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Powerstown Educate Together National School

Ethical Guidelines for Research Projects

This policy has been formulated by Powerstown ETNS to inform personnel who wish to complete research projects in Powerstown Educate Together National School with ethical procedures. All personnel must submit an application for research ethical approval for each project being undertaken. This policy is based on the policies of Trinity College Dublin, Children's Research Centre.

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Section 1: General Guidelines for Good Research Practice with children.

Introduction

This document deals with issues of ethics and safety in research with children. The guidelines have been drafted to developing procedures for dealing with issues of child protection in research that is carried out in Powerstown Educate Together National School, by approved personnel.

Powerstown Educate Together National School recognizes that all research personnel have a duty of care to children with whom it is in contact for research purposes. Powerstown ETNS also recognizes that the safety and privacy of its researchers, both students and staff members, should be protected.

The document provides guidelines for everyone who is conducting research.

Ethics in research with children

Research personnel should abide by the guidelines set out by Powerstown Educate Together National School and by the code of ethics set out by the Psychological Society of Ireland.

In addition, everyone should familiarize themselves with ethical guidelines pertaining specifically to children, which have been developed by a number of organizations. [1] These guidelines vary somewhat, depending on the value basis for the research in different organizations.

The principles, on which the guidelines developed by Powerstown ETNS are based, are as follows:

- Having a commitment to children's well-being
- Having a commitment to doing no harm
- Having a commitment to children's rights including the right of individuals to take responsibility for him or herself
- Being child-centred in its approach to research, listening to children, treating them in a fair and just manner

These principles have implications for decision-making in a number of key areas, including consent and confidentiality, but also in the general manner in which children are treated in any research encounter.

Practical Steps to Minimize Risks in Research with Children

Checks on previous criminal record

It is the policy of Powerstown Educate Together National School that all personnel conducting research with children are required to sign a statutory declaration and to submit the signed form to the Board of Management before commencing research.

This declaration contains a statement that students/staff have no previous record of offences against children and have not, in the past, been excluded from working with children. In addition to signing this declaration, staff and students will be required to obtain Garda
Clearance. This is arranged by the Administrative Officer.

Dealing with issues of consent

- Written request for consent should be sent to the BOM.
- Written consent should be granted by the BOM
- Written consent should be obtained from parents.
- Consent from children can be either written or verbal.
- All consent should be **informed** and **voluntary.**
- Records should be kept of all steps taken with regard to consent.

Parent information and Consent:

Written information for parents should include

a) A description of the nature of the study and methods involved.
b) Information on how the child/family was selected for participation
c) Information on how the data will be stored and who will have access to it
d) Information on how the data will be used
e) Information on the ethical/safety requirements of the Children's Research Centre to which researchers must adhere. This includes information on the limits of confidentiality.

Researchers will be asked to show evidence of parental consent for research conducted with children before proceeding with data collection.
Parents should be given a copy of the consent form to retain for their own use.

Child information and consent

Children should be informed as fully as possible, given their age and competency, about the nature of the study and the methods, at the outset of data collection.

- Information for children should be written in clear and simple language.
- It should be visually attractive and accessible.
- It should be read to children.
- Children should also receive a written copy to keep.
- A child's right to refuse to take part should be respected. This applies even if parents or other carers/guardians have given consent.
- It should be explained to children that they may choose to discontinue the session if they are not comfortable with continuing.
- Appropriate signals should be agreed.

The issue of whether children should be asked to provide written consent is a grey area. Parents may object, on the basis that it might not be meaningful for children and may have no legal standing. In some circumstances, however, it may help to make consent more meaningful for children to ask them for their written consent. In all cases, it is advisable to obtain verbal consent, if possible in the presence of a third party (adult) who is known to the child.

Dealing with issues of confidentiality

Researchers should give careful consideration to what they mean when they tell a parent or child that participation in the research will take place on confidential basis. The *National Guidelines on Child Protection: Children First (Department of Health and Children, 1999)* suggest that *complete* confidentiality should not be given, either to parents or to children themselves, since children may disclose, during the course of the research, that they are at risk or that others may be at risk.

When preparing consent forms for parents and children it is important that the research personnel:

- Discuss the limits of confidentiality with the Principal and come to an agreement about appropriate wording for the information sheet for parents and children. It should be made clear, for example, that if researchers have concerns that the safety of any child is at risk, they will discuss these concerns with the Principal. (See below for guidelines on reporting suspected abuse)

- Ensure that a written record is kept of the steps that have been taken to make parents and children aware of the limits of confidentiality.

Data collection

- It is important to make clear and documented plans for data collection. Records should be kept of arrangements made with 'gatekeepers' such as parents, teachers and schools.

- Arrangements should be made to conduct the research in a suitable setting, from a safety point of view. For example, it is important to ask for the use of a room that is close to a central office, such as a staff room or the Principal's room, where an adult with responsibility for the children can easily see the researcher and the child.

- Researchers should not spend time alone with a child in a school or home, even if an adult in authority asks them to do so. Neither is it advisable for researchers to leave the school with a child, in the absence of a carer or guardian.

- All researchers are asked to make provisions for their own personal safety when conducting their research (e.g. in the case of one-to-one interviews).

- Personal contact details should not be mentioned on either the information sheet or the consent form.

Management & storage of data

The *Data Protection Act, 1998* applies at present to personal data that is 'automatically processed', i.e., computerized. It gives everyone the right to establish whether personal data is being kept, and to have access to any data that relate to them personally, and to have any inaccurate data erased. Data must only be kept for lawful purposes and 'not used or disclosed in any way that is not compatible with those purposes' (Department of Health & Children, 1999, p. 27). The Act applies to both adults and children, but it is worth pointing out that the same level of care should be applied to data collected from children as adults.

As is the case with data collected with adult participants, data collected with children should be stored in a secure way. Computerized data should be password-protected, printed documents should be kept in secure filing cabinets, and all data, including audio and videotapes should be labeled with ID codes rather than names.

Freedom of Information

Requests may be received to release data under the *Freedom of Information Act, 1997*. The Act gives individuals the following rights:

- The right to access official records held by public bodies prescribed under the Act;
- The right to have personal information held on them corrected or updated where such information is incomplete, incorrect or misleading; and
- The right to be given reasons for decisions taken by public bodies that affect them.

In addition to the Act, there are regulations and guidelines relating to its implementation and cover such issues as access by parents to their children's records. These emphasise that the over-riding concern in decisions about whether to release information to parents is the *best interests* of the child. The steps that would be followed in answering an FOI request are given below.

- Powerstown ETNS rule is that a Freedom of Information request received should be referred to the Principal in the first instance who will ensure that it is handled appropriately and in accordance with all the rules.

- The Safety Officer on the BOM has been authorised to decide on the release of information in response to an FOI request.

- Requests for the release of data about any individual child should be discussed with the Principal who should be familiar with the circumstances.

- If there are any concerns that the release of the information would have negative consequences (e.g. where children believed they had given the information in confidence and would not wish it be released, or where the data may be used in ways that place the child at risk in any way, etc), the matter should be brought to the attention of the Chairperson of the BOM.

- The Chairperson will advise the Principal / Safety Officer on how to reply to an FOI request and will inform them of the different provisions, exclusions or restrictions in the Act which may be

employed to withhold information in order to prevent any harm which would be occasioned by release.

Reporting Child Abuse and Neglect

Children First: The National Guidelines for the Protection and Welfare of Children (1999) encourages adults to recognise a shared responsibility for the protection of children[2].

It is advisable for all researchers conducting research with children to read this document, which provides guidelines on recognising abuse and neglect, and on reporting any concerns that may arise (p. 31-33)[3].

Powerstown ETNS has established a procedure for dealing with any concerns about children's safety or well-being that may arise in the course of research, either through the researcher's own observations, or through a disclosure made by a child.

Procedure:

- If a researcher becomes concerned about the safety of a child he/she should discuss the matter the DLP, to tease out what substance there is to these concerns and whether there is a need to report these concerns.
- Detailed information should be gathered about the concerns in question and disclosed fully to the DLP, including information about the possible implications for the child and family if concerns are reported to the Health Board.
- There is legal protection for individuals making such reports in good faith [4].
- Please refer to Powerstown ETNS Child Protection Policy.

- [1] National Children's Bureau at http://www.ncb.org.uk/resguide.htm.
- Psychological Society of Ireland: http://www.psy.it/ordpsic/psy_e_u/psi_cx.html.
- The National Association of Social Workers: http://www.naswdc.org/pubs/Code/standard5.htm
- The American Educational Research association: http://aera.net/about/policy/ethics.htm
- Society for Research in Child Development: http://srcd.org//

[2] Children First: National Guidelines for the Protection and Welfare of Children (1999), is published by the Department of Health and Children. It provides guidelines on procedures for the identification, investigation and management of child abuse.

[3] The document can be accessed as a .pdf file at http://www.doh.ie/publications/cf.html.

[4] Protections for Persons Reporting Child Abuse Act, 1998. This gives immunity from civil liability to those who report child abuse "in good faith" to designated officers of health boards or any member of An Garda Siochana. There is also protection from dismissal from employment or other sanctions by employers. Finally, it provides for a new criminal offence of false reporting of child abuse "knowing the statement to be false".

Section 2 : Guidelines for Letter of Consent

Consent request to Board of Management:

This letter must be addressed to the Chairperson of the BOM

The following items of information must be included in a consent form:

- Introduction stating full name and status. Please be very clear as to your status.
- A brief description of the task involved. Do not overstate the impact of your potential findings.
- Include your contact details (for further information etc) and those of your research supervisor. Contact information must include the name, addresses, telephone and fax numbers of both the researcher/s and the research supervisor. Do not include personal contact details.
- Ethical Approval form
- A Statutory Declaration
- Copy of Consent Letter to parents
- Copy of consent letter to participants

Consent request to parents/ research participants:

This letter must be written in straightforward language, without jargon.

Each participant should receive their own copy of the consent form, which they can keep.

The following items of information must be included in a consent form:

- Introduction stating full name and status. Please be very clear as to your status.
- A brief description of the task involved. Do not overstate the impact of your potential findings.
- A statement on confidentiality and also a statement allowing the participant to withdraw at any time during the study, without prejudice. Please note any limitations there may be regarding confidentiality (e.g. you are legally obliged to disclose any information received regarding child abuse etc.). Include a statement on the participant's rights under the Freedom of Information Act.
- Include your contact details (for further information etc) and those of your research supervisor. Contact information must include the name, addresses, telephone and fax numbers of both the researcher/s and the research supervisor. Do not include personal contact details.
- Please supply your participants with a copy of the consent form. Signatures of consent should be clearly dated.
- The letter of consent may incorporate the information sheet or you may wish to keep them separately.

Section 3: Technical Guidelines for Ethics Applications

Ethics Committee

1. Helena Trench (Principal / Chair)
2. Catherine Coffey (BOM Safety Officer)
3. Cróna Glynn (Staff)

Technical Guidelines for Ethics Applications

- All research conducted in Powerstown ETNS requires ethical approval.
- Applications should be written on the standard application form
- All studies involving the use of minors (i.e. under the age of 18) require written consent from the parents or legal guardians. 'Negative consent' (i.e., the absence of a written statement from the parents or legal guardians refusing their child's participation) is not acceptable.
- All researchers must present the school with Garda clearance
- Applications for ethical approval should be submitted by all researchers as soon as a proposal has been accepted by the commissioning body (university / research supervisor). This procedure should be written into every proposal.
- All researchers should make themselves and their participants aware of the relevant details of the Freedom of Information Act, 1997. The consent form or information sheet should contain the relevant details with regard to data access, storage and confidentiality.
- Every applicant is required to read the Powerstown ETNS Ethical Guidelines for Educational Research.
- The school encourages all researchers to undergo a web-based training exercise in ethical practice in research. This training is provided by the Office for Human Research Protections (OHRP), which is a body responsible for approving all proposed research using human participants in the US. It is a very useful exercise, and takes only 10 minutes.
  The web site is: http://137.187.172.201/cbttng_ohrp

Specific guidelines for application completion

- To submit an application contact the school and request an application form.
- All researchers should submit their applications to the Principal, Helena Trench.
- You must date your application forms.
- You must clearly specify how and where you are recruiting your participants.
- Do not submit incomplete application forms.
- Applications should be submitted by email where possible and will be turned around normally within one week.
- The Researcher will be notified of decisions made by the Ethic Committee.

Section 4: Application for Approval

Office use only
Application number:

Date of receipt:

Powerstown ETNS
Ethics Committee

Application for approval

1. Title of Project	
2. Date of application for ethics approval	
3a Name of Researcher	
3b Status (i.e.)	
3c. Contact Details	
4a. Name/s and status of other personnel involved	
4b. Contact details (e.g. e-mail)	
5. Proposed Start date for project	
6a Has ethical approval been sought from another organisation (university)?	Yes _____ No _____
6b If answer to 6a is No is it intended to seek it?	Yes _____(go to 6c) No _____ (go to 7)
6c If yes from whom?	
6d When is a response expected?	
6e Are any difficulties expected?	
(Please note: You may exceed the space provided if necessary)	
7 What is the research question (or the aims of the study)? (max 30 words) (attach proposal)	Proposal attached. Yes _____ No _____
8. Describe the procedures the participants will encounter during the study. This account should convey, in straightforward language, what will happen to participants in your study	
9. Participant Group (Specify key characteristics: age, gender, etc)	
10. How many participants are required	
11. What research settings are involved (whole class, observation, small group withdrawl etc)	
12. Describe the design of the study	
13. What methods of data collection will be used?	
14. How long (per participant) with the testing /	

interviewing take?	
15. Does the study involve deception or withholding of information? If yes, why is this necessary?	Yes _____ No _____
16. Does the study involve physical risk to the participants? If yes, why is this necessary? How has it been minimised.	Yes _____ No _____
17. Does the study involve any psychological risk to participants (e.g. upset, worry, stress, fatigue, feelings of being demeaned)? If yes how has this been minimised? If yes, what supports have been put in place?	Yes _____ No _____
18. Does the study involve social risk to participants (e.g. lossof status, privacy or reputation) If yes, why is this necessary? How has it been minimised	Yes _____ No _____
19. Does the study require participants to reveal information of a sensitive nature? If yes, why is this necessary? How will the procedure minimise distress caused by such disclosures?	Yes _____ No _____
20. Are there any other risks other than those encountered in every day life? If yes how has this been minimised? If yes, what supports have been put in place?	Yes _____ No _____
21. How will confidentiality of participants be assured?	
22. What is being done to preserve anonymity?	
23. Will other parties have access to information about individual participants (e.g. research supervisors, funders etc)	Yes _____ No _____
24. Have conditions been imposed on the ownership / publication of the findings? If so, please outline	
25. Can participants withdraw from the study at any point? If yes, how will this be communicated to participants	Yes _____ No _____
26. If observational research is to be undertaken without prior consent, describe the situation and how privacy confidentiality and dignity will be preserved.	
27. Doyou anticipate any child protection issued to be relevant for the research process? If so, please describe briefly and state what measures will be put in place to deal with them.	Yes _____ No _____

28. Will participants receive any other reward for participation? If yes, please specify	Yes _____ No _____
29. With reference to the Freedom of Information Act, what measures will you take for data storage?	
30. How will consent be obtained? (Attach a copy of consent form)	Consent form attached : Yes ____ No _____
31. How will you ensure informed consent? Please attaché information sheet	Information sheet attached: Yes _____ No _____
32. What is your feedback procedure?	
33. What do you expect to be the benefits / consequences for participants?	

Declaration of applicant

I confirm that I have read and will abide by the Children's Research Centre Ethical Guidelines and I certify that the information given is correct to the best of my knowledge and that I will

inform the Committee if there is any ethically relevant variation to the project as described in this application

Signature of applicant

Declaration of Principal Investigator

I have read through and approved the contents of this application to the Ethics Committee.

Signature of Principal Investigator

DECISION OF ETHICS COMMITTEE

Ethical Approval Granted Yes ☐ No ☐

Resubmit having reviewed sections as indicated

Signature of Chair of Ethics Committee: _____

Date: _____.

Section 5: Statutory Declaration

Statutory Declaration

It is the policy of Powerstown ETNS that all people who have direct contact with children are required to sign the attached Statutory Declaration Form. The form should be signed in the presence of a Commissioner for Oaths.

The Commissioner for Oaths may ask to see identification.

The form should be submitted to Powerstown ETNS prior to commencing such research.

Please be advised that under the Statutory Declarations Act 1938 as amended by the Standards in Public Office Act 2001, any person who makes a Statutory Declaration which to his or her knowledge is false or misleading in any material respect shall be guilty of an offence and shall be liable on summary conviction to a fine not exceeding €2,539.48 or, at the discretion of the Court, to imprisonment for a term not exceeding 6 months or to both such fine and imprisonment.

Signed:_____

Helena Trench (Principal)
Powerstown ETNS

Appendix 1: Ethical Guidelines of the Children's Research Centre

Notes on Ethical Issues in Research with Children

1.1 Preamble

This document sets out the Children's Research Centre's guidelines on ethical issues in research with children. It has been drawn up primarily to provide support for researchers in the Children's Research Centre and it is based on concerns and solutions which have been identified through their work in giving a voice to children's experiences. It is hoped that it will also serve to arouse interest in these issues among researchers outside the Centre who are working with children and that its dissemination will lead to fruitful discussions and perhaps modifications to the document in due course.

The work of the Centre takes place in a variety of settings, using diverse styles and approaches in a flexible manner and these guidelines were developed in response to a growing awareness that conflicts of interest, ethical concerns and other problems may arise and therefore that it would seem essential to have established a set of obligations to which researchers should normally adhere in guiding their work.

The aims of the document are:

- To provide a clear statement of the values and principles and the ethical and professional standards and obligations under which we aim to conduct our research.
- To alert researchers to issues that raise ethical concerns and to indicate potential problems and conflicts of interest that might arise in the course of their professional activities.
- To provide, for the researcher working with children, tools to engage in developing and maintaining an ethical framework for all research work.
- To suggest strategies in which the researcher may engage if concerns arise in the course of his or her work with children
- To provide guidance in identifying resources available for support

The preparatory process entailed a workshop for all members of staff [1], attendance by a staff member at a seminar organised by the Academy of Learned Societies for the Social Sciences (UK) on Ethics and Research Guidelines and the drafting of a set of guidelines based on the deliberations of the workshops and on consultation with a range of publications in the area issued by professional bodies[2]. The draft guidelines were discussed by staff and revised several times before they were produced in their present form (March 2006).

These guidelines should be read in conjunction with the TCD document on Good Research Practice (available at **http://www.tcd.ie/Research/Dean/local**) which includes sections on Ethics, Integrity, Good publication practice, Supervision of research and Retention of primary data. It seeks to extend the issues considered in that document by drawing attention to aspects of the research process which may give rise to particular concerns where children are involved. These include:

- Consideration of the socio-ecological context and the dignity and respect due to the child within that context,
- The meaning of freedom of consent for a child,
- The meaning of informed consent for a child,
- Anonymity and its implications,
- Confidentiality and its consequences.

The guidelines also outline procedures to be used when dilemmas arise for the individual researcher.

This document embodies the stance of the Ethics Committee of the Children's Research Centre.which serves to support the work of the researchers in the Centre and is available to assist them in finding solutions to difficulties when they arise. It is involved also in approving studies where an external body requires approval by an Ethics Committee or where covert techniques are being planned.

The document should be read in conjunction with the Guide to the Children's Research Centre (appended) which details its mission, ethos, aims, activities and methodologies and with the Guidelines on Good Practice in Research with Children (Section 1)

Notes

1. The initial workshop was led by Dr. Ruth Sinclair of the National Children's Bureau (UK)

2. 2.The publications consulted included those of the National Children's Bureau (UK), the Psychological Society of Ireland, The British Psychological Society, the American Psychological Association, the American Anthropological Association, the Academy of Learned Societies for the Social Sciences (UK), the British Sociological Association, the American Educational Research Association, the National Association of Social Workers and other relevant bodies.

2.1 General Principles

Researchers who are preparing to undertake research in the social sciences should be supported, through their training, in acquiring familiarity with generally agreed ethical principles. They should also have arrived at some understanding of their application and be prepared to seek guidance from them and to apply them in practice. In addition they should be familiar with procedures for resolving ethical dilemmas that may arise.

In general these principles are derived from a set of core values:

- Having a commitment to the well-being of those participating or involved in the research process (Beneficence);
- Having a commitment to doing no harm (Non-Maleficence)
- Having a commitment to the rights of those involved including the right of individuals to take responsibility for themselves (Autonomy)

To these core values the Children's Research Centre adds the following:

- Being child-centred in its approach to research, listening to children, treating them in a fair and just manner (Fidelity)

The present guidelines are intended to provide information based on those core values, as applied to various stages of the research process, which will support researchers as they make decisions. They are

meant as a foundation on which researchers can build through their own experiences rather than a comprehensive set of answers to all possible dilemmas and difficulties.

The core values and the principles derived from them will inform the research process from the very beginning. . In this section we outline some of the issues which may provide challenges for these principles and which will be covered in more detail below.

These include:
(a) Issues arising from the socio-ecological context of the child - danger of violating the Beneficience and Non-Maleficience principles.
(b) The transactional nature of the relationship between the child and the socio-ecological context means that the researcher's actions may jeopardize the child's situation.
(c) Issues arising from the requirement to ensure freedom of consent - danger of violating the Autonomy principle
(d) Issues arising at the stage where preparations are being made to ensure informed consent - danger of violating the Autonomy and Fidelity principles
(e) The management of anonymity - related to all the principles
(f) The management of confidentiality - related to all the principles

3.0 Responsibilities towards child participants in research projects

In general:
Honesty should characterize the relationship between participants and researchers and this means that information about the nature purpose and results of investigations, assessments and research findings should be given to participants in a language that they can understand. Covert techniques raise special concerns and will be dealt with in the section on Consent.

3.1 Respect for the rights and dignity of the child in the socio-ecological context

a) Socio-cultural context
Researchers should be mindful of cultural, religious, gender, ethnic, developmental and other significant differences within the research population in the planning conduct and reporting of research. They should strive to be inclusive.

b) Local institution/group context
Researchers should be sensitive to locally established institutional policies or guidelines where research is being carried out. They should be aware of possible disturbance to ongoing institutional activities, which could result from the conduct of the research and alert appropriate representatives. In the context of the setting, they should remember that decisions made on the basis of research, might have effects on individuals as members of a group even if individual research participants are protected by confidentiality and anonymity.

c) Individual circumstances
Researchers should treat children with dignity and respect. They should be aware of the danger of exploitation and of abuse of influence with children. Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, social status and

powerlessness.
Researchers should be active in identifying and validating appropriate ways of communicating with children – verbal, non-verbal - e.g. through art, music, drama.

d) Protection from harm
Researchers should make provision for the protection of research participants from unwarranted physical or mental distress, harm, danger or deprivation in the course of the research project or arising from their participation in it. They should be alert to the possible consequences of intrusion into the lives of those studied. These can be positive, but some people may feel harmed e.g. if research gives rise to false hopes, uncalled-for self-knowledge or unnecessary anxiety. This means giving careful consideration to and minimizing the use of research techniques, which might have negative social or personal consequences. It also means being responsive to non- verbal indications of distress or discomfort and debriefing in such a way that any harm can be discerned and corrected.

e) Use of proxies
Where research participants are ill, have a severe disability affecting their communication skills or are too old or too young to participate, proxies may need to be used in order to gather data. Certain limitations should apply:

- Care should be taken not to intrude on the personal space of the person to whom the data ultimately refer, or to disturb the relationship between this person and the proxy.
- Where it can be inferred that the person about whom the data are sought would object to supplying certain kinds of information, that material should not be sought from the proxy.

d) Self-determination

- Researchers should seek as full and active participation as possible from research participants in decisions which affect them; they should respect the rights of all involved to safeguard their own dignity and make it clear to individuals that they have the right to discontinue participation at any time.

- Researchers should be alert to indications that a child is unwilling to proceed and be prepared with ways of facilitating withdrawal without loss of face or distress, for example through the use of pre-arranged signals.

e) Sensitivity

- The researcher should be aware of the possibility of causing distress because of data sought, or methods used and possible long-term consequences of feelings aroused by questions

- The researcher may have to decide whether it is proper or appropriate to even record certain types of sensitive information. Guidance should be sought from the Ethics Committee.

4.1 Consent

Potential participants are usually required to give their formal consent to being part of a research project. There are two conditions to formal consent and both must be fulfilled; it must be voluntary and informed and these conditions are explained in more detail below. With adults, consent is normally in written form - samples are provided in the appendix. With children it may be written or verbal.There

may be situations, involving children, where verbal consent is sufficient perhaps because of difficulties arising from language, literacy or cultural differences. Securing consent from a child should generally be witnessed by a third party known to the child and this person should also sign a form to say that the consent process has been properly followed. Records should be kept regarding the consent and participants should be updated about any significant changes in the research programme and their consent re- obtained.

In general consent from parents or guardians must also be sought where children are under the age of 16 years.

There may be rare instances where it is not feasible to obtain consent, the planned intrusion is minimal and no risks are anticipated. Waivers of child, parental or guardian consent may be sought where:

i) The research involves no more than minimal risk for the research participants and
ii) The research could not practicably be carried out were consent to be required or
iii) The consent of a parent or guardian is not a reasonable requirement to protect the child (e.g. neglected or abused children)

Waivers of consent from a child and a parent or guardian require approval from institutional review boards or an ethics committee or from another authoritative body with expertise on the ethics of research. Such boards should also give guidance on what constitutes minimal risk.

It should also be recognised that certain investigations and interventions may be compulsory under the law - consent must still be sought in these cases where possible.

The consent of participants does not absolve the researcher from responsibility for consequences.

4.2 Free and Informed Consent

Two aspects of the Consent process need to be considered - the ethical requirements are that it be

i) Voluntary or given with freedom,
ii) Informed.

i) Freedom of consent (Voluntariness)

Working with children, researchers should take special care to ensure that the voluntary nature of the consent is understood and that consent is not coerced.

Using class or group-based studies, researchers should be aware that individuals have the right to withdraw or to refuse to participate and that they should ensure that potential participants know this. This applies in particular to children who are vulnerable because of their socio-ecological situation - in care, in hospital, in a secure setting, even in school.

Researchers should be sensitive to signs of unwillingness to proceed and be prepared with ways of facilitating withdrawal without loss of face or distress - such as by using pre-arranged signals.

There should be no implied or actual deprivation or penalty for refusal to participate.

Compensation/incentives

Opinions vary in the literature re compensation /recognition of contribution made by participants and whether this would compromise Freedom of Consent. NCB favours recognition of contribution after the event – with a mention of this possibility in the information presented beforehand; PSI and others suggest that participants should be compensated justly for the use of their time energy and intelligence unless such compensation is refused in advance. Costs incurred by participants should always be reimbursed.

Informed Consent

Informed consent means that information is given to participants, in a language and in a way that they can understand, about the aims of the research, the extent and duration of the participation requested and disclosure of the risks and benefits of participation in the research. They must also be told of the uses that will be made of the research, where the data will be held and who will have access.

The degree and breadth of the knowledge given will depend on the nature of the project and may be affected by the requirements of other laws and codes of ethics. Where covert techniques are used (and this should happen only with the approval of an ethics committee) the reasons should be explained to participants when being debriefed.

Where participants are incapable of giving informed consent:

Special consideration will be required regarding children in care, children of ethnic minorities, children with disabilities, children w hose first language is not English and children who have literacy difficulties. In cases where participants may be judged to be incapable of giving informed consent; researchers should provide an appropriate explanation to the participants, obtain the participants' assent to the extent that they are able and obtain written consent from an appropriate proxy.

When participants are not literate in the language of the researcher, every effort must be made to inform their consent in their own language and it may be appropriate to have a witnessed consent.

Where there are gatekeepers, informed consent should be obtained directly from the participant while taking account of the gatekeepers' interest. Care should be taken not to unduly disturb the relationship between gatekeeper and participant.

5.0 Anonymity, Confidentiality

Anonymity (concealing the identity of participants) must be understood as a given when there is no clear understanding to the contrary. Not all studies require anonymity and in some cases identification of participants is essential to enable follow- up. But actual data can be separated from nominal identity and linked only by codes at the analysis stage. At the end of the project, all data should

normally be anonymised. It should be borne in mind that the promise of anonymity may mean rejection of the use of tape-recorders and video unless special conditions are negotiated for their use.

Confidentiality means protecting the privacy of participants by sharing data only with those agreed with participants. The researcher should make clear the uses to which information will be put and to whom it will be communicated.

At the same time, it must be recognised that there are limits to this where child protection is necessary, so the researcher should be realistic about guarantees of confidentiality.

A child participating in research should be told from the outset and as necessary during the course of an interview that confidentiality cannot be guaranteed if information is divulged re the risk of serious harm to the child or to others, or where the researcher observes or receives evidence of incidents likely to cause serious harm. The researcher has a duty to take steps to protect the child or other children and to provide support for the participating child.

In situations where participants are privy to each other's data because of focus groups or group interview sessions, there is always a need to clarify the measures that will be taken to protect confidentiality and what responsibilities the members of the group have for the protection of each other's confidentiality.

It should also be recognised that research data given in confidence do not enjoy legal privilege and may be subpoenaed by a court. Research participants may need to be made aware that it may not be possible to avoid legal threats to the privacy of the data. Data should be stored so that it complies with the requirements of the Freedom of Information Act 1997 and the Data Protection Act.

6.0 Special case scenarios

6.1 Considerations in relation to dilemmas that may be uncovered in the course of research

Areas in which ethical dilemmas often occur in research situations include conflicts between the interests of participants in the research for whom a service is provided (and which is perhaps being evaluated) and those of other interested parties and between those of research participants and those who commissioned the research.

There are specific issues, which may come to light in the course of research in which children are engaged as active participants

These may include:

i) Issues related to service provision/malpractice;
ii) Awareness of bad research practice
iii) Receipt of information from the child or other participants leading to suspicion of child abuse

6.2 Procedures to be followed in such instances

In these and other instances which give rise to concern the following procedures should be followed by Centre staff:

1. Define carefully the issues and participants involved
2. Identify relevant laws and professional guidelines such as Health Board policy documents
3. In the case of suspected child abuse, see reporting procedures in *Children First* pp37-38 (Appendix 1).
4. In other cases, report on each of the aspects of the problem to the senior member of staff supporting the project and s/he will advise on further consultation with all the relevant or interested

parties (who may include individuals in receipt of services, other individuals, family members, co-workers, organisations purchasing or providing services, the general public etc.
5. Identify a number of possible alternative decisions
6. Evaluate carefully the likely outcome of each decision
7. Choose what, in their professional judgement is the best decision, implement it and inform the relevant parties.
8. Take responsibility for the consequences of the decision.

Each stage of the decision-making process should be recorded in writing.

6.3 Issues which may give rise to concern within the research process

Other issues may arise from activities within the research process itself in relation to research with children include

- The reliability of information given by children
- The interpretation and understanding of information given by children
- The eventual transformation and destination of data

6.4 Procedures to be followed

It is advisable that researchers should routinely employ a decision-making strategy to resolve such problems and dilemmas (see 4.1 above). Some overall principles – extending somewhat those listed under 2.0 and 3.0 –3.4 above may be used as guidelines where decisions have to be made about whether or not to proceed and how to proceed in particular instances.

6.5 Value of such procedures

This practice will not only assist in difficult cases but will enhance the quality of day- to-day professional activity. The quality will be further enhanced where social science researchers also routinely consult other researchers about ethical issues and engage in regular monitoring, assessment and reporting about ethical practices and safeguards
(e.g. through peer review and in programme reviews, project reviews and reviews of their own research).

The complexity of ethical issues makes it likely that different principles will sometimes clash and in addition they may clash with the law and/or other relevant guidelines.

NB: Errors of judgement are not the same as malpractice.