

**Title: Nursing research ethics, guidance and application in practice.****Owen Doody and Maria Noonan****Abstract**

Ethics is fundamental to good research practice and the protection of society. From a historical point of view research ethics has had a chequered past and without due cognisance there is always the potential for research to do harm. Research ethics is fundamental to research practice, nurse education and the development of evidence. In conducting research, it is important to plan for and anticipate any potential or actual risks. To engage in research, researchers need to develop an understanding and knowledge of research ethics and carefully plan how to address ethics within their research. This article aims to enhance students' and novice researchers' research ethics understanding and its application to nursing research.

**Keywords** ethics, nursing, research**Introduction**

Ethics is rooted in ancient Greek philosophical inquiry of moral life and relates to a system of principles which can considerably change previous thoughts, actions and decisions (Johnstone 2009). Within research, ethics is an essential measure to protect society, and the earliest research ethics code emerged in the 19th-century Prussian (Vollmann and Winau 1996). While ethics codes have developed over time the question remains: can unethical research practice still arise today? The harsh truth is that without due attention, application and awareness it may. Unethical research always has the potential to occur, as the principles on which ethical research are based are attributed to the beliefs of that era and can change over time. For research to be conducted ethical approval is required from a research ethics committee or institutional review board in order to protect the rights, safety and well-being of participants. This article aims to enhance students and novice researchers' knowledge and understanding of nursing research ethics and its application through the core principles identified by the Nursing and Midwifery Board of Ireland (NMBI) (2015): autonomy, beneficence, non-maleficence, justice, veracity, fidelity and confidentiality.

**Development of ethics codes**

Since the 19th century, ethics codes have been developed to protect research participants, often in response to poor practice (Nuremberg Code, 1947; Declaration of Helsinki, 1964, 2013; Belmont Report, 1979; International Ethical Guidelines for Biomedical Research Involving Human Subjects, 2002; European Union directive/regulation on the conduct of clinical trials, 2014). These codes protect participants through voluntary consent, freedom from coercion, appropriate risk-benefit ratio, respect for autonomy, justice and fair selection. Within these codes, vulnerability is acknowledged where capacity issues are present. However, capacity can be addressed through the process of an independent review committee, informed rather than voluntary consent, and appointment of legal guardians. While the developments of ethical codes have been progressive, they need to be viewed in light of the fact that health research has a history of abuse, where the interests of participants have often been sacrificed for scientific or state gain. These violations of

human rights within research are among the darkest events in history and span the 20th century (Table 1).

**Table 1. Studies highlighting abuse/violations of human rights**

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World War II Nazi experiments. One example aimed to learn how to treat hypothermia. Participants had to endure ice-water tanks or stand naked in below freezing temperatures for several hours so different ways of warming survivors could be assessed (Berger, 1990; Bogod, 2004).

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The Tuskegee syphilis study (1932-1972). Researchers purposely withheld treatment to 399 African-American syphilis sufferers to study the long-term effects of the disease (Brandt 1978). Bill Clinton as president made a public apology to the participants on behalf of the nation in 1997.

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Lying-In Hospital, University of Chicago, 1950–52: an experiment started whereby 1000 pregnant women were administered diethylstilbestrol to prevent miscarriages (United States District Court, 1978). These women were engaged in a double-blind study without consent and 20 years later their children had high rates of cancer and other abnormalities.

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In the 1950s mind-control research was conducted at the McGill University Montreal. Psychedelic drugs were administered to 52 unknowing patients to conduct brainwashing experiments for the CIA (Rauh and Turner, 2016).

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In the Jewish Chronic Disease Hospital (1963). 22 elderly patients were injected with live cancer cells to discover how healthy bodies fight the invasion of malignant cells (Katz et al 1972).

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Willowbrook Study, 1963–66: children with disability were intentionally infected with hepatitis to investigate the course of the disease and to test a potential immunisation vaccine. Most striking is the fact that some individuals were fed faecal matter in order for them to become infected (Rothman and Rothman, 1984).

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National Women’s Hospital Auckland Study, 1966: a doctor conducted a study over 20 years whereby he withheld treatment to 160 women with abnormal cervical smears in order to prove cervical abnormalities would not lead to cervical cancer. Women were enrolled without their knowledge or consent (McIndoe et al, 1984).

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Stanford University, 1971: a social study ended prematurely due to abusive behaviours generated among participants assigned the role of ‘guards’ towards participants assigned the role of ‘prisoners’ (Haney et al, 1973).

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Los Angeles, 1989–91: over 700 babies and 1500 6-month-old children were given an experimental measles vaccine called EZ. Parents were not informed of the experiment or that the vaccine was unlicensed (Awadu, 1996).

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In the Bristol Royal Infirmary (1991-1995). 30-35 children underwent heart surgery as experimental subjects and died unnecessarily as surgeons operated despite poor survival rates and introduced new techniques (The Bristol Royal Infirmary Inquiry 2001).

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Amnesty International has documentation of cases where prisoners have been used as experimental subjects and BBC News reported that prisoners in Iraq were used to test chemical weapons (BBC News, 1998, 2002; Amnesty International, 2006).

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In recognition of the importance of ethical research, and to protect all involved in the research process, international nursing regulatory boards have developed and provide guidance for nurses (Canadian Nurses Association, 2008; Royal College of Nursing, 2009; American Nurses Association, 2010; Australian Nursing Federation, 2012; International Council of Nurses (ICN), 2012; NMBI, 2015). Good ethical nursing research conduct implies adherence to ethical standards where research studies are:

- Subject to scrutiny by an independent ethics committee/ board
- Scientifically sound
- Conducted by researchers who are supervised or have adequate expertise; and
- Adhere to ethical principles throughout the research process

(Richards and Schwartz, 2002).

While diversity in principles exists across the literature, this article focuses on the application of the core principles identified by NMBI (2015), as these principles ensure that the full spectrum of ethical issues are addressed. While there may be an

overlap between principles, it is useful for students and novice researchers to consider each in isolation.

### **Autonomy**

Autonomy considers participants as independent people able to make their own choices and manage their concerns. Thereby when deciding to become involved in a study, participants should be able to make a free, independent and informed choice without coercion (Newell and Burnard, 2011). Participants should be able to express personal decisions, free of outside interference and to have those decisions honoured (Butts and Rich, 2013). Researchers must ensure participants have the right to self-determination (i.e. choose whether or not to participate). To ensure this, participants must receive full disclosure of information outlining the nature of the study, their right to withdraw at any time without consequence, and an identification of the risks/benefits to allow an informed choice (Polit and Beck, 2013). However, the participants' ability to withdraw may not always be possible, such as after analysis and publication, or if they responded to an anonymous questionnaire.

In some cases, people may have diminished levels of autonomy (e.g. babies, those with dementia, or intellectual disability) and need additional protection due to their ability to give informed consent. Special safeguards to protect their autonomy are therefore required, as 'autonomy' considers the capacity to be one's own person, and to make one's own decisions freely, based on personal reasons and motives, and not because of manipulation or coercion (Newell and Burnard, 2011; Polit and Beck, 2013). Full autonomy requires participants to understand fully what is being asked of them and the effect participation will have on them; to be afforded the opportunity to ask questions before/during/after the study; and to comprehend that it is their choice to participate.

Essential components within a valid informed consent process are: disclosure of information, comprehension, competency and voluntariness (Beauchamp and Childress, 2012). In addition, Gillon (1985) identified three types of autonomy: autonomy of thought (choice) or thinking for oneself; autonomy of will (capacity) or freedom to do something based on one's own deliberations; and autonomy of action (sovereignty: governing oneself) or freedom to act as one wishes. To help researchers uphold these components, the authors recommend essential elements be addressed (Table 2).

**Table 2: Elements participants must be aware of to give informed consent**

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| <ul style="list-style-type: none"> <li>• The title of study</li> <li>• The researcher(s) name, place of work, qualifications and contact details</li> <li>• The study population</li> <li>• The purpose of study</li> <li>• The study procedures and steps for data collection</li> <li>• The potential risks</li> <li>• The potential benefits</li> <li>• How anonymity or confidentiality will be upheld</li> <li>• How data will be collected</li> <li>• Who will collect data</li> <li>• How data will be stored</li> <li>• Who will have access to data</li> <li>• Participation is voluntary</li> <li>• The participant has the right to refuse to participate or withdraw at any time</li> </ul> |
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- The participant can choose not to answer any question, stop or cease their involvement at any stage
- The opportunity to ask the researcher questions related to the study
- How participant can obtain the results of the study
- Both parties will receive a dated and signed consent form

### **Beneficence**

Beneficence seeks to do good or to benefit participants, so research should help/benefit individual participants and society as a whole (Beauchamp and Childress, 2012; Parahoo, 2014). Beneficence requires researchers to take actions to benefit and promote the welfare of participants (Butts and Rich, 2013). To ensure this, a risk–benefit assessment should be conducted, considering all potential and perceived benefits. For example, a participant may overestimate the benefits of taking part in an experimental treatment in a chance to gain access (Wertheimer, 2013). While it is common in qualitative research that participants may not directly benefit from their involvement in a research study, it is also worth noting that participants often experience a cathartic effect from telling and having their story heard (Davies and Gannon, 2006; Elmir et al, 2011; Rossetto 2014). Beneficence of any action can be extremely personal and may differ between individuals, where what benefits one person might not benefit another. Researchers should consider what benefit will occur for those being invited to participate and society at large. Often, benefit is interpreted in the broadest sense and not always as the direct benefit of participating in the research; therefore, it is common and acceptable for researchers to offer greater potential benefit to society rather than individual participants. Where incentives are being offered for participation, they need to be considered in terms of risk–benefit analysis, as incentives may affect the participant’s ability to make a truly autonomous decision to partake in the research. Often, although research may be of benefit, it has to be balanced against the vulnerability of the participants (intellectual disability, advanced age) and the research needs to address how they can support the participant before (easy-read format), during (familiar person present) and after (availability, counselling).

### **Non-maleficence**

‘Non-maleficence’ means seeking to do no harm. Researchers have a responsibility to balance potential benefits against potential risks to reduce possible risk and safeguard the protection of participants (Parahoo, 2014). In research, no excessive physical, emotional or psychological demands should be placed on participants (Polit and Beck, 2013). While physical harm may be easily recognised and therefore avoided or diminished, emotional, social or economic factors may be less apparent. Ensuring that support mechanisms (e.g. counselling, employee assistance programme) are in place for participants who become distressed during or after data collection is important, especially when there is potential to highlight sensitive information, past experiences, or when it is difficult to anticipate the direction of data to be collected.

Participants should not be compromised by the demands of the study, and if a participant becomes upset or uncomfortable, the researcher should offer the participant the opportunity to cease and only reconvene at their discretion. Participants should also be afforded a choice of venues in order to reduce inconvenience and opportune costs imposed, such as travel or allowing the researcher into their home (Burns and Grove, 2013). Researchers must also be mindful of the possibility that misconduct or unethical practices could be disclosed, and be familiar

with the health organisations, ethics review board and governing body's policy guidelines in these situations.

NMBI (2015) has highlighted that the researcher should have a clear reason for the disclosure and seek support from their supervisor, ethics committee and other relevant people, and that all decisions are clearly documented. Often overlooked in the process is the risk to the researchers themselves, as they often engage in the research process as a lone worker. Here, the researcher should adhere to their local health authority lone worker policy and maintain a visit proforma that is accessible to colleagues/supervisors monitoring the visits. In circumstances where researchers do not work within a health authority, they should check guidance from the ethics review committee/institutional review board, seek out and consult with their supervisors/colleagues, and maintain a visit proforma monitoring the visits.

### **Justice**

According to the principle of justice, researchers are obliged to treat participants fairly and equitably throughout the research study. Justice should also be applied when providing the opportunity to partake in research and ensure anonymity, privacy and fair treatment (Dempsey and Dempsey, 2000). Within the principle of justice, the researcher is obliged to distribute benefits and risks equally, without prejudice, and certain individuals, groups or communities should neither bear an unfair share of the burden nor be unfairly omitted/excluded from the potential benefits of participation. Alperovitch et al (2009) described two elements of the principle of justice, namely equality and equity, which require research participants to be justly chosen based on the purpose and expected outcome of the research—including thought for the participant as an individual and as a member of society. Research participants in studies should be similar to those who may benefit from the outcome of that research, and be selected for reasons related to the phenomenon being investigated, rather than for convenience (Pratt and Loff, 2011). This principle often proves challenging for researchers in ensuring that all groups in society, regardless of perceived vulnerability, are able to benefit from being involved in research. Avoiding including, or making it difficult to include, any group in research based on perceived vulnerability could be described as 'unjust', as it could be argued that all participants in research are vulnerable because of the possible power relationship between them and the researchers (Riley et al, 2003; Karnieli-Miller et al, 2009). Also, researchers should consider participants' involvement and reimburse them for any costs they might incur.

### **Veracity**

Veracity involves the responsibility of the researcher to tell the truth about the study and the absence of deception. Individuals have the right to be told the truth and not to be deceived about any aspect of the study (Parahoo, 2014). All aspects of a research project require description and clarification by the researcher who must make every effort to ensure participants understand all aspects of the study. Participants should be aware of the expected involvement, duration (i.e. time commitment), what happens to their information, and who will have access to their information. The principle of veracity is often linked with respect for autonomy and is grounded in respect for persons.

For a person to make a choice, they must have the relevant information to make their decision. Moreover, this information must be clear, logical and truthful. To present clear and logical information, the researcher should avoid cloaking information in jargon or language that fails to express information in a way that can be understood by the participant. Truth-telling can be dishonoured in at least two ways: first, by the act of lying, or the deliberate exchange of inaccurate information; and, second, by omission or the deliberate withholding of information.

### **Fidelity**

Fidelity is where trust is given and obtained between the researcher and participants, and involves the researcher maintaining confidentiality (Macnee and McCabe, 2008; ICN, 2012). Participants place trust in researchers and this creates an obligation to safeguard them. The researcher must ensure that participants have an understanding of the risks and foster a trusting relationship to safeguard the rights of the participants (Parahoo, 2014). On agreeing to participate in a research project, participants are entrusting themselves to the researcher, and it is essential that researchers be open and honest so participants can make an informed decision. As part of this process, participants should know they can withdraw from the research at any time (where possible, acknowledging limits expressed in the autonomy section above) and that doing so will have no consequences. This trusting relationship is a two-way process, with researchers needing to trust research participants—for example, about being honest in their descriptions of their experiences or taking medicine according to the study protocol. Where a trusting relationship develops, participants are more likely to remain in the study and are not surprised by the burden of participation (Coghlan and Brydon-Miller, 2014).

### **Confidentiality**

The researcher is responsible for guaranteeing confidentiality of participants and their data. Personal information obtained must not lead to identification of participants and should not be made available to others without participants' consent and prior knowledge. There are extraordinary circumstances where information may have to be revealed without the permission of participants, thus breaking confidentiality. These situations include public interest and safety, or when the researcher believes that there may be a danger in non-disclosure (NMBI, 2015). Here, the researcher must have a strong reason for the disclosure of information and should seek advice and assistance from the research supervisor, ethics committee and other relevant persons, with all decisions clearly documented (NMBI, 2015).

Researchers can ensure that confidentiality is upheld by allocating an identification number or pseudo-name to participants, so that identifiable information is successfully secured and that identifying information is not entered into a computer system or other potentially accessible database (Polit and Beck, 2013). Where small samples and/or quotes are used, there is the potential for participants to be identified, so when transcribing, analysing data and writing up findings, researchers should exclude individual expressions or language nuance, and only include information in fitting with the findings. This can be achieved by the masking of quotations in the presentation of results, whereby specific sayings, expressive mannerisms or details can be masked by using [...] to protect the identity of the participant or other parties.

Raw data should comprise the name and/or identifiers (code, pseudonyms) that can be used to connect the participant's data to their name. While researchers have access to this information, it should not be contained in the final report, nor should anyone other than those stated in the consent form have access to the data (Dempsey and Dempsey, 2000). Confidentiality should not be confused with anonymity, which refers to people being fully anonymous, and as participants become known to the researchers, true anonymity is not achievable (Scott, 2005). Therefore, when participants engage in face-to-face contact with the researcher, it is considered unrealistic to promise anonymity and more appropriate to promise confidentiality. The terms 'anonymity' and 'confidentiality' are used interchangeably, but they are not synonymous—anonymity is a form of confidentiality, where participants' identities are kept secret i.e. data do not include any identifiers, codes or unique information that can be used to identify the participant.

Participants have the right to exclude themselves, or their information, and thus express themselves selectively. This tendency varies among cultures and individuals. In research, the use of interviews can pose difficulties, as the direction of questions cannot always be anticipated, and probing questions are used to obtain meaningful information about the phenomenon under investigation (Richards and Schwartz, 2002; Parahoo, 2014). Therefore, participants may reveal intimate and personal details, and researchers should reassure participants that the information they disclose is confidential.

To uphold confidentiality, consideration must be given to access and storage of data, and the researcher should assign each participant an identification code/number that only the researchers has access to. Data should be stored in a locked facility and all electronic data should be password-protected. Participants should also be aware of where their data will be stored, for how long (duration stipulated by ethics boards is often 5–7 years), and how data will be destroyed after this time.

### **Conclusion**

Ethical issues are concerned with the rules and principles of human behaviour. It is the responsibility of the researcher to safeguard the participants' rights throughout all stages of the research (Holloway and Wheeler, 2010; Nieswiadomy, 2012). Research ethics is fundamentally concerned with the safeguarding of research participants from harm and limiting risk of harm.

Traditionally, ethical approval of research has been seen as an issue for medical/clinical research. However, it is now recognised that it applies to all research projects and a research ethics committee/institutional review board is charged with considering the ethics of proposed research projects, and agreeing as to whether the projected research is ethical—thereby protecting participants' rights, safety and wellbeing by reviewing all aspects of the study and approving its start-up.

A key component of research is informed consent (Shaw et al, 2011). It is the responsibility of the researcher to demonstrate that they have taken the necessary steps to guarantee that the participant whose consent is being sought has been given the necessary information in an understandable manner. Research results must always preserve participants' anonymity unless permission has been given by the participant to use his/her name. All research can in theory be harmful to participants and

researchers (Long and Johnson, 2007) and research should be seen as a privilege, not a right (McHaffie, 2000). Confidentiality is a considerable risk in research, as sensitive data are often collected and analysed (Polit and Beck, 2013). As a nurse researcher, it can be difficult to balance one's role as researcher with the caring responsibilities inherent in the profession (Eide and Kahn, 2008; Judkins-Cohen et al, 2013).

### Key points

- Knowledge and understanding of research ethics principles are fundamental to good research practice
- Without due cognisance of research ethics principals, unethical research practice may arise
- Researchers need to ensure all groups in society who will benefit from research are included, and where vulnerability is an issue this should be appropriately addressed
- It is the researcher's responsibility to demonstrate that they have taken the necessary steps to guarantee the protection of their participants
- The drive to conduct research and gain knowledge does not mean that the rights of participants can or should be sacrificed—research is a privilege, not a right

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