

**Ethical Principles  
for  
Researching Vulnerable Groups**

*Paul Connolly  
University of Ulster*

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# Acknowledgements

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This has been a difficult document to write. Alongside gaining the opinions of many organisations representing a range of different groups and communities, I have also sought the views of researchers and government officials. This document represents a careful attempt to properly balance the needs of researchers with the well-being and interests of those being researched. In attempting to produce a set of ethical principles that are clear and coherent but which are also practical and possible some compromises have had to be made. It has not been possible to incorporate all of the detailed suggestions made either by representatives of community organisations and groups or, equally, by other researchers and government departments. However, I do believe that the ethical principles contained in this booklet capture and address the core issues and concerns that have been raised by all those involved.

Needless to say, the content of this document is my responsibility and does not necessarily reflect the views of OFMDFM or the opinions of those listed above.

Dr Paul Connolly  
University of Ulster  
May 2003



## Introduction

Research plays a vital role in government. Good quality research provides an objective and accurate picture of the differing circumstances and needs that exist within society. It allows those in government to make sound and informed judgements about the issues that require attention and how they can best be tackled. Research also plays an essential role in identifying whether existing government policies and programmes are working or not and, in cases where they are not, what can be done to address this.

The Office of the First Minister and Deputy First Minister (OFMDFM) is not only committed to the pursuit of high quality research but also to the need to commission and conduct research with integrity that meets the highest possible ethical standards. It is with this in mind that OFMDFM has commissioned this set of ethical principles for research with vulnerable groups. It has arisen out of an extensive process of consultation with individuals and organisations representing a range of vulnerable groups within society including: victims of the conflict; children; minority ethnic people; the elderly; and people with disabilities.

The guidelines have been written and are intended for those commissioned to undertake research by OFMDFM that is primarily but not exclusively qualitative in its approach. They are not meant to replace existing ethical guidelines but simply to build upon and supplement existing codes of practice. OFMDFM expects all researchers that are commissioned by it to consider these principles in their own conduct and behaviour.

## What are research ethics?

Ethical issues should not be confused with methodological ones. It is quite possible to conduct a study that uses good techniques of data collection and produces important findings but that also pays scant regard to ethical considerations. Conversely, it is also equally possible

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to conduct a study based upon the highest ethical standards that is also methodologically flawed and contributes very little by way of useful findings as a result.

Research ethics are therefore not about the particular methods that researchers use and whether or not these are the most suitable or appropriate to elicit the information required. They are also not generally about the validity or reliability of the data collected or the accuracy or otherwise of how the data have been interpreted. While these are all extremely important issues, they are methodological rather than ethical ones.

Rather, research ethics involve a consideration of the conduct of researchers in relation to their own personal behaviour as well as how they relate to and treat others during their research. They are about identifying certain norms and standards of behaviour that researchers are expected to follow. This is the purpose of this present booklet.

## **Why do we need ethical principles?**

OFMDFM is responsible for a number of sensitive policy areas. Most notably these include the development of policy with regard to community relations and victims of the conflict. They also include overseeing the development and implementation of policies aimed at promoting equality of opportunity in a range of areas including religion, 'race', gender and disability. Moreover, OFMDFM is responsible for developing policy in relation to a number of vulnerable and excluded people, groups and areas in society, particularly through the New Targeting Social Need policy. Conducting research on such sensitive topics and with groups that can be vulnerable and marginalized presents particular challenges and raises a number of ethical issues.

Whilst most government and academic research is conducted to high methodological and ethical standards, in some instances, the experience of those participating in research has not always been

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positive. For some, they have been left with a feeling of being used and a perception that the researchers had little genuine concern for their particular needs or well-being. Such feelings tend to arise for a number of reasons including:

- being asked to participate in detailed interviews or focus group discussions while being told very little about the precise nature or focus of the research;
- not being shown any appreciation or recognition for the amount of time and effort they have given to the research;
- not being contacted again by the researcher(s) following their participation and thus not knowing what has happened to the information they have shared.

Others have felt that the whole research process has simply reinforced their general sense of powerlessness within society. Again, this can arise from a number of reasons including:

- not being consulted or involved in any capacity in relation to the design and planning of the research that is being conducted about them;
- having no say about the way they are expected to participate in the research;
- being asked to participate in one study after another and yet seeing nothing change in their lives as a result of this.

Finally, some have felt that their participation in research has actually been harmful. This can, for example, arise for a number of reasons including:

- Being asked to revisit and recount extremely stressful or traumatic experiences they have had and yet being offered no help or support in terms of dealing with the distress that this may cause them;

- Perceiving that the research study they participated in has led to a report being published that tends simply to reinforce existing stereotypes or other negative perceptions of them or their specific group or community;
- Although they had been assured of anonymity by the researchers, finding that they or their particular group or community have consequently been identified.

Such experiences are a problem for two main reasons. First, they lead to increasing levels of mistrust of and antagonism towards researchers among the groups or communities concerned. This, in turn, makes it much more difficult for future research to take place. Second, and more importantly, it tends to reinforce the sense of vulnerability and marginalisation of precisely those groups and communities that the research is supposed to be helping.

A need exists, therefore, for a clear set of ethical principles that can guide the conduct and behaviour of researchers so that the types of problems highlighted above can be avoided and, instead, good practice promoted that can help to build up trust and good relationships between researchers and particular groups and communities.

## Key ethical principles

There are three key ethical principles which OFMDFM expects researchers to consider in terms of their own conduct and behaviour. Researchers should, at all times, aim to:

1. Conduct their professional work with integrity and in such a way as to not jeopardise future research, the public standing of researchers or the ability of others to publish and promote the findings of their research.
2. Respect the rights and dignity of all those who are involved in or affected by their research.

3. Ensure as far as possible the physical, social and psychological well-being of all those who take part in their research or are subsequently affected by it.

There are a number of practical implications that arise from each of these three principles and these will be discussed below. For the sake of simplicity and clarity, these will be stated in the form of guidelines. However, it is important to recognise that it is not possible to develop a comprehensive set of ethical guidelines that deal with each and every eventuality. Rather, the discussion that follows below concerning each of the three principles and the key guidelines that arise from these should be regarded as indicative rather than exhaustive. It is expected that researchers take time to understand the spirit that underlies each of the principles so that they can translate and apply it to their own particular circumstances.

## **1. The professional integrity of the researcher**

It is essential that researchers conduct themselves in a professional manner characterised by openness, honesty and objectivity. This not only protects the dignity and well-being of all those involved in the research but also helps to maintain the public standing of researchers. Four particular guidelines arise from this general principle and these are outlined below.

- (1) *Researchers should be committed to the unbiased and objective pursuit of knowledge. They have a responsibility to report their research comprehensively and accurately, including the methods they have used and the data they have gathered. Researchers must avoid selectively reporting their findings or fabricating, falsifying or misrepresenting their findings in any other way.*

There is a clear and obvious responsibility upon researchers to report their findings accurately and comprehensively. However it is

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also essential that they are completely open about the methods and procedures they have used and provide adequate information about these so that the quality and validity of their work can be properly assessed by others.

- (2) *Researchers should interpret carefully the findings of their research, clearly report any potential limitations that may relate to these and only make claims or propose recommendations that are adequately supported by the data.*

In relation to this second guideline, this requires researchers, for example, being careful not to make generalisations about the population as a whole, or particular groups within it, from small, unrepresentative case studies. Similarly, it means that researchers analysing the data from large-scale surveys refrain from stating as fact what are actually only hypotheses about the likely causes of the patterns or relationships they have found in their data. In all cases, the need to ensure that conclusions and recommendations where appropriate relate clearly to the key findings of the research will maintain the integrity of the research and avoid concerns about bias.

- (3) *Researchers should recognise the boundaries of their own professional competence both in terms of their ability to use particular research methods as well as their substantive academic knowledge of the subject in hand.*

This guideline includes, for example, researchers not attempting to conduct a study involving detailed statistical analysis when they do not have the appropriate expertise to do so properly or, similarly, conducting detailed and in-depth qualitative interviews with children or those who have experienced trauma without the appropriate expertise of how to do this or without training in working with victims. What counts as 'appropriate' levels of expertise will clearly vary and will depend upon the nature of the particular piece of research. The key point here is that researchers identify explicitly the specific knowledge and skills

required to undertake the proposed research and ensure that they have these.

It is equally important that researchers are appropriately acquainted with the subject they are studying before they commence their research. At the very least, this will help to avoid unnecessary repetition of work that may already exist.

- (4) *Researchers should consider carefully the consequences of their own behaviour while carrying out research, especially as it affects those participating in the research or, where reasonably foreseeable, those subsequently affected by it. They should avoid conducting themselves in ways that may adversely affect the reputation of researchers more generally or that make it more difficult for future researchers to gain access to particular groups or communities.*

This final guideline is dealt with, practically, in the discussion below concerning the following two ethical principles. However, it is important to include it here as a reminder of the duty that researchers have to their colleagues. Given the importance of good, quality research as stressed at the beginning of this document, researchers have a clear responsibility to ensure that they maintain public confidence in what they do and thus safeguard the ability of others to continue to undertake research in the future.

## **2. Respect for the rights and dignity of participants**

As regards respecting the rights and dignity of research participants, this often amounts to little more than common courtesy as some of the examples of poor practice have highlighted above. A number of key issues arise from this, each with one or more guidelines deriving from them that will now be discussed in turn.

## Free and informed consent

The essence of free and informed consent is the right of the individual to be free to agree or refuse to participate in a study based upon a full and comprehensive understanding of the nature and purpose of the research. This, however, raises a number of complex issues and gives rise to five practical guidelines.

- (5) *Researchers should seek the informed consent of all those they wish to participate in their study. In the case of children this should include the child as well as their parent/guardian. Those involved should be allowed to make a decision based upon a full appreciation of what the research is about and what is expected of them. Researchers should ensure that information about the research is communicated in a way meaningful to the individuals concerned and that, where possible and appropriate, written as well as verbal consent should be gained.*

Where it is intended to collect and store personal data on individuals there is a duty under the Data Protection Act 1998 to ensure that potential participants are clearly informed as to the purpose of the research, the approach being taken and what it hopes to achieve, including the intended outcomes (i.e. whether a report will be produced and, if so, how it will be published and made available). The researcher should also provide clear details concerning what is expected of the individual (i.e. in terms of time commitment and what they will be asked to do), what will happen to the information they provide, the procedures in place to ensure anonymity and confidentiality and also the possible risks they may face as a result of participating in the research study (i.e. whether there may be difficulties ensuring anonymity or confidentiality).

In doing this, researchers should ensure that they provide such information in simple and clear language that is free from jargon. The amount of detail provided, the language used and the manner in which the information is given will also depend upon

the particular individuals concerned. It may not be appropriate, for example, to provide children with the same amount of detail concerning the purpose of the research study compared to adults. Moreover, for those who have visual impairments or whose first language is not English, it may be necessary to provide the written information in a different format in any case (i.e. in Braille or translated into a different language).

- (6) *When approaching an individual or group to request their consent to participate in a study, the researcher should ensure that they are free to decline and do not, in any way, feel either pressurised or obliged to participate.*

Researchers will, understandably, attempt to encourage individuals and groups to participate in their research by stressing the importance and potential value of their work. This, in itself, is not a problem so long as researchers do this honestly and without misleading potential participants or exaggerating the likely significance of their research. The key issue is that researchers respect the decision of those involved and do not persist in their attempts to persuade them once they have said no. This is particularly important in relation to those who feel vulnerable or marginalized within society who may well find it difficult to say no to a researcher whom they view as professional and powerful.

There are, however, other ways in which individuals can feel pressurised to participate. If a school has agreed for researchers to interview their children then the children may feel that they have no choice other than to participate. Alternatively the researcher may be in a position of authority over the individual concerned. This is often the case in terms of practitioner research where, for example, teachers wish to research their children or social workers research some of their clients. In such circumstances, and where appropriate, it may be a good idea to arrange for a third party to seek the consent of those involved.

Finally, care should be taken when approaching those from particularly vulnerable groups, including the elderly, who may find

it confusing or upsetting if approached directly with no warning. This, in turn, may lead them to make decisions regarding participation in research that they may later regret. In such circumstances it may therefore be more appropriate to use an intermediary as a way to contact them.

- (7) *It should be made clear to participants that they have the right at any time to withdraw from the research, either temporarily or permanently, without the need to provide a reason. The extent to which they are also able to retrospectively withdraw any consent they may have previously given and to require that their own data, including any recordings, be destroyed should also be made clear.*

As regards this guideline, no participant should feel that once they have initially given consent then they must participate in the whole study. Those participating in qualitative research who are being interviewed about their experiences of particularly traumatic events in their lives, including victims of the conflict, may find that the whole research process is more distressing than they had originally anticipated. In such circumstances, they should not feel obliged to continue with the research and also should not be put in a position where their distress is heightened by a concern they have about the personal information they had previously shared and how this might be used in the future. It is this latter point that provides the rationale for participants to be given the right to retrospectively withdraw their consent. However, it also needs to be accepted that there are limits to this, particularly when for example the research report has been completed. It is therefore important that researchers explain clearly and agree with participants the point at which they are no longer able to retrospectively withdraw their consent.

- (8) *Researchers should gain additional consent from participants for the use of particular data-gathering equipment, such as tape-recorders or camcorders. In seeking their consent to use such items the researcher*

*should also clearly explain what they intend to do with the recordings.*

- (9) *As a general rule, researchers should not purposely withhold any details regarding the nature or purpose of the research from participants. Where this is absolutely essential for the purposes of the research study they must:*
- *Make arrangements to fully inform the participants of all elements of the research study that were withheld or misrepresented to them as soon as possible after participation and the reasons for this;*
  - *The participants, on being informed of the true nature and purpose of the study, should normally be given the right to retrospectively withdraw their consent to participate and to require that their own data, including any recordings, be destroyed.*

This second guideline is of less relevance to large-scale surveys and is, rather, intended specifically for smaller-scale qualitative research. On first reading, it may seem to completely contradict the emphasis that has been given so far to the importance of researchers' professional integrity and being open and honest with respondents. However, there are occasions when researchers will only be able to gather particular types of data by withholding certain information for a while.

A simple example of this would be in a psychological experiment where researchers may have a hypothesis that participants will react in a particular way to being given certain information. If they were to tell participants what their hypothesis was before the experiment, then this may influence their responses.

Another example would be where a researcher wanted to study the services provided to older patients by a particular organisation. There may, for the sake of argument, have been













































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The Victims Unit  
Office of the First Minister  
and Deputy First Minister  
Block A5.33  
Castle Buildings  
Belfast BT4 3SR

**OR** Equality Unit – Research  
Office of the First Minister  
and Deputy First Minister  
Room E5.25  
Castle Buildings  
Stormont Estate  
Belfast BT4 3SR

Free phone: 080 8127 3333  
Textphone: 028 8052 2343  
Email: [info@victimsni.gov.uk](mailto:info@victimsni.gov.uk)  
Website: [www.victimsni.gov.uk](http://www.victimsni.gov.uk)

Telephone: 028 9052 3254  
Fax: 028 9052 8273