

Ethical Principles for Researching Vulnerable Groups

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May 2003

**Commissioned by the
Office of the First Minister and Deputy First Minister**

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Acknowledgements

A range of people from a variety of organisations were consulted during the preparation of this document. I would like to thank the following for their time and valuable insights and suggestions: Selwyn Black, David Bolton, Sharon Campbell, Seán Coll, Ann Cummings, Fiona Davidson, Stephen Donnelly, Bernie Duffy, Caroline Evans, Sheena Funston, Teresa Geraghty, Paul Hamilton, Arlene Healey, Julie Healy, Daniel Holder, Neil Jarman, Raman Kapur, Paddy Kelly, Patricia Lynas, Seamus Lynch, Derrick Matthews, Patricia MacBride, Alan McBride, Louisa McKee, Brendan Murtagh, Ulrike Niens, Jacqueline Reilly, Clare Quigley, Pauline Rice and Selina Yu.

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.

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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

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

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

concerns raised previously about how the older people were treated by that organisation. In such circumstances, there may be a clear duty for researchers to attempt to assess whether there is any basis to these concerns and also, by doing so, what could be done to address them.

The problem is that if the researchers were to be completely open with staff in the organisation from the outset about who they were and what their research was about then this may well influence their subsequent behaviour when the researchers were present observing them. It may therefore be necessary for the researchers to adopt more covert roles initially so that they can observe what goes on in the organisation without influencing what staff do because of their presence.

Clearly, any plan to withhold information has the potential to antagonise those involved and to lead them to mistrust researchers or become cynical about their behaviour and motivations. It is therefore important that such methods are only used where absolutely necessary and where a clear strategy is agreed to attempt to rectify any short-term damage that may have been caused through the requirement to gain the full, informed consent of the participants immediately following the research as detailed above. In addition, given the trauma that victims of violence have already experienced and their increased vulnerability because of this, the use of covert research with such groups has a strong potential to significantly impede the recovery process and cause further harm. In such circumstances covert methods should generally not be used with these particular groups.

Privacy

Just because an individual or group of people has consented to participate in a research study, this does not mean that they should be expected to divulge information on any aspect of their lives, however sensitive and personal to them. This is a particular issue for small-scale qualitative studies where the research may

be less structured and where, during face-to-face interviews, participants may also feel more under pressure to discuss issues that they would prefer not to. This gives rise to two key guidelines:

- (10) *Researchers should respect the privacy of research participants by making it clear to them that they are free to decide what information they wish to share with the researcher and that they should feel under no pressure or obligation to discuss matters that they do not wish to.*

It should be noted in relation to the above that the need to respect the privacy of participants is not just applicable to individuals but also to communities. Particular communities can have specific cultural or religious festivals to which they feel it may be appropriate to invite researchers along but on which they do not wish researchers to include detailed information.

- (11) *In cases where a researcher has already developed a relationship with an individual or group of people before inviting them to participate in a research study, they have a special responsibility to protect the privacy of those concerned. More specifically, they should seek their explicit consent if they wish to use information that the individuals may have shared with them prior to their participation in the research.*

As regards this guideline, while additional efforts will be required to maintain and demonstrate objectivity there are certainly some advantages to a person conducting research on a group or community that they either already have a relationship with or are a member of. The key point as regards privacy is that they need to make a clear distinction between their existing role and their new role as a researcher. This is important in ensuring, as stressed in the previous guideline, that participants maintain the right to decide what information they wish to divulge for that person to use in their research and what information they wish to discuss with them through their existing relationship.

Recognition of participants' time and efforts

Two guidelines arise regarding the issue of recognising participants' time and efforts:

- (12) *Researchers should ensure that they demonstrate proper recognition to the participants for the time and effort they have given to the research study.*

It is a matter for researchers to decide upon the most appropriate means by which they can recognise the time and effort that participants have given to the study. In terms of large-scale, quantitative surveys this may simply involve including an introductory note recognising the time and effort expected of those involved and thanking them for this. However, in smaller-scale and more in-depth qualitative research it may well be necessary to think of additional ways to recognise the greater time and effort expected of participants. This could involve providing refreshments, for example, to participants as they take part in interviews or focus group discussions. Providing gifts at the end of the study is another possibility and, for children, one approach that has proven successful is to present them with certificates following their participation acknowledging their contribution. At the very least, in relation to small-scale qualitative research it is expected that researchers thank the key participants either in person or by letter for their valuable participation.

- (13) *Researchers should not expect particular organisations or individuals to negotiate access to research participants or organise meetings with them on their behalf without first ascertaining if it would be appropriate to agree a fee with them for doing this, unless this is already an explicitly stated aspect of their roles and responsibilities.*

In gaining access to particularly vulnerable or excluded groups and communities, researchers often make extensive use of particular organisations or key individuals such as community workers. These are often expected to undertake a significant

amount of work in terms of both contacting potential participants and encouraging them to take part in the research and also making specific arrangements for the researchers to meet them. Such work does constitute a significant part of the research process and those expected to undertake it should have the right to some form of recognition and, if appropriate, payment for the services they offer.

Consultation

(14) In the design and conduct of their research, researchers should where appropriate make every effort to consult meaningfully with those groups or communities involved. Researchers need to decide upon the most appropriate means of consulting in each case. However, whatever means are chosen they should give those involved the opportunity to provide their views on the overall focus of the research, the approach that it intends to take and its intended outcomes.

The precise nature of the consultation will depend upon the particular groups or communities concerned and cannot be specified in advance. Full and meaningful consultation also requires significant time and resources and thus needs to be borne in mind when deciding what is feasible for the research. However, many groups or communities will have organisations that represent their interests and it is often good practice to establish an advisory group that includes members from those organisations. There may also be particular members of that group or community that could be invited to participate in the advisory group. Alternatively, or in addition, small focus group meetings could be held with members of the group/community concerned to help inform the nature and focus of the research and also to help decide the most appropriate methods to use.

Where an advisory group is established, its roles and responsibilities must be agreed with members at the outset. Researchers should pay particular attention to those members of

the advisory group from or representing the particular groups/communities involved and any support they may need to participate fully and meaningfully in the work of the advisory group. This may involve, for example, reviewing the language used, providing information in different formats or helping them to understand the particular procedures and processes involved in the research.

Keeping participants informed

- (15) *Researchers should ensure that, where appropriate, they develop mechanisms for keeping participants informed as to the progress of the research.*

The above guideline is not always possible or necessary in relation to larger-scale survey research. However, for more qualitative, small-scale studies where participants have given significant amounts of time, it is important to consider ways of keeping them appropriately informed as to the progress of the research.

Concluding relationships with participants

- (16) *Researchers should be mindful of the significance of the relationships that may have developed between themselves and the research participants during the course of the study and should develop a clear strategy for concluding those relationships when the research has been completed.*

During the course of a research study, particularly research that is small-scale and qualitative, participants often share quite sensitive and personal information with the researcher(s). This, in turn, can tend to encourage those participants to give increased significance to their relationships with the researcher(s). This can occur, for example, in extended research with children or victims of the conflict and those who have experienced trauma where a good rapport can develop between them and the researcher and

where they come to value and depend upon their meetings with the researcher. It can also occur in research with those who feel relatively isolated and who may come to appreciate and benefit from the interest and company provided by a researcher.

In such circumstances, there is a duty on the researcher to think carefully about the most appropriate way to bring the relationship to a conclusion at the end of the research. This will be helped by the researcher being clear at the outset of the nature and purpose of the research and its duration. However, particularly in relation to small-scale, in-depth qualitative studies, it may also require one or more final 'de-briefing' meetings where participants have the opportunity to discuss any final questions or issues they may have with the researcher.

(17) Wherever possible, researchers should ensure that feedback is given to participants regarding the findings of their research. The nature and extent to which this is done will depend upon the type of research carried out.

The above guideline can be seen in part as an extension of both the process of concluding relationships with participants but also of keeping them informed as to the progress and outcomes of the research discussed earlier. How this is done will depend upon the nature of the research itself. For large-scale surveys it would usually be sufficient to inform respondents at the time of data collection if a report is likely to be published and where and when they will be able to obtain copies. However, for small-scale, in-depth qualitative studies where respondents have been expected to invest much more of their time and efforts, researchers have a responsibility to provide feedback more directly. Again, the precise nature and form that this feedback would take will depend upon the respondents themselves and what is both suitable and practical.

The key issue here is the need to feedback the findings appropriately. It is sometimes not sufficient simply to send participants a full copy of the final report that may well be

relatively academic and technical. Depending upon the individuals concerned, it may be necessary to produce much shorter, non-technical summaries or to do so in different languages or in different formats that particular groups will more readily understand. For some, it may be necessary to offer verbal feedback.

(18) At the conclusion of the research study, participants should be given a means of contacting the researcher or research team in the future should any queries or issues consequently arise for them concerning their involvement in the research that they would like to discuss.

3. The well-being of all those involved

The final key ethical principle that should guide the conduct of researchers is the need to ensure, as far as possible, the physical, social and psychological well-being of all those who take part in their research or are consequently affected by it. Most simply put, this requires the researcher to make every reasonable effort to ensure that their research does not cause harm either to those who have directly participated or, more broadly, to anyone affected by it.

Three key issues arise from this principle, each with one or more particular guidelines that will now be discussed in turn.

Confidentiality

(19) Researchers should make every effort to protect the confidentiality and anonymity of research participants. They should also try to anticipate circumstances where this may be threatened and to make arrangements to address this accordingly.

Protecting confidentiality is especially important for research on highly sensitive areas such as that focusing on community relations or involving victims of the Conflict. Protecting the anonymity of participants requires very careful consideration of the details that are to be included in any report when using case studies. Even simply giving just the date or location or nature of an incident relating to the Conflict, for example, may well be enough to compromise the confidentiality of those involved.

Such considerations are not just of relevance to those conducting smaller-scale qualitative studies. A responsibility also falls on researchers conducting survey research to ensure that it is not possible to identify individuals from the data they report. The potential to unwittingly disclose someone's identity is not always as apparent when dealing with data involving larger samples. However, it can sometimes be possible to identify individuals especially when they are a member of a small or distinct group.

Also in relation to larger-scale, survey data there is a growing practice to make datasets available for secondary analysis. In such cases there is a responsibility on researchers to ensure that the data are completely anonymised and that any variable(s) or combination of variables that may lead to the identification of individuals are appropriately recoded or removed from the dataset.

(20) Researchers should take appropriate measures to store research data in a secure manner. In doing this, they should have regard to their obligations under the Data Protection Act 1998. Wherever possible, researchers should store their raw data in an anonymised form to prevent the identification of research participants from it.

The need to appropriately anonymise even the raw data that a researcher holds (including written notes) is important in relation to research on particularly sensitive topics so that participants are protected should the data be lost or stolen. In terms of recorded data (i.e. tape recordings of interviews or video recordings of

people's behaviour), these should be transcribed where appropriate, the transcriptions anonymised and consideration given to the destruction of original recordings.

(21) Researchers need to clearly inform participants prior to the commencement of the research of the procedures taken to ensure confidentiality and any limitations associated with these.

There are three particular instances where researchers may not be able or willing to protect the confidentiality of their research participants:

- In relation to research on children, should the researcher have any concerns regarding the safety or well-being of a child participant they have a duty under the Children Order (NI) 1995 to report their concerns to a relevant authority (usually their local duty social work team or the NSPCC);
- More generally, where there is sufficient evidence for the researcher to have serious concerns about the safety of a participant (adult or child) or about others who may be at significant risk because of the behaviour of that participant, then they have a moral obligation to inform an appropriate third party;
- Even where information is provided by an individual in confidence to a researcher, this information does not enjoy legal privilege and may be liable to subpoena by a court. This is a particular problem, for example, in self-reported crime surveys where individuals may be asked about specific illegal activities that they may have been involved in. In such circumstances, participation rates may be extremely low unless confidentiality can be assured. One way of addressing this specific problem is to arrange for a third party to anonymise the data before forwarding it onto the researchers to avoid the risk presented by subpoena (although even the third party involved can potentially be summonsed to give evidence). Any such arrangements will need to be explained clearly to participants.

- (22) *Researchers conducting research with children should make themselves fully aware of child protection issues and procedures and, where appropriate, attend training on this matter. For those who will have direct contact with children, police checks should be completed before they embark on the research.*
- (23) *Where a researcher wishes to use information provided by a participant in their report that may be difficult to completely anonymise, they must explain the risks associated with this to the individual involved and seek their permission to use that information.*

The adverse effects of participating in research

- (24) *Researchers should make every effort to ensure that their research participants feel secure and at ease during the research process. Where possible, venues for the research to be conducted should be chosen that are familiar to participants and where they feel confident. The decision to use focus groups, and what their composition should be, should also be considered carefully with the needs and wishes of individual participants in mind. Finally, bearing in mind that the well-being of the participant is paramount, if appropriate, they should also be given the opportunity to invite a third party along for support if they wish.*

Participating in research can be an unsettling experience for some people, particularly children, victims of the Conflict and those who have experienced trauma, older people or others who may feel vulnerable or marginalized. It is therefore important that participants be encouraged to invite a friend, colleague or parent/guardian along with them to an interview if they would feel more confident in doing so. This, however, does raise methodological issues concerning the possible effects this may have on the participant's responses and this would need to be considered carefully by the researcher.

Researchers also need to give careful consideration to the venue in which the research is to take place. This is clearly a factor when conducting research on issues of community relations and also with victims where they may well feel extremely vulnerable attending an interview held in certain areas and localities. For children, it may well be quite intimidating to participate in research held in an unfamiliar environment. Care should be taken, therefore, to ensure that research participants are interviewed in what they consider to be safe and familiar settings. This could include their own homes, local community centres or, for children, their school or youth club.

Finally, the use of focus groups has become a popular method for interviewing and consulting particular groups and communities within the population. However, while they may be convenient and cost-effective, they need to be planned very carefully, especially when the focus of the research involves discussing sensitive and/or traumatic events. In such circumstances, participating in a focus group may be helpful to the individual involved and be experienced as a means of support, especially if others in the group are friends. However, for others it can be a deeply impersonal and potentially traumatic experience in itself, especially in circumstances where the individual concerned may not know anyone else in the group and yet is expected to talk about very sensitive and personal issues.

(25) Researchers intending to conduct research with individuals who have experienced traumatic events should be very clear about the precise focus of their research and the information they require. They should avoid asking participants about the actual traumatic events they have experienced unless this is absolutely necessary and, if they do, they should do so with extreme care and sensitivity.

During more in-depth, qualitative research where participants are being interviewed about particularly sensitive or traumatic events in their lives, extreme care needs to be taken by the researcher.

Some may not have the capacity to deal with the feelings and emotions that revisiting such events will raise within them. In such cases the interview itself may cause significant harm and lead to them experiencing secondary traumatisation.

In relation to participants who have experienced traumatic events, therefore, researchers and funders need to consider extremely carefully whether the research is absolutely necessary. If they feel that it is, they need to be extremely clear about the information they require and to explain this clearly to the participants. Great care should be taken to keep the interview focused and not to encourage participants to talk about traumatic issues and events if these are not the primary focus of the research.

(26) Before conducting research with individuals who have experienced traumatic events, researchers should agree with them what arrangements for support they would like to be made both during and after the research.

In relation to qualitative research, even where researchers attempt to keep their interviews extremely focused and to limit discussion of the actual traumatic events that participants have experienced, this may well not be sufficient to avoid those involved feeling upset or distressed by the process. The researcher therefore needs to explain their concerns with the participant and to discuss with them what arrangements they would like to be made in terms of possible support. This could include simply having a friend or relative present in the interview or waiting to meet them afterwards.

However, it may also mean having suitably trained counsellors available to meet them either after the interview or at a later date. At the very least, it should include the researcher identifying appropriate support mechanisms and having details at hand to pass on to the participant. Overall, such issues need to be discussed clearly with each potential participant and arrangements for support agreed and set in place before the research begins.

Finally, it is important to stress that the need to consider the support that participants may require is not restricted to qualitative, face-to-face interviews. For researchers conducting broader surveys they should also consider what practical support can be offered. At the very least this should involve adding the contact details of relevant support organisations to the questionnaire that is being distributed.

(27) Researchers intending to conduct research directly about traumatic events with those who have experienced them should ensure that they are fully aware of the nature and effects of trauma prior to commencing the research. They should also have decided upon clear strategies for dealing with incidents where participants become extremely distressed. On no account should untrained researchers attempt to provide advice or counselling to such individuals.

Again, this guideline relates mainly to more qualitative research where interviews are more unstructured and in-depth. For some participants they may not have discussed their experiences and concerns with another person before and thus, within the context of the interview, may feel a desire to disclose significant amounts of information. They may also ask the researcher directly for help and advice or may become extremely distressed. Such situations are difficult to control and it is therefore important that researchers intending to interview those who have experienced traumatic events gain a full awareness of the issues surrounding trauma beforehand. On no account should researchers attempt to counsel participants directly.

Finally, it is extremely important that participants are in control of the whole process and have the ability to temporarily stop interviews, for example, if they find them too distressing or withdraw entirely from the research either for a period of time or completely. For those who suddenly disclose a significant amount of information during an interview, they may later seriously regret this and feel extremely anxious about what will happen to this

information. It is for these reasons that the earlier guideline (Guideline 7) regarding the right to withdraw from research and retrospectively withdraw consent should be explicitly discussed and made clear at the beginning and end of the research process.

Consequences of research

(28) Researchers should be aware of the possible consequences of their research when published or disseminated more widely. Wherever possible, they should make every effort to anticipate and to guard against the misuse or misrepresentation of their findings, especially where it could potentially cause harm to those individuals or groups and communities that took part in the research.

In relation to the above guideline, it is accepted that it is not possible for a researcher to completely control the way in which their published research may be used by others. However, it is possible for researchers to attempt to anticipate ways in which their findings may cause harm to others and to attempt to guard against this.

For example, it may be possible to anticipate that some of the findings of a particular research study may be misrepresented by some to reproduce negative and unfounded stereotypes about a particular community. In such circumstances it is the responsibility of the researcher(s) to have regard to the potential for such misrepresentation when presenting their findings (both in their reports and also through press releases and other forms).

The Safety and Well-Being of Researchers

(29) In designing and undertaking research, researchers have a duty to safeguard their own safety and well-being as well as those who work for them. This means researchers ensuring that they make every reasonable effort to avoid placing themselves or others in situations where they may be at risk of physical harm. It also means considering the

likely emotional effects that researching particularly traumatic issues or events may have on the researchers involved. In such circumstances, appropriate support mechanisms should be made available for researchers that could include full de-briefing sessions and the opportunity to meet with a counsellor where necessary.

This final recommendation reflects the fact that when we consider ‘the well-being of all those involved’, this also includes researchers. The need for researchers to ensure that they do not place themselves in situations where they may be at risk of physical harm is an obvious point. What is less obvious, however, is the equally important need for researchers to consider their emotional well-being. Conducting lengthy, in-depth interviews with those who have suffered traumatic events is likely to have an effect on the researchers involved. It may be that they feel ‘emotionally burdened’ and just need to talk this through with someone. However, it is also possible that a researcher may actually experience what is called ‘vicarious traumatisation’ where their identification with the experiences and pain of the interviewee leads them to develop a form of traumatisation themselves. Depending upon the type of research being conducted and its focus, it may well be necessary to at least provide the opportunity for researchers to talk to a qualified counsellor.

Appendix: Summary List of the Ethical Principles

1. The professional integrity of the researcher

- (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.
- (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.
- (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.
- (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.

2. Respect for the rights and dignity of participants

Free and informed consent

- (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.
- (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.
- (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.
- (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.

Privacy

- (10) Researchers should respect the privacy of research participants by making it clear to them that they are free to decide what information they wish to share with the researcher and that they should feel under no pressure or obligation to discuss matters that they do not wish to.
- (11) In cases where a researcher has already developed a relationship with an individual or group of people before inviting them to participate in a research study, they have a special responsibility to protect the privacy of those concerned. More specifically, they should seek their explicit consent if they wish to use information that the individuals may have shared with them prior to their participation in the research.

Recognition of participants' time and efforts

- (12) Researchers should ensure that they demonstrate proper recognition to the participants for the time and effort they have given to the research study.

- (13) Researchers should not expect particular organisations or individuals to negotiate access to research participants or organise meetings with them on their behalf without first ascertaining if it would be appropriate to agree a fee with them for doing this, unless this is already an explicitly stated aspect of their roles and responsibilities.

Consultation

- (14) In the design and conduct of their research, researchers should where appropriate make every effort to consult meaningfully with those groups or communities involved. Researchers need to decide upon the most appropriate means of consulting in each case. However, whatever means are chosen they should give those involved the opportunity to provide their views on the overall focus of the research, the approach that it intends to take and its intended outcomes.

Keeping participants informed

- (15) Researchers should ensure that, where appropriate, they develop mechanisms for keeping participants informed as to the progress of the research.

Concluding relationships with participants

- (16) Researchers should be mindful of the significance of the relationships that may have developed between themselves and the research participants during the course of the study and should develop a clear strategy for concluding those relationships when the research has been completed.
- (17) Wherever possible, researchers should ensure that feedback is given to participants regarding the findings of their research. The nature and extent to which this is done will depend upon the type of research carried out.

- (18) At the conclusion of the research study, participants should be given a means of contacting the researcher or research team in the future should any queries or issues consequently arise for them concerning their involvement in the research that they would like to discuss.

3. The well-being of all those involved

Confidentiality

- (19) Researchers should make every effort to protect the confidentiality and anonymity of research participants. They should also try to anticipate circumstances where this may be threatened and to make arrangements to address this accordingly.
- (20) Researchers should take appropriate measures to store research data in a secure manner. In doing this, they should have regard to their obligations under the Data Protection Act 1998. Wherever possible, researchers should store their raw data in an anonymised form to prevent the identification of research participants from it.
- (21) Researchers need to clearly inform participants prior to the commencement of the research of the procedures taken to ensure confidentiality and any limitations associated with these.
- (22) Researchers conducting research with children should make themselves fully aware of child protection issues and procedures and, where appropriate, attend training on this matter. For those who will have direct contact with children, police checks should be completed before they embark on the research.
- (23) Where a researcher wishes to use information provided by a participant in their report that may be difficult to

completely anonymise, they must explain the risks associated with this to the individual involved and seek their permission to use that information.

The adverse effects of participating in research

- (24) Researchers should make every effort to ensure that their research participants feel secure and at ease during the research process. Where possible, venues for the research to be conducted should be chosen that are familiar to participants and where they feel confident. The decision to use and the composition of focus groups should also be considered carefully with the needs and wishes of individual participants in mind. Finally, bearing in mind that the well-being of the participant is paramount, if appropriate, they should also be given the opportunity to invite a third party along for support if they wish.
- (25) Researchers intending to conduct research with individuals who have experienced traumatic events should be very clear about the precise focus of their research and the information they require. They should avoid asking participants about the actual traumatic events they have experienced unless this is absolutely necessary and, if they do, they should do so with extreme care and sensitivity.
- (26) Before conducting research with individuals who have experienced traumatic events, researchers should agree with them what arrangements for support they would like to be made both during and after the research.
- (27) Researchers intending to conduct research directly about traumatic events with those who have experienced them should ensure that they are fully aware of the nature and effects of trauma prior to commencing the research. They should also have decided upon clear strategies for dealing with incidents where participants become extremely distressed. On no account should untrained researchers attempt to provide advice or counselling to such individuals.

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The Safety and Well-Being of Researchers

- (29) In designing and undertaking research, researchers have a duty to safeguard their own safety and well-being as well as those who work for them. This means researchers ensuring that they make every reasonable effort to avoid placing themselves or others in situations where they may be at risk of physical harm. It also means considering the likely emotional effects that researching particularly traumatic issues or events may have on the researchers involved. In such circumstances, appropriate support mechanisms should be made available for researchers that could include full de-briefing sessions and the opportunity to meet with a counsellor where necessary.

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