



ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children
and Young People



Childwatch
INTERNATIONAL
RESEARCH NETWORK

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Te Whare Wānanga o Ōtago
NEW ZEALAND

GLOSSARY OF TERMS

Adolescent - An individual in the state of development between the onset of puberty and maturity; definitions vary according to culture and custom. The World Health Organization's definition is from age 10 years through age 19 years.

Agency - Children's agency refers to their capacity to be active and to act on the social world, rather than be seen as passive recipients of what happens to them.

Anonymity - Anonymity refers to concealing participants' identities in all documents resulting from research.

Assent - An informal agreement to participate in research. Assent is not universally recognised or agreed upon, with some advocating the use of consent in preference to assent.

Benefit - Benefit is one of the three core principles of ERIC. In this context, benefit includes the principle of non-maleficence, doing no harm, and the principle of beneficence.

Beneficence - Beneficence refers to actions that improve well-being and a researcher's obligation to strive for their research to improve the status, rights and/or well-being of children.

Child/Children - ERIC adopts the definition of a child, consistent with Article 1 of the UNCRC, as "every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."

Child abuse - Any action or lack of action by individuals or institutions that directly or indirectly harms children, makes them unsafe, or prevents healthy development. Different forms of child abuse include neglect, sexual, physical and emotional abuse.

Collective cultures - Collective cultures are societies that are characterised by collectivism. They value communal harmony, group goals, and cohesion rather than any one person's satisfaction, goals or achievements. They emphasise interdependence, rather than independence.

Confidentiality - The researcher and all staff involved in the research are ethically obliged to treat information acquired during the research process carefully, in confidence, and to not allow this to be revealed to others. Researchers must securely store, protect and dispose of information/data that has been collected. They must also be prepared to breach confidentiality if a child or others are at risk.

Consent - See Informed consent

Debriefing - Debriefing refers to the process of sharing information about the research with participants after the data has been collected. Generally, this involves seeking feedback from research participants and/or researchers about the research methods, content and process. In experimental research designs, debriefing refers more specifically to providing participants with information that was either withheld (such as the nature of experimental conditions) or misinformation that was provided (i.e., deception) as part of the experimental procedure. In such cases, debriefing aims to undo any harm that may have been caused by the deception/withholding of information.

Discrimination - The unjust or prejudicial treatment of different categories of people, especially on the grounds of race, age, or sex.

Dissemination - The process of communicating research findings.

Dissent - Refusal to participate in research. Dissent may manifest as not signing a consent form, it may be verbally stated, or indicated by indirect verbal and non-verbal behaviours, such as saying "I'm tired", or looking away from, or moving away from the researcher.

Equity - The quality of being fair and impartial.

ERIC - ERIC is the acronym for Ethical Research Involving Children, which is the title of the international, collaborative project that produced the ERIC compendium and the ERIC website. It is not associated in any way with a library database that also has the ERIC acronym.

Ethics - Ethics refers to well-founded standards of right and wrong that prescribe what humans ought to do, usually in terms of rights, obligations, benefits to society, fairness, or specific virtues. Ethics also involves the study and development of our own ethical standards via continual examination of our moral beliefs and conduct.

Evaluation - Research that seeks to assess whether a programme, intervention, policy, or service has met its objectives. The evaluation usually aims to identify ways in which the programme, intervention, policy, or service can be improved.

Focus group - A research method used in field work whereby a group of people discuss the topic of interest.

Gate-keeper - A person who has the authority to grant formal or informal permission or access to approach other individuals, such as children.

Gillick competence - Gillick competence refers to a legal case in England (Gillick v West Norfolk and Wisbech Area Health Authority, 1985) which determined whether doctors should be able to give contraceptive advice or treatment to under 16-year-olds without parental consent. The term has since been more widely used to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions.

Harm - Harm in research includes physical retribution or punishment from others for participating or not participating in research activities, as well as physical harm, emotional distress, anxiety or loss of self-esteem as direct consequences of the research study itself.

Individualistic cultures - Individualistic cultures are societies that are characterised by individualism rather than collectivism. Their values are oriented around the self, personal satisfaction and achievement of personal goals, rather than communal harmony. They emphasise independence, rather than interdependence.

Informed consent - Informed consent refers to the process of fully informing children and their parents/carers as to the purpose of the research and what their involvement will be, prior to their decision as to whether or not they participate in the research. Informed consent is an explicit agreement which requires participants to be informed about and have an understanding of the research. It must be given voluntarily and be renegotiable, so that children may withdraw at any stage of the research process.

Justice - Justice is one of the three core principles of ERIC. The principle of justice requires researchers to attend to the power differences inherent in the adult/child research relationship; to find a balance between who receives the benefits from the research and who bears its burdens, and it must underpin decisions about 'which' children will be included/excluded from research. Children should always be treated fairly and the benefits of research distributed equitably.

Neglect - Continued failure to provide for a child's basic needs, including physical, medical, educational, social, psychological and emotional needs.

Non-maleficence - The principle of non-maleficence, or doing no harm, requires researchers to avoid harm or injury to children, both through acts of commission or omission.

Parent - A child's biological or adoptive parent. The term 'Parent' is used throughout the Ethical Guidance sub-sections to refer to parents, carers, guardians and those in parent substitute roles.

Parental consent - The process of gaining informed consent from parents of children who participate in research.

Participants - The individuals who take part in a study, either directly or indirectly via a representative, and who have given their informed consent.

Participation rights - Participation rights are elucidated in the UNCRC and underpin researchers' obligations to consider, respect and protect children's involvement. They underlie researchers noticing and valuing children and their potential contribution to research, and ensuring that children have a choice about participation, including the right not to participate.

Participatory research - Research carried out with and by participants themselves and involves the use of quantitative and/or qualitative methods, adapted to suit their skills and aptitudes, so as to investigate their own social world.

Payment - Forms of payment in research include: reimbursement payments – when children and/or parents are paid to cover the direct expenses related to participation; compensation payments – in which children and/or parents are recompensed for their time, work and effort, and for any inconvenience caused by participation; appreciation payments - bonuses or tokens given to children after their participation to thank them for their contribution; and incentive payments – which are designed to encourage the participation of children in research.

Peer research - Peer research is a methodology in which children and young people actively participate as researchers in a study with child respondents.

Privacy - Respecting the privacy of children participating in research involves consideration of: how much information the child wants to reveal, and with whom; privacy in the processes of information gathering/data collection and storage that allows the exchange of information to be confidential to those involved; and privacy of the research participants so that they are not identifiable in the publication and dissemination of findings.

Protection rights - Protection rights are elucidated in the UNCRC and in research refer to researchers ensuring the safety and care of children.

Provision rights - Provision rights are elucidated in the UNCRC and in research refer to researchers ensuring that children are supported to be involved in research processes as appropriate.

Qualitative research - A method of inquiry that produces rich, in-depth non-numerical data. Common data collection methods include focus groups, triads, dyads, interviews, observation, and ethnographic participation/observation.

Quantitative research - A method of inquiry that produces data which can be counted or expressed numerically. Common data collection methods include surveys, clinical trials and experiments.

Reflexivity - The capacity of researchers to reflect critically about the impact of their research on participants and their communities, on researchers themselves, and on the body of knowledge under investigation.

Relational - (dimensions of research ethics) The relationships between people who interact during the research process and are integral to good conduct.

Research - ERIC conceptualises research as the collection of data or information within the framework of a methodical study in order to answer specific questions or test hypotheses. This is relevant across the range of research contexts and includes evaluation, monitoring and implementation activities.

Researcher - ERIC has been developed to support all researchers, individuals and organizations who are involved in research that is undertaken with, or potentially impacts on, children. This includes all members of any research team, research organizations, other stakeholders and research ethics review committees.

Respect - Respect is one of the three core principles of ERIC. Respect implies valuing children and the context of their lives, and recognition of their dignity. Respect is linked closely with rights. The UNCRC anticipates three dimensions of respect: participation rights, protection rights and provision rights.

Re-traumatisation - Concerns regarding re-traumatisation in research are related to the possibility of delayed onset or reactivated symptoms related to something traumatic experienced in the past and referred to in the study.

Safeguarding - The action taken to ensure that children are protected from harm. Child safeguarding in research settings applies to situations in which researchers think that children may be at risk and in need of protection; and affording children protection from potentially abusive and incompetent researchers.

Stakeholder - A person or organization with an interest in a research activity and who is affected by the research outcomes.

Stigma - A mark of disgrace associated with a particular circumstance, quality, or person.

Subjects - Can be used to describe the individuals who take part in a study. The term has historically been used to describe a human or animal sample in experimental research, whereas 'participants' has been used more frequently in survey research and qualitative studies.

UNCRC - The United Nations Convention on the Rights of the Child 1989 is a human rights treaty setting out the civil, political, economic, social, health and cultural rights of children. Nations that have ratified this convention (193 in total) are bound to it by international law.

Vulnerable children - A child whose survival, well-being, or development is threatened. Vulnerable children include those who are orphaned, unaccompanied, and separated from family, as well as children with disabilities or who may have special needs.

Young people/youth - Youth is the transitional phase between childhood and adulthood. The term 'youth' is not defined in international law; however, working definitions from the United Nations use the term 'youth' for young people 15 years through to age 24 years. Young people are a heterogeneous group in constant evolution and the experience of 'being young' varies enormously across regions and within countries.