



# The Ethics Journey in Children's Research: Checklist

## I. Choosing the destination

- 1. Risk-benefit analysis:** How will children (defined in Ireland as people under 18 years) and other stakeholders be affected by the research?
  - What are the potential benefits of the research?
  - What are the potential physical, psychological and social risks and burdens related to the research?
  - Could risk be reduced through changes in the research setting, methodology or participant group?
- 2. Scientific and practical value:** Is the study worth the participants' time, effort and the potential risk?
  - How likely is it that the study will yield meaningful results?
  - What evidence is there that the study methodology is suitable for children?
  - Does the study have the potential to contribute positively to children's lives?
- 3. Research setting analysis:** What are the ethically relevant characteristics of the setting and what is the role of the researcher in it?
  - What are the benefits, and constraints, of choosing this particular setting for the research question?
  - Is the researcher familiar with this setting and its challenges?
  - If the research takes place in a setting that the child also attends for other purposes, how is their research role different from their usual role?
  - Could research be affected by power structures in the setting and what will be done to address this problem?
- 4. Stakeholder participation:** Involvement of children and relevant others.
  - Who are the key stakeholders for this research?
  - What elements of the study will children and other stakeholders have an input into and what form will their input have?
- 5. Research ethics committees (RECs) and other ethics requirements:** Accessing appropriate REC.\*
  - Is there a REC in place with the expertise and authority to approve the research? Are multiple applications required?

- Are all aspects of data protection law, and specifically provisions relating to research, understood by the RECs and researchers?
- Are clearly identified ethics complaints procedures in place for participants?

## II. Preparing for departure

- 6. Child protection and well-being**
  - Does the research team/organisation have a Child Protection policy and protocols in line with national laws and best practice?
  - Has a risk assessment and risk minimisation strategy been developed?
  - Are research staff Garda-vetted and otherwise assessed to be competent to work with children?
  - Do researchers have access to appropriate training, supervision and support regarding children's research and child protection?
  - Do researchers have sufficient skills to identify distress signals and react appropriately to them?
- 7. Recruitment:** Is the recruitment process for research participants ethically appropriate?
  - Do all the relevant stakeholders have timely access to information about the research and are they given an opportunity to communicate with the researchers about the research before it begins? Is there a potential role conflict for the researcher between their research and other, pre-existing roles?
  - What steps will be taken to ensure that recruitment efforts are not intrusive or overburden the participants?
- 8. Rewards:** Will participants be given rewards for participation?
  - Could the rewards offered unduly influence the children's decision to participate or bias the results?
  - Are the rewards ethically appropriate and compatible with the values of the organisation and main stakeholders?

\* The Health Information and Quality Authority (HIQA) will become the supervisory body for all health-related research and Research Ethics Committees following the passing of the Health Information Bill and will provide a streamlined process for multi-site REC approval.

### III. Embarking on the journey

#### 1. Participant information sheet and consent form:

Is the written information given to children, parents and other stakeholders accurate and accessible?

- Are relevant facts on research content, process, benefit and harm, and on consent presented in accessible form to children, parents and other stakeholders?
- Is the language, content and presentation of the information tailored to the children's age and level of comprehension?

#### 2. Informed consent process:

How is informed consent obtained once children, parents and other stakeholders have been approached?

- What arrangements are in place to allow children, parents and other stakeholders to clarify or express concerns about the research?
- What procedures are in place to ensure that children are assenting to participation?
- Is the communication with the children conducted in an engaging manner?
- Do participants understand that they are entitled to withdraw from the research at any time without any repercussions.

#### 3. Confidentiality:

How will the confidentiality of information be ensured?

- Are there safety measures in place to ensure that access to data is restricted strictly to those who are authorised to access it according to data protection legislation?
- Are children, parents and other stakeholders aware of potential limitations to confidentiality prior to consent/assent?
- If the research is a longitudinal study, is there secure provision for storing identifiable data throughout the lifetime of the study and plans in place for its destruction when the project is completed?

#### 4. Anonymity:

How is anonymity ensured?

- What measures are taken to remove identifiable information and features from the data?
- Is it possible to ensure anonymity for small populations and, if not, what procedures will be followed?

#### 5. Monitoring and contingency management:

Are procedures in place to ensure problems are detected early and dealt with effectively?

- What measures are in place to prevent or minimise the risk of harm to participants?
- Is there a protocol for follow up to deal with distress experienced by children during and after the research process?
- Do researchers have access to appropriate supervision and support if they encounter distressing experiences?

### IV. Ensuring a good departure and keeping in touch

#### 6. Debriefing

- Should children, parents and other stakeholders be given the opportunity of debriefing, especially if the research is potentially sensitive or negative effects could occur? What form should this take?
- Have the children, parents and other stakeholders been provided with contact details if they later require support arising from their research participation?

#### 7. Information and feedback

- Will children, parents and other stakeholders receive information about the research results? What form will this take?
- Will participants have the opportunity of giving feedback to researchers about their research experience?

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