National College of Ireland
Mayor Street, IFSC,
Dublin 1, Ireland
D01 K6W2

Coláiste Náisiúnta na hÉireann
Sráid an Mhéara, IFSC
Baile Átha Cliath 1, Éire

Tel: +353 1 449 8500
email: info@ncirl.ie
Website: www.ncirl.ie

National College of Ireland Guidelines for Research Projects involving Children

The aim of these guidelines are to advise good practice principles for undertaking research with children (defined in Ireland as people below the age of 18). These guidelines were developed based on the *Guidance for developing ethical research projects involving children* document developed by the Department of Children and Youth Affairs (DCYA, 2012).

In Ireland, research conducted with children is recognised as being of extreme value in providing us with information to understand our children better. It is also important that children's agency is recognised and care is taken to view them as active participants in making decisions about issues that concern them, more so because Ireland is a signatory to the UN Convention of the Rights of the Child since 1992. This understanding allows us to ensure that policy's developed at a national level are ensuring the services and supports children need are being provided to maximise their well-being and development. However, working with children requires close attention to ethics due to their legal status, their knowledge and experience of the world, their emerging cognition and their lack of independence and autonomy (DCYA, 2012).

Research involving children, completed by NCI staff or students, must be approved by the Research Ethics committee prior to the commencement of the research. An exemption may be applied in the case of students undertaking work placement in schools which may have some research component of their placement (e.g. child observations). It is at the discretion of the course director to decide whether this is required to get ethical approval. However, where the research is completed for specific purposes as a research project ethical approval should be sought (e.g. final year project).

When planning research with children there are a number of core ethical principles relevant to all research with human participants which must be addressed:

1. Minimising risk of harm

One of the main concerns in research ethics is to protect participants from harm. When working with children a key ethical concern is the level of risk they may be exposed to. In considering research involving children researchers should evaluate the potential risk to children and interpret minimal risk in relation to the typical experiences of an average healthy child.

Researchers should consider the potential benefits, the potential risks (physical, psychological and social) and whether changing the setting, methodology or participant group would reduce the risk. It should be considered how likely the study is to yield meaningful results which may have the potential to contribute positively to children's lives and if it is worth the participant's time, effort and potential risk. Furthermore, efforts should be made to ensure systems are in place to deal with any potential harm which may arise.

2. Informed consent and assent

In conducting research, it is necessary that steps are taking to ensure that when consent is being asked for that participants have sufficient information to make an informed decision. In dealing with children, parents and/or guardian consent is required for children to participate in research. Good practice also necessitates the child to give informed assent which involves the child agreeing to take part in the research. It is the responsibility of the researcher to ensure that child friendly language is used so that children fully understand what they are agreeing to. Arrangements should be put in place to deal with any questions or concerns participants may have. Participants should be made aware that their participation is entirely voluntary and that they may withdraw from the research at any time without any consequences. If a child declines to participate this overrides parental consent.

3. Confidentiality and anonymity

In conducting research confidentiality must be ensured. Safety measures should be put in place to ensure that access to data is restricted to those authorised to have access according to the data protection legislation. This means that any identifiable information should not be disclosed without explicit consent of participants. An exemption to this is in place in the case of child protection concerns which will be covered later in this document. Participants should be made aware of this exemption. Participants should remain anonymous and not be identifiable unless agreed on.

4. Child protection principles

When conducting research with children, researchers should be aware of best practice standards in relation to child protection. In Ireland, these procedures are based on *the Children: First National Guidance for the Protection and Welfare of Children* published by the Department of Children and

Youth Affairs (DCYA, 2011). These guidelines outline best practice for the protection and promotion of child welfare and the procedures to follow in the case of child protection concerns. The National College of Ireland have developed Protocols and Procedures in relation to child protection.

In order to ensure child protection, the following steps should be taken:

- Completion of a risk assessment prior to the commencement of a research project
- All researchers working with children under the age of 18 should be Garda Vetted- see NCI Policy on Garda Vetting June 2010
- All Researchers should have adequate skills, training and access to relevant expertise in relation to child protection- see NCI Child Protection Guidelines
- All Research should be conducted in an environment with a third party adult present- see NCI Child Protection Guidelines

Child protection best practice principles and legislation require that in the case of child protection concerns the best practice ethical principle in relation to confidentiality may be overlooked. The researcher has a duty to protect the child and/or other children in the case of a disclosure.

Researchers conducting research in the National College of Ireland are required to sign an “Acceptance of the National College of Ireland Child Protection Guidelines & Principles for the Protection of Children” form.

5. Legal obligations and policy commitments in relation to children

In the completion of research with children their participation rights are covered by the United National Convention on the Rights of the Child (UN, 1989). Children and their parents also have rights under the Data Protection Acts (Government of Ireland, 2003). In line with the *European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004* (Department of Health and Children, 2004), parental or guardian consent is required for clinical trials involving minors (those under the age of 16 years). All research in Ireland should be carried out under the framework of the *Children First: National Guidance for the Protection and Welfare of Children* (DCYA, 2011). Researchers should familiarise themselves with these legal obligations and policies.

6. A child-centred, inclusive approach to research

Children have the right to be involved in the research process and in doing so the quality of the research may increase. It is the researcher's responsibility to ensure steps are taking to make the research project accessible to children.

Researchers should be mindful of the power relationships between adults and children which may lead to children agreeing to take part in research. This should be considered in developing the research guidelines.

Research with children with disabilities should be carried out in line with guidelines from the National Disability Authority.

The setting in which research is conducted plays a role in the consent process. Some schools operate a policy of seeking general parental/guardian consent for a variety of activities however this should be utilised with caution. Schools should ensure that any consent obtained is specific enough to cover the research process. Researchers have the responsibility of ensuring that the consent covers participation in the type of research planned. Evidence should be provided of this consent. It is argued that researcher's need to keep an eye open for any indications that they might want to withdraw from the research, even if they do not express it verbally and the researcher needs to attune to children's unique communication styles (Skanfors, 2009).

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NCI Ethics Checklist for Children's Research

Deciding on the research	**Yes**	**No**
Have you completed a risk-benefit analysis in considering the potential benefits of the research against the possible risks?		
Have you considered the scientific and practical value in terms of whether the study is worth the participant's time effort and potential risk?		
Have you considered the setting in which the research is taking place and how this might influence the research or the participants (power structures etc.)?		
Have your considered who the stakeholders in the study are?		
Have you considered the Research Ethic Committees and legislation in relation to the research?		

Preparing the research	**Yes**	**No**
Have you familiarised yourself with NCI's Child Protection policies and procedures?		
Have you signed the NCI's "Acceptance of the National College of Ireland Child Protection Guidelines & Principles for the Protection of Children" form?		
If working in an external setting, have you familiarised yourself with the settings Child Protection policies and procedures?		
Are the research staff Garda-vetted?		
Have you provided evidence of this?		
Has it been considered if the researchers have adequate skills and training to work with children?		
Do researchers have access to appropriate training, supervision and support in relation to children's research and child protection?		
Do researchers have the skills to identify distress signals and react to them appropriately?		
Have you provided the participants with sufficient information to allow them to make informed consent?		
Have you considered how any role conflict may influence the consent process?		
Have you considered if any rewards will be given for participation?		
Have you considered if these might influence participants willingness to consent?		
Have you considered how children might be active participants in issues that concern them?		

Starting the research	**Yes**	**No**
Is the research information (the process, consent, benefit and harm) presented in an accessible way to the children, parents and other stakeholders?		
Is the language used in communicating this information appropriate?		
Are you attuned to children's non-verbal communication regarding their willingness to participate in the research process?		
Have you considered how you will put arrangements in place to deal with any concerns or queries children, parents or stakeholders may have in relation to the research?		
If conducting research in a setting with previous existing consent structures have you ensured your research is covered by this consent process?		
Have you provided evidence to this effect?		
Have you considered how you will ensure children are assenting to the research?		
Have you communicated the right for participants to withdraw from the research at any time?		
Have you put safety measures in place to ensure data is protected in line with data protection legislation?		
Have you ensured children, parents and other stakeholders are aware of the limitations to confidentiality prior to consent or assent?		
Have you considered how you will ensure anonymity by taking measures to remove identifiable information and features from the data?		
Have you considered putting measures in place to prevent or minimise the risk of harm to participants?		
Have you considered a protocol to deal with distress experienced by children during and after the research process		
Have you considered the researchers supervision and support for dealing with distressing situations?		

Finishing the research	**Yes**	**No**
Have you considered how you will debrief the children, parents and stakeholders?		
Will you provide the children, parents and stakeholders with contact details if they require support later?		
Will children, parents and stakeholders be informed about the research results?		
Have you considered how you will inform them?		
Will participants have the chance to give feedback to the researchers on their research experience?		

Disseminating findings of the research	yes	no
Do you plan to publish the findings or release them to the media?		
Have you considered how to acknowledge the participants of the research?		
Will you include		

This checklist has been developed based on the Department of Children and Youth Affairs (2012) *Guidance for developing ethical research projects involving children*. Dublin: Government Publications.