

Research Code of Ethics

April 2009



Foreword

High-quality research evidence is of pivotal importance to informing better policy making, advocacy and practice for the people who use the services and supports provided by UnitingCare NSW.ACT (hereafter the 'Organisation'), its service groups and agencies. Our services include aged care and disability programs; services for vulnerable families, children and young people; the provision of quality early learning and child care; and supports to rebuild families and relationships following separation and divorce. Research can reveal the critical social and economic trends directly impacting on our client's (who may also be described as 'service users' or 'residents') lives and produce results, which will guide us in improving the quality of their care.

UnitingCare NSW.ACT is committed to ensuring that the research we share with the wider community is based on solid structural and ethical foundations, reflecting our core values of respect, integrity and care for our clients, staff and volunteers. This Code of Ethics outlines in detail UnitingCare NSW.ACT's expectations of the research process and the guidelines which will be applied by the UnitingCare NSW.ACT Research Advisory Group to ensure the ethical and accurate conduct of all research and evaluation in which the Organisation is involved.

All employees of UnitingCare NSW.ACT and its constituent service groups and agencies who are responsible for research or program evaluations in their area are obliged to read the Research Code of Ethics. In doing so, the principles in the code will be reflected in the structure and delivery of their research or evaluative work. Further, UnitingCare NSW.ACT requires external researchers and evaluators (whether professional researchers or students) to conduct their research at UnitingCare NSW.ACT in line with this Research Code of Ethics.

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None of these people have contributed to any errors of fact or interpretation. Responsibility for this rests entirely with UnitingCare NSW.ACT

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1. Introduction

The purpose of this Code is to assist researchers from UnitingCare NSW.ACT and other institutions with the development of research proposals and protocols, which comply with standards which UnitingCare NSW.ACT believe underpin responsible and effective research involving its agencies, clients (who may also be described as 'service users' or 'residents'), staff and volunteers and are part of our duty of care.

This code is not intended to cover all possible research situations, nor provide guidelines for all ethical dilemmas. It is a 'living and evolving' document - one which is adapted and shaped as social, political and moral issues are encountered. As part of UnitingCare NSW.ACT's commitment to a partnership approach to research, we welcome feedback on the application and relevance of this Code of Ethics.

1.1 What do we mean by "research"?

Research projects conducted by internal or external staff, which involve the participation of clients, staff or volunteers of UnitingCare NSW.ACT (hereafter the 'Organisation') and its agencies require ethical approval from the UnitingCare NSW.ACT Research Advisory Group (RAG) before they are able to proceed. The requirements stipulated in the Research Code of Ethics will apply to "**research**" which is defined as including:

"All research projects funded by external bodies; major program and service evaluations involving current and retrospective client follow-up, specific action research projects and quantitative or qualitative research which seeks the personal opinions, views and/or experiences of clients, staff or volunteers."

Within the definition of research given above, all data collection involving human participants normally requires prior ethical approval with the exception of the following categories, which are not considered "research": routine audit, performance reviews, quality assurance studies, testing within normal education requirements, and feedback activities designed for the purpose of continuous quality improvement and service development. Ethical review will not generally be required for secondary research which seeks to analyse de-identified records and data sets that exist in the public domain. This includes, for example, datasets available through the Australian Bureau of Statistics, Australian Institute of Health and Welfare, and the Australian Institute of Family Studies where appropriate permissions have already been obtained and where it is not possible to identify individuals from the information provided. Researchers are required to comply with restrictions on the access to, and use of, data as specified by data providers.

This Research Code of Ethics documents the researcher's responsibilities and obligations. Guidelines for negotiating methodological and ethical dilemmas which might arise in the course of designing and undertaking the research are also provided. These key principles are summarised in Table 1 and underpin the *National Statement on Ethical Conduct in Human Research* 2007 which was co-issued by the National Health and Medical Research Council (NHMRC), the Australian Research Council (ARC) and the Australian Vice-Chancellors' Committee (AVCC). These four principles help to shape the relationship between researchers and research participants as one of trust, mutual responsibility and ethical equality.

Table 1: Key Ethical Principles

Respect for human beings	Recognition that each human being has value in himself or herself; and respect for the rights, interests and beliefs of persons and for their place as participants or collaborators in the research process.
Justice	Regard for the human sameness shared by all human beings, expressed in a concern for fairness or equity including fair treatment and fair distribution of the social benefits and costs of research.
Beneficence	Doing good to others (including maximising the benefits of research) and avoiding doing, and providing protection from, harm.
Research merit and integrity	Research is justifiable by its potential benefits and is designed and developed in a way that will achieve the research aims, and is conducted honestly and in a way that ensures respect for the participants is not compromised.

Research investigators should refer and respond to the key ethical principles at every stage in the research process - during the design phase; when collecting, analysing and interpreting data; and when presenting findings. The specific ways in which they may do so are outlined in this document.

Research investigators should also be constantly aware that the costs and benefits of research do not fall equally across society. Often specific individuals or a community bear the burden or 'costs' of research, such as repeated intrusions on privacy and substantial investments of time and energy. These same individuals and communities quite commonly experience few direct benefits from participation in such research. This inequitable distribution of costs and benefits must be addressed by researchers wishing to involve clients and/or staff of the Organisation in their research.

2. Duty of Care

As part of the Organisation's overall duty of care, UnitingCare NSW.ACT has an ethical and legal responsibility to protect its clients - especially more vulnerable groups such as children and young people, people receiving therapy, people highly dependent on medical or residential care, and people with a cognitive impairment, an intellectual disability, or a mental illness - against any risk of harm or exploitation. Priority is given to protecting the dignity, welfare, rights and interests of UnitingCare NSW.ACT clients from any and all risks, harms or burdens which might be associated with their participation in a particular research project. While this duty of care is particularly important in relation to UnitingCare NSW.ACT's client base, its duty of care also extends to those of its staff who may, on occasion, choose to be participants in research (Dodds *et al.*, 1994).

Researchers are required to be sensitive to the needs and interests of all research participants and to design and conduct their research in a way which reflects the core ethical principles outlined in Table 1. UnitingCare NSW.ACT has established a Research Advisory Group (RAG) to ensure the independent and transparent ethical review of all research conducted at UnitingCare NSW.ACT, its service groups and agencies.

Researchers should ensure that the project as a whole reflects the concerns of the community participating in the research and that the information gained is used for the benefit of the research participants. Where appropriate, the researcher is encouraged to develop proposals where participants gain direct and identifiable benefits (e.g. personal development, acquisition of knowledge and skills, monetary payment or payment-in-kind).

Where possible, UnitingCare NSW.ACT encourages research methods which support the collaboration of participants and researcher and promote the equal and full participation of participants in the research. The UnitingCare NSW.ACT RAG Convenor is also available to assist researchers resolve issues arising from these guidelines. The Convenor's contact details are contained in this document.

Specific aspects of UnitingCare NSW.ACT and the researcher's duty of care are as follows:

- Researchers are obliged to notify the UnitingCare NSW.ACT Research Advisory Group (RAG) if, after a research proposal has been approved, any element in the research design is changed. Complete details of, and reasons for, the changes must be provided.
- In the case of commissioned research (e.g. where a government department is the funding body) it is UnitingCare NSW.ACT's experience that ethics approval is often sought by the researcher after the contract has been awarded. In these cases the character and nature of the project have already been negotiated between the investigator and the funding body. The researcher should be aware that the interests of UnitingCare NSW.ACT and the clients to whom it has a duty of care may not be the same as those of the research funding body. Ethical clearance will be required however the areas of inquiry within a particular research project are not always at the discretion of the Organisation.

3. The Research Process

The researcher needs to be aware of, and address, the key ethical concerns arising from the overarching principles of respect for human beings, justice, beneficence, and research merit and integrity. These principles come into play in all aspects of research. They include:

- Designing valid research
- Obtaining voluntary informed consent
- Implementing the research
- Protecting privacy
- Maximising benefits
- Disseminating findings

Researchers are expected to anticipate the consequences of the research at each step in the process, to protect participants from the risks and burdens of the research, and to employ and monitor methods and procedures which reduce the risk of ethical infringement. To assist the researcher, the issues identified above are discussed as they typically arise in the research process. A description of the responsibilities that UnitingCare NSW.ACT believes they give rise to, on the part of the researcher, is also stated.

3.1 Designing Valid Research

Research which produces incorrect or damaging information can do more harm than good. While many different elements can go into the making of a good research design, ethical considerations are essential.

UnitingCare NSW.ACT expects researchers to take into account their position in the research setting. In many cases this is a relatively powerful position and methods and procedures which have the effect of disempowering participants by treating them as 'subjects' to be studied should be avoided. This is especially important where the research population can be described as 'dependent' by virtue of their client status and receipt of support services and other forms of assistance.

Even when the researcher does not hold a position of relative power (for example in the conduct of interviews with the staff of UnitingCare NSW.ACT) all participants should be treated with courtesy. It can be helpful for the researcher to put themselves in the position of the person being interviewed and to consider: "Would I be welcome if a return interview were needed?" or "Would the next researcher who makes a request be welcomed?" Precautions which should be taken to guard against ethical violations arising from an individual's client status are discussed below. While not an exhaustive list, these examples indicate the sorts of issues which need to be addressed during the planning stages of the research project.

- Researchers should not intrude unnecessarily into participants' lives or make unnecessary demands on their time and knowledge. For instance, the researcher should be familiar with the research topic before the project commences and should aim to minimise the amount of time participants spend in providing background information which the researcher could find elsewhere. Researchers may ask themselves: "How likely is it that the people I wish to interview to have been asked these questions previously or frequently, or have been excluded from research processes relevant to their needs?"
- A range of relationships between participants and researchers may develop as a result of the duration and nature of the interaction. Where such relationships threaten to compromise the research role, researchers must consider whether to modify those relationships, or to modify or even discontinue the research. Similarly, where a researcher has professional skills (for example, counselling) that become relevant to the relationship with a participant, the researcher needs to decide whether: (a) it is ethically acceptable to exercise those skills; or (b) it is preferable to refer that participant to another professional. Researchers have a duty to inform participants whenever they are acting in a non-research professional role.
- The participant sample should be inclusive, realistic and based on a sample size and sampling approach which lends itself to producing valid results. Research proposals that include sampling should clearly describe the recruitment strategy and criteria for selecting participants.
- Only necessary data should be collected. In survey work, for example, there is the temptation to collect additional data, often for no immediate purpose. The RAG discourages the collection of unnecessary data. While both costly and time-consuming for the researcher, unnecessary research scrutiny contributes to the likelihood of 'participation burnout' or 'survey fatigue' among vulnerable populations. Already more likely to be the 'subject' of research than most other groups, unnecessary questioning of clients can increase intrusion into their lives to an unacceptable level and can represent a violation of their basic right to privacy. Researchers seeking to conduct projects with clients of the Organisation should first consult relevant Directors and Program Managers to determine whether a proposal needs to be reframed or delayed due to concerns about research fatigue of specific cohorts within the vulnerable service user population.

- Research conducted with Aboriginal and Torres Strait Islander people should ensure that research methods are respectful and acknowledge the cultural distinctiveness of discrete Aboriginal and Torres Strait Islander communities or groups participating in the research. There should be evidence of support for the research project from these groups and the research methodology and processes to report back outcomes and outputs should engage with their social and cultural practices. In general, the research approach should value and create opportunities to draw on the knowledge and wisdom of Aboriginal and Torres Strait Islander peoples by their active engagement in the research processes including research design and the interpretation of the research data (National Statement on Ethical Conduct in Human Research 2007: Chapter 4.7).

3.2 Obtaining Voluntary Informed Consent

UnitingCare NSW.ACT believes there is no single or ideal method of securing informed consent, particularly when the area under study is sensitive (such as family violence) or the participant group involved can be described as a vulnerable group (such as children, people with disability, or people highly dependent on care). Some specific examples of good research practice in obtaining informed consent with vulnerable groups are set out below.

- The UnitingCare NSW.ACT RAG does not generally support withholding information about a project from the participants. If a researcher wishes to withhold information which is part of either the consent form or information sheet, they must explain and provide adequate justification for the exclusion.
- Potential participants should be provided with information to promote an adequate understanding of the purpose, methods, demands, risks and potential benefits of the research. The researcher also has the responsibility of providing each participant with an information sheet which they are invited to keep.
- The researcher should disclose to the participant the name of the body funding the research and why the data is being collected. The researcher should be aware that they are not only obliged to protect the interests of the individual participant, but equally obliged to protect the collective interests of the participant population.
- Accordingly, the explanation should include what benefits the funding body expects to receive from the research and the likely outcomes and consequences of the research for the participant population. The participants should also be provided with a description of the risks and benefits of the research and measures employed to guard against any anticipated negative effects.
- The consent form should reflect the culture, education, literacy and conceptual levels of the participant. Language used should be simple, clear and non-technical. The researcher should adapt the presentation of information to each participant's intellectual capacity and language skills and ensure that the information presented has been understood. Where literacy levels are low or participants are not sufficiently fluent in the written language, the researcher should read the consent forms to the participant or make appropriate arrangements for forms to be translated and/or for the use of interpreters.
- Evidence of informed consent is required. The use of implied consent is not acceptable. For example, the UnitingCare NSW.ACT RAG would not approve an ethics application which states that consent to participate will be sought by letter and that failure to decline the invitation within a specified time period will be taken as a sign that the participant has consented. The RAG would rule that there is no solid evidence of informed consent in this case.

- Consent may be expressed orally, in writing or by some other means depending on: the nature, complexity and level of risk of the research; and the participant's personal and cultural circumstances.
- When negotiating consent, the researcher should discuss the project with participants and answer all questions put to them to ensure that the participant has understood the nature, implications and obligations of participation.

UnitingCare NSW.ACT believes that informed consent is also a process between the researcher and the participant which continues over the life of the project and beyond.

Unequal power relationships and dynamics exist between participants and the researcher. This is especially so where the participant population is in a dependent relationship or situation (for example, in receipt of government services or benefits; or using services provided by the Organisation). In these circumstances:

- The process of communicating information to participants and seeking their consent should not be merely a matter of satisfying a formal requirement. The aim is to create mutual understanding and trust between researchers and participants at all stages of the research process. Participants should be regularly reminded of their right to withdraw from the project at any time without giving reason, and that their initial agreement is not binding. Regular and formal renegotiation of consent may be required in the case of longitudinal research.
- Where the researcher or funding body is also the service provider, the researcher needs to be aware that this dual role may influence a participant's decision to participate. It is the responsibility of the researcher to advise potential participants that they are in no way obliged to participate in the research. Potential participants should be reassured that access to services or benefits will be unaffected by either consent or refusal to participate.

3.2.1 Consent and Vulnerable Groups

UnitingCare NSW.ACT believes that research vulnerability can extend to a range of clients to which our service groups and agencies provide services including children, people in therapy, people (including the aged and people with disability) who are highly dependent on medical and/or residential care, and people with a cognitive impairment or intellectual disability. The ability of participants to provide informed consent may be limited by a number of possible factors. For example, the participant may have little experience of making decisions; have insufficient education to make a properly informed decision; or be without the intellectual capacity to fully grasp the nature of the research and the implications of participation.

Understanding of the consent form and project details is strongly influenced not only by what information is provided but, equally, by the manner in which it is presented. This is especially relevant where the research population includes children.

The researcher should consult with individuals, groups, parents or advocates to develop a familiarity with, and understanding, of the limitations of the research population and, where possible, of the individual skills and abilities of each participant within it.

Some specific approaches that UnitingCare NSW.ACT encourages researchers to consider are:

- The researcher should consider the implications of obtaining signed consent when negotiating participation with vulnerable populations. Where the research topic is sensitive and/or the participant feels vulnerable (e.g. a researcher studying IV drug use or gay and lesbian youth

culture at a youth centre), the researcher must be particularly alert to the interests and the right to personal privacy of participants. In these situations a statement of agreement may be more appropriate. The agreement is signed after the interview is finished, when the participant knows precisely what is being discussed and, consequently, is in a better position to make an informed decision.

- It is the responsibility of the researcher to be sensitive to cultural differences. For example, within some cultural groups the family may be the basic decision-making unit. For these respondents, it might be more appropriate to negotiate agreement with the participant's family. The kind of agreement and how it is negotiated should reflect sensitivity to, and awareness of, the practices and concerns of that group. One specific example would be deciding which parents should be interviewed i.e. mother or father for what aspects of family life. It is also important to be inclusive of all people in general research populations and not, for example, to separate out people from a culturally and linguistically diverse background because the possible need for assistance from a translator or interpreter makes it a 'difficult' cohort to involve.

3.2.2 Consent and Children as a Vulnerable Sub-Group

Prior to including a child or young person in research, researchers must establish that there is no reason to believe that such participation is contrary to that child's or young person's best interest.

UnitingCare NSW.ACT understands that under current legislation, researchers are legally required to obtain parental/guardian consent for minors to participate in research. However, while it may be legally necessary to obtain the carer's consent, UnitingCare NSW.ACT believes that carer's consent by itself is ethically never sufficient to replace the child's voluntary and informed consent to participate. Researchers must respect the developing capacity of children and young people to be involved in decisions about participation in research. As stated earlier, legislation requires that consent be obtained from a parent, guardian or other primary care giver. Where research is being undertaken with children in separating or separated families, the researcher must consider whether it is appropriate to gain consent from both parents and the risks involved if one parent is not consulted on, and approached to provide consent for, their child's participation in the research.

It is important to note that not all persons under 18 years of age have parents or guardians, or it may not be possible or safe to obtain consent from a parent or guardian (for example, in research with homeless youth). In these situations obtaining informed consent from a parent or guardian may be waived after the UnitingCare NSW.ACT Research Advisory Group has satisfied itself that a waiver is necessary based on an assessment of the safety issues for the young person or the impossibility of obtaining parental/guardian consent. In such circumstances researchers should consider whether consent can be sought from another appropriate adult in proximity to the young person (e.g. a social worker). The following points are also important:

- When obtaining consent the researcher should provide information about the research in a format and style which is appropriate to the age and developmental level of the potential participants. This can be done in a variety of ways - verbally, written or in picture format, cartoons, tape recording or video.
- Young children with very limited cognitive capacity should be engaged at their level in discussion about the research and its likely outcomes. The researcher should establish appropriate procedures for obtaining consent from children with learning difficulties. By way of example, the research could be introduced to each child by a professional worker whom the child knows and trusts. During the first visit to the child's home the researcher could devote considerable time to talking about themselves, the research and what it will involve. This kind of method allows the child to become familiar with the research over a period of time. The researcher is also obliged to

remind the child more than once about the nature of the research, confidentiality and their right to withdraw at any time.

3.2.3 Consent and People with Cognitive Impairment, Intellectual Disability or Mental Illness

People with a cognitive impairment or intellectual disability are entitled to participate in research however it is important to recognise that the capacity of a person with any of these conditions to consent to research, and participate in it, may be variable. Researchers should be aware that because of the participants' distinctive vulnerability, care should be taken to ensure that the risks and any burden involved in the proposed research are justified by the potential benefits of the research. The researcher should consider the following points as set out in the National Statement on Ethical Conduct in Human Research 2007 (Chapter 4.5):

- Consent to participation in research by someone with a cognitive impairment, an intellectual disability, or a mental illness should be sought either from that person if he or she has the capacity to consent, or from the person's guardian or any person or organisation authorised by law. Where the impairment, disability or illness is temporary or episodic, an attempt should be made to seek consent at a time when the condition does not interfere with the person's capacity to give consent.
- Where consent has been given by a person authorised by law, the researcher should nevertheless explain to the participant, as far as possible, what the research is about and what participation involves.
- Refusal or reluctance to participate in a research project by a person with a cognitive impairment, an intellectual disability, or a mental illness should be respected.

3.2.4 Consent and People in Dependent or Unequal Relationships

UnitingCare NSW.ACT and its agencies recognises that a number of our clients are in relationships that may compromise the voluntary character of participant's consent, as they typically involve unequal status, where one party has or has had a position of influence or authority over the other. Examples may include relationships between: carers and people with chronic illness or disability or people in residential care or supported accommodation; care professionals (including caseworkers, counsellors and therapists) and their clients; employers and their staff; service providers and vulnerable communities to whom they provide services. The design of the research and consent process should take account of:

- The need to seek consent from people highly dependent on care wherever they are capable of giving consent. Where the person is not capable of making an informed decision, consent should be sought from the potential participant's guardian or person or organisation authorised by law.
- In the consent process, researchers should invite potential participants to discuss their participation with someone who is able to support them in making their decision. Where potential participants are especially vulnerable or powerless, consideration should be given to the appointment of a participant advocate.
- The impact of an unequal or dependent relationship on the conduct of the research. For example, a family therapist should consider the risks associated with conducting research while continuing to provide therapy to a participant. Dual relationships may compromise the integrity of relationships between researchers and participants as well as therapists and clients and may lead to resentment, confusion and potential harm to either party (Cain *et al.*, 2003).

- The impact of involvement in research on the conduct and efficacy of a particular care or treatment plan, or therapeutic intervention. Researchers should stipulate in their ethics application any risks that might be expected to arise and how these will be minimised.
- Researchers need to be mindful that in some relationships of dependency, participants may have an unrealistic expectation of the benefits of research and the prospect of benefit must not be exaggerated.
- The consent process and information sheets provided to potential participants should stress that declining to participate in, or deciding to withdraw from, research will not result in negative consequences such as a reduction in the level of care and respect offered, dismissal from employment or unfair discrimination.
- Researchers should take special care to safeguard confidentiality of all information they receive, particularly in settings such as shared rooms in residential or supported accommodation

3.2.5 Incentives

The voluntary aspect of consent is denied when undue enticement exists. If the researcher is considering some form of payment, they need to assess its likely effect on consent. Incentives may be in the form of, for example, a payment or a gift voucher.

- It is up to the researcher to decide either for or against the use of incentives. However, it is worth remembering that we generally expect to pay for the 'expert' time and knowledge which researchers or consultants devote to a project. In this light, it is equally reasonable to pay for the time and knowledge which community groups, and the individuals within them, contribute to a research project.
- It is the responsibility of the researcher to place the issue of payment within the context of the particular research project and determine as best he or she can at what point the incentive becomes an inducement that places undue pressure on a potential participant to consent to take part.
- The researcher should be sensitive to the fact that what constitutes inducement to one participant may be regarded as reasonable reimbursement to another, or may alternatively be perceived as an insult.

For example, if the incentive is a monetary payment and too little is paid, there is a risk of insulting some participants. By contrast, if too much is paid (relative to the time or travel and parking costs involved) there is the risk of coercion by 'purchasing' respondents. A possible guideline in setting payment level may be to base it on the amount of time and inconvenience involved for the participant. Where the researcher decides to offer payments to participants, they should provide the RAG with an explanation of the rationale for so doing and demonstrate how the kind and level of payment was decided upon.

3.3 Implementing the Research

Risk and harm are related concepts. Risk refers to the possibility of some form of harm, loss or damage occurring. Harm can be physical, psychological (including the devaluation of personal worth), social, economic or legal in nature (National Statement on Ethical Conduct in Human Research, 2007).

Avoiding harm and minimising the risk of adverse outcomes among participants is a central tenet of ethical research. Researchers must consider at the planning stage all possible sources of risk and harm; assess the likelihood and severity of the risks; and establish methods and procedures which avoid or minimise risk and harm.

The researcher should be aware that when their research involves vulnerable and dependent groups, that they have a greater responsibility to protect participants from all potential harms, burdens, risks and disadvantages which may be associated with participation in the research. **Specific examples of protecting participants from potential harm are:**

- Procedures for the prompt alleviation of distress among participants should be in place before participants are approached and be documented in the information sheet. Where there is a risk of emotional distress (e.g. anxiety, lowering or loss of self-esteem, depression) following discussion of sensitive topics (e.g. domestic violence, child abuse, family breakdown or loss of independence), researchers should ensure that members of the team conducting or observing qualitative components of research are equipped with the necessary skills, training and resources to refer participants to professional counselling services or agencies.

In some cases, it might be appropriate to have an alternative list of referrals (for example to clergy, nurses or doctors, or helplines) to meet the needs of those participants who would not normally consult counsellors or other mental health professionals and would be uncomfortable doing so.

- The researcher should assess how well the research procedures and instruments are likely to 'sit' with participants. If there is any risk that participants might be uncomfortable, feel inadequate or embarrassed, or experience some other form of distress, because of a particular procedure or instrument, then the researcher should revise his or her methods so as to minimise the risk.
- Researchers should be aware that there is also the risk of emotional distress for some participants if they are given little or no opportunity to talk about their experiences.
- The researcher must consider in advance how they will deal with disclosed information which suggests the participant might be - or may have been - involved in harmful or illegal activity (including modifiable activity) whether as a victim or perpetrator. Protocols and obligations should be determined in advance. The researcher should consider legal requirements and determine appropriate courses of action while at the same time preserving the confidentiality, privacy, and autonomy of participants to the greatest extent possible within legal constraints. A 'Protocol for Researchers: Children and Young at Risk of Harm' has been developed by UnitingCare Burnside and is available from the Convenor of the UnitingCare NSW.ACT Research Advisory Group.
- In research that may foreseeably discover illegal activity but is not designed to expose it, researchers should explain to participants as clearly as possible: (a) the likelihood of such discovery and of any resulting legal obligation of disclosure the researcher may incur; and (b) the extent to which the researcher will keep confidential any information about illegal activity by participants or others, and the response the researcher will make to any legal obligation or order to disclose such information (National Statement on Ethical Conduct in Human Research 2007).

3.4 Protecting Privacy

Privacy is defined as a domain within which individuals and groups are entitled to be free from the scrutiny of others. It is important that researchers are aware that the need of participants for privacy can vary. For example, while participation in a research interview or focus group might be embraced by one person as a great opportunity for self disclosure, another person may find participation to be an extremely uncomfortable experience which represents an intolerable invasion of their privacy.

The researcher should also be aware that they have a responsibility to maintain both a participant's physical privacy and their social and emotional privacy. For example, emotional privacy might be intruded upon when a participant volunteers more information than they originally intended. Social privacy might be violated if they are given unwanted information about someone. If discomfort becomes evident in the research process, the participant should be reminded that they have the right to withdraw from the research project at any time without giving reason.

3.5 Maintaining Confidentiality

While privacy generally refers to an individual's personal rights, confidentiality refers to information and data about the individual.

As part of the informed consent process, the researcher should come to an agreement with participants about what can be done with the data and how it will be used and stored. In general, the minimum recommended period for retention of research data is 5 years from the date of publication (Australian Government, 2007). UnitingCare NSW.ACT expects all research information to remain confidential, unless specific arrangements have been made to do otherwise. It is the responsibility of the researcher to put in place procedures to protect survey respondents from breaches of confidentiality and a variety of measures should be employed as appropriate to minimise the risk of infringement of confidentiality. Examples of such measures include:

- All research team members, and all those who collect, enter, analyse or have access to participant data should be required to sign confidentiality statements.
- All identifiers (including names, residential and email addresses, and phone numbers) are to be physically separated from questionnaires, transcripts, tapes and all other documents where responses are recorded. This will minimise the links between responses and the respondent's identification.
- All identifiers should be removed as soon as possible. For example, tapes should be destroyed after being transcribed.
- Access to completed surveys and other instruments should be limited to team members and stored in a secure environment.
- If the sample is small the researcher should be alert to the risk of identification of respondents when presenting results and data.

3.6 Maximising Benefits

The types of benefits available to participants largely depend on the type of research to be undertaken and the method or methods adopted. Often the benefit can be diffuse or indirect. For example, archival research cannot provide any direct benefits to those who provided the original data.

The researcher has a responsibility to maximise the benefits of the research to those who choose to participate in a project. Benefits may be in the form of incentives (e.g. payment for time); personal benefits (e.g. lists of, or facilitation of access to, local services); education, personal development and empowerment (e.g. via focus groups, debriefing, workshops, newsletters and dissemination of research findings); and community development (e.g. sharing of ideas, skills and knowledge). However, the researcher should not overstate the particular benefits that a research project can be expected to bring to participants.

Where the research methodology allows - for example, in the case of action research models - UnitingCare NSW.ACT supports a process of discussion with members of the community involved in the research. Researchers are encouraged to develop collaborative relationships with community members who may participate in the formulation of the research questions, in research design and in other stages of the projects. As a result community concerns and interests are reflected in questions and the community gains some control over the contribution of its members to the research.

3.7 Disseminating Findings

As part of ethical research practice some researchers present their findings to participants and encourage them to be involved in their interpretation. In some cases this may be a condition of informed consent. The UnitingCare NSW.ACT Research Advisory Group (RAG) supports a collaborative approach where possible.

- Where appropriate, the researcher should organise debriefing sessions to give participants the opportunity to ask questions, express feelings and opinions about the research, and comment on findings where these are available for presentation. Ideally, debriefing would be planned for at the design stage and be conceived as an integral part of the research process.
- It is the responsibility of the researcher to consider whether publishing the results of the project will harm participants. For example, damage to a community or group may result if 'negative' findings are released. The researcher will need to consider to what extent the participants have a right to prevent findings such as these from being released or to change the format and manner in which adverse findings are presented.
- Where the publication or dissemination of findings is likely to stigmatise participants, agreements should be reached on the handling of results well in advance.

Further Information and Help

If you want more information or assistance please contact:

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