methods. Twenty-six respondents reported using surveys, 12 reported using experiments, 23 reported using case studies, 10 reported using ethnography, seven reported using action research, and 21 reported using other methods (See Table 1: Sample Characteristics).

Table 1 *Sample characteristics*

<i>Item</i>	<i>Number</i>	<i>Percentage</i>
<b>Institution</b>		
University	29	55.8
Research organisation	23	44.2
Mean number of years employed at institution	8.4	
<b>Qualification</b>		
PhD	29	55.8
Masters	22	42.3
Honours	1	1.9
Mean Age	43.9	
<b>Gender</b>		
Male	29	55.8
Female	23	44.2
Mean years of experience as a researcher	15.6	-
Mean number of proposals submitted for ethics review	6.3	-
Mean number of peer reviewed publications	16.7	-
<b>Nature of research</b>		
Quantitative	10	19.2
Qualitative	15	28.8
Both	27	51.9
<b>Research strategies adopted</b>		
Survey	26	-
Experiment	12	-
Case study	23	-
Ethnography	10	-
Action research	7	-
Other	21	-

## 5.2 Sample Characteristics by Institution

A comparison of the sample characteristics between respondents from the university and the research organisation reveals a similar age range and gender ratio in the two institutions. A higher percentage of respondents from the university had PhDs (62.1%), compared with 47.8% of respondents from the research organisation. The average years employed at each institution was almost double for respondents from the university (10.7 years) than respondents from the research organisation (5.7 years). The researchers at the university were more experienced, with respondents having an average of 17.1 years experience compared with 14.7 years experience at the research organisation. Furthermore, respondents from the university had submitted more proposals for ethics review (7.6) than respondents from the research organisation (4.6). On average respondents from the university had more peer reviewed publications (19) than respondents from the research organisation (13.9). The majority of respondents at both institutions reported conducting both quantitative and qualitative research. The remaining respondents at the research organisation reported using quantitative methods (30.4%) more frequently than qualitative research (17.45%) and the remaining respondents at the university reported using qualitative research (38%) more frequently than quantitative research (10.3%). Surveys were the most commonly used research strategy at the research organisation (18 respondents) while most respondents at the university said they make use of 'other' strategies not listed (17 respondents) (See Table 2: Sample characteristics by institution).

Table 2 *Sample characteristics by institution*

<i>Item</i>	<i>University</i>		<i>Research Organisation</i>	
	<i>Number</i>	<i>Percentage</i>	<i>Number</i>	<i>Percentage</i>
<b>Gender</b>				
Male	16	55.2	13	56.5
Female	13	44.8	10	43.5
Mean Age	45	-	42.4	-
<b>Qualification</b>				
PhD	18	62.1	11	47.8
Masters	11	37.9	11	47.8
Honours	0	0	1	4.4
Mean number of years employed at institution	10.7	-	5.7	-
Mean years of experience as a researcher	17.1	-	14.7	-
Mean number of proposals submitted for ethics review	7.6	-	4.6	-
Mean number of peer reviewed publications	19	-	13.9	-
<b>Nature of research</b>				
Quantitative	3	10.3	7	30.4
Qualitative	11	38	4	17.4
Both	15	51.7	12	52.2
<b>Research strategies adopted</b>				
Survey	8	-	18	-
Experiment	9	-	3	-
Case study	12	-	11	-
Ethnography	8	-	2	-
Action research	7	-	0	-
Other	17	-	7	-

Chapter 6 RESULTS AND DISCUSSION I  
ETHICALLY CHALLENGING INCIDENTS

In this chapter the results of Section B of the questionnaire will be presented and discussed. Presentation and discussion of the results are integrated in this chapter due to the large number of ethically challenging incidents reported. A separate 'discussion' chapter would have necessitated a lengthy re-presentation of each result before discussion. Therefore the presentation and discussion of results are combined in the following sections. An overview of the ethically challenging incidents reported will first be presented in order of frequency. This will be followed by a presentation and discussion of the number of ethically challenging incidents reported per respondent by institution. The results of the descriptive thematic analysis of the reported ethically challenging incidents will then be described and discussed. Finally, this chapter will end with an overall discussion of the results of Section B of the questionnaire.

### 6.1 Overview of Ethically Challenging Incidents

Of the 52 respondents four (7.7%) reported not having experienced any ethically challenging incidents. Twenty-two of the remaining 48 respondents reported more than one ethically challenging or troubling incident (45.8%). Subsequently, a number of ethically challenging incidents could be coded under more than one theme. The ethically challenging incidents were coded into 15 themes and ranked in terms of the frequency with which they were mentioned (See Table 3).

Table 3 *Frequency of ethically challenging incidents*

Ethically challenging incident	Frequency
Privacy, confidentiality and anonymity	14
Harm	11
Beneficence	9
Poor Science	7
Role Conflict	7
Informed Consent	6
Recruitment of participants	5
Publication issues	4
Student issues	3
Researching people known to the researcher	2
Deception	2
Communication of results to participants	2
Abuse of power	2
Whistle blowing	1
Constraints imposed by funders	1

The most frequently mentioned ethically challenging incidents concerned issues of privacy, confidentiality and anonymity, followed by ethically challenging incidents involving harm, beneficence, poor science, role conflict, informed consent, recruitment of participants and publication issues. Less frequently mentioned incidents involved dealing with students, conducting research on people known to the researcher, using deception in research, the communication of results to participants, the abuse of power by researchers, whistle blowing and dealing with constraints imposed by funders.

## 6.2 Number of Ethically Challenging Incidents Reported per Respondent

Of the 48 respondents who reported experiencing an ethically challenging incident, 26 respondents described only one ethically challenging incident (54.2%) while 22 respondents described more than one ethically challenging incident (45.8%). This is shown in Figure 1 and Table 4.

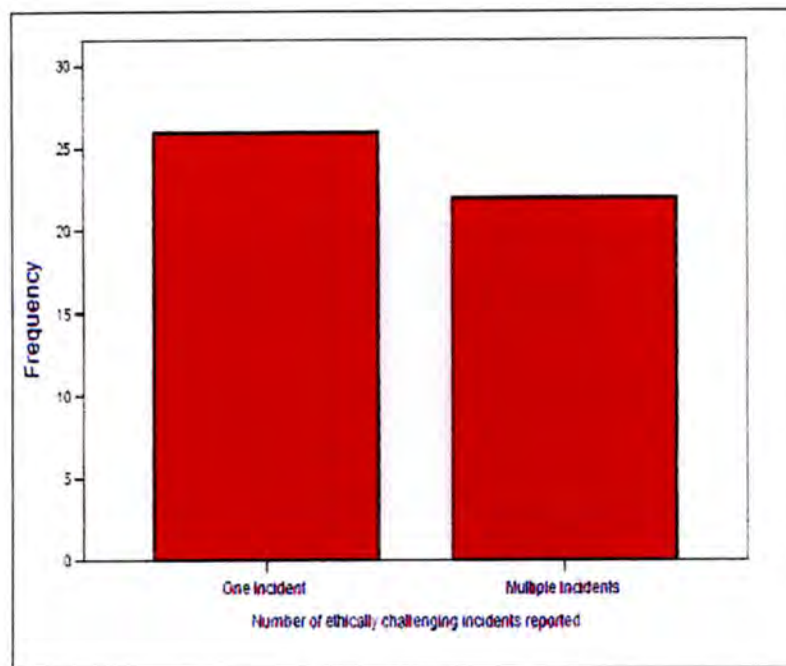


Figure 1 Ethically challenging incidents reported per respondent

Table 4 *Ethically challenging incidents per respondent*

	Frequency	Percent
One incident	26	54.2
Multiple incidents	22	45.8
Total	48	100



### 6.2.1 Number of Ethically Challenging Incidents Reported per Respondent by Institution

Of the 25 researchers from the university who reported experiencing an ethically challenging incident, 20 (80%) described more than one ethical issue, while only two (8.7%) of the 23 researchers from the research organisation described more than one ethical issue. This is shown in Figure 2 and Table 5.

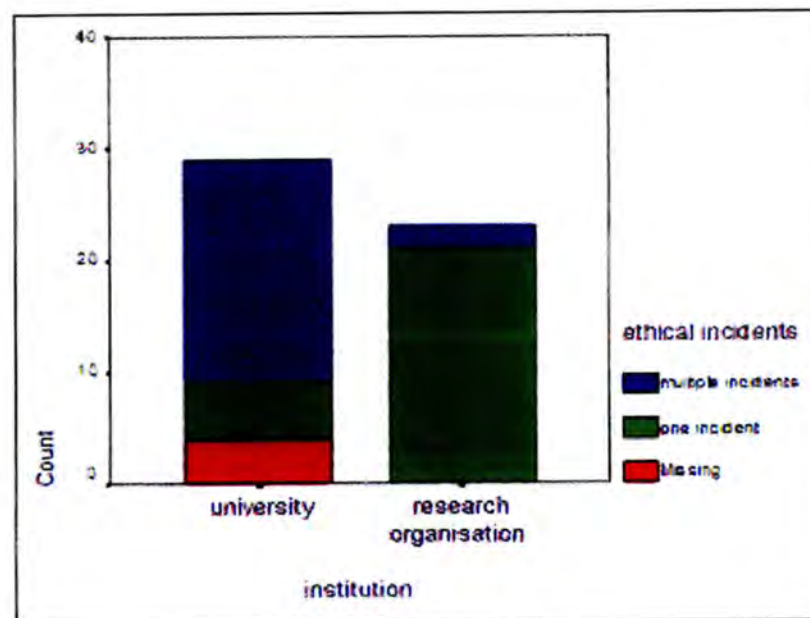


Figure 2 Number of ethically challenging incidents by institution

Table 5

*Number of ethically challenging incidents by institution*

Institution	One incident	Multiple incidents	Total
University	5	20	25
Research organisation	21	2	23
Total	26	22	48

A chi square test of independence was conducted to test the association between the number of ethical issues reported and the institution in which respondents worked. Prior to conducting the chi square analysis the two assumptions of chi square were tested.

The chi square analysis revealed a significant association between the number of ethical issues reported and the institution in which respondents worked ( $\chi^2 = 24.533$ ,  $df=1$ ,  $p<0.05$ , Cramer's  $V = 0.715$ ). Furthermore, the results of Cramer's  $V$  revealed a moderate to strong relationship between the number of ethical issues reported and the institution in which respondents worked. Researchers working at the university therefore reported significantly more ethical issues than was expected.

### 6.3 Thematic Analysis of Ethically Challenging Incidents

The ethically challenging incidents presented in this section were coded inductively using thematic analysis. The results of the thematic analysis will be presented and discussed.

When applicable, existing literature and guidelines, including Emanuel et al.'s (2004)

framework, will be used in the discussion of each theme to illustrate how or why the incident is ethically problematic and to suggest what the preferred ethical course of action may have been.

### 6.3.1 Privacy, Confidentiality and Anonymity

Privacy, confidentiality and anonymity are three interrelated factors that require consideration when planning ethically responsible research as they affect potential participants' willingness to participate in research and to give honest responses (Sieber, 1992). According to Emanuel et al.'s (2004) ethical framework maintaining privacy, confidentiality and anonymity is the first step in maintaining ongoing respect for the research participants.

#### 6.3.1.1 Privacy

Privacy refers to participants' right to control the access others have to them and to information about them (Sieber, 1992). Ethically challenging incidents coded under privacy involved concerns over the invasion of the research participants' privacy. The incidents reflect the researcher's discomfort over observing and/or researching private aspects of people's lives, for example the "observation of hygiene practices in public bathrooms" or, as Extract 1 reveals, the dilemma of coming across private information as a researcher and having to decide what or what not to do with it.

Extract 1: *(respondent 15, university)*

“Finding archival information (in trial documents as well as social welfare and health sections of local and central state, going back to the 1960s and up to the 1980s) which reveals very personal details of income, health (mental and physical) as judged by state authorities, family relations and so on, and trying to work out how to ethically deal with this”

According to the Social Sciences and Humanities Research Council of Canada (2005), when dealing with archival information it is the responsibility of the REC to assess the possibility of identification of the people whose records are to be researched, in particular with regard to the possible harm or stigma that might be attached to identification. It is recommended that researchers only be allowed access to such archival records if identification is impossible. If the researcher already has access to such records, as is the case in Extract 1, and such documents are to be used in research, respect for participants should be maintained and the participants’ privacy should be respected by not including any identifying information in the research (Emanuel et al., 2000).

Extracts 2 and 3 illustrate the many challenges that may arise concerning maintenance of participants’ privacy when conducting HIV/AIDS research.

Extract 2: *(respondent 30, research organisation)*

“...interviewing members of HIV affected households without causing involuntary disclosure”.

Extract 3: *(respondent 49, research organisation)*

“I was faced with a difficult ethical situation when fieldworkers wrote down HIV positive women's names on claim forms that could be seen by anyone”.

Privacy and confidentiality are a central consideration in HIV related research. Release of a participant's HIV status to others may cause serious discrimination, stigmatisation and distress. Researchers must ensure that all personal details are kept confidential and that no identifiers are used on any publicly available material (Australian Government National Health and Medical Research Council, 2005). Researchers also have the responsibility to train fieldworkers and hold them accountable for their actions.

#### 6.3.1.2 Confidentiality

Confidentiality is an extension of privacy, it refers specifically to research data and how that data should be handled in order to maintain the privacy of participants (Sieber, 1992). Confidentiality concerns the researcher's default responsibility to ensure that research participants remain anonymous and their responses confidential, or to work within the confidentiality agreement reached with participants. A number of respondents described incidents in which confidentiality was breached or not maintained. Breaches of confidentiality are usually defined as disclosures to third parties, without participants' consent or court order, of private information a researcher has obtained within the researcher-participant relationship (National Institutes of Health, 2002). Extract 3 illustrates an example of a breach of confidentiality. Breaches of confidentiality such as the one described in Extract 3 have the potential to cause harm to the trust relationship between the researcher and the research participants, to other individuals or groups associated with either the researcher or participant and/or to the reputation of the research community.

Even when researchers intend to maintain confidentiality, it may not be possible. Extract 4 reveals how pressure from funders made it impossible to maintain confidentiality.

Extract 4: *(respondent 3, university)*

“We wanted to keep the (research results) confidential. However, in our negotiations with trial staff it became clear that they would not be satisfied with this "pure" research approach. They insisted that "low scorers" be referred to trial staff for educational intervention. We had to amend the consent forms so that our enrollers would consent to this limit of confidentiality”.

In terms of Emanuel et al.’s (2004) ethical framework, showing ongoing respect for participants also involves informing participants when new information about the study becomes available or when study procedures or methods are changed. Although confidentiality in Extract 4 was not maintained as intended, the researcher dealt with a potential dilemma in an ethical way by informing the participants of the change and obtaining their consent. The change also enhanced participants’ chances of benefiting from participation.

Extract 5 reflects an ethically challenging incident in which researchers were bound by confidentiality agreements, yet felt that their reports would have improved had participants been identified.

Extract 5 *(respondent 35, research organisation)*

“Sometimes respondents do not want to / cannot be identified by designation or name, and often their position is such that if it was identified, it would add so much more value and authority to some of the assertions arrived at in the eventual research report”.



Extract 5 reveals the tension researchers may face between producing valuable research and maintaining ongoing respect for participants. Access to personal information of research participants is often necessary in the conduct of social research (i.e., epidemiology, history and politics). Public interest thus may justify allowing researchers access to personal information, both to advance knowledge and to achieve social goals such as designing adequate public health programmes (Social Sciences and Humanities Research Council of Canada, 2005). It is, however, unethical to put research participants at risk by breaching confidentiality for the perceived social or scientific value the final research findings may have.

#### 6.3.1.3 Anonymity

Anonymity in research means that identifying information will not be linked to the data and/or known to the researcher (Sieber, 1992). Ethically challenging incidents reported included the difficulty of maintaining anonymity when employing certain data collection techniques. Extract 6, for example, illustrates the difficulty of maintaining anonymity during focus groups.

*Extract 6: (respondent 48, research organisation)*

“I am often faced with the ethical challenge of how to plan focus group interviews in such a manner that the legal status of participants is not revealed to the group”.

Focus groups are a popular methodology in social science research, but as Extract 6 reveals they often present difficulties concerning confidentiality, as the researcher cannot



guarantee that all group members will treat the information of other persons with the respect it deserves. This should be reflected in consent forms for focus group research, and the researcher should ensure that focus group members are aware of the importance of confidentiality (Wassenaar & Corbella, 2007). Furthermore all participants should be encouraged to maintain confidentiality and be briefed about the confidentiality risks in advance (Wassenaar & Corbella, 2007). Ideally focus groups should not be used to research sensitive topics or when sensitive information about participants may be revealed as in Extract 6.

Extracts 7 and 8 reveal ethically challenging incidents concerning the limits of anonymity. Even when findings are anonymous to the researcher and/or third parties, researchers face the dilemma of whether research participants will be able to identify *themselves* and/or their contributions in final reports or publications, and the effects this may have on the participants.

Extract 7: *(respondent 16, university)*

“I have particular concerns about the effects of research on participants i.e., participants’ reactions to identifying themselves in completed ethnographies”.

Extract 8: *(respondent 14, university)*

“Doing in depth interviews with people who come from 'the same background', who were known to me personally, who happened to fall in the sample selection, whose views on race and labour relations I found deeply disturbing, and who could have identified themselves in the paper I wrote, even though it was anonymised”.

This dilemma has been described repeatedly in the literature on ethics and qualitative research. In terms of Emanuel et al.'s (2004) framework, maintaining ongoing respect for the research participants entails recognising their contributions by informing them of what was learned from the research, however, in some cases it may not be appropriate to provide participants with the final research report. According to Wassenaar and Corbella (2007) findings should be made available to participants in a manner that is relevant and appropriate. The manner in which findings are presented to participants should facilitate understanding and empower the participants with the knowledge that has been generated (Wassenaar & Corbella, 2007). Feeding results back to participants in the form of a feedback session, for example, allows the participants to ask questions and the researcher to explain certain findings and interpretations. It is likely that participants would experience a feedback session as less distressing than reading an academic report. If the final research report is to be given to participants, researchers should ensure that participants are informed, as much as possible, of the theoretical frameworks and methodologies that influenced the researcher's interpretations and conclusions.

### 6.3.2 Researching People Known to the Researcher

As Extract 8 also reveals, conducting research on people known to the researcher may present a dilemma, especially when the views expressed by participants are disturbing to the researcher or, as is the case in Extract 9, the findings may affect the future relationship between the researcher and the participant.

Extract 9: (*respondent 20, university*)

“Experiencing currently a challenging ethical issue, that is using my own child in a case study in understanding school social cohesion and suicide contemplation”.

According to Emanuel et al.’s (2004) principle of fair selection of participants, people who are eligible to participate, but who stand a higher risk of being harmed, should be excluded from participation. The dual relationship of parent and researcher described in Extract 9 not only has the potential to cause harm to the mother and daughter relationship, but can lead to questionable objectivity and scientific invalidity. The sensitive nature of the research topic makes respect for the participant’s privacy and anonymity even more important. The dual relationship however, makes anonymity impossible.

### 6.3.3 Harm

#### 6.3.3.1 Harm to Participants

Researchers have a responsibility to protect participants from harm and ensure that all potential risks to research participants are minimised and are relative to, or outweighed by the potential benefits (Emanuel et al., 2000). Extracts 10 and 11 reveal ethically challenging incidents where the possibility exists that the research could have unintended negative consequences for the participants.

Extract 10: *(respondent 13, university)*

“Having found through fieldwork that refugees are involved with illegal imports into South Africa and being worried that the information may be used to clamp down on the activities of that particular group of people in Durban”.

Extract 11: *(respondent 32, research organisation)*

“Seeking information about tax compliance from South Africans, that may have had implications for participants who are non compliant”

With regard to Extracts 10 and 11 participants should be fully informed about all potential risks prior to participation, including possible limits of confidentiality.

Furthermore, participants’ privacy should be respected by managing personal information in accordance with confidentiality agreements at all times (Emanuel et al., 2000). While RECs should be able to protect information from being subpoenaed (Illinois White Paper, 2003), neither legislatures nor courts have granted researchers an absolute privilege to protect the confidentiality of their research data (Traynor, 1996). Such dilemmas also illustrate the responsibility researchers have to be familiar with the legal context in which they are conducting research.

Many authors (cf., Cribb, 2004; Oakes, 2002) minimise the potential social science research has for causing harm to participants. Although social science research is less likely to result in direct physical harm than biomedical research, Extracts 12 and 13 reveal that social science research has the potential to indirectly cause physical harm to participants or even endanger their lives.

Extract 12: *(respondent 21, university)*

“I had an in depth discussion with one of my respondents who gave me valuable information for my research. Later she requested me not to use her information in my research as she was afraid for her life”.

Extract 13: *(respondent 6, university)*

“Doing research that had the unintended consequences of conflict between sectors of a community. While the conflict did not and has not had physical expression, it was expressed and people were threatened”.

More common than physical harm is the risk of the participant becoming distressed as a result of participation or experiencing secondary traumatisation as a result of the research, as was the case in Extract 14.

Extract 14: *(respondent 18, university)*

“Discovering that a respondent in one of my studies had a recalled memory as a result of participation which led to intense and ongoing reactions”.

Ethical research requires that potential harms are anticipated and that procedures are put in place to assist participants if they are harmed in any way during the research process (cf., Emanuel et al., 2004).

Extract 15 reveals an instance in which the respondent encountered a situation in which researchers were researching sensitive issues that were potentially harmful to participants without procedures to address the possible consequential harm, such as debriefing of participants or the provision of counseling services.

Extract 15: *(respondent 39, research organisation)*

“I discovered that fellow researchers were conducting research on children affected by violence (large surveys) where they ask questions about the child being raped etc, and make no provision for follow-up referral of the child”.

Children are considered a vulnerable population and as such require special protection (Emanuel et al., 2000). The situation described in Extract 15 reveals that the researcher conducting the study did not give study design the ethical consideration it deserved. It may also reveal inadequate review on the part of the REC responsible for approving the study or that the researcher has deviated from the approved proposal. Either way the ethically right course of action would be to report the incident to the REC responsible for the study.

#### 6.3.3.2 Harm to Researchers

Participants are not the only ones who stand to be ‘harmed’ by the research process.

Extract 16 reflects an instance in which the researchers were emotionally affected by the research being conducted.

Extract 16: *(respondent 10, university)*

“Working in schools in small KZN town and surrounding area to explore barriers to learning related to HIV raised several ethical concerns... Although the research ultimately aims to better services in schools and to reduce barriers, several children spoke of specific pressing immediate needs such as not having beds to sleep on... Facilitators of focus groups were often emotionally affected by the interviews”.

Much social science research is conducted on social problems which have the potential to distress and even traumatise researchers and fieldworkers. It is therefore often necessary for procedures, such as debriefing, to be put in place to assist researchers and fieldworkers and prevent adverse reactions and burnout.

#### 6.3.4 Deception

While the use of deception in research may not be considered to harm participants it may be considered morally wrong (cf., Macklin, 2002). Extract 17 reveals how the use of deception, while scientifically useful, can be troubling for the researchers.

Extract 17: *(respondent 8, university)*

“... using cover simulated clients to evaluate the quality of a health service is a great method but does involve a degree of deception that made us the research team somewhat uncomfortable”.

Extract 18: *(respondent 12, university)*

“My problem is the nature of the informed consent form. Some of my research involves experiments. Here it is not at all in the interest of the investigation to reveal the purpose of the experiment beforehand. It would be extremely beneficial for me if I could give the participants only an idea about the nature of the task they are going to perform and to debrief them afterwards. Even mentioning the name of the project, will lead my participants to generate hypotheses about what expectations I have or what my objectives are with respect to the outcome of the experiment. All these are, however, very bad things to happen and may lead to very distorted results”.

Extract 18 reveals the researcher's desire to use a degree of deception in his/her research and the frustration at having to provide sufficient information so that participants can



make an informed decision whether to participate or not. It also captures the difficulty in balancing the provision of sufficient information so that an informed decision whether or not to participate can be made without revealing the purpose of the research. Wiles et al. (2004) caution researchers to be careful when minimising the amount of information they give to participants as interest in a topic or reluctance to appear uncooperative or even rude may result in participants underestimating risk or not considering participation thoroughly. However, in line with the argument presented in Extract 18 some researchers (cf., Homan & Bulmer, 1982) acknowledge that it is not always appropriate to provide information and obtain consent, as once people know the purpose of the research their behaviour is likely to change. Generally the use of deception (or covert research) is only justifiable when the findings cannot be obtained using open methods (Wiles et al., 2004). When using deception, Pittenger (2002) recommends that researchers should indicate in the informed consent form that deception may be used as a part of the study and that the researchers provide detailed accounts of the procedures that will be used to minimise the potential harm created by the use of deception.

### 6.3.5 Informed Consent

Informed consent concerns the researcher's responsibility to provide potential participants with appropriate information so that an informed decision can be made about whether to participate or not (Emanuel et al., 2000). Ethically challenging incidents involving informed consent include:

### 6.3.5.1 Nature of Informed Consent Forms

While not an ethical issue *per se*, as Extract 19 reveals, the standardised nature of informed consent forms appeared to be experienced as frustrating for several researchers.

Extract 19: (*respondent 2, university*)

“Most of my projects involve collaborators at US universities who have very sophisticated standardised consent and other procedures. Their experience has helped prevent problems. However, the length and complexity of these forms while obviously useful at times seem over the top and unnecessary”

Several authors (cf., Wiles et al., 2004) acknowledge that standardised consent forms are not always appropriate. Rather it is suggested that the format, style and information provided in the consent form be made appropriate to the study population. Researchers should understand the information needs of the study population and use this knowledge to provide information in a way that enables potential participants to understand what participation will involve according to their level of capacity (Alderson & Morrow, 2004). Understanding the information provided is as important as the information itself (Flory & Emanuel, 2004). However, as Extract 20 reveals, providing information in a way that is comprehensible to participants is not always simple.

Extract 20: (*respondent 51, research organisation*)

“It is difficult describing the precise purposes of the research as is required in consent forms because it is located in a theoretical paradigm that would not immediately be graspable by respondents.”

Despite the difficulty involved, researchers need to make a concerted effort to explain the research to the participants according to their level of capacity and to assess whether participants have comprehended the information provided. Prior community participation (see section 2.2.1) should also facilitate this.

#### 6.3.5.2 Difficulties of Gaining Informed Consent

As Extract 21 reveals, when researching school children the decision of whether to obtain informed consent and from whom, may be experienced as ethically challenging. In South Africa this issue has become even more complex since the promulgation of the South African National Health Act, Section 71 (2) and (3) which attempts to detail legal standards for the participation of children in research (Strode, Grant, Slack & Mushariwa, 2005).

*Extract 21: (respondent 21, research organisation)*

“Doing large scale work on the factors determining learner performance requires obtaining background or contextual information from school learners (ages 7 to 18) by means of self-report questionnaires. However, given that the numbers of learners participating typically ranges from 1 000 to even 85 000, getting parental consent/assent is totally impractical. We have often so far been relying on the "contract" between schools and parents to educate their children, to accept or perceive such questionnaires as a normal part of schooling. Otherwise, large-scale work is often requested by and contracted to the National Department of Education, who permits and expects their schools to participate. Key question: Do parents have to sign individual consent forms every time that any learner is completing any piece of information on a form?”

As Extract 21 reveals, it is common with school based research for the National Department of Education or school principals to consent to research. In this context

teaching staff often instruct learners to participate and the research may become, or be perceived as part of the curriculum (Wiles et al., 2004). This becomes ethically problematic when gatekeepers fail to provide learners with the opportunity to refuse participation (Wiles et al., 2004). While obtaining parental consent can overcome this problem, Extract 21 also reveals the impracticality of obtaining parental consent from thousands of learners. A number of suggestions have been made regarding how to manage 'assumed' consent in ways that do not reveal to the gatekeeper that learners are not actually participating in the research. France (2004), for example, suggests that individual learners' choice to remain silent in focus groups should be respected and that they should be given the choice of whether or not they wish to complete questionnaires or participate in interviews.

Extracts 22 illustrates one of the negative effects informed consent is seen to have on the research process.

*Extract 22: (respondent 46, research organisation)*

"Issue of informing participants about the ethical information...they then take it seriously and 'close up' they tend to think then that there is something to worry about when giving the interview".

Such concerns have repeatedly been reflected in the literature on informed consent.

According to Wiles et al. (2004), official informed consent forms that stress confidentiality or possible distress that may arise from participation are likely to make participants reluctant to participate fully or disclose certain information. Wiles et al. (2004) suggest that this can be avoided by not overwhelming participants with excessive

information and keeping consent forms simple and attractive. Also following a written consent form with a verbal discussion can ensure participants' correctly comprehend what they are consenting to and remove any concerns they may have that might make them reluctant to participate or disclose certain information (Wiles et al., 2004).

### 6.3.6 Recruitment of Participants

For recruitment of participants to be ethical the procedures for recruitment should not be coercive and should accurately describe the likely risks and benefits of participation (IRB Guidelines - Subject Recruitment and Advertising, 2006). Ethical concerns regarding recruitment of participants can be addressed using Emanuel et al.'s (2000) principle of fair subject selection. Fair subject selection requires that the scientific objectives of the research, and not privilege, easy accessibility or vulnerability, be the primary basis for participant recruitment (Emanuel et al., 2000). Furthermore, equal distribution of risks and benefits should also guide the selection and recruitment of participants; those who are likely to benefit from the research should share some of the risks and vice versa (Emanuel et al., 2000).

Ethically challenging situations involving the recruitment of participants were mentioned by several respondents. For example, dilemmas over how to deal with "people's expectancy of getting something tangible in return for engagement" were mentioned and as Extract 23 reveals, drawing the line between offering compensation and undue inducement can also become an ethically challenging situation for researchers.

Extract 23: *(respondent 31, research organisation)*

“The issue of compensation payable to participants: In impoverished communities, the line is very thin between compensation and undue inducement”.

The literature offers little consensus on the issue of compensation. Some researchers argue that all participants should be paid for their time and effort, while others share the concerns expressed in Extract 23 that compensation may encourage vulnerable populations to participate in research they would not have otherwise participated in (Wiles et al., 2004). Emanuel et al. (2005) argue that poverty or unfortunate circumstances are not enough to turn compensation into an undue inducement. Inducements only become undue when a person’s unfortunate circumstances are combined with compromised judgement and accepting a seriously unfavourable risk benefit ratio that threatens their fundamental interests (Emanuel et al., 2005).

Extract 24 also provides an example of a dilemma concerning the ethical recruitment of participants.

Extract 24: *(respondent 47, research organisation)*

“I asked respondents of a survey whether they would be prepared to participate in a sequel to the survey to be conducted in the following year - and if they were, for them, to provide their contact details. Many respondents either said they would not want to participate in further surveys or did not answer this question, but provided their contact details anyway. The dilemma was whether to take the provision of contact details as a sign that respondents were prepared to participate in future surveys”.

Ideally, if a participant says that they do not wish to participate in future research that wish should be respected. However, pressure to recruit and enroll participants means that



researchers may often be tempted to use cooperative participants in more than one study. This only becomes problematic if a) the participant does not meet the inclusion criteria and are only being used because they are easily accessible and cooperative or b) the participant does not feel they can refuse participation. According to Emanuel et al. (2004) it is unethical to select participants on the basis of anything other than the scientific objectives of the study.

The latter problem is reflected in Extract 25 which raises concerns about whether participants are capable of refusing participation.

*Extract 25: (respondent 10, university)*

“Working in schools in small KZN town and surrounding area to explore barriers to learning related to HIV raised several ethical concerns ... one that despite the research team’s efforts and reflections, people are not sufficiently empowered to refuse participation”

Ethical research requires that consent to participation is voluntary (Emanuel et al., 2000). Several authors (cf., Barsdorf & Wassenaar, 2005; van den Hoonaard, 2001) have suggested that race, poverty, oppression and previous disadvantage may affect people’s perceived voluntariness to refuse participation. Barsdorf and Wassenaar (2005) have made several recommendations to offset low perceived voluntariness in medical research in developing countries that may be equally applicable to social research on HIV described in Extract 25. Recommendations include the use of recruiters with the same cultural and racial background as potential participants, educating recruiters to be



sensitive to power differentials, and exposure to people who have voluntarily withdrawn from similar studies.

### 6.3.7 Communication of Results to Participants

A number of ethically challenging incidents appeared regarding the communication of results to participants. It is not only the researcher's ethical responsibility to make the findings known to the participants but a useful strategy for a) recognising participants' contributions (Emanuel et al., 2000) and b) verifying one's findings (Oliver, 2003).

Extract 26 however reveals that this is not always being done.

*Extract 26: (respondent 7, university)*

"I find it disturbing and ethically wrong that very little effort is made by researchers to feedback their findings to the communities concerned, or by Universities to enforce such an attitude".

Extract 27 reflects an ethically challenging situation in which 'negative' results need to be communicated.

*Extract 27: (respondent 26, university)*

"Also, an ethical dilemma was experienced when I was required to report back interpretations of findings to respondents which did not reflect favourably on them".

Extract 27 is an example of one of the many unforeseeable ethical dilemmas that arise during research. Such a dilemma cannot be avoided by following guidelines and can

occur no matter how ethically sensitive the researcher has been. Such a dilemma is an example of what Guillemin and Gillam (2004) refer to as 'ethically important moments', and would require a sensitive discussion of the results with an emphasis on the anonymous presentation of the findings. What is important in such cases is that the researcher's response to the dilemma does not depart from fundamental ethical principles such as maintaining the respondent's autonomy.

#### 6.3.8 Publication Issues

Researchers have an ethical responsibility to publish and disseminate the findings of their research (Schneider & Schüklenk, 2005). Publication of research was however revealed to cause ethical challenges for a number of researchers. Authorship has been described as the most controversial publication issue (Game & West, 2002). It was also the most commonly reported publication issue in this study. Extract 28 reveals one such challenge. Extract 28 illustrates how supervisors default responsibility to give first authorship to the student from whose work the publication arises (cf., Wassenaar, 2006) is not always unproblematic.

*Extract 28: (respondent 24, university)*

"As a research supervisor...it has become very common to invite students to participate in research that has been conceptualised and planned by myself. Often my role has extended beyond that of supervisor - the extent of involvement often involves providing relevant literature, analysing data and providing extensive feedback on written work. When the student completes the research and it is deemed adequate for publication, the question of who gets first authorship is one that often presents an ethical dilemma. If the student takes responsibility for writing up and produces work of a reasonable standard, the decision is easy. However, if the supervisor takes responsibility with the student having little or no

input (despite being invited to do so), then how should the authorship issue be handled?”

The International Committee for Medical Journal Editors (ICMJE) has delineated three conditions that must be met in order to claim authorship. In order to qualify for authorship substantial contributions must be made to a) the conception and design or the acquisition or analysis and interpretation of data, b) drafting the article or revising it critically for important intellectual content, and c) final approval of the version to be published (Schneider & Schüklenk, 2005). Furthermore, the order in which the authors' names appear should be determined by the relative size of each author's contribution (Game & West, 2002). In terms of the student-supervisor collaborations described in Extract 28, the student should be given first authorship when the article is substantially based on the student's research (Game & West, 2002). Game and West (2002) highlight that exceptions should be made only if a) the supervisor made major and sustained contributions to the research, and/or b) very close supervision was required to produce the paper, and/or c) the supervisor conducted or closely supervised further analysis beyond the original research. The guidelines provided by Game and West (2002) clearly show that in Extract 28 the supervisor should be given first authorship. However, the criteria for authorship should be discussed with the student before the article is written so that they are aware of what they need to contribute in order to claim first author and an agreement should be reached that if an 'appropriate' contribution is not made by the student, the supervisor will be first author. The above issue of authorship of student work was also coded as one of the ethically challenging incidents described involving students, below.

### 6.3.9 Student Issues

Most training courses for social scientists in South African universities have not paid particular attention to the ethics training of researchers (Wassenaar, 2006). Subsequently, research supervisors may find themselves in the situation described in Extract 29.

Extract 29: *(respondent 5, university)*

“I recently supervised a student whose findings, from a questionnaire seemed too good to be true. For example, the student got almost a hundred percent response rate, which is very unlikely given the method and topic. This in addition to other incidents led me to suspect the findings / some findings had been fabricated. I could not prove anything!”

Extract 30 reveals an ethically challenging incident in which the researcher had to decide whether to put the interests of the student before the ethical guidelines of the organisation.

Extract 30: *(respondent 9, university)*

“...We tried to get the REC to review [the research project] quickly so the project could start. They did nothing for about 4 months, and just dug in their heels and got bureaucratic and stubborn. The student had to start ASAP or the project would not have worked AT ALL, so I had to say that I would take personal and professional responsibility for the consequences of the research, should some ethical problem arise. So, the project went ahead without ethical clearance.”

Failure to obtain REC approval is not only illegal and unethical; it constitutes scientific misconduct (Schneider & Schüklenk, 2005). It is the researcher's, or in this case the supervisor's, responsibility to ensure that the ethics review process is factored into the research schedule. Furthermore, one should always consider the possibility that a request

for an expedited review may be denied. Expedited review is when the chairman of the REC or a designated voting member or group of voting members reviews the proposed research rather than the entire REC. Expedited review should only be granted to studies posing a minimal risk to study participants (National Institutes of Health, 2002). The supervisor in Extract 30 is not only putting participants at risk, he/she is jeopardising the student's academic integrity and setting a poor example.

#### 6.3.10 Poor Science

Poor science was the code given to research that is conducted with a flawed theoretical basis, research design or poor methods of analysis. Such research can be considered unethical as it wastes resources, participants' time and potentially exposes participants to unnecessary risks (Slack, Lindegger, Vardas, Richter, Strode & Wassenaar, 2000).

Extracts 31 and 32 document poorly conducted research that researchers experienced as troubling.

Extract 31: *(respondent 41, research organisation)*

"Having participants participating and they were not supposed to have been included in the study because he or she does not meet the requirements because of the definitions that we have for some issues".

Extract 32: *(respondent 50, research organisation)*

"...researchers including surveys in their samples which have not been filled in correctly and that should have been excluded. This is troubling for me as it compromises the accuracy of research".

Extracts 31 and 32 reveal incidents in which the inclusion criterion was not complied with. According to Emanuel et al.'s (2000) principle of scientific validity the development and approval of valid methods is of little use if the research is then carried out poorly or inaccurately. Incidents described in Extracts 31 and 32 are likely to bias results. Policy or interventions based on biased findings are unlikely to be appropriate or usable for the communities for whom they are designed. This clearly illustrates how poorly designed or conducted research not only wastes resources but cannot produce intended knowledge or benefits or justify the burdens placed on the participants (Emanuel et al., 2000).

#### 6.3.11 Whistleblowing

Extract 33 reveals that witnessing poorly conducted research, plagiarism and/or misconduct by colleagues simultaneously raises the dilemma of whether to blow the whistle or not.

Extract 33: *(respondent 4, university)*

“Discovering major plagiarism and abuse of student work by colleagues and deciding whether to blow the whistle or not”.

Again this ethically challenging incident is an example of what Guillemin and Gillam (2004) refer to as ‘ethically important moments’. These are instances in which it is fairly clear how the researcher should respond, and yet there is still something ethically important at stake where the approach taken or the decision made has further

ramifications. It is often immediately clear that blowing the whistle on unethical research is the correct course of action. Deciding whether or not to blow the whistle, however, is a difficult decision, as whistleblowers are often perceived as enemies of the institution and are subsequently ostracised (Rhodes & Strain, 2004).

### 6.3.12 Beneficence

Beneficence requires the researcher to attempt to maximise the benefits that participants obtain from the research (Sieber, 1992; Wassenaar, 2006). According to Emanuel et al. (2000), beneficence should be centered on the benefits to participants because benefits to society at large, through knowledge generation, should be inherent in the research if it is to be socially valuable and scientifically valid. Ethically challenging and/or troubling incidents involving beneficence took a number of forms.

#### 6.3.12.1 Research that is not Beneficial to the Participants

Extract 34: *(respondent 22, university)*

“I think the biggest ethical challenge in my work stems from the fact that much of it takes place in communities and that often the benefit of the research does not accrue to the community who participates”.

In Extract 34 the respondent raises concerns about the fact that research often has no direct benefit for the participants.



Extract 35: *(respondent 2, university)*

“Taking up the time of respondents when the research had little or no relevance for them”.

Extract 35 highlights the ethically troubling situation that arises when the research is not relevant to the participants. According to Emanuel et al.'s (2000) principle of collaborative partnerships for research to be ethical, the community in which the study is conducted should benefit from the conduct and/or results of the research. Furthermore, in terms of Emanuel et al.'s (2000) principle of fair subject selection, participants who bear the risks of research should also get to share in the benefits of the research. Such dilemmas could therefore be avoided by planning research in collaboration with the host community and selecting participants on the basis of scientific validity and fair distribution of risks and benefits.

#### 6.3.12.2 Research that is Primarily of Benefit to the Researcher

As above, the respondent in Extract 36 voiced concern about the research not being beneficial to the participants, but then honestly acknowledged why it was that he/she continued to conduct the research:

Extract 36: *(respondent 6, university)*

“Doing contract research that I know could improve peoples' lives and state policy, but our discussions and meetings with the funder suggest to me that the funder has already decided the outcome of the research, in a manner that I feel will result in the policy having no positive impact on people's lives. I am very concerned that it will have negative impacts... I strongly suspect that other academics have refused to be involved in the research for the same ethical

concerns that I have, nevertheless I am involved in the research and will not withdraw. The research has substantial benefits for my academic career and my teaching. It also has financial benefits for me”.

Extract 36 was the only instance where the researchers’ personal gains were discussed.

This extract reveals the importance of Emanuel et al.’s (2004) principle requiring independent ethics review. Review by an independent REC should be able to assess the risk benefit ratio and ensure the research has social value and is not only being conducted for the sole benefit of the researchers.

#### 6.3.12.3 Inability to Respond to the Real Needs of Participants

Extract 37 reveals that researchers’ inability to respond to the real needs of participants was also experienced as ethically troubling.

*Extract 37: (respondent 31, research organisation)*

“The dilemma that I experience is a personal one in terms of feeling guilty about the amount of funds spent on doing research with poor/ill/disadvantaged people who do not have the most basic necessities and while they do benefit from the research in terms of policies/interventions their basic needs food/adequate health care/schooling are not catered for”.

This dilemma is common to many researchers working in impoverished communities and cannot easily be resolved. In response to personal experiences of this dilemma, Nama and Swartz (2002) point out that even if it were possible to distribute the money spent on research to communities in need, it would make little impact on people’s lives in anything but the very short term. Conversely, the authors argue that if researchers were able to develop an intervention or influence policy it is more likely to result in sustained

and long term improvements, which will ultimately be more beneficial. A possible way to reduce this dilemma is to design research in such a way that participants and/or host communities receive some tangible benefit from participation. For example, such benefits may include communities improved knowledge of the topic under study or the training of community members and employment in the study.

### 6.3.13 Role Conflict

Role conflict was the code given to ethically challenging incidents in which the researcher felt caught between their mandate to conduct research, i.e., collect data for an institution or project, and their obligation to address the needs of participants which often tempts researchers to become interventionist and provide services and/or resources beyond the scope of the research protocol. Examples include researchers who provide poor participants with food or take sick community members to hospitals, or begin to lobby for needs of participants not directly related to the issues being researched. Extract 38 illustrates an incident in which the researcher intervened to assist participants, while Extract 39 expresses the dilemma researchers face in deciding whether to intervene or not. Emanuel et al. (2004) state that researchers have an ongoing obligation to the study participants, which includes making decisions about how to treat diseases/problems, unrelated to the research, that require care. Emanuel et al. (2004) however acknowledge that no clearly defined guidelines are available to assist researchers faced with the aforementioned ethical issues, and that researchers are not obliged to ensure that all participants' medical conditions/social problems are addressed.

Extract 38: (*respondent 15, university*)

“Herein lies my greatest challenges as a researcher from my field [history] in SA, who cares about the impact of her work. This is a common context: I head off to interview individuals over say 200 kms who were all involved in some key event say 40 years ago. I find on arrival in a homestead/township very grave poverty and desperate need e.g., very ill children in the home when I go to interview an aged person about a specific memory of the past (e.g., a labour strike when they led this in say the 1950s) and find we cannot continue as there are very sick people needing basic help at home. Then spending days on this issue and my money and transport to get sick, small or elderly, people to and from a local safe place, or clinic, and so on and provide food.”.

Extract 39: (*respondent 10, university*)

“Although the research ultimately aims to better services in schools and to reduce barriers [to HIV/AIDS], several children spoke of specific pressing immediate needs such as not having beds to sleep on. There is a dilemma about whether one provides support to specific participants, versus services being provided to all school children”.

Assisting participants in the manner described in Extract 38 and 39, is similar to what is described as providing ancillary care in biomedical research. Ancillary care has been defined by Richardson and Belsky (2004, p. 26) as care that “goes beyond the requirements of scientific validity, safety, keeping promises, or rectifying injuries”. In biomedical research, medical researchers may have the unique capacity to treat diseases/disorders incidentally diagnoses during a study that the participants would normally not be able to gain access to due to poverty or geography (Richardson & Belsky, 2004). As Extracts 38 and 39, reveal social science researchers also regularly have the opportunity and capacity to assist participants beyond the scope of the research protocol. Richardson and Belsky (2004) offer a framework for thinking about the nature and degree of obligation researchers have to assist participants with problems (unrelated to the research) that become evident during the course of the research. It is suggested that

the researchers decide whether the given type of ancillary care falls within the scope of the 'participants evolving partial entrustment' of their wellbeing to the researchers (Richardson & Belsky, 2004). If it does, then the researchers must assess the extent to which they should supply physical and financial resources to provide the care. The rationale to provide care depends on the participants 'vulnerability and dependency' and the debt of gratitude owed to participants (Richardson & Belsky, 2004).

#### 6.3.14 Constraints Imposed by Funders

Extract 40 raises an ethically challenging incident regarding research that is controlled and/or constrained by the funder.

Extract 40: *(respondent 6, university)*

"Doing contracted research where the budget constraints set by the funder make it very unlikely that we will be able to uncover comprehensive data on a conceptually complex practice."

Extract 40 appears to reflect a conflict of interest between the academic demands of the research project and the funders commercial interests. It might be argued that if the data obtained from the research is insufficient the decisions made on the basis of the research will be flawed. According to Oliver (2003) dilemmas such as this can be minimised if contracts are carefully prepared and based on a fair discussion between funders and researchers. RECs should also be vigilant about such issues during the ethical review process.

### 6.3.15 Abuse of Power

Abuse of employees, students, or research participants in any way that takes advantage of the power of the researcher's position is also considered unethical (Wassenaar, 2006).

Dealing with abuse of power by those in senior positions was described as challenging for some respondents. As Extract 41 reveals, it is possible for those in a position of power to manipulate subordinates and abuse their access to data.

*Extract 41: (respondent 36, research organisation)*

“Because project management is not viewed as crucial, areas such as quality control, data management, etc. can easily be manipulated by those who are in positions, which allow them access to data at any given point and in whatever manner they choose”.

## 6.4 Further Discussion

Emanuel et al.'s (2004) framework of ethical principles (outlined in Chapter 2, Section 2.1.3) has been described as a useful approach to the ethical dimensions of conducting research in the social sciences (cf., Wassenaar, 2006; Wassenaar & Corbella, 2007). As the discussion in Section 6.3 above illustrates, Emanuel et al.'s (2004) principles were found to be useful in identifying and examining the majority of ethically challenging incidents reported by respondents

The results of the thematic analysis, however, reveal a number of additional ethically challenging incidents such as; the communication of results to participants, publication



issues, student issues, whistle-blowing, role conflict and abuse of power, that do not appear to be addressed by Emanuel et al.'s (2004) framework. Such ethically challenging incidents appear to fall under professional ethics (or professional integrity). Professional ethics concerns the researcher's conduct of behaviour and practice when carrying out professional work (Davison, 2000). For social science researchers, such professional work may include contracting, consulting, researching, teaching and writing. Existing literature and guidelines on ethical issues in social science research tends to focus on the traditional ethical issues in the conduct of research (such as informed consent, confidentiality, and avoidance of harm). The findings from this study suggest that while such ethical issues are central, professional ethical issues are also of concern to social scientists in their work as researchers.

It is important to distinguish between a *profession* such as a researcher, and a *controlled profession* such as psychology, which requires registration with a professional body and where the loss of membership may also imply the loss of right to practice (Davison, 2000). Therefore, how professional ethical issues such as publication issues, student issues, whistle-blowing, role conflict and abuse of power, are dealt with may depend on what profession the researcher belongs to. However, as many researchers do not belong to a *controlled profession*, it may be useful for general ethical guidelines and frameworks to include professional issues pertinent to research.



While the usefulness of a framework such as Emanuel et al.'s (2004) has been demonstrated, the importance of combining such a framework with a pragmatic approach is also evident. Several of the dilemmas documented above reveal that researchers need to be familiar with universal ethical principles, institutional practices, contractual agreements as well as local practices in order to make decisions on the most ethical course of action. A strength of Emanuel et al.'s (2004) framework is that the authors acknowledge that in order for their guidelines to be universally applicable they need to be adapted to the local conditions in which they occur.

Moreover, several dilemmas concerned issues that are unlikely to be addressed by any ethical frameworks or guidelines (i.e., Extract 27 and 33). Such issues are what Guilleman and Gillam (2004) refer to 'ethically important moments'. These are instances in which it is fairly clear how the researcher should respond, and yet there is still something ethically important at stake where the approach taken or the decision made has further ethical ramifications. Extract 27, for example, describes a situation in which a researcher has to provide participants with findings that reflect negatively on them. Although ethical guidelines make it clear that the ethically correct course of action is to provide participants with the results of the research in which they participated, no guidelines/principles will explain how to deal with this particular ethical issue and RECs are unlikely to preempt the occurrence of such a dilemma. It is important for researchers to acknowledge that no frameworks or guidelines can address all possible ethically challenging incidents and that this cannot be the basis upon which ethical frameworks and guidelines are rejected, as is often the case in the literature (cf., Reissman, 2005).

When trying to resolve ethical issues one should first examine frameworks and guidelines in an attempt to resolve the issue at hand. If however the issue cannot be resolved in this manner the researcher should ensure that their response to the problem involves adherence and consideration of the fundamental ethical principles of autonomy, justice, beneficence and non-maleficence, even if the problem at hand requires such principles to be applied in a manner not previously delineated by existing frameworks and guidelines. Furthermore, RECs should be available to advise and assist researchers overcome difficult ethical situations. In addition, large research centers should employ persons with skills in research ethics to assist procedurally with issues in proposal development stages of research.

## 6.5 Summary

The thematic analysis of the responses from Section B of the questionnaire enabled a profile of the ethically challenging incidents experienced by social science researchers to be determined. The most frequently mentioned ethically challenging incidents concerned issues of privacy, confidentiality and anonymity, followed by ethically challenging incidents involving harm, beneficence, poor science, role conflict, informed consent, recruitment of participants and publication issues. Less frequently mentioned incidents involved dealing with students, conducting research on people known to the researcher, using deception in research, the communication of results to participants, the abuse of power by researchers, whistle blowing and dealing with constraints imposed by funders.

Furthermore, data analysis revealed a significant association between the number of ethical issues reported and the institution in which respondents worked with researchers working at the university reporting significantly more ethical issues than was expected.

The results of the descriptive thematic analysis were considered in relation to Emanuel et al.'s (2004) framework of ethical principles. This suggests that Emanuel et al.'s (2004) framework is both relevant and useful for the consideration of ethical issues in social science research. A limit of Emanuel et al.'s (2004) framework was found to be its failure to address the professional ethical issues that arise in social science research involving human subjects.

## Chapter 7 RESULTS AND DISCUSSION II

### EXPERIENCE OF ETHICS REVIEW

This chapter will present the results of Section C of the questionnaire. The respondents' experiences of ethics review (as either positive, negative or mixed) will first be presented. An overview and frequency count of the reasons for positive and negative experiences will then be presented and discussed. This is followed by the results of a chi square analysis of the relationship between the respondents' experience of ethics review and the institution in which they work. The results of the descriptive thematic analysis will then be presented and discussed in terms of what makes researchers' experience of ethics review positive or negative. The additional themes that inductively emerged during the thematic analysis will also be presented and discussed. As in the previous chapter, presentation and discussion of the results are combined in this chapter due to the large number of categories generated.

#### 7.1 Experience of Ethics Review

Of the 52 respondents 9.6% (n=5) reported not having any experience of ethics review, 21.3% of the remaining respondents described a positive experiences of ethics review, 42.6% described a negative experience and 6.2% of respondents described both positive and negative experiences. This is shown in Figure 3 and Table 6.

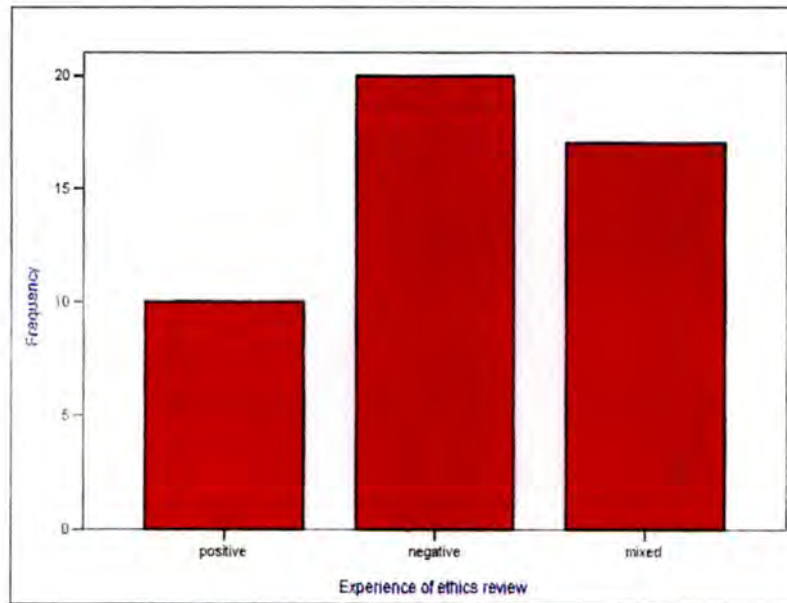


Figure 3 Experience of ethics review

Table 6 *Experience of ethics review*

Experience of ethics review	Number	Percentage
Positive	10	21.3
Negative	20	42.6
Mixed	17	36.2
Total	47	100

In the literature review it was noted that existing literature portrays the relationship between researchers and RECs in a particularly negative light by focusing on researchers' objections and frustrations with ethics review. Such literature was seen as the result of researchers' personal experiences and reflections on ethics review; moreover a need was identified for some empirical research to corroborate such reflections. The findings from this study reveal that although the majority of respondents' experiences could be

classified as negative (42.6%) and are in line with existing literature on this topic, there are also a fair number of positive (21.3%) and mixed (36.2%) experiences which show that some positive aspects of ethics review have perhaps been neglected in the literature.

## 7.2 Overview and Frequency of Reasons for Positive and Negative Experiences of Ethics Review

A frequency count was only conducted on themes directly related to researchers' experience of ethics review. The themes that emerged in the thematic analysis of researchers' positive experiences were a) ethics review as procedurally smooth and b) ethics review as beneficial to the study/researcher.

Table 7 *Positive experiences of ethics review*

Positive Experiences of Ethics Review	University	Research organisation	Total
Ethics review as beneficial to the study/researcher	6	7	13
Ethics review as procedurally smooth	3	2	5

Table 7 reveals that the theme 'ethics review as beneficial' emerged twice as frequently as the theme 'ethics review as procedurally smooth'. Examination of Table 7 also reveals that both themes emerged with the same frequency for researchers from both institutions.

Four themes emerged in the thematic analysis of the negative experiences of ethics review: a) pragmatic reasons, b) problems with the centralisation of review, c) inadequate review, and d) principled reasons.

Table 8 *Negative experiences of ethics review*

Negative Experiences of Ethics Review	University	Research organisation	Total
Ethics review as negative for pragmatic reasons	13	8	21
Problems with the centralisation of review	13	4	17
Inadequate Review	8	5	13
Ethics review as negative for principled reasons	4	2	6

Table 8 reveals that most negative experiences of ethics review could be attributed to pragmatic reasons, followed by problems of centralisation, inadequate review and lastly, principled reasons. While, on the whole, respondents from the university mentioned more negative experiences than respondents from the research organisation, the most notable differences occurred with regard to problems with the centralisation of review: only four respondents from the research organisation experienced ethics review as negative for this reason compared with 13 from the university.



Table 8 also illustrates that principled objections to ethics review were minimal (6) compared to pragmatic problems (21), problems with the centralisation of review (17) and inadequate review (13). It might be inferred from these findings that ethics review, at least in theory, is generally accepted and it is primarily the practical implementations and practices of ethics review that researchers have problems with.

These findings are comparable to those of Keith-Spiegel et al. (2006). The authors asked 886 experienced biomedical, social and behavioural scientists to rate 45 descriptors of REC actions and functions as to their importance. The authors found that most complaints expressed by researchers concerned REC procedures and interpersonal interactions that were perceived by researchers as unfair (Keith-Spiegel et al., 2006).

However the possibility exists that such findings are a result of social desirability bias. It is more acceptable to complain about the pragmatics of research ethics than express a fundamental objection to ethical research.

### 7.3 Experience of Ethics Review by Institution

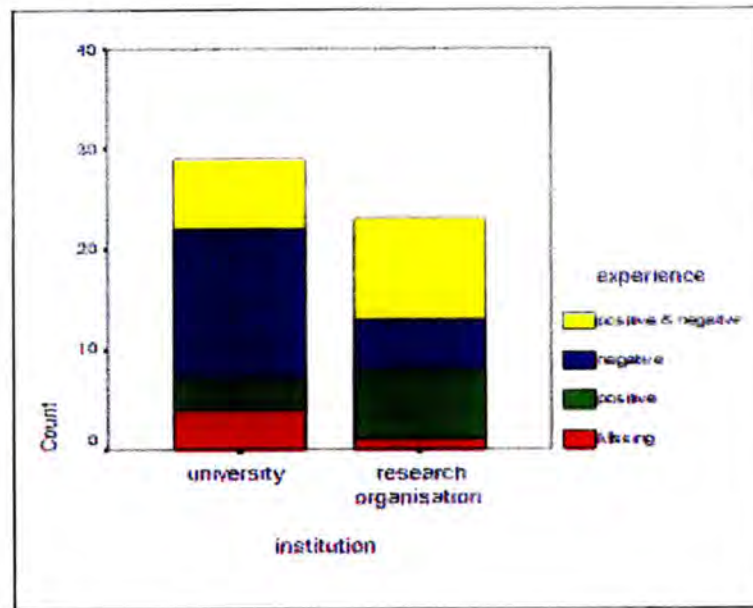


Figure 4 Experience of ethics review by institution

Table 9 *Experience of ethics review by institution*

Institution	Positive	Negative	Positive & Negative	Total
University	3	15	7	25
Research organisation	7	5	10	22
Total	10	20	17	47

A chi square test of independence was conducted to test the association between respondents' experience of ethics review and the institution in which they worked.

Prior to conducting the chi square analysis the two assumptions of chi square were tested. First, it was ensured that all categories were mutually exclusive and second, as Table 9, reveals none of the expected values were less than five.

A chi square analysis revealed a significant association between researchers' positive or negative experience of ethics review and the institution at which they worked ( $\chi^2 = 6.996$ ,  $df = 2$ ,  $p < 0.05$ ,  $\Phi = 0.385$ ). The results of Phi reveal a weak association between researchers' experience of ethics review and the institution at which they worked.

Researchers at the university reported significantly more negative experiences of ethics review than was expected: 60% of researchers at the academic institution described only negative experiences of ethics review compared with only 22.7% at the research organisation.

The chi square analyses and the frequency counts presented above reveal that not only did respondents from the university have significantly more negative experiences of ethics review on the whole, but that notably more respondents from the university experienced ethics review as negative for pragmatic reasons and because of problems with the centralisation of review than did respondents from the research organisation (see Table 9). There are two possible explanations for the difference in experience of ethics review. First, compulsory ethics review for social science research was only introduced in the particular university in 2005, while ethics review was introduced in the research organisation in 2003. As the process is still fairly new at the university the ethics review process and the proposal guidelines may not yet be as clear as they ought to be and

faculty may not yet be familiar with the process. Therefore, it is possible that more misunderstandings and delays occur at the university hence the more negative experience with ethics review. Second, ethics review at the university may be complicated by the diversity of disciplines and practices included in the Faculty of Social Science. Disciplines include anthropology, history, architecture, isiZulu, creative arts, psychology, philosophy and politics to name a few, while procedures and methodologies range from oral history and ethnography to public health interventions and behavioural experiments.

#### 7.4 Thematic Analysis of what makes Researchers' Experience of Ethics Review Positive

This section aims to describe what respondents considered factors that made researchers' experience of ethics review positive. Respondents who reported a positive experience of ethics review were less likely to elaborate/explain what it was about the process that was positive. Most comments were along the lines of the following: "On the whole the experience has been positive", "Good experience generally", and "We are having a very, very positive experience at the [research organisation]". Ethics review appeared to be experienced as positive for two reasons:

##### 7.4.1 Ethics Review as Procedurally Smooth

Firstly, a positive experience was described when the ethics review process was experienced as procedurally smooth and unproblematic. This is reflected in comments

such as: “Process is smooth and effective” and “...with the exception of minor revisions (wording, contact details etc), the process was fairly unproblematic”.

#### 7.4.2 Ethics Review as Beneficial to the Study/Researcher

Secondly, a positive experience was described when ethics review was perceived to be beneficial to the study or the researcher. Ethics review was perceived to be beneficial to the study as it “improves the quality and design of the research”. Ethics review was also perceived to be beneficial to the researcher as it “increased (the researcher’s) awareness and consideration of ethical issues”.

##### 7.4.2.1 Ethics Review Improves the Quality of Research

Several respondents felt that ethics review increased the standard and quality of the research, improved the research design, and prevented possible problems.

Extract 42: (*respondent 5, university*)

“I do think that comments I have received from colleagues in their review of a student’s ethical application and proposal, have resulted in better quality research instruments and research of a higher academic standard than would have been the case without the ethical review process.”

#### 7.4.2.2 Ethics Review Increases Researchers' Awareness and Consideration of Ethical Issues

As Extracts 43 and 44 reveal, the majority of respondents who described positive experiences of ethics review perceived the process to increase their awareness and consideration of ethical issues.

Extract 43: *(respondent 6, university)*

“At this stage, I feel that the ethical application is being taken very seriously and that this has improved my awareness and the awareness of students of ethical issues that we previously did not consider”.

Extract 44: *(respondent 51, research organisation)*

“The research ethics committee is fairly rigorous in its assessment of applications: things I had not thought of including were picked up by the committee, which helped me to think about things I might otherwise have overlooked”.

#### 7.4.2.3 Good to Know Others Approve of your Study

As is evident in Extract 45 some respondents also felt that it was reassuring to know that others were accepting or approving of the study and that it was good to have one's study authorised.

Extract 45: *(respondent 52, research organisation)*

“...relief that other researchers have read and critiqued our proposed studies and found them basically acceptable or acceptable with amendments”.

Much existing literature on ethics reviews in the social sciences casts the relationship between researchers and RECs in a particularly negative light, by focusing on researchers' frustrations with, and objections to ethics review (see Section 2.3.2). The experiences described in Extracts 42-45 above, however, reveal that researchers did have positive experiences of ethics review and reiterates that the ethics review process does have the potential to improve the quality of studies and increase researchers awareness and knowledge of ethical issues.

#### 7.4.3 Respondents as REC Members

As Extract 46 reveals, two respondents disclosed that they were themselves members of an REC, both of whom made positive comments about the purpose and process of ethics review, notwithstanding possible biases.

Extract 46: *(respondent 45, research organisation)*

“We are having a very, very positive experience at the [research organisation]. Not only do I sit on the Ethics Committee myself, but the process was instituted and is being run by the best experts in the country, with an extremely positive mindset towards researchers, and their proposals or studies. That is, they follow a very constructive approach, aimed at really improving the quality of the process, and reducing the risk of running into ethical problems or risks”.

The above extract highlights the fact that REC members may include colleagues. REC members may therefore be competitors, may hold junior positions or may be from other academic disciplines. Keith-Speigel et al. (2006) hypothesise that this may influence researchers' experiences of ethics review as researchers may not necessarily hold their



RECs members in high esteem and may become more upset when receiving negative feedback from competitors or from those to whom they feel superior in status.

## 7.5 Thematic Analysis of what makes Researchers' Experience of Ethics Review

### Negative

This section aims to describe what made researchers experience ethics review as negative. Ethics review was experienced as negative for pragmatic reasons, because of problems of centralisation, and inadequate review and for principled reasons.

#### 7.5.1 Ethics Review as Negative for Pragmatic Reasons

Ethics review was predominantly experienced as negative for pragmatic reasons.

Pragmatic reasons included the slowness of the ethics review process, and the time delays caused as a result of ethics review. The problematic nature of the ethics review procedures, forms and protocols, and problems with the standardisation of the forms were also mentioned.

##### 7.5.1.1 Slow Process

A common pragmatic reason ethics review was experienced as negative was due to the slowness of the review process. This is reflected in comments such as: "...the process is very slow sometimes", "My experience of ethics review? Slow, slow, slow, slow, slow!", and "The turn around time is very long". Extracts 47 and 48 illustrate that researchers'

negative experiences of ethics review, as well as much of their frustrations, were due to the time delays that occurred when proposals are rejected or returned for modification.

*Extract 47: (respondent 33, research organisation)*

“As the committee only meets once a month, there is the potential to delay the entire research process, which is a problem for funded research under stiff time constraints”.

Researchers' frustrations with the slowness of the ethics review process and the potential to cause time delays are well documented in both the international and local literature (cf., Mc Neill et al., 1992; Wassenaar, 2006). While understandably frustrating, the reasons for this are often beyond the RECs control. At present no literature exists on the structure, procedures and workload of Social Science RECs. However, a review of the REC at the Nelson R Mandela School of Medicine, KwaZulu-Natal, South Africa, conducted by Dada and Moorad (2001) may provide some insight into the slowness of ethics review in general. The review found the average turnaround time for processing a proposal to be 96 days. The authors attributed the long turnaround time to firstly, the high workload of RECs, the authors found that the REC reviewed 200, 168 and 170 protocols during 1997, 1998 and 1999 respectively. Secondly, REC members were from the administration and various branches of medicine, as well as the social sciences, and served on the committee on a part time basis and were not paid to do so. Subsequently Dada and Moorad (2001) conclude that the long turnaround time is a result of the onerous workload on REC members, which discourages people from serving on the REC. They argue that institutions wishing to be serious about research should place more resources in the REC, and also consider remunerating its members. As researchers have a

responsibility to be familiar with how the REC at their institution operates, they should be able to factor the ethics review process into their schedules (Wassenaar, 2006). Furthermore, time delays resulting from proposals being rejected could result from incompetence or poor ethical training on the part of the researchers. According to Sieber (1992), if researchers themselves were more competent in the ethical aspects of research their proposals would be less likely to require amendments or be rejected.

Extract 48: (*respondent 9, university*)

“There is a cost to this process [ethics review], and the cost is the slowness of research and the bottleneck in getting potentially life-saving research done”.

It is arguably unlikely that any research, let alone social science research, is truly urgently life saving. Nonetheless, the purpose of ethics review is to encourage ethical research and not to obstruct scientific progress. Ideally any delays resulting from the ethics review process should be outweighed by the benefits of review. Ethics review could be seen as somewhat analogous to peer-review, a practice accepted by all *bona-fide* researchers who conduct and publish funded research (Wassenaar & Corbella, 2007). Like peer review, if conducted competently, ethics review can increase the scientific validity of the research and prevent harm to participants and negative consequences for the researcher (Wassenaar & Corbella, 2007).

#### 7.5.1.2 Problematic Forms and Procedures

Problems with the forms and procedures can be divided into two aspects. First, the issue

of poorly designed forms and unclear procedures is evident in Extract 49.

Extract 49: *(respondent 1, university)*

“I think that the process could be procedurally simplified and that the forms in use at [the university] are badly designed”.

Extract 50 reveals the second issue, which appears to be unique to researchers from the university, is the standardised forms are reportedly not appropriate for all disciplines.

Extract 50: *(respondent 20, university)*

“There is a standard form that usually does not really apply to our research since we do conceptual analysis.”

The problem with standardised forms may result from the centralisation of review at the university. At the university one committee reviews all proposals from the Faculty of Humanities, Development and Social Sciences. The problem is that the Faculty, like the social sciences in general, spans a wide range of disciplines, many of which have very different methodological and epistemological stand points. It is subsequently unlikely that a standardised form will be appropriate to all or perhaps any of the disciplines encompassed within the Faculty.

### 7.5.2 Problems with Centralisation of Review

The centralisation of review in the university and to a limited extent in the research organisation appears to contribute to a number of other negative experiences. The primary one being that the ethics review process was not felt to be considerate of diverse

research strategies, methods and disciplines. The RECs, for example, were not felt to be familiar with or to understand the type of research being reviewed, as is revealed in

Extract 51.

Extract 51: *(respondent 3, university)*

“In my experience of review qualitative research has repeatedly been misunderstood.”

Ethics committees were also believed to lack insight into certain disciplines and methodologies, as is captured in Extracts 52 and 53.

Extract 52: *(respondent 39, research organisation)*

“Where it is problematic is where the committee does not consist of people familiar with my field [history]. I have experienced situations where the committee has obviously not understood the field and the methods. This has resulted in request to change procedures that have been inappropriate on occasion and which have resulted in endless irritations”.

Extract 53: *(respondent 21, university)*

“Sometimes the ethics committee does not understand the theological language in my research. This leads to unnecessary delays and explanations over the stipulated page limit. It would suggest that it is impossible for a centralised board to review all applications, I suspect that this responsibility should be devolved to particular disciplines.”

Several respondents suggested that each discipline should have an ethics committee to review research conducted within that discipline. While this would appear to reduce the frustrations that arise due to the centralisation of review, Emanuel et al.’s (2000) framework emphasises the importance of independent ethics review, and in a university setting it may be argued that independence is more likely to be achieved with a

centralised committee as apposed to numerous discipline specific committees.

Furthermore, the increase in multidisciplinary research within the social sciences (Oakes, 2002) would make discipline specific review equally problematic.

Such frustrations with RECs reported lack of insight into certain research strategies and disciplines and their inability to understand certain methodologies are also commonly reported in the literature (cf., van den Hoonaard, 2001). In general, problems that result from the centralisation of review can be reduced if REC members are not only trained in research ethics but are familiar with the spectrum of social science disciplines and methodologies they are expected to review (Wassenaar & Corbella, 2007). If RECs are not familiar with the methods or topics in a proposal they should invite specialists in such areas to assist in the review of issues that require expertise beyond or in addition to that of the REC members. These specialists, however, would not then be considered voting members (National Institutes of Health, 2002).

Extracts 54 and 55 reveal that some researchers reported that the research models on which RECs are based are derived from the medical sciences or based on positivist and clinical models of research and are not appropriate in the review of all social science disciplines or methodologies and subsequently constrain certain types of research.

*Extract 54: (respondent 49, research organisation)*

“The committees often are more steeped in positivist research traditions or medical models, and then attempt to apply this logic to other methodologies when they clearly do not apply, therefore seriously constraining more ethnographic and participatory research”.



Extract 55: *(respondent 15, university)*

“It is time that Ethical Committees took advice from specialists in disciplines so that each spectrum of learning can be represented and reflected. We feel we are squeezing on ethical shoes not made for our feet. It is as if psychology and sociology are “the norm” and the rest of us humanities and social science people are ‘the weirdos’ and underneath it all is the model of the ‘experiment’ and the ‘clinical trial’. There is a lot more to research than these models, crucial though they of course are!”

The ethics review process was initially established to review biomedical research in the form of experiments and clinical trials (Illinois White Paper, 2003). When RECs were set up to review social science research, instead of being reformulated, the procedures and models were merely borrowed from biomedical research (Illinois White Paper, 2003). In response to the resulting problems described in Extracts 54 and 55, several authors (cf., Redwood & Todres, 2006) have called for a complete change in the way that ethics review in the social sciences is conceptualised.

The complaint that social science research is often judged by the same standards as biomedical research prompted Keith-Spiegel et al. (2006) to hypothesise that, in their study on researchers’ ratings of RECs actions and functions, biomedical researchers would rate their RECs more favourably than would social and behavioural researchers. The findings however revealed that this was not the case. Moreover, Extract 55 again draws attention to the fact that there is great diversity within the social sciences and that although biomedical and or positivist reviews may be appropriate to disciplines, such as psychology, they may not be appropriate to others, such as history.



The findings from Chapter 6 of this thesis appear to suggest that the ethical issues that Emanuel et al. (2004) identified as central to biomedical research are equally applicable to social science. Therefore in the review of any research the key ethical aspects examined by an REC should be similar in both biomedicine and social science. It could therefore be argued that a RECs overall standards/requirements should not be different between biomedicine and social science or even within social science. Rather, it is the researchers' response and methods for addressing the ethical standards/requirements that will differ. For example, all research needs to have informed consent procedures in place but what constitutes adequate informed consent will differ depending on the research paradigm, strategy, method and research risks. The argument needs to be clarified: social science researchers who object to the centralisation of ethics review should not be objecting to the ethical standards/requirements stipulated by RECs but rather insisting that RECs should be diverse and flexible enough to understand and accept different methods of addressing ethical requirements. Ethics committees application forms should, for example, cater for different responses. Ideally, if the necessary ethical requirements are met in a sufficient (yet paradigm/discipline/method specific) manner, research should not be declined ethical approval.

### 7.5.3 Inadequate Review

Experiences of inadequate review include pragmatic as well as more fundamental problems. In Extracts 56 and 57 below respondents appear to have experienced inadequate review for more pragmatic reasons. Respondents reported that it was often

evident from the RECs comments that their proposals had not been closely read, while others felt the review was inadequate as RECs were overly critical of seemingly minor and trivial issues.

*Extract 56: (respondent 11, university)*

“I had one honours ethical form returned, because the student needed to submit the interview schedule (a decent request) but it had been submitted but was embedded in the text. It would suggest that it is too much for one board to review all applications in detail”.

*Extract 57: (respondent 34, research organisation)*

“Committees are overly critical on minor issues, such as including or leaving out a word in the questionnaire to be used, which prolongs the approval process by as much as a month, because the ethics committee only meets once a month”.

More fundamental complaints of inadequate review were evident in Extracts 58 and 59. These extracts reveal that RECs are not always capable of identifying ethical issues or competent enough to provide adequate justification for the decisions they make. Another more fundamental complaint was that RECs did not help researchers address the ethical problems they point out.

*Extract 58 (respondent 8, university)*

“...very very poor and inadequate review, very long turnaround time, that delayed the data collection phase by 6 months on a funded grant, and yielded finally approval comprising a one line email, saying the study was approved. In my view the study was potentially riddled with ethical dilemmas that any REC should have had some recommendations on”.

Extract 59 (*respondent 47, research organisation*)

“RECs give poorly substantiated reasons for ethical decisions and often comments on areas needing correction come back with no suggestions or examples of what could be done”.

Inadequate review may be attributed to the incompetence of an REC due to insufficient training. While RECs have a responsibility to be trained in both research ethics and research methodology, a study of RECs in Africa revealed that only 40% of REC members in the study received ethics training prior to joining their committee while 52% received training after joining their committee (Milford et al., 2006). In a study of health RECs in South Africa Moodley and Myer (2007) similarly found that in only two of the 12 institutions they reviewed had all REC members received training in research ethics, while at other institutions none of the REC members had been trained, at the time of the interview. As with problems with slow turnaround, inadequate review may also be attributed to the high workload of RECs, the lack of remuneration, and the resulting difficulty in recruiting experienced members (cf., Dada & Moorad, 2001).

#### 7.5.4 Acknowledgement of the Shortcomings of RECs

As Extract 60 reveals, some researchers reported negative experiences of ethics review, but were more sympathetic to the plight of RECs and acknowledged that RECs themselves may have difficulty correcting their shortcomings for institutional and bureaucratic reasons.

Extract 60: (*respondent 25, university*)

“Generally RECs have little opportunity to do anything other than scan briefly for obvious shortcomings in the theoretical grounding and research methodology of the applications that come before them. In fairness they are aware of this shortcoming, but for obvious reasons are presently unable to enforce a better structure to their review system”.

### 7.5.5 Ethics Review as Negative for Principled Reasons

Ethics review was also experienced as negative for principled reasons. Such principled reasons include, as implied in Extract 61, that the ethics review process is not capable of addressing the more fundamental ethical issues that arise during research.

Extract 61: (*respondent 6, university*)

“I feel that the more fundamental ethical dilemmas that I face cannot be addressed through the ethical review process – these dilemmas are too deep to address through a technical process”.

Chapter 6 of this thesis alluded to a fundamental difference in the types of ethical dilemmas experienced by researchers. There are standard requirements that need to be met in order to ensure all research is ethical (i.e., informed consent, confidentiality, scientific validity etc.) The purpose of RECs is to assist researchers with identifying these and ensure that they are adequately addressed. However there are also ethical dilemmas, termed ‘ethically important moments’ by Guillemin and Gillam (2004), that arise that cannot be predicted in advance and as such are not specifically addressed by RECs or ethical guidelines (see Section 2.2 and 6.5). Ethics review is not intended nor does it claim to be able to address all issues. For this reason researchers should be able to consult with the chair of their REC to obtain assistance with any unforeseen ethical issues that

may arise. Ideally research institutions should make ethics advisory boards available to their researchers to help prevent or address such problems.

As is evident in Extract 62, the lack of post approval monitoring was felt, by some, to make ethics review a meaningless activity that does not guarantee ethical research.

*Extract 62; (respondent 47, research organisation)*

“However, the rigor seems to end after the initial application has been approved: there is no follow-up by the committee to ensure that all protocols are followed in the implementation phase. In other words, researchers might actually treat the ethics clearance process as an unnecessary irritation, pay lip-service to it, but then go out and do things their own way”.

Although such researchers would lack integrity, previous studies have found that deviations from approved protocols do occur. In a study of researchers' acceptance of ethics review Mc Neill et al. (1992) found that 14% of the 92 researchers interviewed had themselves deviated from their approved proposal without REC approval. These deviations included changes to the study design, study sample, and changes to the participation required by participants. According to the National Institutes of Health (2002) continual review is compulsory for all clinical trials, in proportion with risk but at least annually. However, where social science research is concerned most RECs do not have the resources to monitor studies post-approval to ensure compliance with approved proposals (Wassenaar & Corbella, 2007).

As Extract 63 reveals, another principled objection to the ethics review process came from those who felt that they themselves were capable of dealing with ethical issues and were not in need of assistance from an REC.

Extract 63: (*respondent 46, research organisation*)

“...does not the knowledge of research enable researchers to grapple with ethical issues? Where do the checks and balances stop, do we really need big brother to be over our shoulder?”

In response to the first part of Extract 63, even the most ethically informed and best intentioned researchers can still unintentionally harm research participants, and while ethics reviews are put in place to prevent this, they also function to protect the researcher and their affiliated institution against lawsuits and information being subpoenaed (Illinois White Paper, 2003). Moreover, in response to the second point raised in Extract 63, several authors (cf., Haggerty, 2004) have similarly accused RECs as acting as a gatekeeper to certain forms of research. The purpose of RECs, however is not to act as a gatekeeper or ‘big brother’. Their purpose should rather be conceptualised as analogous to peer review, a practice accepted by all *bona fide* researchers (Wassenaar & Corbella, 2007).

## 7.5.6 Additional Themes

### 7.5.6.1 Problems with the Review of Students' Work

A number of respondents, as illustrated in Extract 64, felt that the REC was not sensitive to the limitations of students' research.

Extract 64: *(respondent 4, university)*

“The main problem has been where the committee does not understand the limitations of student research – usually this is the case where the student has an experiment or a small scale study that does not permit generalisation – simply because the design is limited by cost and scope considerations”.

Others felt that ethics review was preventing experiential research training by insisting that all research with human subjects be reviewed by an REC. This concern is reflected in Extract 65.

Extract 65: *(respondent 7, university)*

“A further concern has been where committees make it difficult (with their sometimes rather burdensome procedures) for students to practice interviews, running focus groups etc. (as part of research training). We must de-link ethics procedures associated with research studies from student project and research training work”.

While it may seem unnecessary and burdensome to obtain ethical approval for practical components of students work it might be argued that because student researchers lack experience in both the ethical and technical aspects of research, they are more likely to harm participants or conduct poorly designed research. Therefore it might be argued that



ethics review should in fact be more rigorous for student researcher exercises, not less. Several authors (cf., Chamberlain, 1986) have shown that research training courses, including research ethics courses, benefit greatly from having a practical component. It is argued that courses with a practical component will increase student researchers' competence in both the ethical and technical aspects of research. The opportunity for students to experience the ethics review process prior to the commencement of practical research courses may thus be argued to form an important part of the learning process.

#### 7.5.6.2 Ethics Review as a Black Box

The code 'ethics review as a black box' was borrowed from Fitzgerald (2006) and used to capture researchers' frustrations with their own lack of knowledge about the ethics review process: how the ethics review process works, how proposals are reviewed and particularly what happens during the RECs meeting, is frequently unknown.

Extract 66: (*respondent 22, university*)

"It feels like ethical applications are sent off into the great unknown and then return sometime later from a great unknown with sometimes ambiguous comments which are hard to understand and seem to stem from a lack of agreement about what constitutes research."

While researchers obviously have a responsibility to familiarise themselves with the ethics review process at their institution, findings from this study reveal a need for institutions to actively educate their employees on the ethics review process, not only in terms of the requirements that need to be fulfilled, but in terms of the purpose, aims, process and practices of the committee.

### 7.5.6.3 Misconceptions of Ethics Review

Several of responses revealed misconceptions about the role, purpose and tasks of RECs on the part of researchers. As is evident in Extract 67, respondents often remarked that RECs do not limit their review to the ethical aspects of a study and comment on the technical aspects such as the research design and so on. This reveals a misconception as it is actually the REC's responsibility to review the technical aspects of a study. Poorly designed or invalid research is unethical as it wastes resources and participant's time and possibly exposes participants to unnecessary risks (c.f. Emanuel et al., 2000, scientific validity).

*Extract 67: (respondent 40, research organisation)*

“Generally helpful, except in those situations where panelists want to take on the role of work supervisors. In these cases, they want to comment on, or review, the specific details of the task (e.g., format of the questionnaire, ‘suggestions’ of adequate sample size) rather than restrict their comments to the ethical aspects of the project”.

Misconceptions of ethics review as evident in Extract 67, again illustrates a lack of knowledge and education of the ethics review process on the part of researchers. As illustrated by Emanuel et al.'s (2004) ethical framework, independent ethics review is an essential aspect of ethical research and as such education on the purpose and procedures of ethics review should be included in all training courses on research ethics. However, in general most social science training courses in South Africa have not paid particular attention to the ethical training of researchers (Wassenaar & Corbella, 2007), let alone the pragmatics of ethics review.

#### 7.5.6.4 Researchers' Frustrations with RECs

The sheer frustration of several researchers was evident in sarcastic responses, such as the respondents' response in Extract 68. Unfortunately such undifferentiated critiques dismiss the purpose of review along with frustrations and pragmatics.

Extract 68: *(respondent 9, university)*

"The problem is the inefficient way the REC sits on a mountain of proposals that they are not even able to understand or appreciate. It would be quicker to have research proposals translated into Russian and sent to Moscow via horseback".

#### 7.5.6.4 Poor Attitudes/Lack of Effort on the Part of Researchers

A few respondents were of the opinion that negative experiences of ethics review should be attributed to the lack of effort or poor attitudes of the researchers and not due to any limitations of the REC or ethics review process.

Extract 69: *(respondent 42, research organisations)*

"I have always made it a point to broadly consult some of my colleagues in the Committee to avoid overlooking any item in the proposal that might pose an ethical dilemma once the research gets underway. This has helped tremendously because it has ensured that I do not approach the submission of my proposals to the Research Ethics Committee complacently. Which I fear many of my colleagues' do -this is what I believe causes problems not the review process itself but the lack of effort and poor attitudes of researchers".

Similarly, Dada and Moorad (2001) in their review of the REC at the Nelson R Mandela School of Medicine, KwaZulu Natal, South Africa attribute the problems with RECs to

the poor quality proposals submitted for review, researchers' delays in responding to queries from the REC makes, and inappropriate responses to queries.

## 7.6 Further Discussion

This study reveals that researchers do have positive experiences with ethics review. Twenty-one percent of respondents described only positive experiences of ethics review. Thematic analysis revealed that ethics review was experienced as positive when it was perceived as being beneficial to the study and/or the researcher or as procedurally smooth. Documentation of such positive experiences of ethics review is useful to establish what it is about RECs that should be encouraged and replicated. Keith-Spiegel et al. (2006) point out that characteristics of an exemplary REC have not yet been studied. Moreover, the literature on ethics review in the social sciences has tended to focus on researchers' objections and resistances to ethics review. Similarly, a large portion of this chapter was dedicated to researcher's negative experiences of research ethics. In this study 42.6% of researchers described solely negative experiences of ethics review. Negative experiences of ethics review were coded as such for principled reasons, pragmatic reasons - including the slow review process and problematic forms and procedures, because of problems with the centralisation of review and inadequate review.

A study of the experiences (both positive and negative) of ethics review is important as Keith-Spiegel et al. (2006) suggest that the ethical behaviour of researchers is closely tied to their perceptions of and experiences with RECs. Drawing on organisational justice

research, Keith-Spiegel et al. (2006) asked 886 biomedical, social and behavioural researchers to rate 25 descriptors of REC functions and actions in terms of their importance. The authors found that researchers place high value on fairness and respectful consideration by their REC and that researchers' who have negative perceptions and who feel victimised by their REC are more likely to behave in a unethical manner in order to level the playing field. Such behaviour is detrimental to the REC, the institution, the researcher and their scientific work (Keith-Spiegel et al., 2006). From this perspective, the study of researchers' experiences of ethics review is important as negative experiences may impact on the range and quality of research being produced. The study of positive and negative experiences may assist RECs in improving their shortcomings and hence improve researchers' experiences, which may in turn improve researchers' ethical compliance.

The findings from this Chapter however revealed that in order for researchers' experiences of ethics review to improve, more is needed than just an awareness of the REC's strengths and shortcomings. The thematic analysis revealed that almost 90% of the negative experiences of ethics review described by respondents were a result of pragmatic problems, inadequate review and problems that arise as a result of the centralisation of review. It might be inferred from the lack of negative experiences for principled reasons that ethics review, is at least in theory, generally accepted and that it is primarily the procedures and practices of RECs that researchers have problems with. Subsequently, it might be argued that the majority of negative experiences reported are avoidable as pragmatic problems, inadequate review and problems that arise as a result of

the centralisation of review are likely (although unconfirmed by this study) to stem from a lack of training and education on the part of either researchers or RECs and poor REC procedures and infrastructure.

## 7.7 Summary

Analysis of Section C of the questionnaire revealed that the majority of respondents reported negative experiences of ethics review and that their negative experiences could be attributed to pragmatic problems, problems with the centralisation of review, inadequate review and some principled objections. However, in contrast to much existing literature, which portrays the relationship between researchers and RECs in a negative light, the findings from this study also reveal that researchers' do have positive experiences of ethics review and reiterate that the ethics review process does have the potential to improve the quality of studies and increase researcher's awareness and knowledge of ethical issues. The thematic analysis revealed a number of additional themes, including problems with the review of student work, and misconceptions and frustrations with ethics review.

A significant association was found between respondents' experiences of ethics review and the institution in which they were employed, with respondents from the university reporting more negative experiences than respondents from the research organisation. The majority of negative experiences reported, however, appear to be avoidable as they were a result of pragmatic problems, inadequate review and problems that arise as a

result of the centralisation of review and not a principled objection to ethics review. It is hypothesised that as such researchers' negative experiences of ethics review can be reduced through increased training and the improvement of REC procedures and infrastructure.



In this chapter the main findings of the study will be summarised, the limitations of the study will be discussed and recommendations for future research will be made.

### 8.1 Summary of Main Findings

The primary aim of this study was to profile social science researchers' experiences of ethically challenging incidents and ethics review. The study was therefore predominantly descriptive and exploratory in nature. Ethically challenging incidents reported included:

- Privacy, confidentiality and anonymity
- Harm
- Beneficence
- Poor science
- Role conflict
- Informed consent
- Recruitment of participants
- Publication issues
- Student issues
- Conducting research on people known to the researcher
- Using deception in research
- The communication of results to participants
- The abuse of power by researchers
- Whistle blowing
- Dealing with constraints imposed by funders

The majority of respondents described a negative experience (42.6%), while 36.2% described both positive and negative experiences while only 21.3% described positive experiences of ethics review. Ethics review was primarily experienced as positive when the ethics review process was perceived to be procedurally smooth and unproblematic or when it was perceived as beneficial to the study or researcher. Ethics review was experienced as negative for both pragmatic and principled reasons and because of problems with the centralisation of review and inadequate review by the REC.

A secondary aim of this study was to consider the ethically challenging incidents reported and respondents' experiences of ethics review in terms of the two institutions from which participants were selected. This was done by means of chi square analysis. The chi square analysis used to determine the association between the number of ethical issues reported per respondent and the institution at which they work revealed that researchers from the university reported significantly more ethically challenging incidents than researchers from the research organisation. Similarly, the chi square analysis used to test the association between researchers' experience of ethics review and the institution in which they work revealed that researchers at the university had significantly more negative experiences of ethics review than researchers at the research organisation. Two possible explanations for this were suggested. First, compulsory ethics review for social science research was only introduced in the university in 2005 while ethics review was introduced in the research organisation in 2003. As the process is still fairly new at the university the ethics review process and the proposal guidelines may not yet be as clear as they ought to be and faculty may not yet be familiar with the process. Therefore, it is

possible that more misunderstandings and delays occur at the university hence the more negative experience with ethics review. Second, ethics review at the university is complicated by the diversity of disciplines included in the Faculty of Humanities, Development and Social Science, many of which have very different epistemological and methodological standpoints.

In addition to achieving both the primary and secondary aims of this study, a number of additional findings were made. As previously suggested (cf., Wassenaar, 2006; Wassenaar & Corbella, 2006) Emanuel et al.'s (2004) framework of ethical principles was found to be relevant to social science research as it accommodated the majority of ethically challenging incidents described by respondents. While the framework was found to be useful, like much existing literature on ethics and social science research, it does not address the professional ethical issues that the respondents in this study reported. While such ethical issues should be addressed in both professional and institutional guidelines, it may be useful for general, universal ethical guidelines and frameworks to include professional issues pertinent to research. This study also highlighted that RECs and ethical guidelines and frameworks may never be able to preempt or even address every ethically challenging incident that may arise and that this is neither claimed nor intended. Such a reality is a result of the complexity of human interactions and cannot be used as a basis to reject ethics review or traditional ethical principles. Traditional ethical frameworks and principles should rather be used to ensure that researchers' responses to such ethically challenging incidents are ethical.

The importance of combining pragmatism and universalism in resolving ethical issues became evident in attempts to suggest an ethically correct course of action for the ethically challenging incidents reported. Several of the dilemmas reported revealed that researchers need to be familiar with universal ethical principles, institutional practices, contractual agreements as well as local practices in order to make decisions on the most ethical course of action. A strength of Emanuel et al.'s (2004) framework is that the authors acknowledge that in order for their framework to be universal, its practical application needs to be tailored to local contexts.

With regard to researchers' experiences of ethics review, it was found that very few principled objections were voiced and that the majority of negative experiences were a result of pragmatic problems, inadequate review and problems that arise as a result of the centralisation of review. It may therefore be concluded that the participants in this study did not have a fundamental objection to ethics review rather negative experiences appeared to stem problematic procedures and practices of RECs. It is hypothesised that such negative experiences may be reduced if REC infrastructure and procedures are improved and both REC members and researchers are appropriately trained and familiar with research methodology, research ethics and REC requirements.

Much existing literature on ethics reviews in the social sciences casts the relationship between researchers and RECs in a particularly negative light by focusing on researchers' frustrations with, and objections to ethics review. The findings from this study, however, reveal that researchers do have positive experiences of ethics review and illustrates that

the ethics review process does have the potential to improve the quality of studies and increase researchers' awareness and knowledge of pertinent ethical issues that might enhance the quality of their work.

While the lack of a clear hypothesis makes it difficult to draw definite conclusions, the results reiterate the need to ensure that RECs are well resourced and funded, that all REC members are adequately trained in both ethical and methodological aspects of research and a need to improve the ethical training social science researchers receive.

## 8.2 Limitations of this Study

The aim of this study was to survey the experiences of a large number of social science researchers in order to establish a representative profile of social science researchers' experiences of ethically challenging incidents and ethics review. As such, data was collected by means of an email questionnaire sent to 513 potential respondents. The low response rate (10.1%), however, limits the representativeness of the findings, even within the research population, and the generalisability of the study in general. The low response rate also leaves open the possibility of non-response bias.

Secondly, the data analysis of the findings was compromised. Many respondents reported more than one ethically challenging incident and numerous experiences of ethics review. Furthermore, many of the responses could be coded under more than one theme. As such, it was not possible to determine mutually exclusive codes which prevented the

association between certain ethically challenging incidents or experiences of ethics review and certain demographic details (i.e., years of experience or number of proposals submitted for ethics review) from being determined.

Thirdly, the lack of a pilot study meant that flaws in the design of the questionnaire were only identified during data analysis. For example, the section on demographic detail should have requested the name of the discipline to which the respondent belongs as it was evident from the analysis that the social sciences span a wide range of disciplines and that experiences of ethically challenging incidents and ethics review may differ depending on which discipline the researcher belongs to.

A final limit of this study involved the large variety of themes that emerged during the thematic analysis. The primary aim of profiling social science researchers' experiences of ethically challenging incidents and ethics review necessitated that each theme be presented and discussed. Consequently, an in depth analysis of each theme was not possible. The limited scope of this study also prevented qualitative interviews from being conducted in which more nuanced ethical issues may have been raised by respondents.

### 8.3 Recommendations for Future Research

This study provides a pilot study of ethics in social science research. It is recommended that further research be conducted using a similar design on a larger sample using a more reliable means of data collection (i.e., mail survey or individual interviews). Also,



extending the questionnaire to include categories such as REC membership, research training received, and ethics training received would be useful.

Recommendations for new research include a study that documents not only researchers' experiences of ethical challenging incidents but what course of action was taken to resolve some challenging incidents. Also, such research should determine not only researchers' experiences of ethics review but their knowledge of ethics review in general and the review system at their institution. Such a study would clarify, for example, whether it was researchers' lack of education or incompetent review that is associated with negative experiences. In this regard it would also be useful to review the training, resources, practices and procedures of specific RECs to determine their competence, efficiency and ethics capacity. In addition to studying researchers' experiences of ethics review it may also be useful to find out from researchers what it is that makes an REC either effective or ineffective.

The problems documented in Chapter 7 regarding problematic forms and procedures and the centralisation of ethics review highlights a possible research opportunity to create an empirically tested REC application form that could meet the RECs' requirements and be appropriate to all researchers who submit proposals to a particular REC.

This study is one of the few attempts to date to empirically document social science researchers' experiences of ethically challenging incidents and ethics review. It is hoped



that it will provide a foundation for more empirical research in this area that will ultimately improve the ethical dimension of social science research.

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## APPENDIX ONE: COVER LETTER

Dear Colleague,

### **ETHICS AND SOCIAL SCIENCE RESEARCH: A STUDY OF SOCIAL SCIENCE RESEARCHERS' EXPERIENCES OF RESEARCH ETHICS AND RESEARCH ETHICS COMMITTEES**

My name is Nicole Corbella and I am a Masters student in Research Psychology at the University of KwaZulu-Natal. I am conducting research on the experiences of social science researchers with research ethics and ethics reviews, for my thesis. This study has been approved by the research ethics committees of the University KwaZulu-Natal and the Human Sciences Research Council.

I would be most grateful if you would complete the attached brief confidential questionnaire, which invites you to outline your own ethical dilemmas as well as your experience of ethics review. The questionnaire should take no longer than 10 minutes to complete. It would be appreciated if the completed questionnaire could then be returned to me at 202501469@ukzn.ac.za as soon as possible.

Please read the attached informed consent form carefully before completing the questionnaire. If you are unable to complete either Section B or Section C of the questionnaire, I would be most grateful if you would nevertheless return the questionnaire and mark the section 'not applicable'.

Your participation is voluntary and if you decline to participate, there will be no penalties and you will not be prejudiced in any way. The choice of whether to participate is yours alone. However I would really appreciate it if you would share your thoughts with me.

You do not need to put your name on the questionnaire and no-one other than the researcher will be able to link you to the answers you give. Your answer sheet will be unlinked on receipt and your email will be deleted. All individual information will remain confidential. Records will be destroyed one year after completion of the study.

If you have any questions, please feel free to contact me at 202501469@ukzn.ac.za. If you have a complaint about any aspect of this study you may either contact the ethics committee of the University KwaZulu-Natal by phone 031 2603587 or by email ximbap@ukzn.ac.za or the Human Sciences Research Council by email jebotha@hsrc.ac.za (whichever applies).

It is hoped that this work will lead to a masters' thesis and a peer-reviewed publication.

Your participation is much appreciated.

Yours Sincerely  
Nicole Corbella  
(Research Psychology Masters student)

Supervised by:  
Doug Wassenaar PhD  
Associate Professor

## APPENDIX TWO: QUESTIONNAIRE

### **Questionnaire on Ethics and Social Science Research**

Completing the attached questionnaire serves as acknowledgement/confirmation of the following:

I hereby agree to participate in the abovementioned research. I understand that I am participating freely and without being forced in any way to do so. The purpose of this study has been explained to me, and I understand what is expected of my participation. I understand that this is a research project whose purpose is not necessarily to benefit me personally. I have received the email address of a person to contact should I have any questions or problems.

**I UNDERSTAND THAT MY NAME AND E-MAIL ADDRESS WILL BE UNLINKED FROM THE QUESTIONNAIRE, AND THAT MY ANSWERS WILL REMAIN CONFIDENTIAL.**

#### **SECTION 1: DEMOGRAPHIC INFORMATION**

1. Qualification:
2. Job Title/ Position Held:
3. Age:
4. Gender:
5. Years of experience as a researcher:
6. How long have you worked at your current institution?
7. How many proposals have you submitted for ethical review?
8. Number of peer reviewed publications?
9. Is your research predominantly
  - a) Quantitative
  - b) Qualitative
  - c) Both
10. Which research strategies do you most frequently make use of?
  - a) Survey
  - b) Experiment
  - c) Case study
  - d) Ethnography
  - e) Action research
  - f) Other: \_\_\_\_\_

#### **SECTION 2: ETHICAL DILEMMA**

Briefly describe one incident that you have faced, in your work as a researcher that was ethically challenging or troubling for you.

#### **SECTION 3: EXPERIENCE OF ETHICS REVIEW**

Briefly describe your experience of having your (or students') research reviewed by a research ethics committee.