



# ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children  
and Young People



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INTERNATIONAL  
RESEARCH NETWORK

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# BACKGROUND



This compendium is part of an international project entitled Ethical Research Involving Children (ERIC). ERIC has been motivated by a shared international concern that the human dignity of children is honoured, and that their rights and well-being are respected in all research, regardless of context. To help meet this aim, the ERIC compendium acts as a tool to generate critical thinking, reflective dialogue and ethical decision-making, and to contribute to improved research practice with children across different disciplines, theoretical and methodological standpoints, and international contexts. Emphasis is placed on the need for a reflexive approach to research ethics that fosters dynamic, respectful relationships between researchers, children, families, communities, research organizations, and other stakeholders. Hence, the content of this ERIC compendium moves beyond prescriptive approaches to encourage a more critical engagement with ethical issues and contemporary research practices across the multiple sectors and national/international contexts in which these take place.

# BACKGROUND TO THE ETHICAL RESEARCH INVOLVING CHILDREN (ERIC) PROJECT

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 researchers, all members of any research team, research organizations, other stakeholders and research ethics review committees.

## WHAT IS ERIC?

The international Ethical Research Involving Children project, or **ERIC**, is focused on assisting **researchers** and others in understanding what it means to plan and conduct ethical **research** involving children and young people in different geographical, social, cultural and methodological contexts.<sup>iii</sup> By 'research involving children' we mean all research in which children are taking part, either directly or indirectly through a representative, irrespective of their role, and the methodology or methods used to collect, analyze and report data or information. In this way, ERIC seeks to ensure the human dignity of children is honoured, and their rights and well-being are respected in all research, regardless of context.

Significant emphasis is now placed on the value, importance and legitimacy of research that captures the views and perspectives of children and young people. Much has been written about why this is important and how such research can be approached, including with quite young children and others considered vulnerable, on issues identified as sensitive, and using a range of research methods and tools. Yet, many researchers report feeling quite isolated in their research activities, particularly when it comes to making informed decisions about complex issues, such as how to balance the protection of children while progressing their participation in research.

This compendium, together with the associated website (see: <http://childethics.com>), has been specifically designed to provide a rich repository of evidence-based information and resources to guide and improve research involving children. These materials are also intended to encourage critical reflection, dialogue and collegiality across the international research community. To achieve this, it is critically important to keep in mind that it is the attitudes, values, beliefs and assumptions of all involved **stakeholders** that ultimately shape the research experience much more than any documentation or checklist possibly could. By fostering deeper engagement with what it means to do ethical research, the compendium and website also challenge and extend understandings of the children and young people involved in research, including the diverse childhoods they experience.

By 'research involving children' we mean all research in which children are taking part, either directly or indirectly, across the range of research contexts, including but not limited to evaluation, monitoring and implementation activities.

## STRUCTURE OF THE ERIC COMPENDIUM

The ERIC compendium consists of nine parts:

1. This Background, which states the aim and explains the history and background of the ERIC project.
2. The Philosophy, which provides the rationale for the development of the ERIC compendium and accompanying website and elaborates on the ethical principles underpinning these.
3. The Ethics Charter, which is an aspirational statement of seven commitments written for researchers and others who engage in research involving children, and who are committed to fulfilling their responsibility to undertake ethical research, irrespective of context. It has been developed to inspire and unify researchers internationally around these core commitments which aim to elevate the status, rights and well-being of all children.
4. The ERIC Guidance, which identifies key ethical issues arising in research involving children.<sup>iii</sup> It is structured to engage researchers and others in thinking critically about:
  - ethical considerations in regard to their research involving children;
  - the challenges that arise that have no clear cut answers;
  - the questions that have relevance and application throughout the different phases of the research process.

The ERIC Guidance is not intended as a procedural document so much as a broad framework and a tool for generating reflective dialogue, where the starting point is a deep respect for human dignity and a desire to advance the status of children in the way called for by the United Nations Convention on the Rights of the Child (**UNCRC**). The ERIC Guidance invites researchers to engage with the complexity of ethical issues as encountered in their specific cultural, social, religious, political and economic contexts. Importantly, it is designed to connect researchers more deeply with their own tacitly held values, attitudes, beliefs and assumptions, and to recognize the ways in which these shape the decisions they make in the research process.

5. Researcher Support, which discusses some of the issues facing researchers, including their own welfare and safety, and offers suggestions for support in the contexts of training, supervision and ethical review mechanisms.

6. Getting Started, which is a series of questions for researchers to consider when planning their research, in light of the ethical principles and challenge-based case studies provided in the compendium (see point 7 below). It is essential that ethical issues are considered at the outset of any research project, so they are accommodated in the resource planning, budget and timeline. It is also critical that ethical consideration is ongoing throughout the research project, from conceptualising the research focus to its post-**dissemination** impact. This will help to ensure that issues are responded to as they emerge and hence position the research to be ethical in its entirety. As well as the key questions raised in the ERIC Guidance (see point 4 above), additional questions related to specific research phases are incorporated in this section.

ERIC invites researchers to engage with the complexity of ethical issues as encountered in their specific cultural, social, religious, political and economic contexts.

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.

It is essential to consider ethical issues at the outset and throughout the research process, from conceptualisation to post-dissemination.

7. Case Studies, which provide examples of ethical challenges and aim to assist researchers to engage critically with the kind of questions and uncertainty encountered by other research colleagues, since these may resonate with their own experience and/or offer a way forward with similar dilemmas. Case study challenges from different international contexts and from different thematic areas and research paradigms are used to exemplify the processes that can be utilised in developing ethical thinking and improving ethical practice.

8. Conclusion, which provides a brief outline of the foundational issues in the compendium, contextualised within the broader ERIC project, and invites researchers to continued engagement with these and ongoing collaboration in the development of ethical research practice.

9. Resources, which is the final section of the compendium and includes a glossary of terms, reference list and an annotated summary of other published ethical guidelines.

ERIC is not just for researchers.

### WHO IS THE ERIC COMPENDIUM FOR?

The ERIC compendium 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 researchers, all members of any research team, research organizations, other stakeholders and research ethics review committees.<sup>iv</sup> It is envisaged that the compendium will be helpful for those starting out on research involving children, such as students and early career researchers, as well as more experienced researchers and other members of the research community who may or may not be experienced in research with children. The scope extends to include researchers who do not specifically work with children, but whose research will potentially impact on children's lives and well-being.

ERIC is relevant across wide-ranging areas of research, within the various sectors, which take place in diverse local and international settings.

ERIC is intended to be a useful tool for research ethics committees engaged in the process of reviewing and approving projects submitted by researchers. It may also be of assistance to policy-makers and organizations who commission research involving children, as evidence-based policy and practice that upholds the rights and well-being of children, calls for quality research underpinned by ethical reasoning.

The approach proposed in ERIC is relevant across wide-ranging areas of research which take place in diverse local and international settings. These may include inquiring into children's health, humanitarian needs, education, protection, social policy and poverty, research concerning nutrition, water and sanitation, as well as evaluative and upstream policy research initiatives. It is relevant across all research contexts, including **evaluation**, monitoring and implementation activities. ERIC is likewise applicable to **qualitative** and **quantitative research**, encompassing any methodology, ranging from large-scale household surveys and longitudinal studies to ethnographic research. In other words, the ERIC approach is foundational to all research directly or indirectly involving children.

ERIC has been developed to support **reflexivity** by researchers and other stakeholders in regard to the decisions they make, and the subsequent actions they take, throughout the research process. At its most basic, 'reflexivity' refers to the capacity of people to be conscious of, and give account of, their actions (Phillips, 1988). This suggests reflexivity may be 'both a skill and a virtue - a process through which tacit knowledge might be rendered explicit' (Moore, 2012, p.67) and subsequently shared. In other words, to be reflexive requires us to be able to detach from what we do and 'reflect on it as a problem' (Flyvbjerg, cited in Emslie, 2009, p. 419).

Such reflexive engagement in the context of enhancing ethical research involving children requires researchers to consider important issues, including:

- whether the research is necessary and should be undertaken;
- their readiness and capacity to conduct the research;
- assumptions about childhood and the children involved;
- the impact of both their own and children's experiences;
- disparities in power and status between themselves and the child research participants.

There are no easy answers or ready solutions to the complex issue of ethical research involving children. Such research is not conducted in a vacuum, but like other enterprises is subject to constraints and limitations related to funding, resources, interpersonal power dynamics and the wider management context. Therefore, the ERIC project explicitly emphasises the importance of deeper reflection and closer collaboration between researchers from different disciplines, working with children in wide-ranging contexts.

The ERIC compendium and accompanying website are freely and openly available in the public domain, making these essential, collectively-owned tools for the research community. The content has been developed in consultation with researchers from a wide range of backgrounds to have relevance across diverse sectors, geographical and cultural contexts, while also recognising some of the challenges and limitations in developing these for such wide use. The content builds on existing national and international guidelines developed for specific sectors, regions or methodological orientations.<sup>v</sup>

ERIC will prove most useful when used in conjunction with additional guidance developed for specific organizations, sectors and/or professional requirements. These requirements may take the form of existing ethical guidelines and codes of conduct which researchers adhere to, in either a research or professional capacity, or it may be that organizations and sectors will seek to develop their own supplementary materials that detail very particular organizational or sector-specific requirements. The ERIC approach encourages both.

## **HISTORY AND PROCESS**

ERIC is a joint project between UNICEF's Office of Research and Childwatch International, the Centre for Children and Young People at Southern Cross University, Australia, and the Children's Issues Centre at the University of Otago, New Zealand.

**Reflexivity refers to the capacity of people to be conscious of, and give account of, their actions.**

**There are no easy answers or ready solutions.**

**The ERIC compendium and accompanying website are essential, collectively-owned tools for the research community.**

ERIC is an ongoing invitation to share, connect and question research experiences.

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.

The ERIC project has involved over two years of research and consultation with the international research community. ERIC emerged out of a recognised need to connect researchers and other research stakeholders who are largely motivated by a desire to pursue the kind of research that promotes rather than diminishes the dignity, rights and well-being of children.

A core tenet of ERIC is an ongoing invitation for researchers to share their experience, questions, concerns and stories about their engagement with research **ethics**. Sharing experiences and stories is crucial to our humanity: it is an unavoidable task in our ethical lives, because stories open up a space of contestation and of possibility (Kearney, 2002).

To date, researchers and other stakeholders have shared their experiences and stories through a number of key ERIC activities including:

- **An International survey** on ethics-related issues undertaken in 2010 to ascertain the views of researchers doing research involving children in diverse social and cultural contexts and disciplines. Two hundred and fifty seven participants across 46 countries responded (Powell, Graham, Taylor, Newell & Fitzgerald, 2011).
- **A meeting of 17 child and youth research experts** held in London in July 2011, with the survey and a literature review focusing on ethics in research with children providing stimulus for discussion about issues, gaps and concerns that require ongoing attention from the international research community. Participants at the meeting agreed that while the importance of ethical research involving children and young people is now widely accepted, there is an increasingly evident need for the development of an International Charter and Ethical Guidance as well as closer attention to major matters of ethics governance, training and access to available resources.
- **An email consultation with the international research community** undertaken via well-known online/internet-based networks in December 2011, advising of the project and inviting advice and information about ethics issues and initiatives relevant to the development of an International Charter and Ethical Guidance. A total of 66 responses were received from researchers working in a range of different contexts who shared experiences, questions, resources and offers to be further involved in an international dialogue about the best way forward with the Ethics Charter and Ethical Guidance.
- **An expert project advisory group** convened in April 2012 at the UNICEF Office of Research, comprised of leading international researchers to provide feedback and guidance on drafts of the Ethics Charter and Ethical Guidance.
- **An extensive consultation process** undertaken with nearly 400 researchers and other stakeholders, in a wide range of regions and organizations internationally, on the draft Ethics Charter and Ethical Guidance. The consultation resulted in extensive feedback from approximately 100 individuals or organizations, which in turn emphasized the need for a more expansive ERIC compendium, accompanying website as well as the development of tailored training activities.



## In addition, the ERIC project has also involved:

1. Detailed mapping of existing Charters and Guidelines to identify content and approaches, including primary areas of focus as well as gaps – both in terms of ethical principles and practice, and in relation to methodological approaches.
2. Collation, review and analysis of existing ethics systems, guidelines, practices, training programmes and resources from different countries, particularly those relevant to a multidisciplinary perspective, to identify the core principles, strengths, gaps and questions arising from these that are related to the ethics of research involving children and young people.
3. Production of a comprehensive literature review of research publications related to ethical issues with research involving children, published by Powell, Fitzgerald, Taylor and Graham (2012).
4. Commission of a review on relevant philosophical ethics and governance systems and practices in different local and disciplinary contexts (including strengths and limitations) for consideration in the development of the Ethics Charter and Ethical Guidance.

## AGE OF THE CHILD

The ERIC project 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”. The term youth is not defined in international law; however, working definitions from the United Nations use the term youth for a young person aged 15 through to 24 years. We are aware that the age-based definition of a child incorporates a wide range of children and **young people/youth**, who have very different life experiences.

It is important to acknowledge in conjunction with this, that definitions of children and young people/youth vary according to law, culture and custom, as well as in accordance with other context-specific socio-cultural, institutional, economic and political factors. While the ERIC compendium may offer the most evident support for ethical research practice with (younger) children, the ethical principles can also be readily applied to research with (older) youth, since these provide a strong foundation from which to consider ethical issues across the age ranges.

Researchers are obligated, in accordance with Article 5 of the UNCRC, to provide guidance and direction consistent with the evolving capacities of the child, in the exercise by the child of his or her rights. This emphasizes the importance of recognizing children's competency, alongside age, as a determining factor in the exercise of human rights. Importantly, underlying Article 5 is the recognition that the diverse life experiences of children in different environments and cultures means that children's acquisition of competencies will vary, at different ages and according to personal circumstances (Lansdown, 2005). Researchers are required to take the contexts of children's lives, their experiences and competencies into account in ensuring that children are afforded opportunities for decision-making and respect in the exercise of their rights, while being protected in accordance with their age and still evolving capacities.

ERIC recognises that definitions of children and youth vary with context.

Researchers are responsible for ensuring that children are afforded opportunities for decision-making and respect in the exercise of their rights, while being protected in accordance with their age and still evolving capacities.

## ETHICS AND THE LAW

Legal responsibilities to uphold children’s rights within the research process, enshrined by the UNCRC, are aligned with researcher obligations to respect the kind of principles signaled in the Philosophy section of this compendium – whether children are **subjects**, respondents or researchers themselves. In developing the ERIC compendium we therefore assume that researchers know and heed their relevant state and national laws.<sup>vi</sup> Critical to this is the importance of gaining formal approval for projects, in line with local legal, institutional and community requirements, for example, relating to the storing of personal data, or reporting concerns about serious present or future harm to the child or to others.

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<sup>i</sup> Throughout the text, bold type is used to indicate terms defined in the ERIC Glossary of Terms.

<sup>ii</sup> 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.

<sup>iii</sup> There is an intrinsic tension between the ERIC Guidance, which seeks to encourage more expansive engagement and critical reflection, and the Ethics Charter, which synthesises these issues into seven core commitments. While necessarily succinct, the aspirational Charter still seeks to reflect the underlying philosophy and intent of the overall ERIC project.

<sup>iv</sup> For ease of reading the term ‘researcher/s’ is used from this point on to encompass this wider research community.

<sup>v</sup> Some important and influential ethical guidelines are included in the Resources section, Review of Other Ethical Guidelines and on the ERIC website [www.childethics.com](http://www.childethics.com).

<sup>vi</sup> It is beyond the scope of this document to address national legal frameworks, or the relationship between these and the UNCRC in any depth. Researchers are encouraged to be familiar with these in the locations in which they are conducting research.



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P. Otgonjargal, 4, smiles while jumping excitedly next to one of her family's reindeer in a remote area of the 'soum' (district) of Tsagaannur, in the northern Khövsgöl 'Aimag' (province), Mongolia.





# PHILOSOPHY

Ethical Research Involving Children (ERIC) assumes that ethics is much more than procedural compliance with a prescribed set of rules or code of conduct that can deliver good or safe research in any given context. While such codes play an important role, the ERIC approach recognises the myriad ways in which researchers' own knowledge, beliefs, assumptions, values, attitudes and experience intersect with ethical decision-making. As such, ERIC requires critical reflection; cross-cultural, inter-sectoral and cross-disciplinary dialogue; context-specific problem-solving; and international collaboration, learning and engagement. In order to safeguard and promote the rights, dignity and well-being of children in and through research, ERIC calls on researchers and the research community to be open, reflexive and collaborative in their ethical decision-making, and to be specifically attuned to the relational dimensions of research ethics. The core ethical principles underpinning the ERIC approach are respect, benefit and justice.

Ethical principles and issues cannot be disconnected from researchers' attitudes, values, beliefs and assumptions about children and childhood.

Respect for the dignity, well-being and rights of all children, irrespective of context, is central to the philosophy that underpins the Ethical Research Involving Children project. Such respect is integral to researchers' decisions and actions concerning the nature and conditions of children's involvement in research, regardless of sector, location or methodological orientation.

ERIC opens up an opportunity for international dialogue around the more difficult issues and questions that shape our work as a very diverse community doing research that either directly involves children or potentially impacts on their lives and well-being. The ERIC approach acknowledges that ethical principles and issues cannot be disconnected from researchers' attitudes, values, beliefs and assumptions about children and childhood, since these invariably shape our decision-making and underpin important matters of power and representation.

Children's rights as expressed in the UNCRC underpin the approach taken in ERIC, whereby researchers are presumed to be informed of and guided by their responsibilities to respect the rights, well-being and human dignity of every child. The UNCRC, therefore, is a central starting point for the ERIC project.<sup>vii</sup> It is the first and most complete international instrument to assert a full range of rights for children and, in effect, is "a legal articulation of a broader philosophical perspective" (Lundy & McEvoy, 2012a, p. 77). While keeping in mind that the UNCRC is a set of obligations on states (and their actors) and not on individuals, and therefore does not necessarily put direct obligations on researchers, it is a useful and important framework that connects to and may inform ethical research with children (Lundy & McEvoy, 2012b).

The UNCRC is a central starting point for the ERIC project.

The UNCRC gives visibility and legitimacy to the **agency** and participation of children, while also drawing attention to their **protection** and **provision rights**, thus recognising children as both able to and entitled to participate in activities such as research. While it does not refer specifically to research, when read in conjunction with the UN Committee on the Rights of the Child General Comments, the articles are elastic enough to address most aspects of children's lives, including participation in research (Lundy & McEvoy, 2012a). The near-universal ratification of the UNCRC holds considerable potential for inspiring and pursuing a shared commitment to the development and conduct of ethically sound research.

Ennew and Plateau (2005) articulate children's 'right to be properly researched' based on combining four articles of the UNCRC,<sup>viii</sup> thereby merging children's right to protection with their right to participation.

They contend that children's 'right to be properly researched', along with the basic human rights principles of dignity and respect, support children's partnership in research and make the development of an ethical strategy an integral part of all research design.

Ethical research requires recognition of and reflection on the multiple contexts that shape children's lives and experiences, and inform and influence research involving children, both implicitly and explicitly. These contexts include the wider cultural, social, political and economic milieu and also the multiple relationships that are formed around the research (including, but not limited to, researchers, children and young people, **parents**, guardians, caregivers, significant adults/**gate-keepers**, institutions and funding bodies). Ethical research involving children is critically important across all contexts, both in **collective cultures**, in which children's identity and voice is closely bound within family, tribal and/or community contexts, and **individualistic cultures** in which individualism and independence are emphasised.

ERIC offers a reflexive process to guide research decision-making and is specifically attuned to the **relational** dimensions of research ethics – that is, the relationships between people who interact during the research process and are integral to good conduct.

### **An international context for research involving children**

There has been increased attention internationally to the involvement of children in research of all kinds, although to date the ethics of such research has been largely circumscribed by concerns about conduct and guided by compliance-focused exercises. Several international organizations and researchers have played a critically important role in developing ethical guidance for research involving children. Consequently, there are a number of national and international guidelines focused on research within specific sectors, regions or methodological orientations.<sup>ix</sup> These guidelines have made a valuable contribution to ethical research practice and provided a sound basis for further development.

Research involving children is vital for understanding children's lives. It ensures their experiences and perspectives closely inform the study, providing accurate and culturally specific information, which consequently enhances the value and validity of the findings. Systematic information obtained from children can contribute to strengthening laws, policies and practices that advance their human dignity, rights and well-being. Children's involvement in research is vital in ensuring their right to participate in matters that affect them, as recognised in the UNCRC, is upheld. Recognising the methodological significance of involving children in research, the potential impact that research findings may have on their lives, and the importance of upholding children's rights to both protection and participation, underpins the need to have internationally-agreed ethical guidelines and principles that can be applied across multiple contexts.

High quality, ethical research requires close attention to the principles and practices that reflect the highest respect and regard for children in any given research context. The development of ethical guidance specifically for children highlights the growing recognition that, while the ethical principles underpinning research are consistent, the issues, considerations and nuances are conceptualised and experienced differently between child and adult populations, with differing implications and outcomes.

Relationships are at the core of ethical research.

Children's involvement in research is vital in ensuring their right to participate in matters that affect them and in enhancing the value and validity of findings.

## Protection and participation: A reflexive research approach

Contemporary research involving children has evolved from a rich mix of diverse research ideologies, methodologies and practices, with ethical approaches shaped by researchers' own understandings in conjunction with wider theoretical, socio-political and cultural considerations. Such research has evolved historically from being conducted in an environment that is largely unregulated, to one which is characterised by complex, multi-dimensional and dynamic challenges, reflecting the multiplicity of children's environments and experiences. The extent to which research involving children is regulated varies across international contexts. However, increased consideration of children's involvement is evident in the different perspectives shaping research practice.

Ethical considerations have shifted significantly from a predominant focus on protectionist discourses, which positioned children as vulnerable and requiring **safeguarding** by adults including researchers, to an emphasis on recognising children's agency and competency, and highlighting children's **participation rights**. Both dimensions are critically important to children's well-being, however these can, at times, present as contradictory and/or opposing.

Mindful of the tensions between protectionist and participatory standpoints, the ERIC project is focused on supporting high quality research practice, while navigating the ethical challenges that arise from such tensions. Rather than being seen in oppositional terms, children's protection and participation are viewed such that the competence, dependence and vulnerability of children do not, in themselves, determine their inclusion or exclusion from research so much as inform the way in which their participation takes place. Such an approach is best supported through more reflexive ethical research processes. Emphasis is placed on the multiple relationships occurring throughout the research process, which are where ethical issues play out, including those related to protection and participation. Hence, attention is drawn to the important role of dialogue, collaboration and critically reflective practice in navigating the uncertainty that often arises in ethical decision-making.

Furthermore, the ERIC compendium is the result of extensive research and consultation with the international research community and one of the key recommendations emerging from this work was the need for a clear statement of internationally-agreed ethical principles that could be embedded into the everyday research practices of governments and organizations within and across cultural contexts.

Several core ethical principles, such as **respect, benefit and justice** are broadly agreed and accepted in research involving children, and underpin the increased attention on specific ethical issues, such as **harms and benefits, informed consent, privacy, confidentiality and payment**. However, little focus has previously been given to the kind of reflexive engagement required by researchers in applying these within particular projects, which involve particular children, utilise particular methodologies, take place in particular contexts and are motivated by particular intents.

The competence, dependence and vulnerability of children should not determine their inclusion or exclusion from research. It should inform how their participation takes place.



## KEY ETHICAL PRINCIPLES UNDERPINNING ERIC

The ERIC project is underpinned by three core ethical principles that will likely be familiar to researchers undertaking research involving children. These principles require that researchers attend to the relational as well as the procedural dimensions of research:

- Respect
- Benefit
- Justice

Each principle is worthy of critical reflection, debate and discussion. ERIC invites researchers and the research community into a more reflexive engagement with the meaning and application of these principles, from both a researcher and a child's perspective, across different contexts.

In focusing on the above three principles we also acknowledge that existing ethical guidelines generally include these and/or related principles. The overarching ethics framework offered here takes these principles as a point of departure only - while remaining open to the possibility of adding and/or merging others based on the shared dialogue that is so central to their interpretation and application.

### Respect

For our purposes with ERIC, respect means more than tolerance. It implies valuing children and the context of their lives, and recognition of their dignity. Obtaining informed consent for research involvement is an important means of demonstrating this respect for children's dignity.

Respect in research tends to be a principle with which everyone agrees, but which is rarely explicitly articulated in relation to undertaking research involving children. With ERIC, it is assumed that to respect a child in research, one must know:

- who the child is;
- what cultural context they are living in;
- how culture shapes their experiences, capabilities and perspectives.

This involves the subjective and relational experiences of children within their communities, including family, peers and social structures. Respectful research is situated in the lives of children and founded on the assumption that children's experiences and perspectives will be, and should be, taken into account. Such consideration envisages that researchers acknowledge the unequal relationships of power between researchers and children, between children and their communities, and between children.

These unequal relationships require negotiation with the children involved, as well as with potential gate-keepers or other adults participating in the research process. This takes place within the cultural context in which the research is situated and requires reflection on the positioning of children in the local ecosystem, particularly when the researcher brings an 'outsider' perspective to the local context. Respectful research involves acknowledgement and careful consideration of societal emphasis on collective and individual rights in the negotiations of the research process.

Respect is linked closely with rights, and implies valuing children and the context of their lives, and recognising their dignity.

Respect extends to all children impacted by the research, not just those directly involved in the process.

Respect also extends to research that impacts on children even if they have not been directly involved as **participants** in the research process. It requires researchers to pay close attention to the broader ethical implications for children of conducting such research, including the balance between the best interests of individual children directly participating in research, as distinct from children as a social group who may be impacted by the research.

The rights articulated in the UNCRC hold considerable potential for focusing our attention on where and how respect is integral to research involving children, particularly in relation to their protection and participation. Protection rights emphasize that researchers must ensure the safety and care of children. Children's participation rights are activated by researchers noticing and valuing children and their potential contribution to research, and ensuring that children have information and a choice about participation, including the right not to participate.

### **Benefit**

There are two components to the ethical principle of benefit: **non-maleficence** and **beneficence**.

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.

**Non-maleficence** The principle of non-maleficence, doing no harm, requires researchers to avoid harm or injury to children, both through acts of commission or omission. It reminds researchers that research that is likely to do harm to children is unethical and should not proceed. While involving children and young people in research holds many possibilities for enhancing research, practice and policy (Greene & Hill, 2005; Hinton, Tisdall, Gallagher & Elsley, 2008) researchers have a clear responsibility to ensure that no harm comes about from their inclusion. To this end, research should be methodologically and ethically sound, rigorous, relevant and likely to have impact.

In addition, harm as a consequence of exclusionary research practices must be avoided. Researchers must consider potential negative impacts of research for children's lives, sense of identity and belonging. This responsibility includes later consequences of the research, after the researcher has left, as well as during recruitment and the course of data collection, information gathering, interpretation and analysis of the data collected. Researchers have an obligation to ensure that protecting children is an integral part of the planning, implementation and dissemination of all research (H. Fossheim, personal communication, December 14, 2011).

Research likely to harm children should not proceed.

The principle of non-maleficence has particular resonance in research involving children as a consequence of the disparities in power between adults and children, and the responsibility of researchers to ensure that children's rights to protection, as expressed in the UNCRC, are upheld. There are further nuances, in ensuring that no harm is done, with the tension that arises between children's protection and participation rights. While the UNCRC does not specify children's right to participate in research, the articles within it are pliable enough to address research, and the participation rights elucidated in the Convention underpin researchers' obligations to consider, respect and protect children's involvement. Engaging in dialogue with children, in recognition of their status as rights-bearing citizens and authorities in their own lives, as well as potential research participants, provides opportunities to bridge the tension and respect

children's capacity for meaningful involvement in research.

**Beneficence** The principle of beneficence refers to actions that promote the well-being of children. It refers to a researcher's obligation to strive for their research to improve the status, rights and/or well-being of children. Beneficence is understood as more than acts of kindness and charity and envisages that both the research process and outcomes include positive benefits. Put simply, gaining information from children should result in children, their families and/or local community receiving something in return for this information (H. Fossheim, personal communication, December 14, 2011). Benefits also accrue to children as a social group (who have not been research participants) through the implementation of evidence-based policy-practice. Such benefits may take a diverse range of forms, from undertaking research in caring, attentive and responsible ways so that children feel they are heard, and that their experience is validated and respected, through to providing children and communities with tangible benefits, such as payment or provision of resources, appropriate policies or programmes. The principle of beneficence requires researchers to identify clear benefits likely to arise from research involving children and to reconsider proceeding if these cannot be articulated.

## **Justice**

The principle of justice is foundational to a number of dimensions of research involving children. Justice arises in the relationship between researcher and child and in any dialogue and conversation that takes place between them. The principle of justice requires researchers to attend to the power differences inherent in the adult/child research relationship. Respectful listening to children's views, giving due weight to these and responding to what they have to say is part of facilitating just outcomes from research and is consistent with Article 12 of the UNCRC.<sup>x</sup>

The principle of justice requires researchers to find a balance between the perceived benefits of the research and perceived burdens placed on the participants (Belmont Report, 1979). Children should always be treated fairly and the benefits of research distributed equitably. The concept of justice must also underpin decisions made by researchers about which children will be included and which children will be excluded from research, always ensuring that selection is consistent with a clearly stated research purpose and methodological choice, and not driven by discriminatory intent.

All these issues are as relevant to the relationship between the research project and the wider political and social world as they are to the relationship between each child and the researcher.

Justice also concerns the (re)distribution of burdens and benefits of research, including consideration of the allocation of material and social resources to support the respectful and ethical involvement of children (Fraser, 2008). Justice requires that children participate in public discussion and processes of decision-making not only as objects and subjects of research but also, wherever possible, as advisors and consultants in research and the policies it informs.

Research should never be unjust. In research involving children this means children should not carry an undue burden of research

**Beneficence refers to the obligation to improve the status, rights and/or well-being of children.**

**If researchers are unable to identify clear benefits likely to arise from research involving children they should reconsider proceeding.**

**Justice ensures children are treated fairly and equitably. This includes attention to power imbalances, and issues of distribution of benefits and burdens, and inclusion and exclusion.**

Treating children fairly includes ensuring unjust institutions, policies and practices are not indirectly supported by research, as well as ensuring children are treated fairly in face-to-face encounters.

nor should they be denied benefits of research. Justice thus requires researchers to consider whether and how research potentially dominates children and places constraints on their self-determination, and how oppression renders particular perspectives of children invisible or stereotypical of childhood (Dahlberg & Moss, 2005).

The question of whether someone is treated fairly or unfairly is relevant not only in face-to-face encounters. A research project may, for instance, indirectly help uphold unjust institutions, as well as unjust policy choices and practices, whether or not there is any direct contact between the child and the researcher.

Finally, justice is as relevant to the relationships that exist between children involved in research as it is to the researcher-child relationship. Power also affects the relationships between children and it is important to ensure that the views and interests of more than merely a powerful and/or articulate few children, whether they are participants or child-researchers, are represented in the process and dissemination of research.

In summary, the ERIC approach:

- Views children and young people as persons in their own right and as worthy and capable of recognition, respect and voice in research.
- Acknowledges the right of children and young people to have a say and to be heard, as afforded to them under the UNCRC, including in the context of well-planned, ethical research.
- Assumes children's involvement in any kind of research takes place in partnership with caring, skilled adults who need to provide appropriate support and guidance, in order to help them formulate their views and participate in a safe and meaningful way.
- Underlines the importance of research focused on understanding and improving children's lives and circumstances, including within the context of family, school and community.
- Engages critically with well-attested ethical principles of respect, benefit and justice in light of the above, promoting the importance of dialogue and a more reflexive approach in attending to the complex ethical issues that can emerge with research involving children.

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<sup>vii</sup> By virtue of their status as human beings, children are the beneficiaries of rights as articulated under a number of international human rights instruments (for example, the International Covenant on Civil and Political Rights (ICCPR). However, for the purposes of this document, the UNCRC is utilised as it is the core international human rights document pertaining specifically to children.

<sup>viii</sup> The four articles combined by Ennew and Plateau (2004) are: Article 12.1 – the 'democracy principle'; Article 13 – freedom of expression; Article 36 – protection against exploitation; and Article 3.3 – competence of responsible bodies for care and protection of children.

<sup>ix</sup> See Review of Other Ethical Guidelines in the Resource section.

<sup>x</sup> Article 12: State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.



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Youth leaders stand in a circle, holding hands, to symbolize the slogan 'We can do it together', at a child care centre run by Precious Jewels Ministry, a local NGO that supports AIDS-affected children in Manila, the capital of the Philippines.



# 21 ETHICS CHARTER

The International Charter for Ethical Research Involving Children is an aspirational statement of seven key commitments aimed at elevating the status, rights and well-being of all children involved in research. It has been written with and for researchers and others who are committed to children and to fulfilling their responsibility to undertake quality, ethical research, irrespective of context.





# INTERNATIONAL CHARTER FOR ETHICAL RESEARCH INVOLVING CHILDREN

As a research community working with children, we are committed to undertaking and supporting high quality ethical research that is respectful of children's human dignity, rights and well-being. The following seven commitments guide our work:

## **ETHICS IN RESEARCH INVOLVING CHILDREN IS EVERYONE'S RESPONSIBILITY**

We, the research community, including all who participate in undertaking, commissioning, funding and reviewing research, are responsible for ensuring that the highest ethical standards are met in all research involving children, regardless of research approach, focus or context.

## **RESPECTING THE DIGNITY OF CHILDREN IS CORE TO ETHICAL RESEARCH**

Ethical research is conducted with integrity and is respectful of children, their views and their cultures. Involving children respectfully requires that researchers recognise children's status and evolving capacities and value their diverse contributions.

## **RESEARCH INVOLVING CHILDREN MUST BE JUST AND EQUITABLE**

Children involved in research are entitled to justice. This requires that all children are treated equally, the benefits and burdens of participating are distributed fairly, children are not unfairly excluded and that barriers to involvement based on discrimination are challenged.

## **ETHICAL RESEARCH BENEFITS CHILDREN**

Researchers must ensure that research maximizes benefits to children, individually and/or as a social group. The researcher bears primary responsibility for considering whether the research should be undertaken and for assessing whether research will benefit children, during, and as a consequence of, the research process.

## **CHILDREN SHOULD NEVER BE HARMED BY THEIR PARTICIPATION IN RESEARCH**

Researchers must work to prevent any potential risks of harm and assess whether the need to involve the individual child is justified.

## **RESEARCH MUST ALWAYS OBTAIN CHILDREN'S INFORMED AND ONGOING CONSENT**

Children's consent must always be sought, alongside parental consent and any other requirements that are necessary for the research to proceed ethically. Consent needs to be based on a balanced and fair understanding of what is involved throughout and after the research process. Indications of children's dissent or withdrawal must always be respected.

## **ETHICAL RESEARCH REQUIRES ONGOING REFLECTION**

Undertaking research involving children is important. Ethical research demands that researchers continually reflect on their practice, well beyond any formal ethical review requirements. This requires ongoing attention to the assumptions, values, beliefs and practices that influence the research process and impact on children.



# 25

# GUIDANCE FOR ETHICAL RESEARCH INVOLVING CHILDREN

A key component of ERIC is the provision of sound guidance that invites researchers and institutions to reflect critically on the complexities of research involving children. The Guidance elaborates on specific considerations, challenges and questions that arise across unique and diverse research contexts. Reference to particular case studies, featured in full at the end of the compendium, is made throughout this Guidance section with the intent of fostering 'like to like' peer learning, dialogue and problem-solving.

# INTRODUCTION TO THE ERIC GUIDANCE

This Guidance is designed to support researchers as they engage more critically with the ethical issues that arise in conducting research involving, or impacting on, children.<sup>xi</sup> It takes into account the unique nature of each research project and context, as well as the common ground of ethical principles and considerations. The ERIC Guidance acknowledges and builds on excellent existing ethics guidelines developed for particular contexts or organizational settings.<sup>xii</sup> It points to considerable further potential for improving ethical practice when researchers and other key stakeholders engage more reflexively with underlying principles and emerging issues within and across different contexts.

The ERIC Guidance is designed for research with children and young people under the age of 18 years. While it tends to focus more attention on children than youth,<sup>xiii</sup> the underpinning ethical principles and considerations provide a useful foundation for reflecting on ethical issues in research practice with all children and young people.

**The dignity, well-being and rights of all children, irrespective of context, are fundamental to the ERIC Philosophy and Guidance.**

A core tenet of the ERIC Guidance is the relational nature of research ethics. Ethical issues and challenges are located in the space between researchers, research organizations, children, parents/caregivers/guardians,<sup>xiv</sup> communities and others involved in the research process. The practice of research ethics is negotiated within these relationships. This underscores the interpersonal and organic nature of the research endeavour. It also highlights the opportunities for creativity and expansiveness that ultimately promote and strengthen children's well-being, dignity and rights.

The emphasis in the Guidance on the relational nature of research ethics also draws attention to the multiple contexts in which these relationships, and indeed research, are situated. The relationships are founded on the understandings, assumptions, values and experiences of all those participating. While the underpinning ethical principles of respect, beneficence and non-maleficence, and justice are universally relevant across sectors, disciplines and international contexts, the ways in which these are applied and considered are shaped by the context in which the research is situated.<sup>xv</sup> This includes the broader social and cultural context as well as the more specific locale in which the research is being conducted, for example, in emergency environments, or in educational settings such as schools or via the internet or other ICT technologies.

While some research areas would benefit from the use or development of specific supplementary guidance, the ERIC Guidance frames the discussion around ethical dilemmas on the basis of universal ethical principles, for critically reflecting on and responding to the ethical

issues in their specific context. Self-awareness and reflexive thinking are essential for researchers to negotiate the ethical challenges and dilemmas that emerge from these multiple contexts in relation to considerations such as harms and benefits, informed consent, privacy and confidentiality, and payment, in undertaking research involving children. Reflexive thinking is considered by some to be the hallmark of ethical practice (Davis, 1998; Gallagher, Haywood, Jones & Milne, 2010) while training, support and supervision of researchers play an important role in developing this.

The sections in this ERIC Guidance support researchers as they engage in ethical research practice by reflecting on the key issues, including dilemmas and challenges that may arise in specific contexts. Each section of the ERIC Guidance starts with best practice statements that highlight fundamental, non-negotiable keystones for ethical research involving children, in regard to that particular topic. Key ethical considerations are then outlined, which are grounded in a comprehensive review of the international literature and extensive consultation within the research community.<sup>xvi</sup>

Reference is made to relevant UNCRC articles and the guidance offered by these when applied to research involving children. While the UNCRC does not directly specify any research rights for children, researchers have obligations to consider, respect and protect children's rights in any given context, including in research.

Examples and case study narratives from a range of international research contexts, involving children and young people of different ages, are referred to in the Guidance to exemplify the ethical challenges that can arise in different contexts. The complete narratives can be found in the Case Studies section of this ERIC compendium. Finally, each section of the Guidance also includes questions to promote critical engagement and reflexivity.

The ERIC Guidance has been developed with an awareness of the range of roles involved in different parts of the research process, such as commissioning research, designing studies, undertaking fieldwork, and reviewing research proposals. These roles are clearly linked to different responsibilities and lines of accountability, however, they are united in the common endeavour of making research involving or potentially impacting on children ethical. The Guidance and Getting Started questions are designed to encourage people engaged across different research roles to reflect on the ethical considerations that may arise, to consider their response to these, and to share (and, at times, to negotiate) these with their colleagues.

**Each section of the ERIC Guidance starts with best practice statements critical to ethical research involving children.**

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<sup>xi</sup> As noted in the Background section, researchers includes all those who are associated with undertaking research that involves or potentially impacts on children, such as all members of the research team, research organizations and other stakeholders; and children are defined in accordance 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", although it is important to acknowledge in conjunction with this, that definitions of children and youth vary according to law, culture and custom.

<sup>xii</sup> This guidance is included in the Resource section, in the Reference List and/or the Review of Other Ethical Guidelines subsections.

<sup>xiii</sup> As noted in the Background section, young people aged between 15 and 24 years are defined as youth by the United Nations.

<sup>xiv</sup> For ease of reading, from this point on the word 'parent' is used throughout the Guidance sub-sections to refer to parents, carers, caregivers, guardians and those in parent substitute roles.

<sup>xv</sup> As outlined in the Background section.

<sup>xvi</sup> See the Background section for details of the literature review and consultation process. A summary of the key points from the review of organizations' ethics documentation is included in the Resource section.



# 29

## ETHICAL GUIDANCE: HARMS AND BENEFITS

The most fundamental consideration in undertaking research involving children is deciding whether the research actually needs to be done, if children need to be involved in it, and in what capacity. Accordingly, at the very outset of the research process researchers need to engage with critical issues regarding the purpose of the research and the impact that participating in the research may have on children in terms of potential harms and possible benefits.

# HARMS AND BENEFITS

## BEST PRACTICE REQUIRES THAT YOU:

- Be able to justify why the research is being done and why children or a specific group of children are being included in or excluded from the research.
- Work to ensure that children are not harmed as a consequence of their participation in research from the outset of the project through to its completion.
- Consider, as widely as possible, any potential harms and/or benefits for child participants, their families or wider community groups.
- Employ strategies to minimise distress for children participating in the research.
- Have child protection protocols in place to safeguard children from abusive or incompetent researchers.
- Have an agreed upon plan for responding to child safety concerns.
- Consult locally when planning the research and developing protocols, without jeopardising children's safety or well-being.
- Ensure that support for children, if needed during and after the research process, has been planned for.
- Take measures to ensure that harm is not caused to children, families or communities in the dissemination of the research findings.

## KEY CONSIDERATIONS

Decision-making about children's involvement in research entails reflection on the part of researchers, institutions, funding bodies and other stakeholders, on several issues, including:

- whether the research will extend knowledge, and potentially influence policy and practice;
- if it is necessary to include children or if the knowledge can be obtained through other means;



- if there are sound and informed reasons for excluding children;
- if the researchers have the competence, expertise, resources and capacity needed to undertake the research involving children;
- if the research will be of benefit to the individual child participants or children as a wider social group.

Ethical research is underpinned by the principles of justice, beneficence and non-maleficence, essentially seeking to ensure that the research activity brings about good and does no harm. Assessing potential harms and benefits is not straightforward as these are affected by a range of factors across the multiple contexts in which research occurs. Furthermore, there are clearly divergent opinions about what constitutes harm and benefit, and related issues such as acceptable levels of risk. However, ethical research requires reflecting on these and making decisions accordingly, with the aim of minimising risks and maximising potential benefits for the children participating and others.

***Researchers need to assess potential harms and benefits to children if they participate in the research***

Harm in research may take several forms, arising from different sources and shaped by the research topic, methods and local setting. Harm can occur whether the research is quantitative or qualitative; for example, as a consequence of asking children for information in a way that is mismatched to their current capacities and/or introducing them to new and sensitive information of which they were previously unaware. It is critically important that the research methodology is sound, with appropriate methods used to collect and analyse data. Harm can occur in the way information is collected and utilised in the research process, if flawed, inappropriate or unscientific methods are used.

Risks and benefits can appear more clear-cut in biomedical studies than in other areas. For example, in randomised controlled trials (RCTs) used to develop vaccines for children, some children may be exposed to risk, but there may be great benefit for the broader child population. While the potential for physical damage is less likely to apply in social research (Hill, 2005), it can also be intrusive and cause great distress to participants (Alderson & Morrow, 2011). The concept of utility contributes to assessing harms and benefits as the usefulness and value of the research is a basis of legitimacy in all studies, including those that might conceivably involve some risk or discomfort (H. Fossheim, personal communication, December 14, 2011).

Forms of potential risks and harm to children include: physical harm as a direct consequence of the research study itself; physical retribution, punishment or harm from others for participating in research activities; and distress, anxiety and loss of self-esteem in social research studies (Alderson & Morrow, 2011). Harm to children, in the form of reprisal or retribution, may come from within households, as a consequence of children being included or excluded from the research and any associated benefits, or from within the wider community. This raises the issue, upon reflection, of how best to include or inform parents or caregivers in ways that enable them to support their children and understand the importance of them being involved in the research (bearing in mind that in some

Assessing potential harms and benefits is not straightforward.

Harm can occur whether the research is quantitative or qualitative.

instances, depending on the research topic, this might not be the wisest course of action).

Researchers have a responsibility to ensure that children are not in jeopardy if members of the community are consulted for research purposes. If the research topic is particularly sensitive, additional care is required with regard to the pre-existing relationships between different community members. For example, it is possible during investigations into violence against children, including in conflict and post-conflict settings, that the people being consulted may be perpetrators of violence or abusing positions of power, beyond the awareness of the researcher.

Harm may also come about through the revealing of stigmatising information about a child within the community as a consequence of research participation. This may occur, for example, when children have been affected by HIV or are exploited. There may be a risk of detrimentally affecting a child's position in their social sphere or network. This risk is further amplified when local community members are involved with the research, for example as interviewers, interpreters or drivers, and maintaining confidentiality needs to be emphasised.

Particular groups may also be unfairly burdened by being over-researched when studies are replicated or expanded, or particular communities or villages are included in multiple studies and experiments. This can impact particularly negatively on groups that are already disadvantaged. A further potential harm is the disappointment for participants if certain (possibly hidden) expectations are held, or created, and the expected benefits do not materialise.

In child- or youth-led research, in which children themselves inform the research question, conflicting agendas between children and adults need to be expected and planned for. Harm can occur when children's voices are sought only when they match the interests of adult researchers, but are overlooked when they do not (Save the Children, 2002). The differences between children's perspectives and those of adults need to be negotiated in a transparent and fair manner, and the responsibilities of managing conflict usefully factored into team members' roles.

These forms of potential harm highlight the importance of researchers being aware of potentially conflicting understandings, issues and/or expectations (particularly when undertaken by researchers from outside the community), which require careful and considered reflection. Expectations and norms within the community concerning, for example, social etiquette may influence families and communities interactions with researchers to the extent that those participating in the research are disadvantaged in some way as a consequence of their participation. For researchers who are aware of the potentially disadvantageous consequences of participation for families and communities this raises a number of considerations as discussed in the case study by Sadaf Shallwani, in which the hospitality offered by participants to researchers may come at a personal cost.

**A potential harm is the disappointment for participants if certain expectations are held and not met.**

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**Case study 1: Implementing international research ethics in the complex realities of local contexts: Poverty, the cultural value of hospitality, and researchers trying to 'do no harm' in Pakistan, by Sadaf Shallwani (see Case Study section p.116).**

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These issues also highlight the importance of involving parents, caregivers and communities in a way that enhances the value of the research in their eyes, and consequently the value of children participating in it, as well as helping to increase understanding and minimise the possibility of researchers inadvertently causing offense or harm.

Using secondary, existing data is a way of avoiding the possible risks to children from participation in research and is a very useful form of research. If the informative data already exists then children do not necessarily need to take part in research. However, researchers should ensure that the secondary data they use have been collected in an ethical manner. Furthermore, children's participation should not be avoided as there are also potential benefits for children from participating in research, although these often appear to be less well recognised. Importantly, a broader vision of protecting children encompasses protection of their opportunities and their development, while also protecting them from harm.

Key issues to reflect upon, therefore, are whether children's participation is necessary to gain the knowledge sought, and whether there are sound reasons for excluding children from participation in the research. Clearly, there will be different opinions about this amongst researchers, even when there is agreement on the broad ethical principles. Contextual and personal factors contribute to the way in which potential harms and benefits are assessed, in relation to individual children, children as a social group, families and the wider communities. It seems prudent for researchers to engage in a form of risk assessment or planning before undertaking research, by using tools to reflect on the potential risks that might arise in the research, such as the questions at the end of each section in this Ethical Guidance and in the Getting Started section of the ERIC compendium, and considering beforehand strategies to deal with the potential risks.

***Participation in research should have benefits for children***

In addition to not causing harm, research should also produce benefits. These tend to be future-oriented for children as a social group, rather than directly relevant to the children participating in the research, with the possible exceptions of participation in therapeutic clinical studies and some action research. However, regardless of the primary aims of the research or the methods used, in all research the principle of beneficence incorporates reciprocity - the idea that as well as making a contribution children should also gain something from their participation in research.

Researchers should ensure that the secondary data they use have been collected in an ethical manner.

Researchers are advised to engage in risk assessment or planning before starting research, using tools to reflect on the potential risks that might arise.

In addition to not causing harm, research should also produce benefits.

However, there are some situations in which it is unlikely that children will benefit personally from their participation, although there are potentially significant gains for other children. This may occur, for example, in some biomedical research undertaken by clinicians, as discussed in the case study by Andrew Williams, and requires careful consideration of the why and how the research should be undertaken if the participating child is not likely to benefit.

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**Case study 2: Facilitating future benefit when a participant has a degenerative illness and cannot give consent, by Andrew Williams (see Case Study section p.118).**

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A benefit for children may be learning the findings from the study.

A benefit for children may be learning the findings from the study. This requires researchers to follow-up with the children and provide them with the findings in a language and style they understand. Other benefits for children may include having a joyful experience, education, knowing that their views and opinions are listened to and may lead to further action, direct political/economic betterment, therapeutic referral, and the opportunity to access resources. This latter possibility requires careful monitoring though, as in some contexts, such as low income settings, participants may embark on research with false expectations about how the research project or subsequent programmes will benefit them or their family and such high (unmet) expectations of assistance may be a form of harm (Nyambedha, 2008). In addition, there may also be high expectations of structural change through policy action which underlines the importance of researchers providing realistic information and clarity about the goals and possibilities of research.

***Children may reveal harm or safety issues while participating in the research***

If children or others are at risk of harm an immediate and sensitive response is required from the researcher, with provision made for follow-up support or referral to appropriate services.

Children may reveal harm or safety issues, including **child abuse** or **neglect**, during participation in research activity, or researchers may suspect that children or others are at risk and in need of protection. This requires an immediate and sensitive response from the researcher and follow-up support or referral to appropriate services. These situations include discovering during the research process that a child (who may or may not be the research participant) is being abused or neglected; is being harmed or threatening to harm another person; is harming or threatening to harm him or herself (Schenk & Williamson, 2005); or has a communicable or sexually transmitted disease which is required by law to be notified (Avard et al., 2011). Concerns can also arise about the violation of children's rights, which are not directly safety related. For example, children who live in out-of-home care may express concern that they are not having contact with a biological parent.

Concerns about children's safety can be raised in any research, but are most often an issue for researchers in the context of research involving sensitive topics (Powell et al., 2011) or in sensitive environments such as conflict and humanitarian emergencies. A higher rate of abuse or risky behaviour reporting may be anticipated in relation to particular research topics or contexts. For example, studies with homeless children and young people have an increased likelihood of disclosures of concern (Meade & Slesnick, 2002). Similarly, research on violence against children is likely to have a higher reporting rate of child maltreatment or related safety concerns.

Attending to potential well-being concerns and ensuring that children are safe, and that follow-up support is provided as necessary, is an integral component of high quality and ethical research planning. The responsibility that researchers have to consider child protection and manage safety concerns highlights the need for relevant training, expertise, and supervisory support. Working in partnership with experienced researchers and child protection experts can help to ensure a rigorous approach (Gorin, Hooper, Dyson & Cabral, 2008), as well as providing opportunities for **debriefing** (Duncan, Drew, Hodgson & Sawyer, 2009).

A significant challenge arises regarding confidentiality when researchers suspect child abuse or other unsafe or criminal activity. Respect for the child's right to confidentiality may be difficult to harmonise with the researcher's ethical responsibility to ensure that children are protected from harm [this is discussed in greater detail in the Ethical Guidance section: Privacy and Confidentiality].

In some instances, the reporting of safety concerns or referral to social support services may be a direct, immediate, beneficial consequence of children's participation in research. However, in some contexts there is a lack of services to report safety concerns or abuse to, and researchers need to consider in advance how to respond to any disclosures made by the child. Researchers also need to keep in mind possible negative consequences for children, in the form of punishment or stigmatisation, if safety concerns are reported, based on children's accounts, which are not then substantiated.

An additional complexity occurs when concerns are raised during online internet research. There may be no feasible way of tracing or contacting the participant who has raised the concern if they have assumed an anonymous or pseudonymous identity. Even when accurate information regarding the child's identity is available, their location may remain unknown or it may be that intervention is unlikely or impossible. As with other forms of research, the inclusion of safety management in online research planning is integral. This may include having a 'private message' facility for children to contact the research team, encouraging children to seek help and providing the details of relevant support agencies (Sharkey et al., 2011).

### ***Children may be harmed during research by abusive or incompetent researchers***

Researchers need to take into account the reality that adults with abusive intentions may use research as a means of gaining access to children (Hill, 2005). In addition, children may be subject to unintentional abuse, through researchers' incompetent or poor practice. Incompetency can include having insufficient knowledge or not applying knowledge and principles adequately, lack of adequate skills in research design and methodology and/or lack of integrity, acuity, cultural awareness and sensitivity. It is also important to note that it may not be the researchers themselves who are practising incompetently, but their support staff, for example drivers, interpreters and others, who may not have received any ethical training. An additional dimension in such contexts might be the way in which researchers' expectations of interactions and relationships with children may differ from the usual cultural practices. This is further exacerbated when the researcher does not speak the local language and is dependent on interpreters to conduct data collection activities, as discussed in the case study by Silvia Exenberger.

**Safety management is an integral aspect of online research planning.**

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### Case study 3: The work with interpreters in a cultural-sensitive environment, by Silvia Exenberger (see Case Study section p.120).

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The key ethical principles, along with legal and professional responsibilities, underpin the steps taken by researchers and organizations to ensure that children are safe from any possible abuse. These may include conducting checks during staff recruitment procedures, such as police checks; developing and implementing a staff code of conduct specifying appropriate behaviour; establishing procedures for reporting suspected abuse by research staff; and providing training and support for staff (Save the Children, 2003), including training on techniques for responding to incidents in which children become upset, prior to field testing of research.

Many organizations, such as humanitarian agencies, have Codes of Conduct that are seen as crucial parts of the foundation for ethical practice. Local consultation is critical in developing protocols to ensure that the standards expected are consistent with cultural expectations as well as documented international human rights.

An anticipated outcome of researchers' engagement with ethical issues in research practice is the development of an ethical rationale for actions taken. In relation to safeguarding children this may include using cautionary practice, following ethical guidelines and ensuring that fieldworkers and research participants can be observed while not necessarily overheard, to protect both researchers and children (Barker & Smith, 2001).

As well as having protocols and procedures in place to help prevent and to report abuse, it is also important that children, family and community members are aware of avenues through which they can report concerns related to any aspect of the research, including children's safety and inappropriate interpretation. This can be included in the information provided to children and parents when gaining their consent for research participation.

#### ***Harm may occur after participating in research***

Harm to children, their families and communities may occur at the point of dissemination or reporting of findings. The ethical principles of beneficence and non-maleficence are relevant beyond the completion of data collection. Harm can be minimised at the dissemination stage through maintaining privacy regarding the identities of participants, their families, and communities, and if necessary, the location, although **anonymity** is not always necessary depending on the nature of the topic, the context and the role and wishes of children in the research [see Ethical Guidance sub-section on Privacy and Confidentiality].

Researchers should maintain integrity and strive to ensure that research is reported accurately, fairly and in ways that are not discriminating or misrepresentative of children's voice, experiences and circumstances. There is a possibility that myths or

Local consultation is critical in developing protocols that are consistent with cultural expectations as well as international human rights.

The ethical principles of beneficence and non-maleficence are relevant beyond the completion of data collection.

misperceptions may be introduced or perpetuated by the media in reporting research findings. While the extent to which representation of children by adults can ever be truly authentic is a matter for debate, the representation of children and their views can be ethical and appropriate, or conversely it can conform to stereotypes, be unrealistic and/or potentially harmful. The views of children and young people can sometimes be canvassed for research that is poorly designed, biased and politically driven. While no research can be apolitical nor can the chosen methods be totally objective, maintaining professional standards and integrity is vitally important to counter the exploitation of children for headline grabbing 'research' that may in fact misrepresent/distort their views and experiences.

Harm can also be caused to groups and communities if policies are recommended by researchers which are ineffective or damaging (Alderson & Morrow, 2011) or findings are used to support such policies. Researchers are not always (or often) in a position to influence policy or practice development beyond dissemination of their findings. However, the ways in which research may be used and policy recommendations taken up and implemented are ethical issues that warrant consideration. Those who are commissioning research have greater accountability in this regard and need to be particularly aware of the potential impact of implementing and disseminating the findings on children, families and communities, exercising caution and responsibility as required to ensure any possible harm is minimised.

Ineffective policy recommendations may come about for a number of reasons. At times this may be attributable to a cultural mismatch between researcher understandings and expectations and local knowledge, practices and beliefs. For example, researchers from cultures which are predominantly individualistic may interpret findings from research within cultural contexts that are collective, in a way that is consistent with their own understandings, beliefs and experiences but inappropriate to the context in which the research is taking place. This highlights the absolute importance of researchers having an awareness of the influences and assumptions that they bring to research, and the necessity of critically examining and reflecting upon these for ethical research practice.

However, it is not just cultural issues and misunderstandings that can influence ineffective policy recommendations. Research methodology is not ethically neutral and poor recommendations can come about through methodological or design flaws in conducting research that produces questionable results, such as the use of inappropriate lines of questioning and/or methods of analysis. Methodology can also be flawed by researcher incompetence arising from lack of knowledge, appropriate skills and training. This may result, for example, from a lack of adherence to broader principles concerning rigour, impartiality and relevance of research designs and methodologies.

Specific and differing concerns regarding potential harm to participants can arise in relation to the methods used in research. Using **focus groups**, for example, to collect data can give rise to a range of concerns, as discussed in the case study by Hilde Lauwers, including the impact on participating children's relationships of sharing previously unknown information.

Maintaining professional standards and integrity is vitally important to help ensure that children are not misrepresented or their views and experiences distorted.

Those who are commissioning research need to be particularly aware of the potential impact of implementing and disseminating the findings on children, families and communities.

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#### Case study 4: The impact of shared information in focus groups on children's relationships, by Hilde Lauwers (see Case Study section p.121).

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##### ***Research involving children should be equitable and non-discriminatory***

Research should be inclusive of children without discriminating on the basis of gender, ethnicity, disability, age, language, geographic location or any other individual or social characteristics.

Research should be inclusive of children without discriminating on the basis of gender, ethnicity, disability, age, language, geographic location or any other individual or social characteristics. It is appropriate to include all relevant groups of children and young people in research. Underlying children's inclusion, the ethical principle of justice concerns the relationships of all involved in the research process, with each other and with the wider political and social world (H. Fossheim, personal communication, December 14, 2011). Justice implies that children should be treated fairly and equally in these relationships, with respect for their dignity and human rights.

A rights-informed approach to research means that all children have equal rights to involvement in research without **discrimination** or bias. Upholding Article 2 of the UNCRC requires researchers to identify children who may require special measures for the full implementation of their rights and to ensure that these are attended to. This does not mean that all children have to be included all the time. Rather it implies that Article 2 must be applied in the exercise of other rights, for example Article 12, such that all children should be able to participate in matters that affect them.

Specific measures, such as choosing methods that enable inclusiveness and ease of access, need to be put in place to ensure the meaningful participation of discriminated against, disadvantaged and vulnerable groups of children.

Measures may have to be taken to enable the most discriminated against, disadvantaged and **vulnerable** groups of children to take part, meaningfully, in the research on an equal footing with other children. Certain groups of children, such as homeless children, children with disabilities, children of illegal migrants, unaccompanied children, trafficked children, children in the workplace, children with certain diagnoses, gay and transgender children, are typically excluded from participation. These children are usually more difficult to reach, and perceived as more difficult to engage in certain research topics. Specific measures, choosing research designs and methods that enable inclusiveness and ease of access relevant to particular groups and/or situations, need to be put in place to ensure their meaningful participation, if such involvement is warranted. Researchers may need to consult with others, using appropriate recruitment methods such as snowball sampling, in order to gain access to and include groups of children who are vulnerable. Research designs can include creative written and visual methods, such as using/creating images, photographs or video. Solberg (2012) also argues that interview methods can be used in decisive and ethically sound ways, even when research issues are sensitive and children are very young, with "researchers' reflections about their own research encounters form[ing] a useful basis for developing additional and more nuanced insights into the dynamics of the research relationship" (p. 14).

Children who are considered especially vulnerable may require additional safeguards to protect their welfare, as well as particular methods to ensure their inclusion in research. For example, the history of biomedical research since the mid-20th century has shown children and young people with developmental disabilities represent



a particularly vulnerable (and under-researched) population in terms of major ethical violations (Yan & Munir, 2004). While excluding these vulnerable children from research is aimed at protecting them from abuse and avoiding the complexities of informed consent, exclusion is not defensible in terms of **equity**, justice and the potential benefit of the research findings.

In addition to the importance of ensuring that particular groups of children are not excluded from research, there are also calls for more research involving specific groups which need to be handled sensitively. For example, the United Nations Committee on the Rights of the Child (2006) considers that “the causes, prevention and management of disabilities do not receive the much-needed attention on national and international research agendas” (p.17) and should be awarded priority status for funding and monitoring of disability focused research.

Power relationships exist between children, as well as between adults and children, and can impact on the equality of children's participation in research, both in terms of access to and actual participation during research projects. Certain methodologies can be employed as a way of minimising power imbalances and supporting children's participation, through the use, for example, of child-led and **peer research** methodologies in which children participate as researchers. Measures can also be taken to address issues of inclusion and representation as a way of increasing opportunities for a wider range of children to participate in the research, as discussed in Clare Feinstein and Claire O'Kane's case study.

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### **Case study 5: Inclusion and representation issues with child researchers in Uganda, by Clare Feinstein and Claire O'Kane (see Case Study section p.123).**

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In peer research, it is important to ensure that children who take a researcher role receive benefit from the research process, such as learning about the topic they are interested in and developing research skills. It is also vital that peer researchers are engaged throughout the research cycle, adequately trained and supported, and that this is not a tokenistic exercise.

#### ***Different emphases are placed on concerns regarding harm to children across international contexts***

An international survey of researchers (Powell et al., 2011) indicated that emphases placed on concerns regarding harm to children differ across international contexts. The findings showed that researchers participating from low and middle income countries considered their capacity to include children's views in research to be most restricted by concerns related to children's safety and potential distress, including worries that a sensitive research topic would upset the child; that children could be made vulnerable to discrimination/retaliation through participation in research; and fear for the child's safety. However, findings indicated that researchers participating from high income countries were more likely to consider themselves restricted by overly-protective ethical review processes and consent/gate-keeper/access issues.

Certain methodologies, such as peer research, can be employed to help minimise power imbalances and support children's participation.

Peer researchers must be engaged throughout the research cycle, adequately trained and well supported.

Ethical regulatory mechanisms and review processes may be experienced as supportive or restricting, but they do not ensure ethical practice, and cannot replace researchers' contingent ethics in the field.

These findings may partially reflect the establishment and use of research regulatory mechanisms in different contexts. In countries where there is relatively low reliance on regulatory mechanisms, there is an increased possibility of risky research being carried out by researchers, companies, organizations and others whose interests conflict with those of the child participants, and the onus for ethical research rests more heavily with the individual researcher. On the other hand, in parts of the world where research involving children is heavily circumscribed by concerns about children's vulnerability and takes place in an increasingly risk-averse context, with increased surveillance and regulation of research ethics (Graham & Fitzgerald, 2010), potential harm is screened by regulatory mechanisms rather than solely by researchers' ethical judgements. However, regardless of the emphasis in any setting, ethical regulatory mechanisms and review processes may be experienced as supportive or restricting, and although important, they do not in and of themselves ensure ethical practice, and cannot replace researchers' contingent ethics in the field (Edmonds, 2005).

It may be that the emphasis placed in the survey findings (Powell et al., 2011) on the safety of children by researchers in low and middle income locations may reflect the increased visibility and greater likelihood of harm occurring to particular groups of children in some specific contexts. For example, undocumented children and those whose safety is directly physically threatened, such as in situations of armed conflict, peace-building and humanitarian emergencies may fall into this category. In these countries which tend to have fewer resources, there is also less likelihood of professional help to ameliorate the effects for children who have been harmed or distressed (Clacherty & Donald, 2007). The emphasis on children's safety and potential distress thus appears to be influenced by the research context (in terms of features of the location and setting), the mechanisms of research ethics regulation and review, and the socio-cultural understandings surrounding concepts of risk, childhood and research. There may also be other cultural aspects contributing to the different emphases indicated in the findings of the research survey, which remain unexamined.

As harm to children through participation in research is of particular concern in emergency settings, it is essential that the research team take proper account of any impact the situation has on everyday practicalities and the consequent ethical challenges. This includes the relationship between research and any therapeutic interventions, as research may act to enhance or inhibit such interventions. Other risks may include reprisals to children and their families, and the risk of **re-traumatisation**. Researcher responsibility in assessing harm and risks has an added dimension when the children involved are unaccompanied, orphaned or separated from family (Schenk & Williamson 2005). The usual requirement for **parental consent** is challenged and minimising harm by referral to support services may be difficult or impossible in such contexts, emphasising the critical importance of assessing the benefit of doing research. Some ethics guidance suggests that unaccompanied children, in contexts such as humanitarian emergencies, should only participate in research if it is of direct benefit to them (WHO, 2007, 2011).

## CHALLENGES YOU MIGHT MEET

The ethical approach taken by researchers regarding harm and benefits in any particular research activity is shaped by the

understandings the researcher has (and those of the institutions/ organizations) in combination with wider research, socio-political and cultural considerations. Limitations and strengths of these positions are reflected in the research relationships and the outcomes for the children involved.

Power differences between adults and children, in particular, are widely recognised as one of the biggest ethical challenges for researchers seeking to include children in research (Alderson, 1995; Mayall, 2000; Morrow & Richards, 1996; Thomas & O’Kane, 1998). Socio-cultural expectations in most contexts favour the researcher as the powerful adult and the child as less powerful, with expectations of compliance with adult authority. In interview situations or receiving survey instructions from an adult, children may easily assume the familiar student role, where they feel they must perform in a particular way, be on their best behaviour, and provide information that the adult researcher (positioned as teacher) wants to hear (Phelan & Kinsella, 2013).

The power dynamics between adults and children can be further influenced by factors such as social status and background, for example, urban educated researcher and rural young people. Researchers’ ethical and methodological decision-making related to harms and benefits can serve to exacerbate or ameliorate the effects of power disparities. Reflexive thinking on the part of researchers can contribute to them creating conditions where children have agency and share power to the greatest extent possible (Punch, 2002).

### ***How are potential harm and benefits assessed in research involving children?***

As mentioned in the previous sections, defining, assessing and minimising potential harm to children from research involvement is a critical and, at times, difficult task. Harm may be invisible and elusive, subjectively defined, and complicated by differing viewpoints and short- and longer-term outcomes (Alderson & Morrow, 2011), with tension arising between the underlying ethical considerations. In some studies direct harm may not be anticipated, however, there may be some risk and/or discomfort for participants, whether the project concerns the testing of a new drug or interviewing children about traumatic experiences (H. Fossheim, personal communication, December 14, 2011). Similarly, potential benefits are also hard to define, uncertain and difficult to accurately assess as being a result of research participation (Alderson & Morrow, 2011).

A best-outcomes, consequentialist approach can be applied to assessing and reducing harm and promoting benefits. In this approach actions are considered right or wrong depending on the nature of their consequences (Gallagher, 2009). Accordingly, decisions in research may be guided by what are the best expected outcomes, with the anticipated benefits needing to be bigger, and more likely to occur, than any possible negative consequences. This can be interpreted as the right actions being those that result in the greatest overall good for the greatest number of people. An additional factor in the equation is the harm that may occur if the research is not done.

However, a challenge arises using this approach in the potential conflict between the ‘greatest good for the greatest number’ and the consequences for individual children participating in the research. From a rights-based perspective, drawing on the general principles

**Power differences between adults and children are one of the biggest ethical challenges for researchers seeking to include children in research.**

From a rights-based perspective, researchers have a responsibility to ensure that no harm is done to individual children participating in the research, as well as attending to the long-term and/or larger good for children as social groups.

expressed in the UNCRC of best interests of the child (Article 3.1) and protection from all forms of violence (Article 19), researchers have a responsibility to ensure that no harm is done to individual children participating in the research, as well as attending to the long-term and/or larger good for children as social groups.

A further challenge to applying the best-outcomes approach lies in the reality that there may be several outcomes to an action, which include both positive and negative consequences for the individual child. For example, the means utilised to achieve an outcome, such as an interview, may have retaliatory and negative effects for the child, while the future intended outcome, such as access to a service or heightened attention to a severe social problem, could be deemed positive. When the focus is on research outcomes, this can mask the potential for more complicated and heterogeneous consequences related to the tools and processes of data collection. This strongly suggests a need for the means of the research, that is, the research process, to be the key aspect under scrutiny. This topic is addressed in Mary Catherine Maternowska's case study of a survey on violence against children, undertaken with participants aged 13 to 17 years.

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**Case study 6: Interviewing children on sensitive issues around violence: Do survey instruments and processes on violence against children provide adequate measures to protect children aged 13-17 years?, by Mary Catherine Maternowska (see Case Study section p.125).**

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Individual children may be best placed to assess any risks to themselves, which is one of the reasons why informed consent is so important (Laws & Mann, 2004). However, researchers are likely to have a greater appreciation of the potential wider and long-term implications of research participation, and therefore increased responsibility to assess risks posed to children through their involvement in research. Seeking local or specialised advice is important for researchers, when they are in cultural contexts other than their own or working with particular groups of children, in order to have a better understanding of the potential risks. Researcher responsibility is further emphasised when the children involved are particularly vulnerable, such as children separated from family in emergency and transition settings.

***How is harm minimised or eliminated in research involving children?***

Researchers are responsible for protecting research participants from any physical, emotional or social harm that might result from the research (Ennew & Plateau, 2004; Laws & Mann, 2004) and must do everything possible to anticipate any potential adverse consequences. The minimisation and, in some instances, elimination of potential harm can be achieved by ensuring that it is identified and that ethical issues are reflected on from the very outset of the project, as well as throughout its implementation. Once identified, researchers can make efforts to minimise or eliminate any potential risks of harm, distress or discomfort, including incorporating practical measures. For example, certain geographical locations or socio-political contexts may carry specific risks which researchers can develop strategies to manage. In areas where armed conflict or peace-building are occurring, this might include researchers ensuring that children do not travel alone, late at night or in unsafe areas where there are landmines or other dangers (Feinstein & O'Kane, 2008).

Identifying potential harm at the outset of the project allows researchers to make efforts and incorporate measures to minimise or eliminate it.

Other areas for consideration include those in which the potential harm may be less clearly obvious or easily resolved. Reflection on the multiple possibilities requires knowledge of the local context in relation to the research process and/or topic. There may be consequences for children when they are involved in research which is consciousness-raising. Such consequences may occur, for example, where the research raises awareness of labour rights for children in situations where the child's employment is a critical source of sustenance for the family. In another example, there may be opportunity costs if children are removed from class to be involved in school-based research.

As well as knowledge of the local context, it is critically important that researchers are knowledgeable in relation to the characteristics of the sample population with whom they are conducting the research. For example, if children from minority groups are involved in the research then researchers (depending on their own associations) may need to consult appropriately within those communities in order to identify potential harms or adverse consequences. Similarly, if the research involves children with particular disabilities it would be essential to identify potential harms to ensure children's equitable access to research participation. Reflecting on the possibilities can help prevent or mitigate damaging follow-on consequences and ensure that researchers have information or referral sources on hand if required.

Research methods can contribute to minimising or exacerbating harm. In order to do no harm it is vital that the research methods are scientific and reliable. This underscores researchers' obligation to ensure that children's views are accurately reported. It can be argued that unsound designs or inadequate sampling methods are unethical, since they take up time and effort but will not produce satisfactory results or because they may unintentionally lead to the exclusion of groups of children. Reliable methods include the use of several well-validated research tools that have been adapted to match the capacities of the children involved as well as the issues being researched; at least two steps in data collection with adjustment of the tools and/or the research plans in between; and triangulation. Large scale surveys, especially when children are not involved in the development of the survey questionnaire, and methods such as direct interviews and focus group discussions, may not be tools that are the most adequate or appropriate in research with young children.

The predictability of risks may differ in different research paradigms. For example, in biomedical research, it may be necessary to develop medicines that are trialled on child samples, as extrapolating adult data to children is inappropriate (Yeung, 2007). It can be difficult to quantify the risk for participating children and consider these in relation to the benefits of developing medicines for children more generally. If the nature of risks is unable to be predicted reliably, then providing accurate information to children and their caregivers to enable informed consent for clinical trials becomes an essential ethical challenge.

A research situation in which it is challenging to predict the risks and likely outcomes is one in which there is a possibility that indications of previously undetected conditions or abnormalities may be discovered incidentally during the research process. The revelation of such chances and consequences would cause added concern to the child and the parents, and therefore requires great sensitivity.

**Unsound designs or inadequate sampling methods are unethical.**

**The predictability of risks may differ in different research paradigms.**

A number of risk-related issues raised in such situations, requiring sensitive consideration, are discussed in the case study by Sebastian Lipina.

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**Case study 7: Incidental brain findings in neuroimaging research, by Sebastian Lipina (see Case Study section p.128).**

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The use of new technologies in research, such as the internet, adds another dimension to conceptualising and minimising harm. Children may have unrealistic expectations of privacy, individual information may be more readily accessible, participants can provide false details or maintain fake identities (disguising adult voyeuristic or harmful intent) and the distinction between public and private domains is blurred (Alderson & Morrow, 2011; Lobe, Livingstone & Haddon, 2007). Certain safety features, as used on websites, can be built into internet-based studies. However, it is essential that these are appropriate to children's evolving capacities and/or that such built in safety features are enabled by default as evidence shows that children struggle with user tools, safety devices, privacy settings and reporting mechanisms (O'Neill, Livingstone & McLaughlin, 2011). In addition, new modes of access to the internet are increasingly mobile, with children going online via their own laptop, mobile phone, ipod, ipad or handheld device, and thus less open to adult supervision. While this may contribute to children's privacy from parents or others in the environment during research participation, it also underscores the need for children to be aware and empowered with regard to internet safety risks (O'Neill et al., 2011).

**Ethical considerations must be taken into account in the planning stage of research, itemised in the project budget and factored into the timeline.**

In addition to the importance of identifying potential harm, to aid efforts in minimising it, a further key aspect is attending to the resource aspects of research initiatives. It is absolutely critical that ethical considerations are taken into account in the planning stage of research, itemised in the project budget and factored into the timeline, in order for ethical principles and practices to be implemented throughout each phase.

***How can children's distress during research be eliminated or minimised?***

Any research involving children may incur distress and researchers need to be prepared for this. It is especially likely to be an issue when the research topic may be upsetting for children, perhaps because it is a reminder of painful experiences, or when children are particularly vulnerable. This may occur, for example, when children have been abused, maltreated, or are separated from their parents as a consequence of humanitarian emergencies or death. A fundamental concern in research involving children who have been abused or maltreated is whether they might be seriously disturbed, or even re-traumatised, by the research process. In such studies researchers can incorporate specific measures into the research design to ensure children's protection and care, such as ensuring the child has the support of the primary carer, using a child-centred methodological approach (Mudaly & Goddard, 2009) and incorporating child-friendly debriefing processes. Where appropriate, some studies may involve recruiting children who have had prior access to therapeutic studies, which may also be a protective factor for children.

**Any research involving children may incur distress and researchers need to be prepared for this.**

In addition to sensitive topics or situations obviously more likely to cause upset, researchers will not always be aware of topics that may be distressing for individual child participants. Seemingly innocuous questions or situations may trigger strong and unexpected reactions. Children may be caught off-guard emotionally by unintentionally disclosing too much. It is therefore important that researchers know how to respond appropriately in the face of children's anxiety or distress. Researchers should be prepared in advance for the kind of emotional responses that children may have and seek to differentiate harm from discomfort and/or research-engendered distress.

Key considerations in deciding about research activity in the light of risk and harm assessment might include: the expertise and skill of the researcher and members of the research team; the level of supervision and support required from senior researchers and experts in the relevant area; and the availability of follow-up support for children. Considerations in relation to dealing with distress are discussed in the case study by Elsbeth Robson and Ruth Evans, as they reflect on interviews conducted with young caregivers in the context of the HIV epidemic in Zimbabwe, Tanzania and in the UK.

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**Case study 8: Dilemmas of dealing with distress during interviews with children, by Elsbeth Robson and Ruth Evans (see Case Study section p.130).**

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It is also important to note that some of the worst psychosocial harm from an interview may not be apparent during or immediately after the interview session. One suggestion is to incorporate a post-interview check-in by someone who is a known, trusted support, familiar with the child's usual behaviour, and can read the signs and find additional help if needed.

***What are researchers' responsibilities if children show signs of harm or distress?***

Researchers need to ensure that support is available to children, if needed, during and after the research process. An important part of research planning is anticipating potential adverse consequences of involvement in research and ensuring that arrangements are made to address these (Schenk & Williamson, 2005). It may be appropriate, in some studies, for researchers to help equip or support children's parents or carers to respond to emotional reactions their children may have. Psychosocial support or counselling may be required for children to help them cope with the consequences of recalling distressing experiences or feelings. Other forms of support, such as health or welfare-oriented support services, may be needed to help children address difficulties that become apparent during the research process. Researchers' responsibilities to do good and to do no harm to research participants requires them to plan for such eventualities. It may be helpful to have explicit protocols for addressing potentially concerning situations, and for making referrals (WHO, 2011) and providing a list of services that can provide support to children and families.

Referring children and families to support services requires an awareness of available resources. Most likely this involves consultation and gathering information within the local community

Protocols for making referrals and providing a list of support services for children and families may be helpful.

Referring children and families to support services involves consultation and gathering information within the local community context to ascertain suitable organizations or agencies to offer skilled support.

If support services are not identifiable, and the need for support is likely, the decision to undertake the research should be reconsidered.

context to ascertain organizations or agencies that are available and suitable to offer skilled support. Researchers can seek to engage with the local support service working with children and children's issues if any, by seeking their services if required, informing them of the study and getting their local intelligence on the matter. In some contexts identifying or accessing child-focused services may be impossible for a range of reasons - support agencies may not have the capacity, they may be geographically removed or be inadequate and likely to cause more harm than good - in which case alternative strategies will need to be explored.

In the absence of child-focused services it may be appropriate to request help from organizations offering similar support. For example, if researching violence against children there may be local organizations supporting women affected by violence who are able to adapt some services to meet children's needs (Laws & Mann, 2004). Research participants may also draw on individual resources, local culturally relevant mechanisms of support, and strong local community or faith-based organizations and groups (Ruiz-Casares, 2013). If support services are not identifiable, and the need for support is likely, the decision to undertake the research should be reconsidered.

***What if there are not appropriate follow-up services to refer children or parents to when there are safety concerns?***

The existence and nature of follow-up services can impact on researchers' decisions about reporting suspected child abuse. Some researchers argue that the risks to children and their families in reporting maltreatment, such as harm to children, unnecessary humiliation and **stigma** (if allegations are unsubstantiated) and lack of follow-up services, may outweigh the benefits (Kotch, 2000). The challenge regarding a breach of confidentiality in the light of suspected abuse or safety concerns is further complicated in some contexts where there may be a complete unavailability of services to afford child protection or attend to psychosocial or mental health consequences. For example, in some contexts, particularly in developing countries, there are no government sponsored child protection services, or there is a limited set of social services to which children and families can be referred and children may be mistrustful of social services (Abebe, 2009; Hutz & Koller, 1999; Veena & Chandra, 2007). Furthermore, it may not be in children's best interests to report abuse, as reporting may increase their vulnerability with corrupt figures in authority (Young & Barrett, 2001).

Local consultation is critically important and researchers need to have a sound understanding of the legal requirements, suitable referral sources and alternative resources within the area in which the research is being conducted prior to commencing it. As noted above, and discussed in the case study by Mónica Ruiz-Casares, researchers can explore alternative strategies in contexts where identifying child-focused services is unlikely.

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**Case study 9: Finding the balance between protection and participation: What do you do when follow-up services are not readily available?, by Mónica Ruiz-Casares (see Case Study section p.132).**

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In addition, the skill and responses of researchers in managing safety concerns are important, and can help children cope emotionally and facilitate transitions to the necessary services. Ideally, research staff should have training in child protection, particularly with regard to recognising and managing concerns and, where possible, work in partnership with experienced researchers and local child protection experts. Ethical supervision allows researchers to discuss concerns, seek guidance and debrief, as well as providing a forum for accountability [this is discussed further in the Researcher Support section].

***What about when there are likely to be negative implications of reporting safety concerns?***

Reporting concerns about children's safety is not always straightforward. As noted above, there may not be suitable or adequate services available. Child protection services may be inadequate, heavy handed or dreaded by children who have had previous experience or knowledge of them. Children may already be accessing such services and may disclose the inadequacy of these to the researcher. Reporting can also be further complicated in situations in which children are living in the care of the state or a non-government organization and disclose institutionalised punishment or violence from their carers. If children are already receiving care, reporting may put them further at risk.

Research in areas where there is an increased likelihood of children being at risk, such as research with children who are sexually exploited, may be compromised by children not engaging in the research process if they expect such safety concerns to be reported by the researcher. An additional challenge for researchers in some contexts are the legal harms that can arise for children if they were brought to the attention of the authorities. For example, children who are stateless or asylum-seeking and those engaged in criminal practices, can be at risk of arrest, deportation, detention, corporal punishment and attainment of criminal records. One way some researchers manage these concerns is by 'raising the reporting bar' so that only really extreme cases of immediate risk would be reported.

In many cases, researchers may not be aware of what their actions might complicate or precipitate for a child, especially if there is little recourse to effective protective systems. There are no easy answers to these dilemmas, but it is critical that researchers are aware of the possibilities and plan responses in advance of conducting the research, which take into account strengths and limitations of the local context, the services available, the child's evolving capacities and individual situation, and the potential impact on them of reporting safety concerns. It is also possible that researchers stand to learn from children themselves about the potential risks and harms of them being involved in a study. A preliminary discussion with a group of children in a safe environment may elucidate ethical issues that only children perceive, such as bullying or stigmatisation or unwanted attention from public security officials.

***Why is it important to balance children's rights to protection and participation?***

In some research contexts tension exists between protecting children from harm and respecting their right to participate in research.

Researchers may learn of potential risks and harms through discussion in a safe environment with children.

Researchers' capacity to include children in research is particularly restricted if the research topic is considered sensitive (Powell et al., 2011) and children are also less likely to be given the opportunity to participate if they are considered particularly vulnerable (Powell & Smith, 2009). In addition, children may not be included in research for pragmatic reasons, such as lack of skilled personnel to undertake sensitive research with children and lack of adequate funding. The importance of protecting children from harm is ethically mandated by the philosophical principles of non-maleficence and justice, and reflects children's rights as expressed in the UNCRC (specifically Articles 3.1, 3.3 and 36). However, a strong protectionist discourse denies children the right to participate and express their views on matters of concern to them (Powell & Smith, 2009) and children may be 'gate-kept' out of research on the basis of potential risk (Graham & Fitzgerald, 2010).

The tension between protecting children from harm and respecting their right to participate derives in part from the underlying conceptualisations of children held by different disciplines and across differing contexts. Ethical debates in the clinical sciences have tended to highlight protection of children from risk or direct harm, whereas in the social sciences debates have focused on children's exclusion from research and argued for greater inclusion as a means of addressing power imbalances and ensuring that children's voices are heard (Dixon-Woods, Young & Ross, 2006). To the extent that it is possible, children should be consulted about actions that may best balance their participation and protection rights, in accordance with the principles of justice, beneficence and respect.

### ***How can researchers ensure that children's participation in research is equitable?***

Discrimination or bias in children's participation in research may come about as a consequence of the power relationships that exist in society and between children. Researchers are not immune from such power relationships or societal influences. Their own values, beliefs and experiences impact on children's equitable participation in research. Therefore, gaining insight and understanding into their own assumptions, as well as the social, community and family representations around such characteristics as age and gender, is critical in ethical decision-making and can be greatly facilitated and enhanced through ethical supervision and training.

In some contexts, where there is acute social differentiation, certain children may be silenced by others. Children from linguistic minority groups, for example, may face discrimination from other children. This presents a challenge to researchers during recruitment, identifying children who may potentially be excluded through discriminatory processes, and in data collection, particularly in focus group situations, ensuring that all children's voices are heard and realities are presented.

The methods used may also make it difficult for some children to participate. For example, children who are hearing-impaired may require additional support, such as the engagement of a skilled interpreter, to facilitate the process of informed consent and ongoing communication through the research process. In another example, online research may be difficult or impossible for children who do not have convenient access to internet. Researchers using online methods are encouraged to consider whether digital exclusion may reinforce or further compound social exclusion. **Participatory**

Discrimination or bias in children's participation in research may be caused by power relationships that exist in society and between children.

Researchers using online methods are encouraged to consider whether digital exclusion may reinforce or further compound social exclusion.

**research** should confront and not reinforce existing patterns of discrimination and exclusion, encouraging groups of children who typically suffer discrimination and are often excluded to be involved (Feinstein & O’Kane, 2008). Additional ethical issues are raised when researchers become aware of discrimination, exclusion or unfair social incidents and experiences affecting children while conducting research. Researchers then have to make difficult decisions related to accountability and advocacy, as discussed in Jude MacArthur’s case study, in which an incident of bullying and exclusion of a child with disability was witnessed.<sup>xvii</sup>

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### **Case study 10: Dilemmas at school: How and when to support the inclusion of students with disability, by Jude MacArthur (see Case Study section p.134).**

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In focus group research more subtle forms of “inner diversity” (Eurochild, 2011, p.7) may impact on children’s equitable participation, such as how they learn, communicate, solve problems, make sense of the internal and external environments, and manage sensory input. For example, some children listen best when they are engaged in a tactile manner so having objects or material for them to handle will enable them to listen more fully. In another example, “some children need to begin speaking in order to understand what they are thinking; others don’t speak until they have ‘gathered their thoughts’” (Eurochild, 2011, p. 8). Having an awareness of these differences can help researchers to develop and implement ways to address them, thereby facilitating the more equitable involvement of all focus group participants.

In RCTs and other experimental designs it is important to maintain random assignment to conditions, so that all children in the sample have equal opportunity to be selected in all conditions. Randomisation should be purely by chance, such as using computerised allocation or random numbers, and should not use any systematic characteristics, such as date of attendance at the clinic or social security numbers. In RCTs, the control group should be given the current best treatment, rather than a placebo, and be offered to go on a wait-list to receive the new treatment/s after the trial is completed and if the trial shows favourable results.

Children’s involvement in research design, as in child-led research, can be enormously beneficial to the research itself. It does not necessarily resolve issues of power and representation, as research with children is mediated by adults (Clavering & McLaughlin, 2010; Kellett, 2010). However, the meaningful participation of children and young people throughout the design and implementation of research studies can be a critical factor in the success of the project (Radford et al., 2011).

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<sup>xvii</sup> There is an ongoing debate regarding the language used to refer to people and children with disability (Robinson, 2013). Social model theorists and researchers in some countries use the term ‘disabled children’ to acknowledge the fundamentally social, political and structural processes of disablement. However, in other countries, the term ‘child/ren with disability’ is more frequently used and the usual preference of self-advocates. The latter terminology ‘children with disability’, is used throughout the ERIC compendium, however this does not necessarily reflect the preferred wording of case study authors.

A related area in which children's opinions have been sought very rarely and which needs to be redressed as a matter of some importance, is children's views on ethics in research, including debates over ethical considerations such as those discussed in the ERIC compendium. Jurrius and Uzozie (2012) suggest that a good start to finding concrete methods to cope with ethics issues is the conversation about ethics between researchers and, importantly, between researchers and children. Considerations with regard to discussing ethics with children are the focus of the case study by Kitty Jurrius.

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**Case study 11: Discussing ethics with children, by Kitty Jurrius (see Case Study section p.136).**

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### **WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO HARMS AND BENEFITS?**

- No child should be discriminated against on the basis of their sex, race, religion, abilities, or any other social or political characteristics, in terms of their participation in research (Article 2).
- Researchers, research organizations and governments have a responsibility to do what is best for children and make sure that all children are protected (Article 3).
- Children have the right to protection from research that is exploitative, harms them or is bad for their health, education or development (Articles 6, 19, 32 and 36).
- Researchers have a responsibility to ensure children have access to advice and support if they are adversely impacted by issues raised in the course of the research process (Article 39).
- Research should honour children's right to express their opinions, by talking, drawing, writing or in any other ways. Researchers have a responsibility to listen and take children's views seriously (Articles 12 and 13).
- Being involved in research has a formative value and therefore should help children use and develop their talents and abilities. (Articles 5, 6, 12 and 13).
- All children have the right to be protected from being hurt and mistreated, in body or mind, throughout the research process (Article 19).
- Children are not allowed to be punished in research (Article 37).

## KEY QUESTIONS

### ***Does this research need to be done?***

- Will the research contribute new knowledge?
- How have you ensured that the information being sought is not available elsewhere?
- Is children's participation in the research necessary or can the information be obtained in other ways (excluding endorsing adults speaking on behalf of children in preference to children speaking for themselves)?
- What form will children's involvement in the research take?

### ***Do you have the resources necessary to do the research?***

- What resources (money, time, staff, equipment etc) are necessary to obtain the best possible local knowledge and to undertake the research, and are these readily available? If not, is there a plan for how these will be obtained/managed?
- How much time needs to be allocated for obtaining necessary resources in order to undertake the research project ethically?

### ***How well prepared are you, the researcher, to meet with children?***

- What do you know about the children who you want to involve?
- How will you find out what you need to know about the children and their lives?
- Do you have the necessary skills (technical and interpersonal) to involve the children in research? What experience do you have of dialogue with children? What do you know of child development?
- What means (or methods) will you use to address the power difference that exists between you and children?
- How will this research be inclusive of all children?
- What steps can be taken to identify marginalised/hard to reach children and ensure they are included in the research?
- If it is not your intention to include children, on what basis will they be excluded and why?

### ***How will you ensure children are safe?***

- Are there any identifiable risks for children?
- Are there any risks posed if the findings from the research are made public?

- What plans can be put in place to reduce risk?
- Are there children whose particular circumstances place them at high risk? If yes, who are they and why?
- How will you find out what community and/or professional resources and services are available to children if needed?
- What actions will you need to take to respond appropriately if a child discloses harm or abuse?
- Who will you need to inform about these actions?
- What are the legal requirements for reporting child abuse in the area the research is taking place?
- What possible stigma may attach to children if they participate in the research? What will you do about this?
- Do you need to develop and/or implement safety protocols or policies in your project to protect children, during and/or following the research? If so, why, and what protocols or policies are these?
- Have you considered instigating a post-interview check-in by someone who is a known, trusted support, familiar with the child's usual behaviour, and can read the signs and find additional help if needed?

***How will you respond to children if they become distressed or upset?***

- Do you have the experience and/or skills to respond to children's distress?
- What supervision or support do you need to have in place for research team members?
- What arrangements do you need to make to support children who become distressed? And how will you ensure that their issue or concern was attended to?



© UNICEF/NYHQ2009-0222/Estey  
Girls from an indigenous community read outdoors at Ban Pho Primary School  
in Bac Han District in remote Lao Cai Province, Vietnam.





# 55

## **ETHICAL GUIDANCE: INFORMED CONSENT**

Obtaining consent from parents/carers and children is central to the research relationship and signals respect for the research participant's dignity, their capability to express their views and their right to have these heard in matters that affect them. Informed consent is an explicit agreement which requires participants to be informed about, and have an understanding of, the research. This must be given voluntarily and be renegotiable, so that children may withdraw at any stage of the research process.

# INFORMED CONSENT

## BEST PRACTICE REQUIRES THAT YOU:

- Obtain consent from all children participating in research.
- Make sure children are fully informed as to the purpose of the research and what their involvement will be.
- Respect children's decision about participating in research, including their dissent or unwillingness to participate.
- Carefully consider the strengths and limitations of obtaining parental consent.
- Ensure that children (and others) understand that consent is negotiable and that children can withdraw at any point.
- Design the consent process to take into account the evolving capacities of the child as well as the overall research context.
- Consult locally to ascertain if informed consent needs to be obtained from community leaders or representatives.

Obtaining consent from parents/carers and children demonstrates respect for the individual research participant's dignity; their capability and right to make decisions about matters that affect them.

## KEY CONSIDERATIONS

Obtaining consent from parents/carers and children is a usual part of the research process (Powell et al., 2011). It is the cornerstone of the research relationship and reflects important underlying ethical considerations, including demonstrating respect for the individual research participant's dignity; that is, their capability and right to make decisions about matters that affect them. This extends to respecting the participant's knowledge about their own situation and ability to assess potential risks associated with research participation, recognising that children may be best placed to assess any risks to themselves (Laws & Mann, 2004). Such respect underpins researchers' responsibility to uphold children's right to **dissent**, that is, to refuse participation and to withdraw at any time and to prioritise this over their parents' or others' wish for them to participate. Gaining participants' informed consent also shows honesty, in that the researcher has not deceived the participant about the research study or the nature of their relationship.

Informed consent has four main features: consent involves an explicit act (for example, verbal or written agreement); consent can

only be given if the participants are informed about and have an understanding of the research; consent must be given voluntarily without coercion; and consent must be renegotiable so that children may withdraw at any stage of the research process (Gallagher, 2009). These four main features, which are often challenging to put into action, are explained below.

### ***Consent involves an explicit act***

A critical issue for researchers is deciding who is involved in the act of consent and how it is signified. There are unique ethical complexities in research involving children as there are multiple research relationships, which centre on a triad (rather than a participant/researcher dyad) consisting of the researcher, child participant, and parent or carer. Obtaining children's consent directly, for their participation in research, signals respect for their autonomy and human rights. Children's right to participate in decisions that affect them is a basic human right, and emphasised in two of the key participation Articles of the UNCRC, in particular Articles 12 and 13.

Parental consent (or guardian/carer consent) is also usually required for children's participation in research. Children's right to consent on their own behalf may be regulated by law. For example, in Norway, youth between 16 and 18 years are usually allowed to give their own consent, while the parents are informed, but depending on the character of the proposed research. Below the age of 16 years children may consent in special circumstances, while children under the age of 12 years always need their parents' active consent before they can be asked to participate (E. Backe-Hansen, personal communication, October 12, 2012). Given the usual requirement for parental consent, researchers are frequently in the position of balancing two ethical imperatives: ensuring that children can freely choose to participate (respecting their autonomy) and acknowledging parental responsibility to ensure children's safety and well-being (Munford & Sanders, 2004).

In addition, researchers are at times compelled to seek consent from a range of adults in children's lives (for example, school boards, school principals, teachers, community leaders/chiefs, health professionals and social workers) and negotiate a hierarchy of gate-keeping (Hood, Kelley & Mayall, 1996) before children are allowed to be approached about participating in research. In some cultural contexts the focus on individual consent for participation in research is at odds with cultural and societal customs, in which the right to consent and pass on knowledge is a collective concern, involving the wider family and community (Suaalii & Mavoa, 2001). Local consultation is therefore an important aspect of determining who, other than the children themselves, should be approached regarding children's participation in research. A factor to consider in local consultation is the research topic. For example, it may be more appropriate to set limits on the status and number of people from whom consent is sought or who have access to information about the research in sectors such as violence against children, in order to ensure children's ongoing safety.

### ***Consent must be informed***

A requirement of ethical research is that participants are informed and have an understanding of the research activity, whatever research methodology is being used. Therefore, children must be provided with information that is appropriate to their age and

There are unique ethical complexities in research involving children as there are multiple research relationships centring on the researcher, child participant, and parent or carer.

Local consultation is an important aspect of determining who should be approached regarding children's participation in research, bearing in mind the research topic.

Children must be provided with information that is appropriate to their age, competencies, context and evolving capacities.

competencies, bearing in mind the environmental context, differing experiences and evolving capacities of each child [as discussed in the Background section of the ERIC compendium]. An approach to research that is informed by children's rights and the UNCRC "requires that, in appropriate circumstances, children are given information (Articles 13, 17) and adult guidance (Article 5) while their views are in formation, in order to be assisted in determining and expressing what will then be both a formed and informed view (Article 12)" (Lundy & McEvoy, 2012, p.140).

Children must understand what the research involves, including the risks and potential benefits. Giving children information allows them a meaningful choice about participation, preserves their trust in researchers and the research enterprise, and demonstrates respect (Spriggs, 2010). If children are involved as researchers, both they and the children from whom data is being collected, need to be aware of the purpose of the research, the potential benefits and risks of participation, and the time commitment required.

Other people giving consent for children's participation must also be provided with information about the research. Parents and gate-keepers may need and welcome guidance about their child's role in research and their own role and responsibilities. Information can be provided which underlines children's capacity to be involved in research and helps parents to assist children to make decisions about taking part, rather than substituting their own views or acting on their own convenience, except in situations when the child is unable to express a view or is especially vulnerable. For some children, for example, those with particular disabilities, proxies or advocates, who speak on behalf of or about the children and decide whether to consent to their participation in research, make it possible for them to be included (National Disability Authority, 2009). However, to respect children's autonomy, the use of proxy informants should be minimised. The child needs to give informed consent as well as the person who is acting as the proxy wherever possible.

### ***Consent must be given voluntarily***

The requirement for consent to be given freely and without coercion has additional nuances in research involving children. The nature of power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely. [This is discussed further below, in Challenges You Might Meet]. The order in which consent is gained, as well as from whom, can have an impact on children's subsequent participation, with children potentially feeling constrained or empowered by their parents' consent or lack thereof.

### ***Consent must be renegotiable***

Consent is conceptualised as an ongoing process throughout research (Alderson & Morrow, 2011; Hood et al., 1996). This process includes, but is not limited to, the initial agreement to participate prior to data collection commencing. Consent is therefore viewed as negotiable throughout the research activity, with informed dissent being as important as informed consent. Different research paradigms produce different time-periods over which participation may be required. For example, in longitudinal studies that take place over many years and in which the research aims may change significantly

The order in which consent is obtained, and from whom, can impact on children's participation.

Consent is negotiable throughout the research activity, and informed dissent is as important as informed consent.

over time, ongoing consent that is aligned with the child's evolving capacities is ethically warranted. Similarly, in group contexts that involve research taking place over time, re-negotiating consent with each phase is an ongoing ethical challenge. In addition, negotiating consent in group contexts requires time to ensure that the rights of all individuals are respected in regard to research participation. Ethical issues raised in obtaining voluntary, informed consent when conducting research in a group context are discussed in the case study by Muireann Ni Raghallaigh and Robbie Gilligan, in relation to a project with asylum seeking young people in a residential hostel.

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**Case study 12: Obtaining informed and voluntary consent in a group context, by Muireann Ni Raghallaigh and Robbie Gilligan (see Case Study section p.138).**

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## **CHALLENGES YOU MIGHT MEET**

Consent to participation in research is an ethical consideration that has been discussed extensively in the literature (Powell et al., 2012). However, it continues to raise significant challenges and requires ongoing clarification. Whilst general guidance can be (and has been) given in ethical guidelines, researchers are encouraged to consider each research study individually, taking into account the local context and the children's age, capacity and understandings in determining how consent should be obtained and signified. The topic of the research and means of gaining consent also have to be considered in the light of social, political and cultural considerations within the local context. A reflexive approach allows for the consideration of relevant contextual issues and tailoring of the consent process to meet the needs of all involved in each research study.

### ***Are all children capable of providing consent?***

The UNCRC recognises children's evolving capacities (Article 5) and it is clear that consent processes need to be designed in accordance with these. This is particularly important as the age at which children are considered capable of providing informed consent for research is a contentious subject, varying between countries and in relation to different contexts within countries. The inconsistent and contradictory requirements, and underlying assumptions about children's capabilities, can be a source of frustration for researchers (Powell et al., 2011).

However, assumptions in certain contexts that children lack the cognitive maturity and/or moral development to make informed decisions about their involvement in research are challenged by studies showing that children, including those who are very young or have learning difficulties, are able to make informed decisions when provided with appropriate information (Powell et al., 2012). When such children are deemed to be unable to give consent, their exclusion from the decision-making process reinforces the view of their dependency and incompetency (Gallagher, 2010). Resolving this issue is perhaps less about determining whether children are capable of providing consent and more about researchers' abilities to provide information and creatively adapt consent processes to meet the needs of children, while simultaneously ensuring that rigorous research practice is maintained.

### ***Is it better to gain children's consent or assent?***

**Assent** is frequently referred to in the documentation, particularly in the North American and international biomedical guidelines (such as those reviewed by Avard et al., 2011). Some researchers advocate the use of assent, the affirmative agreement of a child, rather than consent, in certain situations. However, these do not have to be mutually exclusive and both assent and consent can be used within the same study.

However, the use of assent is not universally recognised or supported. Criticism includes that it can be used: to refer to an agreement by minors who have no legal right to consent, despite arguments that support children's competence to consent (for example, **Gillick competence** in England and Wales); in place of consent if children do not fully understand the issues required for consent, meaning children are only partly informed; or it may mean 'at least not refusing' and so be misused to cover children's wish to not participate or non-verbal refusal (Alderson & Morrow, 2011).

On the other hand, the use of assent has been advocated as providing researchers with a way of navigating and transcending differences in language, ability, cultural, social and international borders, and ensuring they can access children's agreement to participating in research (Cocks, 2006). This is particularly significant as the focus on competence has inadvertently led to some children, for example those with language impairments, being excluded from research. However, it is important to note that Cocks contends that "'assent' cannot be in itself sufficient in ensuring ethical integrity, rather it is complemented by the researcher operating reflexively and within a framework of ethical reflection" (p.249).

### ***What material form should consent take?***

Consent usually involves the participant providing a written signature or thumb print, but sometimes a verbal agreement is made. Flexible means of providing information and signifying consent are essential for children, or parents, who are not able or willing to use written methods. Signing consent forms can be problematic and/or intimidating for those who are not physically able to, and populations who are not literate or are particularly vulnerable. For example, undocumented migrants may prefer not to sign documents. In some cultural contexts written consent may be highly problematic, if written practices are different or hold other meanings, for example, related to deception, domination or abuse. This may create distress for people if they are required to sign something they do not understand well. Flexible and appropriate methods of providing information can be employed [see following sub-section, How Can Researchers Ensure That Children Are Fully Informed?] and consent can be indicated verbally or actively. In situations where children or parents do not provide written consent it is important to have a planned process and witnesses (or means of auditing) that can verify a proper process was followed and can confirm that the child appears to have given their consent freely.

Obtaining informed consent can be difficult in online research, because of the transient nature of many online environments, the fluctuating form of the research population who may be difficult to identify and the mediated nature of the relationship which makes it more difficult

Obtaining online consent has additional complexities to consider.

to ascertain the participant's genuine understanding (Jones, 2011). Jones suggests that informed consent may not be reasonably sought or obtained online prior to the research taking place and considers that it may be a better ethical judgement to obtain informed consent when the research is at the point of reporting and the participants can see what is to be reported. However, regardless of the additional complexities involved in online research, it is critically important that consent is obtained and consideration needs to be given to exploring this and the means of ensuring that it is genuine and informed.

### ***How can researchers ensure that children are fully informed?***

Researchers can provide information appropriate to children's age and competencies in written form and verbally, and this is emphasised in existing ethics guidance. Rather than using a formal and scientific ('jargonistic') form of language, researchers need to translate ideas into very simple terms to promote and enhance understanding in communication between researchers and participants. Innovative methods of informing children can also be used, for example, using photographs or video vignettes to decrease reliance on written consent forms. The case study by Jennifer Thompson provides an example of using photographs in a visual consent form, to facilitate informed consent in a community with relatively low levels of literacy and limited access to technology.

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### **Case study 13: Picturing consent: Using photographs in a visual consent form, by Jennifer Thompson (see Case Study section p.141).**

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It is important that children have a source of information for future reference about what they are consenting to. Information should include the research topic, the purpose of the research, what participation involves, any potential risks or benefits that the researcher is aware of, the ongoing option to withdraw, and practical matters, such as where the research will take place and how long it will take. In addition, children should be informed as to what the researcher intends to do with anything they produce in the process of doing research, including, for example, drawings, artwork and photographs. If the intention is that such products will be taken away by the researcher then this should be made explicit to the children, and issues of ownership and acknowledgement discussed and clarified in order for consent to be given.

However, ensuring that the information is received and understood by children (and parents) can be problematic in practice, regardless of how comprehensive and encompassing it is. Mismatches in understanding are likely and difficult to detect (Gallagher et al., 2010). This is particularly highlighted when the researcher/interviewer and children participating do not speak the same language. The use of interpreters presents unique challenges, with another layer of communication to be navigated in ensuring that the intended meaning of the information is conveyed and received. Simply providing information (particularly in written form) is not enough to ensure understanding; researchers need to engage with ways of ascertaining if potential participants and their parents understand. Cognitive testing of research instruments can be helpful, but even with information provided and understanding indicated, it is difficult

**Researchers need to translate ideas into simple language to promote and enhance understanding.**

for anyone, including children, parents and researchers, to fully anticipate the outcomes of participation and what all the potential risks or benefits may be. The case study by Kate McAlpine discusses challenges occurring in relation to the application of ethical standards, for example in gaining informed consent in fieldwork practice.

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**Case study 14: Responding to real world ethical challenges when conducting research with young children in Tanzania, by Kate McAlpine (see Case Study section p.145).**

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Another consideration in long-term research projects, such as longitudinal studies, is whether there is a need for children to receive additional information as the project progresses, appropriate to their age and capacities, in order to 're-consent' to participation. Some projects have clearly defined phases, which lend themselves to gaining children's consent at each consecutive stage. An important aspect of this is ensuring that children are informed about, and in agreement with, the storage and use of their personal data over time, particularly in cases of secondary analyses of previously collected data.

***What about obtaining consent from non-participating children in research using visual methods?***

When using visual methods with children, such as data collection involving children taking photographs, there is another level of informed consent required, as other people (including children) may appear in the pictures taken by the participants (Phelan & Kinsella, 2013). The ethical consideration of gaining informed consent in relation to the child appearing in the visual images can be challenging, particularly as it is likely to be the child research participant taking the photo and who is then in the position of asking the child and/or parents for consent, with the researcher unlikely to be present. This adds a further layer to the already complex task of ensuring that children and parents are fully informed and understand both the present context of the research and the future use which may be made of the photograph, for example in publications, reports and presentations. In a study by Phelan and Kinsella (2013) the following questions were used to design the assent process for children: "Why are you being asked to be in a picture? What will happen to you? What will happen to the pictures?" (p. 83).

***How can researchers ensure that children's consent is freely given?***

As noted, the nature of power relations between adults and children means that it can be difficult to ascertain that children have a genuine choice regarding participation and that their consent is given freely. Indeed, "children's consent must be seen in the context of constraints, obligations and expectations over which researchers have little control" (Gallagher et al., 2010, p. 479). For example, in some contexts, such as educational or medical settings, children's compliance with adult/authority requests and requirements is often compulsory. Children in school settings are likely to view the researcher as a school visitor and feel obliged to co-operate (Gallagher, 2010; Hill, 2005). It may therefore be difficult for children to decline the request to participate in research and participation could verge on coercion (David, Edwards & Alldred, 2001).

**Power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely.**



Cultural considerations, such as strong expectations regarding obedience of children to adults or collective decision-making, impact on children's autonomy and their expressions of willingness to participate, or decline participation, in research. Some researchers argue that the impact of power relations on children's freely-given consent to participate in research is thrown into sharp relief in developing countries, in which children are most often subordinate to adults and obedience is strongly entrenched (Clacherty & Donald, 2007). Children's consent can be influenced by wanting to show respect to adult caretakers (Nyambedha, 2008), or constrained by power relations in the community (Ahsan, 2009). In addition, cultural standards and traditions may impact significantly on consent in ways that researchers from outside the community or area are unaware of, or unsure of how to respond to respectfully. For example, the ethics of hospitality are very strong in some cultures and may influence consent and research relationships, with people unable to decline participation and sharing food or other items with researchers that they can ill afford [see Case study 1 by Sadaf Shallwani in the Harms and Benefits subsection of the Case Studies section in this compendium].

Cultural considerations impact on children's autonomy and their expressions of willingness to participate, or decline participation, in research.

While it is critically important to provide children and parents with information and gain their informed consent in all research, particular care must be taken in biomedical and clinical studies in line with the specific risks. Some children have had their rights infringed through being subjected by business enterprises to unnecessary or inappropriate biomedical research without their or their parents' full and informed consent being given (United Nations Committee on the Rights of the Child, 2012). Special care must be taken in gaining consent to avoid any risks of 'therapeutic misconception' in which individuals do not understand that the defining purpose of clinical research is to produce generalisable knowledge, regardless of any potential benefit (WHO, 2011). This is an especially high risk in clinical research when participation in research may be perceived by participants and their families as an opportunity to access medical treatment, and in social and epidemiological research when it may be seen as a route to accessing services or benefits. Similarly, children and parents need to be informed of and understand that results from genetic research are more likely to be less certain and may involve clinically unvalidated tests, compared to those used in clinical genetic procedures (Patenaude, Senecal & Avard, 2006).

Another area for potential misconceptions concerns the nature of the researcher-participant relationship. For example, in ethnographic studies, children may have expectations of continued friendship with the researcher, and thus feel hurt or confused when the research participation ends. Researchers may need to be cautious in this regard, particularly with young children or those with certain types of disabilities, for example, learning disabilities (Stalker, 2003). Consent is thus influenced by raised expectations and unrealistic perceptions of beneficial outcomes.

Consent can be influenced by raised expectations and unrealistic perceptions of beneficial outcomes.

### ***How can children's dissent to take part in research be respected?***

Respect for children requires researchers to accept children's decisions regarding participation. It requires them to actively engage with children and assist them to exercise their power and decline participation should they wish. This has particular implications in focus group research. If consent is obtained in a group setting it may be difficult for children to indicate their dissent, due to social and power dynamics at play. For example, doing so may risk disapproval

and subsequent bullying or ostracism from their peers. Researchers may build in some informal time before activities begin to allow those who do not want to participate to leave without being noticed. Strategies can be discussed and rehearsed with children, assisting them to exercise their dissent or withdraw their participation in the research study (Ahsan, 2009), for example, with younger children, using 'stop signs' can be practised in a playful way before interviews. Even with these strategies in place it may be difficult for children to stop their participation in the face of potential or perceived adult disapproval. Hence, it is important to attend to children's visual, verbal and non-verbal cues to monitor unspoken expressions of unease or dissent (Ahsan, 2009; Cree, Kay & Tisdall, 2002) and recognise these points of resistance as children using the power they have to express their response to research participation.

**In research that involves children in group settings there are consequences of an individual's decision to decline participation or withdraw consent.**

In research that involves children in group settings there are consequences of an individual's decision to decline participation or withdraw consent. The issue of consent when engaging in ethnography within a confined space presents added difficulties that do not exist within other forms of research. For example, when a parent or child refuses consent, but the researcher nonetheless remains in the setting conducting the research with some other children present. [See Case study 12 by Ni Raghallaigh and Robbie Gilligan in the Informed Consent subsection of the Case Studies section in this compendium.] Respect for the individual child suggests that researchers should ensure there is no note taking or other data collection techniques used that involve the dissenting child (for example, when they are interacting with the rest of the group). This limits, though does not completely preclude, data collection as a whole in these contexts. The case study by Michael Gaffney discusses challenges in obtaining informed consent in ethnographic classroom-based research with children who have a disability.

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**Case study 15: The challenge of ongoing consent?, by Michael Gaffney (see Case Study section p.147).**

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It is also important that salary and reward structures for research field staff do not unintentionally provide a perverse incentive to encourage consent from participants. For example, payment per interview for field staff, rather than salary, may provide an incentive for staff to persuade potential participants to take part in the research (WHO, 2011).

**Behavioural and verbal signs of dissent need to be sensitively observed and attended to by researchers.**

Behavioural and verbal signs of dissent need to be sensitively observed and attended to by researchers. Very young children, such as babies and pre-verbal infants (Dalli & Stephenson, 2010), or those with physical disabilities, may not be able to move themselves out of situations in which they are uncomfortable. Children who are able to verbalise may not make an explicit spoken request to withdraw from research (Spriggs, 2010). As noted by Clark (2005), listening to children is an active process of communication that is not limited to the spoken word. Behavioural signs of dissent include: passivity; lack of cooperation; fussiness; silence; crying or puckering; constant looks towards the door; lack of eye contact with the researcher; and signs of boredom such as multiple yawns (Keith-Spiegel, 1983). Verbal indicators of dissent made by young children may include: 'I want to go to the toilet'; 'I'm tired'; 'When will I be done?'; and responding repeatedly to direct and age appropriate questions with 'I don't know'

(Keith-Spiegel, 1983). Even in one-off questionnaire-based studies children may signal dissent by not doing this very comprehensively, by making obviously irrelevant answers, or by not participating again if the study is repeated.

### ***Is parental/adult consent always required in research involving children?***

Decisions about ethical research practices are made within a cultural context, including whom consent is required from (Bogolub & Thomas, 2005), and the usual requirements for parental (and other adult) consent reflect underlying understandings and assumptions about children, childhood, child-parent and wider community relationships. Contextual understandings of children's capacity to give informed consent in some countries are influenced by conceptualisations of childhood which frame children as immature and vulnerable. This is particularly true for younger children. In these contexts children usually cannot be approached directly, "their sociopolitical positioning means that adults must give permission" (Hood et al., 1996, p. 126). Consequently, research in institutional hierarchies, such as schools, can give rise to an ethical tension around consideration of the child's agency versus the need to first obtain consent from school principals, teachers, parents and other adult authorities (Gallagher, 2010). Across different contexts, care needs to be taken to ensure that focusing on individual capacity to consent does not lead to overlooking the social aspect of consent. In school settings, for example, the child's relationship with parents, teachers and peers is likely to influence the consent process (Gallagher, 2010).

Adults in gate-keeping positions may govern children's access to research, particularly when the children are considered especially vulnerable, such as children in care, and researchers are advised to establish sound relationships with gate-keeping adults (Bogolub & Thomas, 2005; Thomas & O'Kane, 1998). Researchers involving younger children may also be confronted with a higher threshold for getting parental consent than with older children, especially if the topic of research is considered sensitive (for example, related to violence against children). Consequently, parents and other adults play a significant role in restricting researchers' capacity to include children's views and limiting children's participation in research (Powell et al., 2011).

It is critically important to acknowledge that parents and other adults in gate-keeping roles have an important and positive function in protecting children from potential harm. However, they can also use their power to censor young people (Masson, 2004) and may not always have the best interests of the child in mind. While the vast majority of parents care deeply and act in the interests of their children, in some instances, the assumption (usually made in gaining parental consent) that parents will always act in their children's best interests simply may not be true, and the child's parent may have reasons for not wanting the child to participate based on their own concerns or interests. Parents who are abusive, for example, may not consent to their child participating in particular research studies for fear of the child revealing the abuse and the researcher subsequently reporting it to authorities. The case study by Lucie Cluver, Franziska Meinck and Mark Boyes discusses the dilemmas faced conducting research with children affected by HIV and AIDS in South Africa in regard to obtaining informed caregiver consent when guardians were unavailable, unable or unwilling to provide this.

**Decisions about ethical research practices are made within a cultural context, including whom consent is required from.**

**Care needs to be taken to ensure that focusing on individual capacity to consent does not lead to overlooking the social aspect of consent.**

**Parents and other adults have an important, positive function in protecting children, but some may use their power to censor children and young people and may not always have their best interest in mind.**

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**Case study 16: Caregiver consent for child participation in research: Reaching and protecting the most vulnerable, by Lucie Cluver, Franziska Meinck and Mark Boyes (see Case Study section p.150).**

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Passive consent procedures, in which parents are only required to let researchers know if they do not want their child to participate, allow researchers to bypass the usual parental consent requirement, and children to participate and contribute in research. However, this is a contentious area, particularly for young children and those with decision-making impairments. The ethics of this have mostly been debated in relation to sensitive research topics, when gate-keeping is more likely to occur (Powell et al., 2012). Ethics committees tend to favour active consent, or 'opt in' consent procedures, which respect people's privacy and allow for autonomy, but also have the effect of silencing children who are dependent on someone else giving consent for them to participate (Alderson, 1995).

In some contexts there are valid reasons for not gaining parental consent.

Some researchers consider that parental consent, or consent from those in a parental role, should be the rule and not the exception, and that researchers should need to argue from case to case why such consent is not necessary, but not the other way round. Valid arguments for not gaining parental consent might include the risk of suppression of children's information, or situations in which it is impossible or inappropriate (see section below).

***What if researchers are unable to obtain parents' consent?***

The already complex matter of obtaining the informed consent of parents or carers is further complicated in some contexts by certain practical challenges. These may include difficulties identifying and locating parents or guardians, low rates of literacy, scepticism about signing documents, and concern that signing a consent form may carry risk to participants or their families in certain contexts (Abebe, 2009; Clacherty & Donald, 2007; Hutz & Koller, 1999).

In the absence of parental support, children's participation in research should be guided by the best interests of the child and the involvement of child advocates.

Undertaking research involving children who are unaccompanied or orphaned significantly complicates issues of consent. The conditions around which this occurs may include humanitarian emergencies, such as situations of civil war, conflict and peace-keeping, or natural disasters. It may also include unaccompanied children migrating to seek refuge in response to humanitarian emergencies or for other reasons. In such situations children are exceptionally vulnerable and the research may be driven by political or other imperatives which are operating under time, resource and other constraints. Therefore, in the absence of parental support and concern for their children's welfare, it is critically important that the primary factor in deciding children's participation in research is the best interests of the individual child and that responsible child advocates are involved in the consent process.

Usually, there are caretakers or legal guardians who, in accordance with domestic laws in force, may have the same responsibility and powers as parents. In some instances, the state may have a role regarding responsibility for children that needs to be respected. To this end, some ethical guidelines stipulate a descending order of people from whom consent should be sought or a waiver required. Guidelines prepared by the Human Sciences Research Council of

South Africa (2010), *Informed consent guidelines re minors (including orphans and vulnerable children (OVC)) and parental substitutes*, for example, suggest the order should be: parent; guardian; foster parent (per order of Children's Court); caregiver (per Children's Act); or if minor is a caregiver in a child-headed household then consent should be sought from a responsible person (per s137 Children's Act), or a trusted adult nominated by the minor, including but not limited to social worker, community worker or teacher.

### ***What if it is inappropriate or impossible to seek parental consent for children?***

There are some situations whereby it may be inappropriate or impossible to seek parental consent, for example when children are 'runaways' and homeless (Meade & Slesnick, 2002), living on the streets (Richter, Groft & Prinsloo, 2007; Vakaoti, 2009), or emancipated minors (King & Kramer, 2008).<sup>xviii</sup> This is particularly relevant when the children being sought for the research are older, for example, young people over 15 years of age. Some researchers also argue that it is not appropriate to ask for parental consent in certain contexts, such as studies with sensitive research topics that require confidentiality and privacy for the protection of the young people participating. This applies, for example, in studies concerning sexuality (Valentine, Butler & Skelton, 2001) or drug use (Langhinrichsen-Rohling, Arata, O'Brien, Bowers & Kilbert, 2006). Gaining consent poses particular challenges when seeking to engage hidden populations of young people to participate in research. In such contexts, other people's knowledge of the young person's involvement in the research may be a breach of their privacy and/or a serious and potentially dangerous threat to them, and the young person is unlikely to respond to conventional (and relatively public) approaches to gain their consent.

### ***Is it ethical to hide or disguise the purpose of the research?***

An ethical consideration is the extent to which it is permissible (if at all) to hide or disguise aspects of the purpose of the research. There may be an inherent tension for researchers between wanting to ensure that research participants are fully informed, with consent freely given, and wishing to maximise participation in their research (Hill, 2005). This tension arises when it is anticipated that full disclosure of information will limit the number of people who are likely to participate. Some researchers argue that limiting information is not acceptable for the purposes of increased recruitment and is only acceptable when there is good reason: for example, where disclosure may place the children in the path of potential harm; the research involves no more than low risk to participants; potential benefits justify the limited disclosure and possible risk to trust in research and researchers; and the precise extent of limited disclosure is defined and articulated (Spriggs, 2010). Not disclosing information, or covert research, challenges the ethical principles of respect, justice and honesty, and considerable ethical debate exists as to whether deceit of participants can ever be fully justified (H. Fossheim, personal communication, December 14, 2011).

**Not disclosing information, or covert research, challenges the ethical principles of respect, justice and honesty.**

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<sup>xviii</sup> In some countries/states statutes allow minors to become legally emancipated and treated as an adult for legal purposes, for example, through marriage or based on petition from the minor or the minor's parents (King & Kramer, 2008).

The nature and use of deception in research may vary depending on the topic of the study, methodology and research paradigm. For example, in naturalistic observations, participants' knowledge of the specific behaviours that are being recorded (such as, altruistic behaviours - sharing toys or helping another child) may alter the behaviours that are demonstrated by the participants, and thereby reduce the validity of the study's findings. Similarly, in some experiments, participants' knowledge of the study's purpose/ research question, experimental conditions and how the scores on outcome variables will be interpreted, may change their responses and potentially reduce validity and benefits of the findings.

Debriefing procedures are of vital importance to all research, but particularly so if any deception is used.

For example, in repeated measures designs in which participants experience all conditions of the experiment, their knowledge of the conditions could lead to manipulation of responses, thus producing a response bias and inaccurate data. The tension between provision of informed consent and minimising harm versus producing valid results with potential beneficial outcomes needs to be carefully considered, within a context of respect for the dignity and rights of the children participating, by researchers' who are contemplating the use of any degree of deception. Provision of debriefing procedures is of vital importance to all research, but particularly so if any deception is used. Researchers need to fully explain to children the purpose and procedure of the study, the risks involved and the benefits expected, in a manner suitable for their age and competency. Researchers also need to provide age and competency appropriate answers to any questions the children have before, during and after their participation, and to provide support for any ongoing issues arising from their participation.

### ***What about using information provided without consent by children for research purposes?***

A significant amount of meaningful and important knowledge about children and their lives can be generated without involving children directly, for example, analysing registries and other statistical information. However, there are important ethical issues raised for researchers who access, or have privileged access to, children's information that was provided for other than research purposes. These might be further heightened if the organization holding the records is highly specialised and easily identifiable. For example, a practitioner working in a therapeutic service for children might want to conduct research based on the children's files, or researchers may want to use information provided by children to child helplines. This raises the question of whether it is ethical to use information, perhaps for a cause such as raising awareness about issues children face, without having asked the children who provided the information for their permission to do this. Realistically, it may not be feasible to ask a distressed child in crisis whether the service might at a later date use their case to raise awareness or influence change. One option, without having gained consent, is for researchers to try turning children's cases into anonymous vignettes. However, the children themselves may still have the impression that their experience, disclosed in confidence, is being used to influence others or for publicity purposes.

An ethical issue is raised when researchers want to use information provided by children without having asked the children for their permission.

## WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO INFORMED CONSENT?

- Children are entitled to see, receive and impart information; they have the right to know what the research is about and what it involves. Adults have a responsibility to ensure that the information makes sense to children and the research does not place them at harm (Article 13).
- Children have the right to give their opinion about research and participation, and for adults to listen and take children's views seriously (Article 12).
- Children have the right to find out things and share what they think with others, by talking, drawing, writing or in any other ways, unless it harms or offends other people (Article 13).
- Children should be aware of their rights in research. Researchers should know about these rights and help children learn about them too (Article 42).

## KEY QUESTIONS

### ***Who else do you need to consult to involve children in the study?***

- Which adults, if any, do you need to meet in the family or local community in order to understand the needs and rights of the children involved?
- Whose consent do you need for children to be involved?
- What information will you need to provide them with?

### ***What information do children need to consent to being involved?***

- What information do children need to enable them to consider giving consent?
- How will you find out the information children need?
- How will you tell children about the study?
- What procedures have been put in place to prevent children being coerced to participate?
- What further information will children need (in long-term or longitudinal projects) as the study progresses to enable them to consider their continued consent, and at what stages?

***What form should the information provided for children take?***

- Will you provide written information for children? If so, why?
- If you do not provide written information, how will you convey the information? Why have you chosen this method?
- Is there a designated person that the child (and/or parents) can go to if she/he has any questions or concerns (now and in the future)?

***Do children require extra support to contribute?***

- How will you identify the special needs of individual children?
- How will you respond to these needs?

***How will you assess the competence of children to consent?***

- How will you ensure children understand what consent is? How will you support children to understand and weigh up any risks?
- How will you ensure that children are able to withdraw without negative consequences?
- How will you ensure children understand that they are able to withdraw consent at any time without penalty?
- How will you make provision for gaining children's informed consent or allowing their dissent at different stages over long-term projects?







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# ETHICAL GUIDANCE: PRIVACY AND CONFIDENTIALITY

Respecting the privacy and confidentiality of children participating in research involves close consideration of several aspects, including: privacy with regard to how much information the child wants to reveal or share, 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.

# PRIVACY AND CONFIDENTIALITY

## BEST PRACTICE REQUIRES THAT YOU:

- Respect children's right to privacy and ensure that their information remains confidential.
- Securely store, protect and dispose of information/data that has been collected.
- Be mindful that any assurance about confidentiality also includes explicit mention of the limits to this, and always be prepared to act sensitively on safety concerns.

Respecting privacy and confidentiality requires awareness and sensitivity during the planning and data collection phases of research.

## KEY CONSIDERATIONS

Respecting the privacy and confidentiality of children and others participating in research requires awareness and sensitivity during the planning and data collection phases of research. Some of the concerns can be considered and attended to when planning the research, with the development of specific protocols, for example, for keeping information private, responding to disclosures of concern, storing data, and maintaining anonymity. Other issues require researcher flexibility and adaptation during the process, for example, in response to difficulties securing a location that provides privacy and confidentiality, or conducting interviews when others are present.

### ***Privacy with regard to how much information the child wants to reveal or share***

Children participating in research may wish certain information to remain private and not want to share this with the researcher or others. Privacy and the right to be free from intrusion or interference by others is a basic human right, articulated for children in the UNCRC (Article 16). This right underlies the importance of respecting that children share only the information that they wish to when participating in research activities and, if necessary, ensuring that they understand that in some circumstances it may be preferable to keep certain information private.

The type of data that is collected during research creates various ethical concerns in regard to how much information children wish to share.

The type of data that is collected during research creates various ethical concerns in regard to how much information children wish to share. For example, in biomedical research that involves children, the collection and storage of biological data, such as genetic/ DNA information, raises an ethical issue concerning the child's

understanding about what will potentially be revealed from providing this type of data. In gene-based prevention trials, the implications of the disclosure of the test results needs to be fully considered by researchers, disclosed during the consent process and understood by the parents and the children (Spriggs, 2010).

***Privacy in the processes of data collection and storage that allows the exchange of information to be confidential to those involved***

Privacy means that entrusted information received from children must be respected and safeguarded. Other people, including parents, may be interested in the information that has been collected, but the researcher is ethically obliged to treat the information carefully and retain confidentiality. This obligation extends to all staff involved in the research, including, for example, interviewers, interpreters, translators, drivers, and 'cultural brokers'. Training makes a significant difference in the quality of research and this should incorporate issues related to cross-cultural competence and responsibility, including managing confidentiality.

The location and methods used in collecting data impact on the privacy of the participant and the confidentiality of the research information collected. To ensure confidentiality, the setting should allow children involved in research to impart information privately and freely. For example, children being interviewed should be able to speak without being overheard, and children providing written or visual material should be able to do so without it being seen by others. Sensitive topics may produce social desirability biases and therefore require innovative methods that encourage honest answers and maintain privacy and confidentiality of responses. An example of such an innovative method is provided in the case study by Urvashi Wattal and Angela Chaudhuri, as used in research on early marriage including child marriage in India.

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**Case study 17: Maintaining confidentiality of responses and preventing social desirability bias with an innovative method: The polling booth in research on early marriage including child marriage, by Urvashi Wattal and Angela Chaudhuri (see Case Study section p.152).**

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Maintaining confidentiality in group research requires additional consideration, and cannot be guaranteed (WHO, 2011). Similarly, in RCTs confidentiality is not guaranteed with certain designs and procedures, such as surgical interventions where 'blinding' of medical staff and patients is not possible, or single blinded trials where the medical and research staff know the participant's experimental status but the participant does not. By comparison, in other RCTs where double blind designs are used to minimise participant and observer bias, confidentiality of experimental status is provided and as such, wherever possible, double-blinded designs should be used over single blinded and unblinded designs.

In some research contexts it is important that children's actual participation in the research remains confidential. Privacy is particularly important when the research study is exploring topics that are potentially stigmatising and have secrecy attached, for example, in research related to sexuality (Valentine et al., 2001) or

Privacy means that entrusted information received from children must be respected and safeguarded.

The location and methods used in collecting data impact on the privacy of the participant and the confidentiality of the research information collected.

HIV/AIDS (Clacherty & Donald, 2007; Hunleth, 2011; Nyambedha, 2008). It may be necessary to avoid children retaining tangible items related to research participation, such as information forms, material produced during the process (such as artwork) or research reports, which may place child participants at risk or cause difficulties if discovered by, or inadvertently revealed to, others (WHO, 2011).

The nature of the information collected has implications for the development of protocols and processes with respect to confidentiality of the information gathered. Research that includes collection of personal information which could potentially lead to identification of research participants (for example, names, addresses, age, gender, ethnic origin, qualifications and experience) requires particular consideration of storage facilities and processes. Personal information should be stored securely and accessible only to those who are authorised (National Children's Bureau, 2003). If possible, data should be kept separate from identifiers, such as name and address.

Consideration needs to be given to the transporting, storage and disposal of information, bearing in mind the different forms of data collected, such as audio and video tapes, handwritten and electronic data, and biological data, such as genetic material. Personal data should be accessible only by those who need to use it, and sensitive data kept in a locked room with controlled access, or kept in a locked filing cabinet or drawer, or in password protected computer files (Shaw et al., 2011). If electronic data needs to be sent through the internet, confidentiality can be secured by the use of encryption protocols. Such protocols involve a process of altering data to render it incomprehensible to any eavesdropper, with the recipient being able to convert the received data back into meaningful information. Specific national and international guidelines regarding transporting, storage and disposal of biological data need to be consulted and implemented by researchers undertaking biomedical research, with explicit consideration of the ethical considerations for children. This includes adhering to guidelines regarding the maintenance, amalgamation and closure of genetic registers, with thought given to the procedures for seeking informed consent, ensuring confidentiality, and security of genetic registers for child participants.

### ***Privacy of the participants in dissemination of research findings***

Privacy includes ensuring that research participants are anonymous and not identifiable in research reports, presentations, and other means of disseminating findings. In certain research sectors, this is a stage where there exists potential to do great harm to children, their families and communities. Harm can occur through participants being identified in association with the research and information disclosed to powerful groups (such as government departments) that may compromise the well-being of individuals in certain situations. Similarly, communities require protection from any adverse consequences that may come about through identification in research. The ethical principle of non-maleficence obligates researchers to ensure that participants are not harmed or compromised through the dissemination of findings. Strategies can be used to help maintain anonymity, for example, removing identifying information from reports, changing the name of communities, omitting participants' names, and using pseudonyms. However, it needs to be borne in mind that the use of non-gender-specific pseudonyms means the data is not analysable in terms of gender (Gallagher, 2009). Particular attention needs to be given to

Privacy includes ensuring that research participants are anonymous and not identifiable in research reports, presentations, and other means of disseminating findings.

the use of photographs containing images of children, other people, location landmarks and other identifying features, as well as to the use of direct testimonies of children.

While anonymity is the norm, it is also important to acknowledge that in some contexts children want to be identified in relation to the research and this should be considered if it does not pose any threat to them and/or provides recognition of their involvement. In addition to this, information provided to researchers that is not 'in confidence' but is given freely, with informed consent, and intended for wider dissemination, is not necessary to keep confidential per se.

## CHALLENGES YOU MIGHT MEET

Privacy is a key factor in ethical research practice, contributing to the authentic participation and protection of children during research. However, in certain situations and contexts, attending to privacy matters can present significant challenges to researchers. Tensions arise when researchers' understandings and expectations regarding privacy and confidentiality are at odds with the customary cultural, community or family practices of research participants or conflict with other ethical considerations, such as child protection. The disparity in power relations between adults and children is reflected in some of the challenges surrounding privacy, with adults not necessarily considering privacy an important or routine consideration for children, and children's preferences being subordinate to those of adults if there is conflict. Social and cultural contexts give rise to different considerations and challenges regarding confidentiality, and require researchers to critically reflect on the potential issues arising in each unique research situation.

### ***How can privacy be provided for children if this is not the usual social/cultural practice?***

In some cultural contexts privacy may not be the usual experience within families and communities and may be difficult to maintain in research. Parents, family members and other children may join interviews because the cultural customs, power relations, conceptualisations of childhood and status of children precludes privacy for children, and/or the belief that adults are more able to provide 'correct' answers (Abebe, 2009; Ahsan, 2009; Clacherty & Donald, 2007). In such contexts conducting research interviews in public places may draw less attention and consequently allow greater privacy than attempting to find a private location (Abebe, 2009).

The importance of public and social network confidentiality (Hill, 2005) is highlighted when members of the research team are from the same or linked communities to the participants. There may be inherent risks attributable to established social relationships and existing power dynamics with interviewers from the same community, which are beyond the awareness of an 'outsider' researcher. These may not be readily resolved, even if the risks are recognised, as selecting interviewers from other communities may see aspects of the research relationship, including those related to confidentiality, influenced by historic rivalries or different social backgrounds.

Parents and others may be interested in the information that has been collected and consequently they may ask about the data collected or the content of interviews, which can put stress on the

Particular attention is needed for the use of photographs containing images of children, other people, location landmarks and other identifying features, as well as to the use of direct testimonies of children.

In some cultural contexts privacy may not be the usual experience within families and communities and may be difficult to maintain in research.

Respecting the privacy of the child requires the researcher to keep information confidential and not pass it on intentionally or inadvertently to family members, friends or others known to the child.

Where possible children should be involved in choosing where the research is to take place.

child and the researcher. However, respecting the privacy of the child requires the researcher to keep information confidential and not pass it on intentionally or inadvertently (for example, by making comments among research team members in open space) to family members, friends or others known to the child.

### ***Which location best supports privacy for children in research?***

The social and cultural context contributes to determining which setting best allows respect for children's right to privacy, assisting them to provide information in research openly and freely. In research contexts in high income countries the usual expectation is that interviewing children in a quiet, private location where it is possible to talk without being overheard or interrupted is the most suitable approach. However, there are practical difficulties inherent in this approach arising across international contexts, as most research occurs in the child's home, at school or in recreational clubs where space may be at a premium (Valentine, 1999), there can be multiple interruptions (MacDonald & Greggans, 2008), adults may feel entitled to join the child participating in the research (Clacherty & Donald, 2007) and children may not be able to refuse to participate. Ideally, children should be involved in choosing where the research is to take place, in order to find a setting which is most suitable for them. However, tensions may arise with such an approach in regard to research costs and convenience.

In some contexts finding a location that allows confidentiality can be further complicated by societal concerns about protecting children from abusive adults, which leads to an unease with research being conducted by lone adults in settings that are not public (Barker & Smith, 2001; Matthews, Limb & Taylor, 1998). It may therefore be advisable to use locations that are visible to others but not within their hearing. However, tensions can arise if there are risks associated with research participation for children which are increased by being visible. The considerations have to be carefully weighed, in the unique context of each research study, to ensure that the risks are minimised and benefits maximised by whatever course of action is taken regarding privacy.

### ***How does the presence of others impact on children's privacy and information gathering during interviews?***

Despite the emphasis on privacy, difficulties with confidentiality in home settings can arise as some parents may insist on being present during research interviews, due to their curiosity or concern for the child (Fargas-Malet, McSherry, Larkin & Robinson, 2010). In some contexts, when interviews are being conducted, the gender of the interviewer may have a bearing on parents' decisions regarding privacy. For example, for a range of personal, social and cultural reasons, parents may feel more comfortable having their **adolescent** daughter interviewed alone by a female researcher, but not by a male. Parental presence can lead to a number of outcomes, both positive and negative, including spontaneous family discussion with more detailed accounts, shy children feeling supported (Powell et al., 2011), parents becoming involved by reinterpreting the questions for children (Hood et al., 1996), or the silencing of children (Valentine, 1999). The individual child's response to the parent's presence contributes to determining if this has a beneficial outcome for the child and with regard to the quality of the data collected.



An additional consideration is that some children may wish to have parents, siblings or friends present during the information gathering process. In such instances, it may be difficult to provide assurances of confidentiality and may also impact on how much information individual children wish to share. Respect for the child's wishes and autonomy would ideally provide guidance, however, this could be challenging and inappropriate in certain cultural contexts in which this is not the accepted custom. The reality is that researchers may not always be able to accommodate children's wishes if they are at odds with the parent's wishes, especially if the researcher needs to negotiate their position as a guest in the child and parent's home (Alderson & Morrow, 2011; Mayall, 2000; MacDonald & Greggans, 2008; Sime, 2008). The reality of the power dynamics in most situations is that when child and adult wishes conflict, children's wishes are usually subordinate to those of the adults.

When parents remain present for interviews, a range of covert and overt techniques can be used to minimise parental involvement (Bushin, 2007). These may include, limiting eye contact with the parent, specifically using the child's name when asking a question, raising subjects it is more likely only the child would know about, and reiterating the importance of ascertaining the child's opinions. These suggestions are subject to an awareness of the local context and, if necessary, discussion with community elders, to ensure that any minimisation techniques are culturally sensitive.

The researcher may need to adapt their expectations of data collection in response to parents who are reluctant for researchers to interview children privately or insist on being present. Respect for children's privacy regarding how much information they wish to share, which may be affected by who is present, should be privileged over the researcher's wish to elicit more information. A degree of reflexivity and flexibility is required on the researcher's part to ensure that they do not encroach on children's privacy in their desire to attain quality data. Some of the challenges that may be encountered in respecting children's privacy are highlighted in research with children with disability, in which traditionally parents or other adults have been expected to act as proxies representing children's voices and interests. In her case study, Berni Kelly discusses challenges to children's privacy in this context.

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### **Case study 18: Interviewing children with disability in the presence of a parent, by Berni Kelly (see Case Study section p.154).**

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#### ***How can confidentiality be respected in research with focus groups?***

Respecting individual privacy and confidentiality in the context of focus group consultations is an issue that needs careful reflection. This is particularly important in research within close-knit communities or on sensitive topics. Privacy issues in focus groups are further complicated by research which draws on internet chat rooms and blogs. There may be difficulties maintaining confidentiality in group settings (WHO, 2011) or when children wish to have friends or siblings present during interviews. How other children manage private information shared in the research forum requires agreement within

Respect for the child's wishes and autonomy would ideally provide guidance, however, this could be challenging and inappropriate in certain contexts.

Respecting individual privacy and confidentiality has added complexities in the context of focus group consultations.

the group from the outset and sensitive guidance on this issue by the researcher. There may be a need in some research studies for focused de-briefing of group interview participants with the aim of defusing any potential difficulties for the child once the research group has disbanded.

***What are the limits to confidentiality when there are safety concerns?***

A significant ethical challenge can arise in research involving children when researchers suspect child abuse or other unsafe or criminal activity, or have acquired information indicating this from child participants (intentionally or inadvertently shared on the child's part). This might include discovering that a child is being abused or neglected; is being harmed or threatening to harm her/himself or another person (Schenk & Williamson, 2005); or has a communicable or sexually transmitted disease requiring notification (Avard et al., 2011). The researcher has to decide whether to share the information and with whom, for example, parents, the police or care and protection agencies. This is a particularly contentious matter, and opinions and practice about breaching confidentiality to report suspected child abuse are divergent (Cashmore, 2006). In such instances, respect for the child's autonomy and right to confidentiality may directly conflict with the researcher's ethical responsibility to ensure that children are protected from harm. This issue may be further complicated if the researcher is a practitioner who has a dual role with the children involved in research, and the ethics of confidentiality directly conflict with professional standards.

The challenge involves the prioritising of ethical principles. The principle of respect for children's dignity and preservation of confidentiality underlies arguments against reporting issues such as suspected child abuse. Other arguments centre on the principle of beneficence (King & Churchill, 2000), on the basis that reporting will decrease the risk to the child, which can be perceived as a beneficial outcome (Knight et al., 2000).

There are numerous views about confidentiality and reporting concerns in research involving children. Some researchers recommend ensuring rather than guaranteeing confidentiality, and informing participants explicitly, prior to starting data collection, of the limits of confidentiality, the actions that will follow any safety concerns and which organizations will be involved (Duncan et al., 2009; Meade & Slesnick, 2002). A consequence of being explicit about the limits to confidentiality may be the loss of participants at the stage of recruitment, and attrition during the study, as well as impacting on the completeness and quality of the information obtained.

However, researchers' ethical commitment to respecting children is not diminished by applying limits to confidentiality and being explicit in relation to these allows for respectful conversations with children about the relevant issues. Researchers, ideally, should be able to talk with children before acting on their concerns and, where possible, plan the safest and most effective ways to take action, thus applying good practice in supporting children's participation which promotes the safety and protection of children (Feinstein & O'Kane, 2008). Ultimately though, it is the researcher's responsibility to ensure that the safety of children is prioritised. The case study by Lorraine Radford discusses ethical dilemmas related to protecting children and

**Ideally, researchers should be able to talk with children before acting on their concerns and plan the safest and most effective ways to take action.**

addressing confidentiality, in a UK study about children's experiences of violence, abuse and neglect. It describes a system that was put in place with alert, review and referral processes.

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**Case study 19: Child protection and confidentiality: Surveying children's experiences of violence, abuse and neglect, by Lorraine Radford (see Case Study section p.156).**

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The age of the child and the familial, as well as societal, context may have some bearing on the approach taken by the researcher in regard to child protection. The researcher response needs to take the evolving capacities of the child into account in relation to the perceived concern, potential reporting action, inclusion of the child in deciding this and the possible outcomes. For example, it seems unlikely in some situations that older children or youth would agree to participate in research if they thought that such participation would result in them being referred to the authorities of whom they (and perhaps the researcher) are mistrustful. In addition, researchers need to be aware of both law and customary law on when adulthood is reached, recognising that there are differences between countries in relation to these. This is particularly pertinent with regard to reporting safety concerns regarding children. In peer research it is important that training is given, parameters of confidentiality are clear and that support mechanisms are in place for young researchers. The case study by Clare Lushey and Emily Munro looks at challenges that arose in peer research, with regard to differing degrees of concern and opinions about confidentiality in relation to a specific incident.

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**Case study 20: Peer research and young people in and leaving out-of-home care, by Clare Lushey and Emily Munro (see Case Study section p.159).**

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Researchers need to be aware of requirements with regard to mandated reporting. The decision to report concerns or knowledge regarding harm or potential harm to children may be a legal one as well as an ethical one (Fisher, 1994). Legal requirements with regard to reporting suspected abuse or child maltreatment differ across international contexts (Williamson, Goodenough, Kent & Ashcroft, 2005). In some areas legal or professional requirements may mandate reporting of suspected child abuse (for example, by health professionals, teachers and psychologists), even if researchers as a professional group are not specifically mandated to report. However, these requirements are not consistent internationally, or even nationally in some cases.

Some ethics review committees and institutional review boards require mandated reporting of suspected child abuse, and this mandatory approach is recommended by some researchers to provide clear guidelines, prioritise child protection and ensure uniform research practice (Allen, 2009; Steinberg, Pynoos, Goenjian, Sossanabadi & Sherr, 1999). The lack of consistency across international contexts, within countries and across ethical review boards underscores the importance of researchers considering the issue of reporting prior

Researchers need to be aware of both legislative and customary law on when adulthood is reached in the context they are working in.

The lack of consistency across contexts underscores the importance of researchers developing reporting protocols prior to starting data collection.

The needs of the research must not subsume ethical responsibilities toward children who may be at risk.

to starting data collection and creating a plan or protocol to follow if required. Making a contingency plan before the research starts, for providing support or referral to appropriate services for children who reveal themselves to be at risk of harm, provides some relief from the dilemma.

The needs of the research must not subsume ethical responsibilities toward children who may be at risk. However, some researchers intentionally use methods to prevent disclosure, avoid reporting child abuse and assure confidentiality (Socolar, Runyan & Amaya-Jackson, 1995), such as limiting response options, warning participants not to tell, and masking the responses so that the data is anonymous, thus avoiding researcher knowledge of individual disclosure of concern. These methods avoid compromising confidentiality, but clearly the principles of beneficence and justice and the researcher's obligation to act in the best interests of the child are neglected. In addition, children who may have an expectation that disclosure of concern in a research context would lead to help and support, despite assurances of confidentiality, are disregarded.

### ***What if children (or parents) do not want to be anonymous in dissemination of research findings?***

Various strategies can be used by researchers in order to maintain anonymity, as discussed above. However, children sometimes want to have their real names used in publications and research reports in recognition of their participation. In some situations parents, supported by professionals, also may want to waive anonymity when they perceive that publication, which includes identifying information, will bring about sufficient benefits to warrant this. An example of this is apparent in the case study provided by Andrew Williams, which gives identifying information that is already in the public domain as a means of illustrating benefits of research involving a child with a degenerative condition who is unable to provide consent. [See Case study 2 in the Harms and Benefits subsection of the Case Studies in this compendium.]

However, waiving anonymity presents a challenge for researchers who take the approach that participants are best not identified, for example, in research that is sensitive in nature. One consideration is the extent to which it may be difficult for children to assess the potential risk and/or long-term implications in using their own name. They may not have the experience to know where the material will end up and how it may be distorted by the media (Laws & Mann, 2004). However, this has to be balanced against individual children's ability to make a sound judgement and the reality that children may be better placed to assess the risks to themselves in familiar contexts. Discussing the concerns with children is an important step in this decision-making process.

Anonymity is a means of avoiding harm, however, precautions against recognition of participants (such as removing identifiers) are not always necessary, and may even impede appropriate recognition. Researchers also need to be aware of the importance of ensuring that children's participation is recognised and valued in forms that are discernible and meaningful to the participants. In participatory research where children are actively involved as researchers they may want their names included to recognise and value their important contributions. In such contexts children can be

encouraged to identify any potential risks and advantages (now or in the future) of their names being included, so that informed decisions can be made.

The use of photographs in the dissemination of research raises issues around privacy and anonymity, both at the time of dissemination and also in the future, when the child may have a different opinion about the use of their image. It also raises issues related to power and representation of children (Phelan & Kinsella, 2013). Researchers may use ways to hide the identity of children involved in their research (or photographed by children involved in their research) in order to ensure they are not identified and maintain their anonymity. Strategies may include pixilation, blurring the face or image, or perhaps using only text in representation of the findings (Nutbrown, 2010). However, Nutbrown contends that this raises an ethical debate about children's voice — arguing that if consent or assent has been obtained from children to use their images might researchers be silencing children in attempts to protect them? The issue of anonymity in relation to children's authentic representation raises the tensions between protection and participation that are not easily resolved, particularly with the added dimension of speculating about future (unknown), as well as present, contexts.

### ***What are the privacy and confidentiality challenges related to technological developments?***

Privacy and confidentiality, when conducting research using technological media, such as computers or mobile phones, with children, is an important consideration. There is the potential risk that people known to the children may gain access, intentionally or inadvertently, to the information. Mobile phones and computers may be shared within households or organizations compromising the privacy of participants and their information.

The issues are further compounded in research that uses information and communication networks such as the internet, instant messaging and social media for data collection. The expectations research participants may hold of privacy online may be exaggerated, if not illusory (Lobe et al., 2007). Diverse modalities of online internet communication have different features and, consequently, different practicalities in regard to privacy and confidentiality. For example, some internet forums are intentionally public and therefore anyone can read messages that are posted without leaving a trace of their presence. However, people's presence in chat rooms is more apparent and real time communication makes it awkward to observe without interacting (Lobe, Livingstone, Olafsson & Simões, 2008).

The complexities of obtaining online informed consent, the ability of researchers and participants to assume anonymous or pseudonymous identities, and the potential for them to have multiple online identities, contribute to the ethical concerns in online research with children (Lobe et al., 2007). There is the risk that people not belonging to the group of selected child participants, may give false details and participate under false pretences, threatening the privacy and safety of the group (Alderson & Morrow, 2011).

Research using new technologies requires consultation with communities (including online communities) and children, prior to undertaking research, to reduce risks of breaking confidentiality

**Privacy and confidentiality when conducting research using technological media is an important consideration.**

**Research using new technologies requires consultation with communities (including online communities) and children, prior to undertaking research, to reduce risks to confidentiality.**

(WHO, 2011). In addition, the challenges around protecting images of children and data collected (for example, children's artwork or photographs) on the internet are an increasing concern.

## WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO PRIVACY AND CONFIDENTIALITY?

- Children have the right to privacy (Article 16).
- Children's best interests should be a primary consideration (Article 3).

## KEY QUESTIONS

### ***How will children's privacy and confidentiality be respected?***

- How will you ensure children and their families cannot be identified?
- How will privacy be attended to in the research setting?
- Do you plan to allow parents or persons in authority to be present when research is being conducted with children? Why? What impact may this have on children's involvement in the research or the information they may share?
- How will you respond if parents or others will not allow children to be interviewed on their own?
- What will the gender and number of interviewers be in relation to the children being interviewed? Why?

### ***How will you attend to concerns about children's safety that arise during the research?***

- How will you ensure children (and parents) understand the circumstances under which confidentiality should be breached?
- What actions will you take in response to a child's disclosure of harm or abuse?
- How will you ensure that children are informed in regard to these and their views taken into account?
- Who else will you need to inform about these actions?

### ***How will you ensure that research findings are disseminated safely?***

- How will you ensure that the identities of children, families and communities are not revealed?

***How will you ensure data is safely stored and destroyed?***

- What strategies do you have in place for the safe and secure storage of data?
- When and how will you ensure the secure destruction of all nominal information?

***Are there additional strategies that would enhance research staff's capacity to respect children's privacy and confidentiality?***

- To what extent would developing and implementing explicit protocols for research staff regarding privacy and confidentiality be helpful?
- Have research staff received training relevant to privacy and confidentiality in research involving children?





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# ETHICAL GUIDANCE: PAYMENT AND COMPENSATION

Research participants should be appropriately reimbursed for any expenses, compensated for effort, time or lost income, and acknowledged for their contribution. Payment should be avoided if it potentially pressures, coerces, bribes, persuades, controls, or causes economic or social disadvantage. The guiding principles of justice, benefit and respect underpin the need for research participants to be properly acknowledged, adequately recompensed and given fair returns for their involvement.

# PAYMENT AND COMPENSATION

Any financial dealings in the research context change relationships and impact on the power dynamics already at play.

## BEST PRACTICE REQUIRES THAT YOU:

- Ensure that any payment is not used to unduly bribe, coerce or pressure children or parents to participate in research, or influence the nature of their responses.
- Take social and cultural contexts into account and consult locally about payment and other forms of reciprocity in research.
- Work to ensure that payment does not directly raise unrealistic expectations or cause disappointment.

## KEY CONSIDERATIONS

Ethical issues arise in relation to payment to research participants, as any financial dealings change relationships (Laws & Mann, 2004) and impact on the power dynamics already at play. There are different reasons for researchers choosing to make payments to children, parents or community groups. Essentially, four types of payment have been identified in research: reimbursement, compensation, appreciation and incentive (Avard et al., 2011; Wendler, Rackoff, Emanuel & Grady, 2002). Each of these forms of payment has ramifications for ethical practice and issues that require consideration.

### ***Reimbursement payments***

Participation in research for children and families may have financial costs associated with it. Reimbursement payments compensate children and/or parents for their direct expenses related to participation (for example, transportation, meals, accommodation and childcare). This form of payment complies with the principle of justice, ensuring that research participants are treated fairly.

### ***Compensation payments***

In some contexts, the economic and/or social position of children and families may be adversely affected by participation in research. Compensation payments provide recompense to children and/or parents for their time, work and effort, and for any inconvenience caused by participation (for example, loss of income). The ethical principle of justice requires that children's contribution be recognised and the principle of non-maleficence underlies researchers' obligation to ensure potential harms from research, such as lost income, are assessed and minimised or eliminated.

### ***Appreciation payments***

Appreciation payments are bonuses or tokens given to children after their participation to acknowledge their contribution to the research and to thank them. This form of payment reflects reciprocity in providing direct benefits to the participant as a consequence of their participation in the research. Research participants are frequently unaware of appreciation payments until after they have consented to participate or after the data collection is completed.

### ***Incentive payments***

Incentive payments are designed to encourage the participation of children in research. These may be cash payments or alternatives such as vouchers to a popular shop or mobile phone credit. Incentives can be considered a means of persuasion, pointing out to potential participants that there is a financial benefit to be gained from involvement in the research. However, the use of such persuasion is contentious and some researchers consider that payments purporting to encourage participation contravene the Nuremberg standards that no persuasion of any kind should be put on participants (Alderson & Morrow, 2011). Incentives, and indeed any payments, may bribe, coerce or pressure children to participate in research, or parents to consent to children's participation. This compromises the ethical principle of respect, impacting on an individual's ability to act freely in making reasoned decisions about research participation and provide voluntary, informed consent. Another important dimension involves considering incentives in relation to the potential risk involved in the research. Some researchers argue that small incentives to improve recruitment levels are ethically acceptable where research involves low risk or negligible risk (that is, no more than discomfort), whereas offering incentives to secure the involvement of children and young people in risky research is exploitative, undermining public trust and support for research involving children and young people (Spriggs, 2010).

## **CHALLENGES YOU MIGHT MEET**

Challenges arise for researchers and organizations in determining the nature of payment in different social and cultural contexts. Issues around payment can impact on the distribution and expressions of power within families and communities, raise unrealistic expectations and further entrench the uneven power dynamics already existing in the researcher-researched relationship.

### ***When will participants be given information regarding payment?***

The timing of disclosing that payment will be made and of making the payment are issues that require consideration. Researchers may elect not to inform participants in advance that there will be an appreciation payment and give the payment or gift at the end of the data collection, in order to ensure that it is not used to induce children and families to take part and impact on their freely given consent. In addition, delaying disclosure of payment can help reduce the occurrence of children trying to please the researcher by telling them what they perceive would make them happy, rather than sharing their actual experiences and feelings. However, not informing participants about reimbursement and compensation payments in advance to the research taking place may negatively influence recruitment with participants choosing not to take part for financial reasons. This is

particularly relevant in contexts in which children and/or families are economically dependent on income earned by the child.

Careful consideration of the local social and cultural context is crucial in determining the nature of any payment or compensation for children's participation in research.

### ***How can payment of research participants be addressed in locally specific ways?***

Careful consideration of the local social and cultural context is crucial in determining the nature of any payment or compensation for children's participation in research. In some contexts, particularly those in which children are involved in the economic support of their family and/or live in poverty situations, participation in research takes children away from productive work that contributes to family well-being. Compensation is therefore necessary for the time in which children would have otherwise been earning money (Porter et al., 2010; Robson, Porter, Hampshire & Bourdillon, 2009; Vakaoti, 2009) and important to ensure that participants are not exploited or disadvantaged in any way through their participation. In these contexts payment or financial compensation may be the most appropriate form of recompense.

In some contexts, forms of compensation other than monetary may be more appropriate.

In some contexts, forms of compensation other than monetary may be more appropriate. These may include, for example, certificates of recognition, gifts or vouchers. While the benefits of participating directly in research do not equate with or replace payment, it is worth bearing in mind that participation in research can have a formative value and a range of benefits that may be non-monetary. These might include learning about the findings, education, having an enjoyable experience, children knowing that their views and opinions are listened to and it may lead to further action, direct political/economic betterment, and the opportunity to access resources. A range of issues related to ethical decision-making regarding the use of incentives are discussed in the case study by Kathryn Seymour. A participation strategy was developed for use in the study with 12-18 year olds, reflecting the multiple layers of consideration given to the issue.

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### **Case Study 21: Ethical considerations when using incentives in youth research, by Kathryn Seymour (see Case Study section p.162).**

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Addressing compensation in locally specific ways requires researchers to reflect on cultural contexts about the value of people's time, their willingness to undertake research activities, the reality of poverty and the capacity to miss work to talk to researchers (Morrow, 2009). A critical issue for researchers therefore is finding avenues through which to access and consult with local communities of interest. These can be relatively informal or through more formal means, such as the establishment of community consultation boards (Schenk & Williamson, 2005). Local consultation also allows for transparency and accountability of the research process in the wider community and may facilitate the interpretation and dissemination of results.

Another matter for consideration is the need for flexibility in research design. An implication of being guided by consideration of local context, reciprocity and fair returns is that remuneration can vary accordingly in research studies that span different localities.

It may not always be appropriate for research participants to have exactly the same payment type or amount, as equity may be more readily achieved through responding sensitively to the local context. For example, in the Young Lives study researchers addressed remuneration differently in different countries – some paid respondents, others gave small thank you gifts and others encouraged children to buy school materials (Morrow, 2009). These issues are discussed in greater depth in the case study by Virginia Morrow.

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**Case Study 22: Payment in different contexts: How can payment reflect local considerations? by Virginia Morrow (see Case Study section p.164).**

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***What are the additional considerations related to payment in situations of acute poverty?***

In contexts where children and families live in poverty, ethical concerns regarding payment (particularly incentives) are accentuated, as potential participants are especially vulnerable to coercion, exploitation and bribery (Schenk & Williamson, 2005). Participants may place themselves at greater than usual risk because they need the goods and services offered by the researcher (Rice & Broome, 2004). Even when inducements are not offered, potential research participants may have raised expectations of benefits or advantages to participation as a consequence of opportunities and interventions offered by other unrelated research projects and non-government organizations (Ahsan, 2009; Ebrahim, 2010; Nyambedha, 2008), that compromise their autonomy in freely consenting to participate.

Communities and potential participants need to be clearly informed if research, such as that which is being conducted under the auspices of academic institutions, will not be tied to implementation or policy change. Potential participants may also have raised expectations, in relation to academic and other organizations, that being involved in research will gain them access to these organizations. The subsequent disappointment may be accompanied by a sense of deception, and represent a harm experienced as a consequence of research participation. These issues require researchers to be critically aware of the expectations that may be raised, to present expected outcomes as clearly as possible and to clarify misperceptions around the benefits that may be forthcoming.

Research in poverty situations also brings to light the relationship between the researcher and research participants, and the issues of fidelity and reciprocity, in ethical decision-making about payment. Some researchers argue that when faced with poverty it is ethical and humane to help participants out with gifts, tokens or small amounts of cash (Abebe, 2009; Angucia, Zeelen & de Jong, 2010; Vakaoti, 2009). Other possibilities include putting people in touch with sources of support and advice. Some researchers advocate remuneration options that are sensitive to practical needs with low income or disadvantaged participants (Barron Ausbrooks, Barrett & Martinez-Cosio, 2009; Mosavel & Oakar, 2009; Sime, 2008). Researchers are required to balance reciprocity with the other ethical issues and implications of payment.

**In contexts of poverty, ethical concerns regarding payment (particularly incentives) are accentuated, as potential participants are especially vulnerable to coercion, exploitation and bribery.**

### **What are the implications within the community of payment to research participants?**

In contexts of extreme poverty there is a possibility of fuelling tension and resentment against children who participate in research and gain some material benefit (Clacherty & Donald, 2007; Hart & Tyrer, 2006). If resentment from others results in retribution or ostracising of the child participant or their family, the research has essentially caused harm.

Researchers may choose to give payment to groups such as schools or community groups for the benefit of the children involved in the research, their families and the community, rather than to individual children or families (Schenk & Williamson, 2005). This may reduce the potential for resentment and help ensure beneficence, but relies on local knowledge and/or discussion with a broad representation of community members and stakeholders to ensure fair distribution.

### **WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO PAYMENT AND COMPENSATION?**

- No child should be disadvantaged through their involvement in research (Article 2).
- Children should be protected from any kind of exploitation from research (Article 36).

### **KEY QUESTIONS**

#### ***How will children's participation be recognised and supported financially or otherwise?***

- How will you ensure that children's participation will not conflict with other responsibilities they have related to their family's economic well-being?
- Will children or parents need any financial compensation (for example, for lost earnings) or reimbursement for costs associated with participation in the research?
- Will there be any appreciation payments for children's participation in the research?
- What form will any payment take (for example, money, food, gifts, educational materials) and who will receive the payment – the child, parents, community?
- How and when will information on payment be disclosed? Will it be disclosed in the consent process, after children have agreed to participate, or at the end of the research?
- Have payments associated with children's participation been factored into the research costs?



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A girl smiles while attending a workshop for HIV/AIDS peer educators at a UNICEF-supported social-service centre established by the Ministry of Social Affairs in the southern port city of Aden, Yemen.





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# RESEARCHER SUPPORT

Researchers and others involved in research with children are ultimately responsible for ensuring that research is ethical. Critical engagement with ethical considerations in research requires knowledge and skills, which are sustained and enhanced by appropriate, ongoing support, training and opportunities for professional development. Ethics review boards also have a role to play in supporting researchers in ethical research practice.

# RESEARCHER SUPPORT

**It is the responsibility of all those engaged in research with children, and in particular researchers, to work out how ethical principles apply to their specific projects and to ensure that their research practice is ethical.**

**While mechanisms of governance and review cannot guarantee ethical practice, ethical guidelines and formalized ethical review processes can provide support for researchers and participants.**

It is the responsibility of all those engaged in research with children, and in particular researchers, to work out how ethical principles apply to their specific projects and to ensure that their research practice is ethical. Researcher experience alone cannot ensure ethical practice. Both novice and experienced researchers face difficult ethical issues (Duncan et al., 2009) and experience alone is insufficient to anticipate and plan for all relevant factors (MacDonald & Greggins, 2008). Each research project has specific and unique ethical and contextual considerations that require the researcher, and others involved in the research process, to reflect on, decide about and implement ethical principles in practice.

Consequently, it is essential that mechanisms of support and opportunities for ongoing development of critical research skills are in place for researchers, as well as access to resources to help guide and inform their work undertaking research with children. Support mechanisms may include formal and informal training and supervision arrangements, and other means of ensuring that researchers are supported in critically reflecting on their research practice, decision-making and ethical issues that may arise. While mechanisms of governance and review cannot guarantee ethical practice, ethical guidelines and formalized ethical review processes are important and can help support researchers and participants. However, there is some tension in researchers' experience of the role and/or functioning of ethics review boards (Powell et al., 2011).

## RESEARCHER SKILLS AND TRAINING

Respecting the dignity, rights and well-being of children in research requires that researchers understand, and are adequately skilled, in implementing the increasing evidence about what constitutes ethical research. While many of the skills used by researchers who undertake research with adults are important and transferable, these alone are not sufficient and additional ones are required for conducting research with children. The need for researchers to have specialised skills and training is identified as critically important throughout the ethics literature and by researchers themselves (Powell et al., 2011).

It is not only researchers who need to have specialised skills for research with children, but also other members of the research team - specifically research assistants and field workers in large scale research projects where the researcher only oversees the

activities of field workers. Researchers, interviewers and all members of the research team undertaking data collection need skills in communication and forming relationships with children, young people, parents, community members and stakeholders. Essential training includes developing abilities in establishing rapport with children, putting them at ease, understanding verbal and non-verbal cues, and responding to needs they might reveal during the research process (Schenk & Williamson, 2005; WHO, 2011).

Some guidance suggests that training programmes should establish professional boundaries for researchers (WHO, 2011). This requires an understanding of and engagement with the importance and meaning of boundaries in the specific local context, as this may vary. For example, boundaries may become blurred when community-based researchers are assisting with research in their own communities. Also, perceptions of boundaries may vary across international or cultural contexts. In some cultures the definition of professional boundaries implies a more distant approach, which may actually be culturally inappropriate and even offensive in other cultural contexts. In other contexts trust and closeness may be necessary prerequisites for sharing meaningful information and may even help toward balancing the uneven power relationship between researchers and participants. The quality of the data is dependent, to a degree, on the quality of the relationships formed. This further highlights the value of reflection on forming and sustaining relationships, with boundaries that are professional and appropriate to the context.

**The quality of the data is dependent, to a degree, on the quality of the relationships formed.**

Existing guidance also points to the importance of specialised training in certain areas. These include, for example, identifying and managing safety issues, including suspected child abuse and neglect (Gorin et al., 2008; Schenk & Williamson, 2005); supporting child-led research (Kellett, 2010); gathering information related to violence (WHO, 2001; Zimmerman & Watts 2003); sexual violence (WHO, 2007) and child labour (Edmonds, 2005); and collecting biological samples (CIOMS & WHO, 2002, 2008).

Major influences on the way research is done, as identified by researchers, include their own ethical principles, personal experiences and institutional requirements (Powell et al., 2011). Existing guidance suggests that training should provide all staff with opportunities to recognise and overcome their own prejudices (WHO, 2007, 2011), be aware of the limits of the researcher's role and what researchers can achieve (Laws & Mann, 2004) and establish professional boundaries and self-care for researchers (WHO, 2011). This emphasis on personal dispositions, principles, awareness and experience, highlights the central importance of providing opportunities for researchers to reflect critically on their practice, examine their assumptions, develop their understandings and review their ethical decision-making on a continuing basis. Hence, ongoing support, supervision, training and professional development are essential components of the research process.

In addition to training and support, supervision with a focus on ethical considerations can play a useful part in researcher professional development and ethical research practice. Ethical supervision provides researchers with an opportunity to reflect, discuss concerns, extend thinking, seek guidance and debrief, as well as providing a forum for accountability.

## RESEARCHER SAFETY

Ethical research with children is research that is ethical in regard to all aspects, including making certain that all people involved are safe from harm. In addition to ensuring the safety of children involved in research, researchers need to consider their own safety from harm, placing this above completion of the research tasks at all times (Laws & Mann, 2004). Research staff may face safety and security issues whilst engaged in fieldwork and may therefore require specific training and strategies to ensure safety, in accordance with the context in which the research is occurring. Researcher safety may require attending to security plans, back up communication systems, secure transportation and team strategies (WHO, 2007). The variation in safety-related issues across locations suggests the need for explicit safety protocols for researchers, which take the particular research context into account. Local consultation and knowledge is a necessary component in developing these protocols to ensure that local cultural, social and geographical factors are taken into consideration.

In addition to physical safety, it is important that researchers give thought to attending to their own distress, particularly if they are working in contexts where that is likely to arise. It is not always possible to predict what may cause distress in members of the research team, just as it is not possible to predict what may cause distress in children. However, as with all aspects of the research process, the key issue is to have an awareness of possible issues that may arise and prepare in advance to manage these. Supervision can usefully provide a forum for debriefing and attending to researchers' own distress arising from aspects or events within the research contexts.

## ETHICS REVIEW BOARDS

Research ethics committees (RECs) and institutional or ethical review boards (IRBs or ERBs) are a potentially very useful source of support to researchers.<sup>xix</sup> Most national legal regulations require research institutions to establish an independent ethical review board to thoroughly review all research plans (Schenk & Williamson, 2005) and researchers are generally required to apply for ethical approval from ethics review boards prior to starting research projects (Alderson & Morrow, 2011).

Ethics review boards are established within organizations to review the ethical acceptability of all research involving humans conducted within their jurisdiction or under their auspices. They are mandated to approve, reject, propose modifications to or terminate any proposed or ongoing research involving humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (TCPS) 2010).

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<sup>xix</sup> For ease of reading, from this point on the term 'ethics review boards' is used to encompass all ethical review mechanisms involving groups of people appointed for the purpose of reviewing the ethical acceptability of research involving humans conducted within their jurisdiction or under their auspices, such as ethics review boards, ethics review committees (ERCs), institutional review boards (IRBs) etc.

In an international context, the biomedical sector is most likely to have existing ethics review mechanisms. Ethics review boards ensure that ethical standards of conduct of research activities are met, and therefore participants are protected from harm. As such, they are a resource that could potentially help researchers in their ethical decision-making.

However, the usefulness of ethics review boards is a source of contention and debate, with a tension apparent between ensuring ethical scrutiny of research on the one hand, and avoiding an excessively onerous bureaucratic process on the other. This has been identified by researchers as an important ethical issue, with 'overly protective ethical review processes' being identified in an international survey as one of the issues most restricting researchers' capacity to include children's views in their research, and the issue of greatest ethical concern for researchers overall (Powell et al., 2011).

Some researchers are critical of the increasingly formal, bureaucratic regulation, seeing it as 'rule fetishism' that does not help develop understanding of ethical decision-making in specific contexts (Gallagher et al., 2010). Ethical review processes are experienced by some researchers as overly protective, preventing children's access to participate in research, and causing unnecessary and frustrating time delays (Powell & Smith, 2009). Particular issues of concern also include a lack of specialised child research knowledge in some ethics review boards' membership and lack of institutional memory in boards as membership changes. There is also a serious concern that researchers may pass on ethical responsibility to ethics review committees, who cannot guarantee that ethical research is supported and poor research is prevented (Alderson & Morrow, 2011).

However, ethics review boards play a critical role and "can help prevent poor research, safeguard research participants and be a protective barrier between potential participants and researchers" (Alderson & Morrow, 2011, p. 74). The increase in formal ethics mechanisms and subsequent scrutiny of research studies and researchers can result in better protection for children (Alderson & Morrow, 2004; Balen et al., 2006).

Contemporary research often involves collaborative partnerships among researchers from multiple institutions or countries, and may call upon a number of local populations and multiple ethics review boards. Consequently, this raises concerns as to how to manage the ethical review of research across these multiple contexts. The issues include managing the formal ethics review requirements of organizations and countries in which the research is taking place, as well as conforming to international guidelines. A serious and growing concern is the "double standards when minority world RECs/IRBs demand high standards but research in other countries may have little or no ethical scrutiny or accountability" (Alderson & Morrow, 2011, p. 80). This concern points to the need for establishment of review processes that take a range of national and international contexts into account. The Nuffield Council on Bioethics (2002) recommends that all countries should establish effective systems for ethical review, including establishing and maintaining ethics review boards that are independent of governments and sponsors of research. In addition, it recommends that research should be reviewed in both the country hosting the research and the country sponsoring the research.

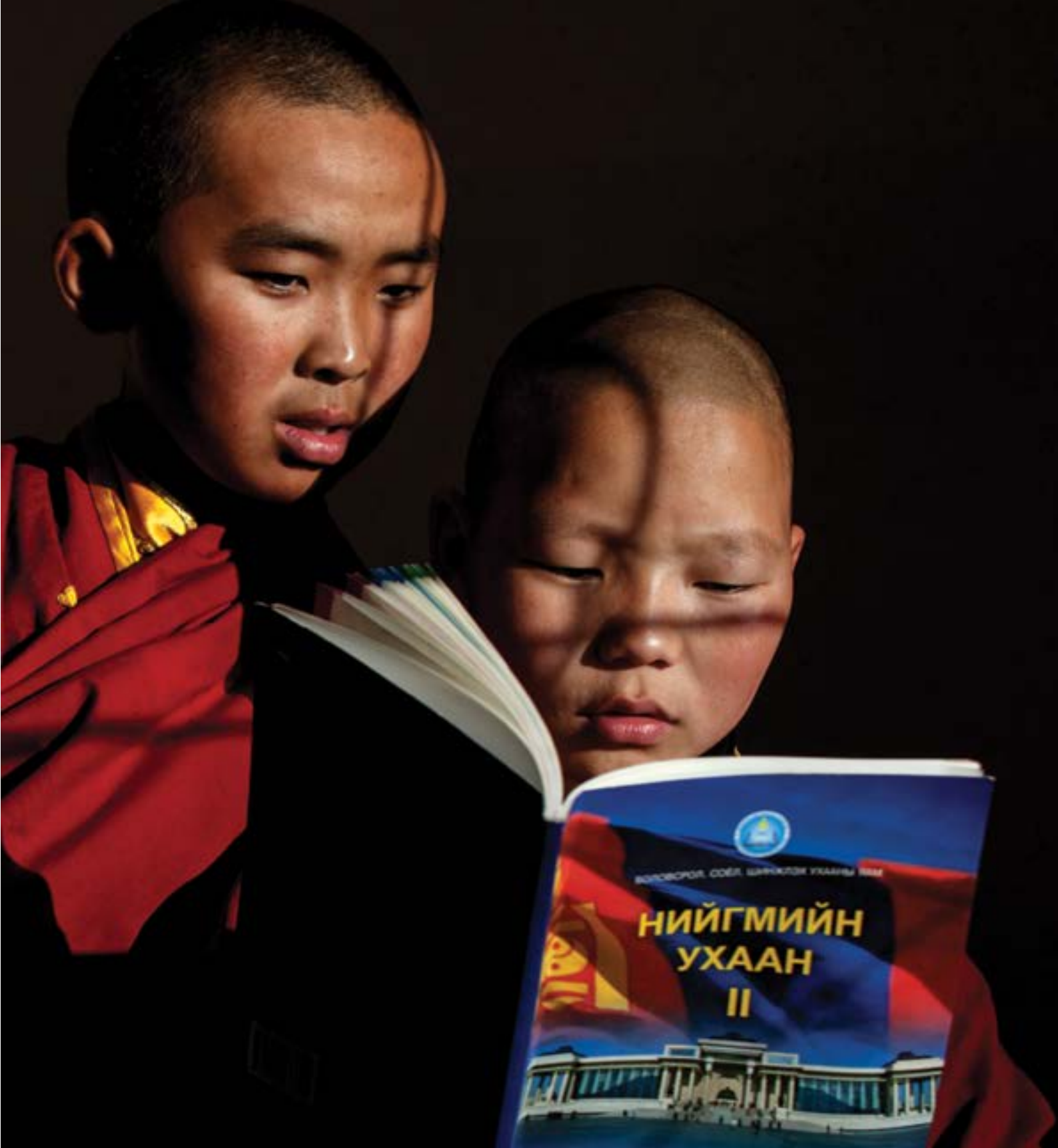
**The usefulness of ethics review boards is a source of contention and debate, with a tension apparent between ensuring ethical scrutiny of research on the one hand, and avoiding an excessively onerous bureaucratic process on the other.**

**Contemporary research often involves collaborative partnerships and may call upon a number of local populations and multiple ethics review boards.**

Recommendations and suggestions to improve the role and capacity of ethics review boards (drawn from Powell et al., 2012, pp. 48-49) include:

- Inclusion of children, young people and parents on ethics review boards and/or involved in screening research projects (Carter, 2009; Coyne, 2010a). However, Carter (2009) cautions care would be needed to ensure that children's roles were not tokenistic and that the heterogeneity of children was represented.
- Developing specialist research ethics review boards, specifically for consultation regarding research with children and young people (Powell & Smith, 2006; Stalker et al., 2004).
- Co-opting individuals who have expertise in the area of research with children onto ethics review boards (Coyne, 2010b).
- Ensuring ethics review boards members are required to update themselves regarding current understanding of children and their levels of competence (Campbell, 2008; Coyne, 2010b).
- Using independent agencies to review research proposals (Gilbertson & Barber, 2002).
- University ethics committees redesigning their systems of approval to ensure that: supervisors have an understanding of the risks involved and will monitor student researchers effectively; student researchers have adequate experience and/or training for working with children's issues; and children participating in research are fully informed (Campbell, 2008). These issues resonate with those argued to be fundamental to ethical requirements in a wider than university context: that children should always be required to give consent; information should always be provided to them; and researchers should have sufficient knowledge to reflexively consider children's responses as the research process unfolds (Powell & Smith, 2006).
- Engage an independent local community advisory group to monitor activities (Schenk & Williamson, 2005).
- Ethics review boards reviewing health research protocols involving children and adolescents should be multidisciplinary and independent, with at least one member having expertise in conducting paediatric research (Avard et al., 2011; CIOMS & WHO, 2002, 2008). If none of the members have such expertise, the Board should seek the advice of an ad hoc expert (Avard et al, 2011).

The implementation of such recommendations may better position ethics review boards to protect the children and families participating in research and provide valuable, on-going support for researchers.



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(Left-right) Munkhbat Tulga, 13, and Baljinnyam Bat-Ulziibayar, 13, read from a social studies textbook in the Sain Nomun monastery in Nalaikh 'Düüreg' (district), near Ulaanbaatar, the capital of Mongolia.





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## GETTING STARTED

Getting Started is designed to prompt critical reflection by researchers, members of the research team, organizations and other stakeholders as they plan and undertake research in their local contexts. The intent is to generate shared, useful, practice-based insights throughout each of the phases of the research process. Getting Started is not merely a checklist of do's and don't's and should not be considered in isolation from other important contextual information found elsewhere in the ERIC compendium. The most important overarching question in Getting Started is: How does the proposed research respect the dignity of children?

# QUESTIONS TO GUIDE ETHICAL RESEARCH INVOLVING CHILDREN

Researchers are invited to use these questions in practical ways to support the design and implementation of ethical research practices. The questions reflect a range of ethical decisions to be made as challenges arise in matters concerning harms and benefits, informed consent, privacy and confidentiality, payment and compensation, and other related issues discussed in the Guidance section of the ERIC compendium. These questions also direct attention to the ethical principles of justice, beneficence and non-maleficence, and respect.

## 1. PLANNING AND PREPARATION

### ***Does this research need to be done?***

- Is the purpose of the research clearly defined?
- Will the research contribute new knowledge?
- What new knowledge will children contribute?
- How have you ensured that the information being sought is not available elsewhere?
- Is children's participation in the research necessary or can the information be obtained in other ways?
- What steps have you taken to maximise protection of participating children and their communities from being over and/or under researched?
- Who are the likely users of your research and in what ways have you taken into account the possibility that your research findings could be misused?
- Does the research enhance children's participation and other rights (under the UNCRC)?

## The Children

### **1.1 Is this research important for children?**

- How will children benefit from this research?
- What would be the likely benefits for the individual child participating in the research?

- What form will children's involvement in the research take?
- Can children be involved in the planning of the proposed research? If so, what strategies will you use to facilitate this?

### **1.2 How will this research be inclusive of children?**

- Have you established clear inclusion criteria?
- What steps can be taken to include marginalised/hard to reach children in research?
- Are any children to be excluded?
- If any children will not be included, on what basis will they be excluded and why? (For example, on the basis of their age, gender, sexuality, culture, ethnicity, disability, language, and/or family structure, mental health and well-being status? And/or for non-child specific reasons such as scope of the study, methodological choices, or financial, geographical or other constraints?)

### **1.3 How will children's safety be ensured during the research process?**

- Are there any identifiable risks for children?
- What plans can be put in place to reduce risk?
- Are there children whose particular circumstances place them at high risk? If yes, who are they and why?
- What arrangements do you need to make to support children who become distressed or who disclose sensitive information?
- What actions will you need to take to respond appropriately if a child discloses harm or abuse?
- Who will you need to inform about these actions?
- How will you find out what community and/or professional resources and services are available to children if needed?
- Do you need to develop and/or implement safety protocols or policies in your project to protect children? If so, why and what protocols or policies are these?
- What possible stigma may attach to children if they participate in the research?

### **1.4 What information do children need to consent to being involved?**

- What information do children need to enable them to consider giving their consent? (For example, in relation to participation, methods of data collection, dissemination etc.)
- How will you find out the information children need?
- How will you tell children about the study, ensuring that the information is age and context specific?

- Will you provide written information for children? If so, why?
- If you do not provide written information, how will you convey the information? Why have you chosen this method of doing so?
- Is there a designated person that the child (and/or parents) can go to if she/he has any questions or concerns (now and in the future)?
- What further information will children need (in long-term projects) as the study progresses to enable them to consider their continued consent, and at what stages?
- What procedures have been put in place to prevent children being coerced to participate?
- How will you communicate the decision to include or exclude children to them?

## The Researcher(s)

### 1.5 Have you considered your role in the research?

- What are your own values, assumptions and beliefs about: Children? Childhood? Their place in research? The context in which the children live?
- How will these shape the decisions you make about the research process?
- How do your understandings of culture (generally and in relation to the local cultural context) impact on the decisions you make in planning and preparing to do the research?
- What do you imagine might change as a result of involving children in the research?
- What beneficial outcomes will there be for children (both individual child participants and children as a social group) as a result of your research?

### 1.6 How well prepared are you, the researcher, to meet and conduct research involving children?

- What do you know about the children you wish to involve?
- How will you find out what you need to know about children?
- Do you have the necessary skills (technical and interpersonal) to involve the children in research (including, for example, skills in facilitating respectful conversations and knowledge related to children's ages and evolving capacities)?
- Do you have support and supervisory relationships in place (for example, with experienced researchers, relevant local groups, local child protection experts, local experts in the field of research)?
- Are you aware of the local legal definitions and regulations relevant to your research, for example, the definition of adult or

emancipated minor, the legal age for employment, requirements regarding child abuse reporting?

- Have you considered, and sought appropriate advice, as to how you will respond if you become aware that children are breaking the law?
- Have you considered whether (and how) children will be informed of test results related to their health status which may result from their participation in the research?
- How will you ensure that your research team, (both local and international as appropriate) share your ethical concerns and approach?
- What means (or methods) will you use to help address the power difference that exists between you and children, and between you and other family and community members?

### **1.7 Who else do you need to consult to involve children in the study?**

- Which adults, young people and children, if any, do you need to meet in the family or local community in order to understand the needs and rights of the children involved?
- Whose consent do you need for children to be involved?
- Does the age of the participating child impact on the person or agency from whom you will seek consent?

### **1.8 Have you considered the role of parents (or carers) in the study?**

- What are the responsibilities of parents with regard to the research?
- What information do parents need to have to be able to make informed decisions and to support their children in research participation?
- Have the expected benefits of children's participation been clearly explained to the parents?

### **1.9 What community and stakeholder concerns exist about this research?**

- Have you consulted all related community and stakeholder groups regarding the involvement/exclusion of children and the nature of the research?
- Are you able to incorporate any community and stakeholder feedback into your research and/or respond to concerns?
- How have you ensured that the community groups and stakeholders understand the research questions and process?
- How have you ensured that there are not unrealistically-raised expectations of the outcomes of the research?

### **1.10 How will children's involvement be resourced?**

- What resources (funding, time, staff, equipment etc.) are necessary to undertake the research and are these readily available? If not, is there a plan for how these will be obtained/managed?
- How much time needs to be allocated for obtaining necessary resources in order to undertake the research project ethically?
- What costs are incurred with involving children? (For example, transport, accommodation, food, interpreters, space, materials, communication with children, rewards/payments, staff time and preparation etc.)
- Have the payments associated with children's involvement been factored into the research budget? How will you ensure that the source of funding is consistent with the promotion of children's dignity, rights and well-being?

### **1.11 Ethics Approval**

- Does this study require ethics approval? If so, from whom and who determines this?
- How have you engaged with the Ethics Committee / Institutional Research Board?
- After gaining formal ethics approval, how will you ensure that ethical standards are adhered to throughout the research process, by you and your research team?

### **1.12 Are there any risks for you in undertaking this research?**

- What risks, if any, are there for you in undertaking the research?
- What will you do to manage these risks?
- What supports are available to you?

## **2. RESEARCH DESIGN AND METHODS**

### **The Children**

#### **2.1 Will children be involved in the design of the research?**

- What opportunities are there for children to provide input or feedback regarding the research design?
- What strategies will you employ to facilitate this?
- How will you incorporate feedback from children about the study design?

#### **2.2 Is the research methodology including data collection inclusive of all children?**

- How will you ensure your research design does not discriminate against particular children?

- How will you ensure that all children, where relevant to do so, have equal opportunity to participate irrespective of their age, gender, ethnicity, disability, literacy level or any other specific characteristics/circumstances?
- How will research methods help identify and gain appropriate access to children?
- How have you ensured that secondary data sources have been ethically collected and analysed?

### **2.3 Are the research methods appropriate for children?**

- Are the key questions easily understood by the children who will be involved?
- Are the questions (particularly in surveys) appropriate for the child's characteristics, including age, and surrounding context?
- How will the research methods facilitate children's engagement with the research?
- Are the methods responsive to the specific needs of children (i.e., adaptable methods for particular situations/needs/ages of children)?

## **The Researcher(s)**

### **2.4 Do all staff involved have the requisite skills and expertise to undertake the research?**

- Is any additional training or up-skilling required for this particular research study?
- Are all staff mindful of cultural considerations?
- Are all staff respectful of those involved in the research study?
- Are specific policies or protocols required to assist staff (for example, policies relating to different aspects of the research process, child protection, confidentiality, data storage etc.)? If so, what policies or protocols, and who determines they are necessary?
- Are there any design and/or data collection methodology-specific ethical considerations to be aware of? If so, what strategies will you adopt to deal with them?

## **3. DATA COLLECTION**

### **The Children**

#### **3.1 How will children's participation be supported?**

- Will you be able to include children at a time of the day that is suitable for them?

- How much time do you require from children? (Is this reasonable?)
- How will you ensure that children's participation will not conflict with their other responsibilities and commitments (e.g., school work, employment/work, leisure time, religious and cultural festivals etc.?)

### **3.2 How will children's involvement be recognised and supported financially?**

- How will you ensure that children's participation will not conflict with their other responsibilities they have related to their family's economic well-being?
- Will children need financial compensation for their participation (for example, for lost earnings)?
- Will children or parents need any financial reimbursement of costs associated with participation in the research?
- Will there be any appreciation payments for children's participation in the research?
- What form will any payment take (for example, money, food, a gift, educational materials) and who will receive it – the child, parents, community?
- Have you taken the local context into account when deciding about payment?
- How and when will information on payment be disclosed? Will it be disclosed in the consent process, after children have agreed to participate, or at the end of the research?

### **3.3 How will children's privacy and confidentiality be respected?**

- How will you ensure children and their families can and cannot be identified, as needed?
- How will privacy be attended to in the research setting?
- Do you plan to allow parents or persons in authority to be present when research is being conducted with children? Why? What impact may this have on children's involvement in the research or the information they may share?
- How will you respond if parents or others will not allow children to be interviewed on their own?
- How will you respond if the child requests that others be present?
- What will the gender and number of interviewers be in relation to the children being interviewed? Why?
- How will you ensure children (and parents) understand the circumstances under which confidentiality should be breached?
- Are there additional strategies that would enhance research staff's capacity to respect children's privacy and confidentiality?



(For example, would developing and implementing explicit protocols for research staff regarding privacy and confidentiality be helpful? Have research staff received training relevant to privacy and confidentiality in research involving children?)

- How will you protect confidentiality if your research includes situations in which you are required to share certain research results with service or clinical teams (for example, to provide services to those with infectious diseases) or government agencies?

### **3.4 How will concerns about children's safety that arise during the research be attended to?**

- What actions will you take in response to a child's disclosure of harm or abuse?
- Who will you need to inform about these actions?
- What are the legal requirements for reporting child abuse in the area the research is taking place?

### **3.5 Do children require extra support to contribute?**

- How will you identify the special needs of individual children?
- How will you respond to these needs?

## **The Researcher(s)**

### **3.6 How will you assess the competence of children to consent?**

- How will you ensure that children understand what consent is?
- How will you support children to understand and weigh up any risks?
- How will you ensure that children are able to withdraw without negative consequences?
- How will you ensure that children understand that they are able to withdraw consent at any time without penalty?
- How will you make provision for gaining children's informed consent or allowing their dissent at different stages over long-term projects?

### **3.7 How will you respond to children if they become distressed or upset?**

- Do you have the experience and/or skills to respond to children's distress?
- What arrangements do you need to make to support children who become distressed?
- Have you sought local advice regarding existing psychosocial supports?

- Have you considered instigating a post-interview check-in by someone who is a known, trusted support, familiar with the child's usual behaviour, and can read the signs and find additional help if needed?
- What supervision or support do you need to have in place for research team members?

### **3.8 How will you ensure your own emotional and physical safety?**

- Have you considered the need for debriefing at the conclusion of research procedures? If needed, how will these be established?
- Are colleagues aware of your location, travel plans and expected time of return during fieldwork?
- Are you able to contact your colleagues/supervisor or emergency services should an incident arise where you need help?
- Have you considered the possible ways your safety might be compromised and made contingency plans if necessary?

## **4. ANALYSIS, WRITING AND DISSEMINATION**

### **The Children**

#### **4.1 Are children to be involved in the analysis of data?**

- If children will be involved in data analysis, what support will they require?
- How will you ensure the privacy and confidentiality of participants is respected by children involved in the analysis of the research?

#### **4.2 How will the research findings be disseminated to children, other relevant stakeholders and wider audiences?**

- How will children hear about the findings of the study?
- How will you ensure children involved in the study can access, understand and, where appropriate, act on the findings?
- How will you ensure that feedback on the research findings from children and their communities is incorporated in any follow-up actions?
- How will you ensure children's contributions, and their value in the research, receive due recognition?

#### **4.3 How will you ensure that research findings are disseminated safely?**

- How will you ensure that the identities of children, families and communities are not revealed?
- How will you respond if children want to be identified?

- If children have been researchers will their names be included in the published materials, in recognition of their contribution?
- How will the participants be assured of the safe-keeping of confidential information they shared?
- How will you ensure that reporting and dissemination is appropriately managed, particularly in relation to language issues, as well as immediacy and ease of accessibility to children and communities?

## The Researcher(s)

### 4.4 Will the research make a difference to children?

- What outcomes do you hope for?
- What are the considerations to ensure rigorous, transparent analysis of data?
- What are the considerations to prevent the misuse of findings?
- What obligation, if any, do you have to promote the consideration and use of research findings in programming, service delivery, staff practices and policy-making? How will you go about doing this?
- What are the key elements of the plan for giving children, community members and stakeholders access to the findings of the research?

### 4.5 How will you ensure data is returned or safely stored and destroyed?

- Will data be returned to children? If so, how will this be done?
- Have you considered the use of information collected that was additional to that specified in the initial consent process? How will you gain consent to use this?
- How will you ensure that the data is returned with respect for maintaining confidentiality?
- What strategies do you have in place for the safe and secure storage of data?
- When and how will you ensure the secure destruction of all nominal information and data when it no longer needs to be kept?



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# CASE STUDIES

A key purpose of ERIC is to share stories, experiences and learning about ethical issues and concerns that shape research involving children and young people. Case studies have been contributed by researchers, using their own words, to assist others to reflect critically on some of the more difficult and contested ethical issues they may encounter. These case studies which are from diverse international contexts and different research paradigms are used to highlight the processes that can be engaged in developing ethical thinking and improving ethical practice in research with children. Researchers are invited to consider these case studies in light of their own experience and context.

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## **Case study 1: Implementing international research ethics in the complex realities of local contexts: Poverty, the cultural value of hospitality, and researchers trying to do no harm in Pakistan**

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### ***Background context:***

In many cultures around the world, hospitality is a strong value. This is the case in Pakistan. The ethic of hospitality means that guests are treated with great respect and honour, and hosts will go out of their way to give their time and help to visitors. Guests are given tea, snacks, and sometimes even a full meal, to honour their visit. The cultural expectation of the guest is to accept this hospitality graciously, often after an initial cursory refusal.

Through my work with different organizations in Pakistan, I have had the opportunity to visit homes, schools and communities in different parts of the country with other research team members. When our research teams visit homes and schools in Pakistan, we are welcomed with this strong sense of hospitality. Families and school representatives prepare or make arrangements for refreshments for research team members who visit them.

### ***The ethical challenge:***

This value of hospitality is strong in Pakistani communities – even from, and perhaps especially from, families and schools that are struggling financially. Arrangements for refreshments can be a financial strain on families and schools that are already struggling to make ends meet. At schools, the arrangements often involve pulling female teachers and female students out of classroom activities to prepare and serve refreshments to visitors.

However, to refuse families' and communities' hospitality – even if it is done in a gracious and respectful way – risks being perceived negatively. The refusal may be perceived at best as cursory (cultural etiquette where you first say no but then accept), and at worst as disrespectful and even arrogant. It could negatively affect the relationship with communities, limiting the willingness and openness of potential research participants to share their time and perspectives in the research process. Also, the offering and accepting of tea and refreshments provides a culturally familiar space and time in which informal conversation and interaction can happen, easing some of the formality around the research process for both the prospective research participants and the research team.

Our research teams struggled with this. We have felt that the ethic of respecting cultural values and norms here was at odds with the research ethic of 'do no harm'.

We had the following choices. We could accept families' and schools' hospitality graciously, acknowledging the strain it placed on them. We also considered accepting the hospitality, but offering compensation for their inconvenience (e.g., giving money to cover the costs of the tea or refreshments) – but were told by community members that this could be viewed as insulting. Alternately, we could refuse families' and schools' hospitality altogether, risking being perceived as ungracious and disrespectful.

***Choices made:***

We decided that we would try to graciously refuse food and refreshments, citing “organizational policy” if needed so that research team members themselves would not be perceived personally as disrespectful of communities' hospitality.

This was easier said than done. Despite our gentle insistence that we could not accept food and refreshments, families and school representatives would often arrange them anyway and place them in front of us. Perhaps our refusal was considered cursory, part of the cultural etiquette. At that point, when the cost and energy had already been spent in providing the refreshments, it would be considered very rude for us to refuse. Sometimes we would just accept one biscuit and leave the rest untouched – in the hopes that others, including children, might eat them later.

This issue is something with which other researchers and I continue to struggle. Our response to this issue continues to evolve as we understand and negotiate cultural expectations and relationships. We try to state right at the beginning that we cannot accept any tea or refreshments. Sometimes this works, but more often than not we are offered refreshments anyway. Either way, we make sure to give a gift of thanks at the end of the visit. We do not frame it as compensation but rather as a token of thanks. We try to ensure that the gift is something that the research participants would appreciate, and that in financial value it is equivalent to, if not more than, the financial expenses they would have incurred. For example, at a school, we may give a small bag of school supplies such as pencils, erasers, and crayons which can be used by the children and teachers.

***Reflexive questions/considerations:***

It can be difficult to reconcile research ethics which are considered universal with the complex realities of the local contexts in which research is carried out. How do we manage it when cultural values and norms are at odds with a research ethic?

The case study here is an example of how research ethics can be complex in cultures which strongly value hospitality. Hospitality not only places a strain on the hosting families and communities, but also often makes it difficult for families and communities to refuse consent when guests have entered their home or community. If welcoming and helping a guest is culturally expected, even required, then how can you know if consent is truly voluntary? This applies even more strongly in the case of children. Children are raised with these same values, to welcome and help guests, and in addition, to respect their elders. In this context, can a child truly refuse to participate in an interview or other research activity? And if they cannot refuse, then is their consent or assent really voluntary? How can we know?

How do you integrate research ethics and the research process with cultural expectations and norms around interactions and relationships?

Is this something that could be discussed openly and honestly at a meeting with community representatives and elders? Is there a local ethics review

board, or could one be established, to discuss and advise on such issues in light of local realities and cultural values and norms?

**Contributed by:** Sadaf Shallwani, Department of Applied Psychology & Human Development, Ontario Institute for Studies in Education, University of Toronto.

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## **Case study 2: Facilitating future benefit when a participant has a degenerative illness and cannot give consent.**

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### ***Background context:***

Very often a child with a severe fixed, or an evolving, neurodegenerative condition cannot give meaningful consent to research. The child's age and the profundity of their evolving neurological condition make consent impossible. Neurodegenerative conditions are extremely rare, are still very poorly understood and require tertiary/quaternary centre management for appropriate diagnosis and subsequent management. Such management is often highly complex and is at the very frontiers of understanding.

Health care professionals involved in managing such children are faced with accepting the status quo or endeavouring to effect a change that will benefit other such cases in the future through increasing knowledge of the condition by conducting research.

### ***The ethical challenge:***

There is a fundamental necessity to develop a knowledge base about the causes of and the evolving clinical pathology of degenerative conditions in order to assist future case management.

The ethical challenge is whether:

- a) Such a journey should be undertaken at all, as the medical management is challenging in itself without this additional role.
- b) Tempering understandable expectations against realism, that such discoveries generally occur unexpectedly, but usually after a great deal of time and background effort has been put in place.
- c) Any answers generally will have a very limited role, if any, for that particular child.
- d) Whether to proceed with the research when consent from the child has not been, and is unable to be, obtained.

### ***Choices made:***

- Limit the investigations to clinical and research necessity and where there is a realistic chance of a result based on previous empirical literature or strong clinical evidence, rather than pure exploration. That is, the research should have a robust scientific and/or clinical rationale.
- Maintain meticulous medical records over many years including medical imaging and photography.



- Take sufficient DNA, after appropriate signed consent, and store it for future, presently unknown, diagnostic tests. Consider also skin and muscle biopsies to allow cell cultures.
- Obtain full consent from the child's parents or guardians for discussion of cases and presentation at relevant regional, national and international meetings.
- Even when consent is impossible, explain to the child, using verbal, pictorial (i.e., drawings, photographs or videos), dramatic or other appropriate methods about all aspects of his/her care including investigations and storage of DNA or other material for potential future testing. Do this in the parents' presence.
- During their lifetime and afterwards, keep these children in your own and other clinicians' memories, so that their contribution to research is acknowledged and their humanity emphasised. For example (using real life examples in which the decision was made by parents to waive anonymity), if parents give consent, the children can be used on a national television broadcast,<sup>xx</sup> photographs of the child could be displayed in medical offices or children's wards; a prize, scholarship or charity could be named after them,<sup>xxi</sup> parents may be included as co-authors on conference abstracts and individual children named.<sup>xxii</sup>

#### ***Reflexive questions/considerations:***

- Are you going to just do your job or, as well, put in extra time, over years, to improve knowledge and provide future benefit?
- Ask yourself what is motivating you. Are you doing this to benefit the child and his/her parents, future patients and their families, or yourself?
- How are you going to balance the need to find an answer against the possibility of unrealistic family expectations of the timeframe for delivery and what such an answer will realistically mean, when it eventually arrives?
- When the child's condition makes it unlikely that they can provide consent, how will you meet the requirements for them and their parents to be informed?
- The child's interests must always be first and foremost- and never the family's or your own.

**Contributed by:** Dr Andrew N. Williams, Virtual Academic Unit, CDC, Northampton General Hospital, Northampton, NN1 1BD, United Kingdom.

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<sup>xx</sup> [http://www.youtube.com/watch?v=y\\_w\\_lD7UhQ](http://www.youtube.com/watch?v=y_w_lD7UhQ) Children in Need Appeal 2012, introduced by Dame Helen Mirren accessed December 27th 2012.

<sup>xxi</sup> <http://www.thomassfund.org.uk/> accessed September 10th 2012 Thomas' Fund in Northamptonshire, United Kingdom. This provides in-patient music therapy on paediatric and neonatal wards in Northamptonshire as well as at home for children and young people with life-limiting illnesses or a disability which, for medical reason, means they are too ill to attend school for extended periods.

<sup>xxii</sup> Alzoubidi R., Price S., Smith L., Baas F., & Williams A.N. (2010). A New Subtype of Pontocerebellar Hypoplasia. *Dev Med Child Neurol.*, Volume 52, Issue s1, p. 31.

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### **Case study 3: The work with interpreters in a cultural-sensitive environment**

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#### ***Background context:***

Important and unique challenges arise when conducting research in a cultural environment more or less unknown to the researcher who follows a Western cultural tradition. Even though researchers arrive well-prepared at the research site in the different culture, they will face many expected and unexpected obstacles which they have to overcome. One of the most persistent problems constitutes the lack of knowing the language. In a study which was implemented four years after the 2004 Tsunami at the worst hit part of Southern India the researcher learnt about the confronted multi-layered challenges. One of the study's work-packages focused on the identification of subjective well-being indicators from a caregiver's and child's perspective in the given sub-culture. It aimed to develop a culturally-sensitive instrument in order to gather data on children's resources as a complement to the data collection concerning the children's long-term effects of trauma.

#### ***The ethical challenge:***

The region where the study took place was a very remote district of Southern India. Mostly fishing families who were affected by the Tsunami lived there. Study participants were children who lived with their biological parents as well as children who lost their parents due to the Tsunami and lived in alternative out-of-home care. The children hardly spoke English and their only experience with people of a Western cultural background traced back to the Tsunami relief actions. During her stay in India the researcher learnt more and more about what the application of the concept of vertical collectivism in real life means and specifically for children: full approval of authorities and hierarchies; non-questioned respect towards adults; obedience; duty; and reliability. In order to gain insight into children's subjective well-being, a harmonious atmosphere with very few behavioural restrictions was created. This atmosphere should stimulate children to answer frankly to the focus group questions. They were stimulated to behave in a way that was not in accordance with their usual way of behaving towards adults. This was one side of the coin. The other side concerned adult interpreters who exactly would have expected the behaviour of children as described above. The tightrope walk was to find adequate interpreters who, on the one side, served as culture brokers and, on the other side, were able to integrate a rather different way of approaching children without losing sight of their cultural values.

#### ***Choices made:***

From the local university's Department of Social Work, two students (male and female) for interpreting in same-sex groups were recruited. The students were recruited according to the following criteria: bi-lingual (Tamil and English) – especially their spoken Tamil was of importance as in the Tamil language there is a huge gap between spoken and written Tamil; openness to follow another approach in dealing with children without giving up their own cultural values; consequence and perseverance in the requested manner of interpreting. The choice was consciously made not to use professional interpreters as it was feared that their professional attitude would have silenced the children. The students were trained for two days on the aim of the project, and were provided with relevant background information on different theoretical concepts (e.g., trauma, well-being).

A code of conduct was written concerning how to deal with the children (e.g., no punishment; self-determined working in small groups) and why the researcher would like that they deal in that specific way with the children. The reasoning for this code was also interactively discussed with the interpreters. In addition, they were trained in their actual task: interpreting. They were requested (1) to interpret in short units of meaning, (2) to avoid self-initiated interposed questions, (3) to avoid side-conversations with the children during the focus group sessions, (4) to participate in games and other relaxation exercises, and (5) confidentiality. Before each session we discussed the implementation plan and prepared mentally for the group. After each session a feedback round with the interpreters was undertaken. As a result we were able to create a group atmosphere characterized by mutual friendliness and trust, so that children frankly shared their thoughts and feelings.

***Reflexive questions/considerations:***

- What is the cultural custom to deal or work with children?
- Does the study implementation require the creation of a trustful atmosphere with the help of the interpreters?
- How to work with interpreters when their task is on the one hand “pure” interpreting, but the group setting requests their involvement?
- Which strategies are developed preventively in case of potential distress through the research intervention? How are interpreters prepared for this possible harm?

**Contributed by:** Dr. Silvia Exenberger, Department of Psychology, University of Innsbruck/Austria. SOS Children’s Villages International, Research & Development Department, Innsbruck/Austria.

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**Case study 4: The impact of shared information in focus groups on children’s relationships**

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***Background context:***

The Flemish Commission of Children’s Rights (Kinderrechtencommissariaat) commissioned Research Centre Childhood & Society (Kind & Samenleving) to construct a questionnaire to determine the incidence and prevalence of child abuse and negligence in Flanders. The questionnaire focused on children between 10 and 18 years old. To do so, international questionnaires were compared, analysed and adapted to the Flemish context. Based on interviews with experts as well as children and young people, the questionnaire was adapted further.

Through extensive conversations with children and young people about care, authority and punishment, a broader framework of care and authority relationships was constructed. We organized eight focus groups with in total 46 boys and girls aged between 10 and 18 years. Each focus group consisted of six to eight children and assembled three times for a discussion. During the first discussion they talked about care and neglect, in the second about authority and punishment, in the third about their attitudes towards abuse and neglect.

### ***The ethical challenge:***

Focus group discussions are very apt for research with children. The inequality between children and the adult researcher is far less outspoken than in an individual interview with an adult stranger. The overall atmosphere is less formal; less like research and more like a natural conversation.

However, as in every focus group discussion or interview, difficult experiences can unexpectedly be expressed and they can make a deep impression on the participating children. In discussions on care, authority, punishment, abuse and neglect this is even more likely. Although our questions were framed in such a way that we did not focus on personal experiences, but on their general views on children and care/authority, the participants could have been confronted (directly or indirectly) with abuse and neglect. During the focus group discussions, these experiences can come to the surface. What's more, the focus group's discussions can operate as an opener of a Pandora's box, revealing hidden thoughts and emotions.

In addition to the sensitivity of the research theme for the individual participants, these discussions could also influence the interpersonal relationships of the participants. During the discussions, some children spoke about harsh punishments. Other children reacted with astonishment: "That is child abuse!". Did this information alter the relationship of the children? Will the revelations of harsh punishments later be used during disputes? Although we told the participants that the focus group discussions were confidential, we did not have any influence on what would happen afterwards.

### ***Choices made:***

To make the focus group discussions as safe as possible for the participating children, we took the following measures:

- Each participating school received an information brochure. This brochure contained information on the global research (developing a questionnaire concerning child abuse and neglect) and on the specific qualitative research concerning the perspectives of children on care, authority and punishment. The research procedure was described and possible measures concerning follow-up care were proposed.
- Each child from the selected classes received, after a short introduction to the research, an information brochure and a written consent form. They were asked to read the brochure, and if they wanted to participate, to fill in the form and hand it over to the teacher. In the information brochure children could find: the purpose of the research, a presentation of the researchers, their rights (confidentiality, anonymity, the right to stop participation), and information on different assistance services. These services were adapted to the local context of the participants and mentioned, if possible, the names of the local social workers.
- During the focus groups we took an open attitude towards the topics children brought up. We emphasized their expertise and that the focus was not on personal experiences but on what children in general thought about care and authority.
- Because the focus groups treated a potentially sensitive subject, we used a cartoon figure printed on small posters to ask the questions. In this way, it was not an adult researcher who asked the questions, and whom children "had to" answer. Instead, it was a funny figure who didn't really understand how children were being raised. He/she asked questions such as "What do people do when they take care of children?" Children

could talk about their own experiences, but also about other children's experiences. Considering that children could keep aloof on their personal experiences, meant the focus groups could be experienced as safer.

- We promised the participating children confidentiality of what was said in the focus groups. We asked them to respect this confidentiality too. Only in this way, everyone would feel confident enough to share their opinion or experiences.
- During the focus group discussions, a silent box was placed in the room. Children received an envelope and some paper. If they did not wish to share specific thoughts during the discussions, they could write them down and drop their letters in the silent box. These could be: too difficult or private things, but also funny things; things that they had forgotten to mention; or things that had nothing to do with the subject. In this way, we gave children the opportunity to express themselves individually.
- To make the focus groups less mysterious towards the non-participating children, we returned to the classroom after the focus group and let the participating children tell the others what had happened without going into detail of what was said. In this way the non-participating children would be less curious and wouldn't ask individual children to tell them what was being told.

***Reflexive questions/considerations:***

- How can you provide or instigate follow-up care?
- Can you ask children to keep the discussion confidential?
- How can you assure confidentiality in a focus group discussion?
- How do you deal with sensitive or difficult accounts in a focus group?

**Contributed by:** Hilde Lauwers, Research Centre Childhood & Society, Brussels (Belgium)

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**Case study 5: Inclusion and representation issues with child researchers in Uganda**

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***Background context:***

From September 2006 – October 2008 Save the Children Norway supported children and young people's participation in a thematic evaluation on children's participation in armed conflict, post-conflict and peace building in Bosnia-Herzegovina, Guatemala, Nepal, and Uganda. Collaborations with Child Clubs / Peace Clubs in each country enabled girls and boys to play active roles as advisers, peer researchers, active respondents, documenters and advocates. As part of the participatory research and evaluation process, in-country 'research groups' and 'advisory committees' were formed involving children, young people and national researchers (adult/s). Members of the research group (and sometimes the advisory committee) were provided with opportunities to join capacity building workshops on participatory research to enhance their knowledge, confidence and skills in undertaking ethical and participatory research and evaluation. An initial 'start up' workshop, held in Uganda, brought together children and adult research team members from each country; and subsequent capacity-building and reflection workshops were organized locally.

### ***The ethical challenge:***

In Uganda, four children's representatives (two girls and two boys) took part in the initial start up workshop. In the process of establishing the adult-child research groups and advisory group in Uganda an ethical challenge arose as to which children would have an opportunity to be part of these structures and related capacity building workshops. During a Peace Club meeting attended by the national researcher (an adult), children asked whether the same Club members who attended the last workshop would also attend the next workshop. One member remarked "If the same members keep on going for workshops, then there is no need why we should stay as members in this club."

The issue of representation was raised by almost all the clubs and associations involved in the Thematic Evaluation process. As a result of this, the research team arranged for consultations with other stakeholders about issues concerning representation, inclusion and participation. For wider sharing and discussion this ethical issue was also shared during the Virtual Interest Group meeting, which brought together the Save the Children Norway Senior Adviser, Global Researchers, Lead Researchers and Save the Children Focal Points from each participating country via monthly teleconferencing to encourage ongoing efforts to ensure ethical practice.

### ***Choices made:***

Through consultations with different Peace Clubs and Children's Associations in Uganda it was subsequently agreed that different children/young people would have a chance to attend each participatory research workshop to ensure increased opportunities for a wider number of girls and boys to be actively involved in the participatory research and evaluation process. The decision about inclusive participation and representation was communicated and shared among all clubs and associations. Since then, the rotational system of representation has been the mode of selecting children and young people to participate in activities organized under the Thematic Evaluation.

How the rotational system of representation works:

- Democratic elections: Children/ young people through a democratic process elect their own representatives to represent them each time in any activity.
- Inclusive and ethical participation: Children/ young people ensure that the process is inclusive and ethical. That is, equal numbers of boys and girls involved of different: age groups; ethnic/tribal background; abilities (including children living with disabilities); and educational background.
- Peer sharing and learning: Elected children/young people have the responsibility to share the knowledge and skills they have gained with peers in clubs and associations.

This system of rotational representation enabled the active participation of 603 children and young people (225 females and 378 males) in the participatory research and evaluation process in Northern Uganda. The children and young people were mostly aged 10-14 years, but also included some youth up to the age of 20 years. They included: in and out of school boys and girls, children with disabilities, formerly abducted children, child mothers and orphans. Many of the children were living in camps of internally displaced people. Children and young people also reported that "children who went for workshops and trainings rolled out the knowledge gained to other children" (Save the Children Norway and Save the Children in Uganda, 2008).

However, for the advisory committee to ensure continuity, the Peace Club and association members decided it would be better to have elected children's representatives in the advisory committee. However, rather than have only a few children elected, 24 children and young people (12 girls and 12 boys) were elected to be part of the advisory committee, together with six adults (national researcher, representatives of matron and patron – adult facilitators, representatives from local NGOs and Save the Children, and a member of the local authorities). The Advisory Committee held meetings every three months to raise issues, discuss, analyse and give advice to the Peace Clubs and Child Associations concerning the participatory research and evaluation process and outcomes.

### ***Reflexive questions/considerations:***

- What efforts can you take to ensure that participatory research processes reaches out to and involves girls and boys from different backgrounds and ages (especially the most marginalised)?
- How can you promote inclusive and rotational representation of children and young people in the research process to ensure wider numbers of girls and boys have opportunities to be actively involved, rather than only involve a few children and young people?
- How can you ensure children's participation in s/electing their representatives?
- How can you encourage and support children and young people to share their learning with their peers?
- How can you ensure transparent information and communication mechanisms among children and young people about selection processes?

### ***References***

Save the Children Norway and Save the Children in Uganda (2008). National Report – Uganda – Children's participation in armed conflict, post conflict and peace building.

**Contributed by:** Clare Feinstein and Claire O'Kane. This is a more detailed version of a case example that was included in Save the Children Norway (2008) Ethical Guidelines for ethical, meaningful and inclusive children's participation in participation practice. We also extend appreciation to Dr. Kato Nkimba for his contributions in developing this case example from Uganda.

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## **Case study 6: Interviewing children on sensitive issues around violence: Do survey instruments and processes on violence against children provide adequate measures to protect children aged 13-17 years?**

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### ***Background context:***

Numerous countries are engaged in the development and implementation of a nationwide household survey intended to determine the levels of emotional, physical and sexual violence against children. These surveys are being conducted under the direction and with full participation from the governments of the countries involved. The surveys are being conducted

as part of a global private-public partnership called Together for Girls. The Centers for Disease Control and Prevention and UNICEF are taking lead roles in providing technical and logistic support for these surveys. The survey, planned or completed in 8 countries globally, provides important information on the circumstances surrounding abuse, as well as the long-term consequences. The results of the survey, where it has been completed, have advanced the field in terms of increasing understanding of this highly stigmatized and unfortunately common event, engaging governments and improving policies and programmes to address violence against children.

***The ethical challenge:***

The 2006 UNSG World Report on Violence against Children qualified and quantified the extent of violence against children and subsequently urged countries to 'develop and implement systematic national data collection and research efforts'. In response, the Violence against Children Surveys (VACS) ask 13-24 year olds about their experiences of violence as children in nationally-represented household surveys. Concerns have been raised about the wisdom and value of including 13-17 year olds in the survey.

Proponents of the survey include 13-17 year olds because the survey addresses experiences of violence and there is substantial evidence of recall bias as events become more distant. Likewise, important and rapid social changes—all of which may likely impact children and experiences with violence across the age span—are significant and underway related to education, policy reform, communication technology, social media, etc. Moreover, they believe valid and effective strategies for protecting children from harm during the survey exist and that the benefits of the surveys for children far outweigh the potential harms.

Opponents have raised concerns about the wisdom and value of interviewing 13-17 year olds. They argue that possible unintended consequences of involving these children in the interviews might include potential retribution by parents or guardians and the development of post-traumatic stress, a concern in developing countries where there is a lack of trained providers and associated systems to provide support and care to children who request it. It has also been argued that certain portions of the questionnaire were inappropriate for 13-17 year olds.

***Choices made:***

- Numerous steps were taken to protect children in the context of the survey:
  - Disclosure of the study's purpose was limited to village leaders or heads of Household to reduce possibility of retaliation by caretakers who may be abusing the respondent;
  - A non-judgmental environment was created for conduct of interviews;
  - Interviewers were matched with respondents by sex;
  - Female and male respondents were interviewed in separate enumeration areas to limit the possibility that a perpetrator in the same community as a respondent would learn of the nature of the survey;



- Interviews were conducted in private to protect confidentiality of the information shared by the respondent;
  - Lists of services were provided to all respondents so that they were aware of places they could seek help if needed;
  - A response plan was established that linked service agencies and/or counsellors with respondents who were upset or expressed a desire to get help;
  - A simple and easy to understand consent process was provided;
  - The respondent was allowed every opportunity to decline to answer questions or stop the interview process.
- Ethnographic research was implemented prior to the survey's implementation to ensure that the instrument was culturally appropriate and addressed issues in a sensitive manner for the entire age range.
  - Cognitive testing of the survey instrument was carried out to investigate how well questions performed when asked of survey respondents, that is, if respondents understand the question correctly and if they can provide accurate answers. Cognitive testing ensured that a survey question successfully captures the scientific intent of the question and, at the same time, makes sense to respondents. Questions that are misunderstood by respondents or that are difficult to answer can be improved prior to fielding the survey, thereby increasing the overall quality of the survey data.

***Reflexive questions/considerations:***

- What steps should be taken to protect children from harm in the context of a survey addressing violence?
- What are the potential benefits to children of participating in a survey about violence?
- How do we determine if a survey is age-appropriate or not? Do we consider average age of sexual debut?
- Excluding young people means that results will rely on 18-24 year olds giving information on violence, services and circumstances that may be 5, 10 or even 15 years removed from the year of the survey. What is the value of such a survey?
- What is the risk of NOT doing research with young adolescents? What is the risk of inaction? Is it that more girls and boys might suffer mental and physical disorders because we refrain from asking children their own views on these issues or because we produce research that provides a less than accurate view of reality as it is now?
- Can a clear policy on children and ethics assist in debates around age appropriateness?

**Contributed by:** Mary Catherine Maternowska, UNICEF Office of Research at Innocenti.

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## Case study 7: Incidental brain findings in neuroimaging research

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### ***Background context:***

Incidental brain findings (IBFs) are brain abnormalities with no outward symptoms that are detected in healthy children and adults during their participation in research studies which apply neuroimaging techniques such as structural (MRI) and functional (fMRI) magnetic resonance imaging, magnetoencephalography (MEG), electroencephalography (EEG-ERP), and near-infrared spectroscopy (NIRS). IBFs could have clinical significance because of their potential to cause future symptoms or influence eventual treatments. However, the scientific community does not yet have an accurate estimate of their incidence since no systematic reporting exists, and there is no consensus that disclosure of findings that are minor or normal is in the interest of research participants. Furthermore, at present there is a significant procedural variability in research units regarding engaging and protecting participants, and detecting and communicating abnormal findings to them. When IBFs occur in children and adolescents, multiple ethical concerns are raised.

### ***The ethical challenge:***

The presence of any significant clinical findings in a non-clinical research setting is a matter of bioethical and medical concern. A major challenge is whether to treat research participants with IBFs and how to do it. Consequently, the detection, significance, and management of the IBFs are keys to the welfare of the research participants as well as to the integrity of the studies. However, the evidence is insufficient on what to do because of the lack of appropriate controlled studies of treatments and the availability of neuroimaging studies – mainly MRI and fMRI – for only two or three decades, which means that there are no data on long-term prognosis. Based on studies from the last decade, IBFs incidence varied between 7% and 36% and can be classified as neoplastic (e.g., benign and malignant tumors) or non-neoplastic (e.g., cysts, structural vascular abnormalities, agenesis of the corpus callosum, inflammatory lesions, hydrocephalus, malformations, white matter hyperintensities, silent brain infarcts, brain microbleeds, early multiple sclerosis). Once IBFs are discovered, researchers have to decide what to do. From the researcher's perspective, the awareness of the presence of an abnormality might lead to interventions aimed at modifying risk factors. In this sense, a primary need is to establish procedures for handling IBFs. For example, possible actions may include providing no referral, neurologic routine referral, urgent referral, immediate referral and/or later follow-ups. However, the urgency of referral is difficult to consider without available evidence on whether and how to treat asymptomatic incidental findings. The absence or lack of appropriate procedures increases the likelihood of a potential imprudence if waiting for a catastrophic event or even for legal actions. From the participant perspective, the detection of incidental findings can provoke anxiety about a possible abnormality – which in turn might be a false positive finding, a cascade of costs for further studies and eventual complications, and worries about the consequences of no treatments. Thus, a second need is to decide how to communicate the findings to participants, especially when they are children or adolescents, and to consider the limits of participant confidentiality, for example in regard to parents and primary care physicians.

### ***Examples and choices made:***

In a recent study, Kumra and colleagues (2006) found IBFs in 8 out of 60

(13.3%) healthy children and adolescents who participated in MRI research at their center. All of the identified cases were communicated to the child or adolescent, their parents, and the primary care physician. In three cases, a clinical neuroradiologist suggested referrals: (a) in the first case (i.e., hyperintensity within the left cerebellar hemisphere), a MRI with a contrast agent was recommended. After a follow-up analysis the neuroradiologist and the neurologist thought that the finding was nonspecific; (b) in the second case (i.e., an increased signal in the right parietal white matter), the neuroradiologist considered that the finding could be nonspecific or secondary to migraine headaches, Lyme disease, a reaction to an inflammatory or infectious process, and/or demyelination. After a two-year follow-up study the same unchanged finding was found, which allowed the abnormality to be viewed as not clinically significant; (c) in the third case (i.e., prominent flow voids in the pineal gland potentially associated with a vascular malformation), the participant was re-evaluated with an alternative neuroimage protocol and no signal or anatomic abnormality was reported. The previously described finding was thought to be a technical artifact. In the remaining five cases, the findings did not require additional referrals after interventions of a neuroradiologist and pediatric neurologist, who considered them as normal variants of anatomical events.

### ***Reflexive questions/considerations:***

Guidance on ethical issues regarding the participation of healthy children as volunteers in brain imaging research is just emerging. Several researchers in the field of neuroethics have raised questions that deepen the approach to the IBFs during brain research. The following summarizes some of the key points that are necessary to consider:

- Volunteers (children and parents) for research studies that use brain imaging technologies should be provided with accurate information on the chance and consequences of discovering IBFs, as part of the informed consent process. Specifically, they should be informed of how findings will be handled, and the limitations of each neuroimaging technique. Parents and participants should be asked their disclosure preferences, and given the choice to not be told about the IBFs with the exception of urgent and immediate referrals (follow-up).
- Researchers need to consider potential IBF findings when designing studies and creating research teams (i.e., building capacity for graduate students and postdoctoral researchers, and access to pediatric neuroradiology and neurology consultation for researchers and participants to eventual referrals and follow-up interventions).
- Research centers and Ethics Committees should collaborate to build ethical approaches for adequate handling and communicating incidental brain findings to participants. Part of this effort should consider archiving IBFs, and the adoption of guidelines for handling variation in neural activation.

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## **Case study 8: Dilemmas of dealing with distress during interviews with children**

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### **Background context:**

We conducted research projects involving interviews with young caregivers in the context of the HIV epidemic in Zimbabwe, Tanzania and the UK. The children had recent or current caregiving responsibilities looking after a chronically sick family member (often a parent with AIDS). Some children had recently been orphaned following a period of being a carer.

### **The ethical challenge:**

Interview questions about children's caring responsibilities, and parental illness and/or death sometimes led to tears and emotional upset of the young carer. At times the young people became distressed during interviews when describing the emotional and physical demands of caregiving or recalling the loss of their loved ones. Some young people broke down crying.

In response to their emotional distress we had to decide whether to continue, pause or cease the interview with the young person. We also had to consider whether to continue to investigate the child's experiences of caring by continuing the interview at another time, using a different research method or to discontinue research with particular individuals altogether. We had to reflect on our role as researchers regarding whether the distress we caused was ethically justifiable – were the interviews worth the tears?

### **Choices made:**

Some interviews where young carers broke down in tears and were too upset to continue were rapidly brought to a close. This resulted from situations

when the young person no longer responded to questioning (i.e. withdrawing their active participation), confirmed that they did not want to continue when asked by the interviewer, when another person present (e.g. guardian, parent or older sibling) requested an end to the interview, or when the interviewer judged it inappropriate to continue. We tried to be sensitive to signs of distress and offered opportunities for breaks, to continue the interview at another time, or to end the interview. In the Tanzania and UK research, the use of participatory methods, such as talking about photographs children had taken, drawings or a life story book they had completed, sometimes provided a helpful means to divert attention from emotionally distressing topics.

### ***Reflexive questions/considerations:***

Responding as professionals and fellow human beings to the distress experienced by the young carers interviewed led us to reflect on the ethical appropriateness of our research approach and its method. Our intention was to listen directly to children as experts on their own lives - to make children's voices heard, not to access their experiences indirectly through adults. However, when recounting their caring lives was traumatic, embarrassing, uncomfortable and stressful for the young interviewees, in the Zimbabwe research, our approach was described as "unfair", "uncalled for", even "cruel" by the social worker employed to conduct the interviews in local languages (Shona and Ndebele). In the research in Tanzania and the UK, however, young people who shed tears during the interview wanted to continue and appeared to value the opportunity to talk about their experiences, with one young woman saying afterwards that no one had ever asked her about her caring responsibilities before. This raises a number of questions:

- How can researchers balance the potential (short-term?) harm, such as emotional distress and tearfulness, that may be caused by interviews against the potential long-term benefits of the research process for children, both individually and collectively? Potential benefits include the opportunity for an individual young person to share their feelings and voice hidden experiences which may lead to a sense of empowerment and collective identification with other children in similar circumstances by contributing to research which may improve the situation of other young carers in the future.
- How can researchers best listen to children and be sensitive to signs of distress? What skills and preparation are needed for interviewers and interpreters?
- How can the privacy of interview settings be ensured so that children feel comfortable to express their emotions? This may be particularly challenging when conducting interviews in people's homes where there may be little space to talk to children away from hearing of other household members or neighbours.
- How can researchers best evaluate whether and when interviews should be continued or terminated if children being questioned are emotionally distressed?
- What steps can be taken to consider how children's access to emotional support (e.g., counselling) from project workers and others may be facilitated when appropriate?
- What alternatives can be used instead of interviews? Providing children with other methods of engagement and a range of ways to express their feelings and experiences (such as drawing, photography, story boards, body- maps, and diaries) may be less distressing.

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## Case study 9: Finding the balance between protection and participation: What do you do when follow-up services are not readily available?

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### **Background context:**

A challenge for researchers is to find the right balance between protecting young people from risk while also providing them with an opportunity for meaningful participation. Researchers confront an ethical dilemma when appropriate follow-up services are not available to young people who disclose, for example, mental health needs. Such a dilemma emerged in a study conducted with child-headed households in three regions highly affected by HIV/AIDS in Northern Namibia. Despite anecdotal information on the psychosocial needs of children in this context, the absence of scientific evidence set limits to programme planning and policy-making/ programmes and policies aimed at improving the lives of young people. To respond to this, a study was developed to map the social networks of children heads of household and to measure depression among young people. The Children's Depression Inventory (CDI; Kovacs, 1985), a 17 item self-report depression questionnaire widely used cross-culturally for children aged 7 to 17 years, was adapted to the local context, pilot tested, translated, and back-translated (into Oshindonga, Rukwangali, and Silozi) in collaboration with local professionals.

### **The ethical challenge:**

In the study regions, access to adequate services and supports was limited due to poverty, large distances, limited means of transportation, seasonal floods, domestic and international migration that separated families, and limited health and social infrastructure and human resources. Most notably, there was not a single psychiatrist or psychologist available and the very few social workers employed by the government were located in the regional capitals only. At the time of the study, there was no registry of orphans or child-headed households in the country. Taking into account the best available research evidence and consultation locally, it was believed that the study was not likely to cause serious harm to participants yet there was substantial confidence in the positive impact of the research for the community and young people in similar circumstances. In contrast with clinical screening, which should not proceed if certain treatment services cannot be provided to participants, other assessments such as the one proposed may create a healing space for disclosure and help young people access social supports. In fact, young people reported feeling appreciative of the opportunity to share personal feelings, resources, and support networks in a safe space.

### **Choices made:**

Given this situation, the researcher identified and built collaborative partnerships with local stakeholders and experienced youth-serving agencies prior to starting data collection. Partners helped identify child-headed households and assisted in cases of disclosure of harm, with the permission of participants. Among those, there were several ministries, traditional authorities, community-based agencies, faith-based organizations, schools, and home-based care volunteers. This process of determining whether there were appropriate services available and accessible to young people was time consuming. Nonetheless, it provided legitimacy and visibility to the study, helped determine the type of follow-up that was appropriate for children according to age, gender, ethnicity, etc., and built networks of information and support so that assistance could later be offered to participants in need.

In many cases, individual resources (e.g., existing personal networks), local community-based or faith-based organizations (e.g., Catholic AIDS Action's home-based care volunteers in Namibia), and even informal community supports were potential sources of necessary assistance. For example, a child who had suicidal thoughts—although she had never acted upon them was, with her agreement, referred to a local organization working with orphans and vulnerable children for follow-up. In many other cases, the research team shared information about suitable local sources of help—from how to obtain a birth or death certificate to apply for government assistance to who they might discuss their fears with. The choices made show that risk may be significantly reduced by careful consideration and adoption of alternative procedures.

### **Reflexive questions/considerations:**

- How is the context where your research will take place similar or different from the one described here?
- How likely are young people to need support as a result of their participation in the study?
- What could be done differently in the study to minimize young people's risk of harm and, therefore, their need for support?
- What type of support will they require?
- If professional services and programmes for young people do not exist in the community, can they be created in the context of the study?
- Otherwise, how can you ensure that adequate follow-up will be made with young people in need?

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## Case study 10: Dilemmas at school: How and when to support the inclusion of students with disability

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### **Background context:**

In our ethnographic work with children with disability at school, our research team has observed a number of situations where children and young people have been marginalized and excluded from the curriculum, social life and wider activities of the school. In this study we followed seven young students with disability as they transitioned from primary to secondary school to explore how their school experiences impacted on their developing sense of self and group identity. This is one example of exclusion and the ethical dilemmas it raised.

Sam is 13 and has a long list of unofficial labels, although his view of the world is not well understood and funding and support for his education has been elusive.<sup>xxiii</sup> He is a proficient reader but struggles to understand social situations and aspects of his school work, becoming upset and angry when stressed. He was excluded from one primary school because of his behaviour, and was subsequently taught at home. Thanks to a welcoming teaching-principal, he attended a small rural primary school for 1½ years before making the transition to secondary school. He had been at secondary school for three months when these observations took place.

### **The ethical challenge:**

Sam is in the hallway outside the social studies class, the students are retrieving their books from their schoolbags before entering the classroom. It's a busy and noisy time with lots of jostling and banter, particularly amongst the boys. One of the boys pushes Sam as he tries to retrieve his books, and calls him "a retard". Sam retaliates, shouting back at the boy. He is clearly upset. He enters the classroom and sits at a desk in the centre of the room, next to the teacher aide. He is agitated and unable to focus on his work. The teacher explains the purpose of the lesson to the class, but Sam is noisily complaining to the teacher aide, and pointing to the boy who bullied him. The teacher asks him to pay attention, but Sam cannot settle. The teacher tells Sam that his behaviour is unacceptable in class and points to the door, asking him to leave. Sam storms out of the class and goes to the Learning Support Centre.

Questions relating to researcher boundaries and responsibilities, and to matters of primary accountability to the child are raised here. To what extent, and how, should the researcher intervene in this incident? In the case of challenging issues that arise when gathering data in the field, guidance for researchers can come from research protocols developed in advance (for example, we can encourage the young person to talk to appropriate adults, or they may agree to the researcher doing this on their behalf). Yet while advanced preparation is always desirable, we cannot predict every situation that will arise and we will encounter situations like this one that require us to 'fly by the seat of our pants'.

### **The options:**

Bullying is an insidious problem that is often poorly understood by teachers as much goes unseen.

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<sup>xxiii</sup> Sam is a pseudonym.



Sam was actively trying to be part of the peer group at school, and this impairment-related abuse was a barrier to his inclusion and well-being. The teacher misunderstood the context and Sam's anxiety and the effects were exclusion from class and from the opportunity to learn. The bullying went unrecognised and was not addressed, but the researcher's observations provided a context in which teachers could come to understand bullying as a barrier to Sam's learning and participation. The researcher has several options:

- Do nothing (the researcher is a 'fly on the wall');
- Intervene in the hallway bullying (as a proxy teacher);
- Discuss the matter directly with the teacher and inform him of the context;
- Discuss the matter with Sam and take action (or not) from that point.

***The choices made:***

I stayed in class for a while after these events then went back to the Learning Support Unit to see Sam. I asked him whether he wanted to report the bullying, but he was adamant that he did not wish to do this. He did not want the teacher to know as he was concerned about retaliation. He worried that some of the boys would find out and that this would damage his attempts to be accepted in the peer group. We discussed the implications of not following up with the teacher, and the negative effects that repeated bullying was having on Sam. He agreed that it would help if the researcher informed the social studies teacher in a general way, and without naming names, that bullying often happened in the hallway and it made it hard for some students to learn. He also said that it was okay for the social studies teacher to share this information with other teachers in the school.

***Reflexive questions/considerations:***

The researcher's role is in a state of flux in this scenario as they shift between researcher and advocate for the young person. A key principle guiding the researcher's role and behaviour is their responsibility and primary accountability to the young person. Research is justified through the potential benefit to children and young people themselves, not to our own curiosity (Munford & Sanders, 2001), and in this scenario the researcher is balancing harm and benefit for the young person.

1. What is the primary role of the researcher in this scenario? The researcher could:

- Be a fly on the wall;
- Be an informant to the teacher and/or respond to teacher's comments, questions and observations with or without Sam;
- Behave as another teacher in the classroom;
- Focus on the rights of the young person and advocate for them.

2. The researcher moves into an advocacy role (which is not neutral) in this scenario. Under what circumstances is an advocacy role appropriate?

3. Where does primary accountability to the child begin, and keeping this in mind, how would you respond to this scenario as a researcher? You might like to consider the following:

- Should the researcher intervene when the bullying occurs outside class?
- Should she advise the teacher about the circumstances leading up to the student's eviction from class?
- Was it appropriate to follow-up with the student after the event and discuss possible solutions with him, or should the researcher go directly to the teacher?

### **Reference**

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## **Case study 11: Discussing ethics with children**

### **Background context:**

In the quest for ethical guidelines for research into and with children, children themselves are important partners, especially in research on difficult themes as in a Dutch research project of Stichting Alexander (Netherlands) on children's voices in fighting child abuse. In this project, we consulted youth on the ethical guidelines they felt were important. In another research project, Child Research Groups were engaged in role plays on ethics in research, to define what important ethical directives are according to children. How do they feel that they should be treated within a research setting?

### **The ethical challenge:**

We faced a number of challenges thinking about ways to discuss ethics with children. For example, what methods would we use, and how could we adapt the methods to the ages of the children? How could we introduce the theme and make sure children know what is meant by ethics? What was the right moment to talk about it?

### **Choices made:**

We developed two methods. The first method was developed together with the children of the Child Research Groups. By means of a number of small role plays where the children themselves portrayed the role of researcher and respondent, there was a discussion about what is and what is not ethically responsible behaviour. This way, together with the children, ethics rules were drawn up, to which they could then commit themselves. This method has proven to be successful because it appeals to children: they can watch the scenario acted out and are well able to tell which behaviour is good or not and why. They find it fun, it stimulates them to think and matters previously taken for granted are scrutinized. Children can think up rules precisely because they can imagine what a situation could look like if the relevant rule is not observed.

### **Working method:**

1. Two children act out a role play in front of the group. They are shown their assignment on a card where they can read a description of a situation. One child takes on the role of researcher, the other child that of the respondent.

2. The two children will act out the described situation. They can add and make up whatever they want so that it becomes a fun short 'theatre play' (of 1 minute).

3. After the brief performance the two children will sit down again. The mentors first ask the two children how they felt it went (cooling down).

4. Then the audience will explain what they saw. The mentors will ask a few questions about the play:

- Was the researcher right or wrong?
- Why was this good or bad?
- Which rule(s) with respect to the behaviour of a researcher can we think of with reference to this short play?

5. The rules are laid down on a sheet.

6. Then another duo will stand in front of the group to act out a different situation.

The second method was aimed at discussing ethics with young people (aged >14 years), through a group conversation. After acquaintance and the creation of a familiar atmosphere, we went into the theme of ethics more directly. Group conversation was a suitable method, because ethics is a theme that lends itself pre-eminently to dialogue and exchange. You can record the conversation and elaborate afterwards, so that you can try to formulate guidelines on the basis of the statements. You can then give feedback about these directives to the young people and in this way continue to develop the discussion.

*That you then simply say: If you find it difficult to answer the questions you don't have to feel obliged at all. Then you can simply say that you don't want to talk about it. (Boy, 13 years old)*

### **Reflexive questions/considerations:**

- Can we discuss ethics with children we involve in our own research?
- Is it possible to discuss ethics with regard to the topic with children, before the actual research starts?
- What if children's ethics differ from the standard ethical guidelines?
- How can children's ideas and experiences on difficult themes be known, especially if researchers themselves hesitate to discuss them?

So that you really give the child the feeling that they are now also truly helping other children who have experienced things. (Boy, 13 years old)

### **References**

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**Contributed by:** Kitty Jurrius, Stichting Alexander.

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## Case study 12: Obtaining informed and voluntary consent in a group context

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### ***Background context:***

In designing a doctoral research study of the experiences of unaccompanied/separated asylum seeking young people in Ireland, it was decided that the core of the study would involve individual interviews with relevant young people, aged between 13 and 18 years. From the beginning it was recognised that, by virtue of their status and prior experiences, some of the young people who met the inclusion criteria for the sample might be suspicious or sceptical of the true intent behind social research and that this was likely to impact on their engagement with the study and the quality of the data gathered. While in some ways this group differ from other young people, in other ways their suspicion and scepticism might reflect the views of other potential participants of a similar age, albeit of a different background, particularly those who are considered vulnerable for various reasons. While this discussion relates to a specific population, it is likely that it is also relevant to research in a group context more generally.

It was clear from the outset that the study faced a number of issues. The first issue was how to build trust in young people whose basis for trust in other people, especially people in authority, had been severely tested by prior experiences (Ní Raghallaigh & Gilligan, 2010). While the study was focused on their experience since arriving in Ireland, a further sensitive issue was the frequently uncertain immigration status of many of the young people which also made them wary of questions about their lives. Therefore, it was thought that they might feel powerless when faced with 'options' presented by authority figures. Another issue was that a single interview was unlikely to be able to do justice to the complexity and range of experiences encountered by the young people. It was felt that an additional method was needed so that the researcher could develop a more in-depth understanding of the everyday lives and circumstances of the young people. Thus, it was decided to undertake participant observation in a hostel accommodating separated young people, prior to commencing interviews. The authority responsible for placing the young people in the hostel was approached and permission was granted to conduct the participant observation.

### ***The ethical challenge:***

The main ethical challenge posed by the research was that of obtaining informed and voluntary consent from the participants. This is particularly relevant in research with young people as they might construct the researcher as an authority figure to whom they must defer (Mahon et al., 1996), perhaps

even more so in the case of asylum seeking young people because of a range of issues (see Hopkins, 2008), including their uncertain immigration status. In addition, obtaining informed consent can be particularly complex in situations where participant observation is used. We recognised that individuals might have different reactions to the researcher being in the hostel. Should the researcher seek the unanimous consent of the whole group of young residents, meaning in effect that even one or two dissenting views could veto the whole project, despite perhaps strong interest in participation on the part of others, and possibly even a majority? We wanted to respect the rights of each young person. The rights of some unaccompanied minors not to participate were of course important. However, we felt that others might be enthusiastic about the research and that they had as much right to be allowed to participate as did others to refuse participation.

**Choices made:**

It was decided that if a significant majority were in favour of the research going ahead it would continue. However, those not wanting to participate needed to be accommodated also. For this reason informed consent from the young people was sought on two separate issues. In order to move forward in a way that sought to balance the rights of both potential groups, the ‘consenters’ and ‘non-consenters’, the researchers framed the process in two parts: The first related to the researcher’s presence in the hostel, whilst the second related to the actual participation of the young people in the research process. We recognised that whilst a young person might not mind the researcher (Muireann) being in the hostel, he or she might not want her to be gathering information in relation to him or her. Therefore, consent to the first did not imply consent to the second. Arising from this differentiation, Figure 1 (Ní Raghallaigh, 2006) illustrates the potential combination of responses that the young people could give when the researcher sought their consent.

**Figure 1: Illustration of responses from potential participants in relation to their participation in the research and to the presence of the researcher in the hostel**

		PARTICIPATION	
		NO	YES
P R E S E N C E	NO	“I don’t want Muireann to be in the hostel and I don’t want to tell her anything.”	“I would like Muireann to interview me but I don’t really want her to be hanging around the hostel.”
	YES	“Its o.k. if Muireann is in the hostel but I don’t want her to collect information from me or about me.”	“It would be great if Muireann came to our hostel to find out about our lives. She can interview me too if she likes”

Verbal agreement to the researcher's presence in the hostel was obtained from all young people. Written consent to participate was obtained from a majority. It was made clear in each one-to-one discussion about consent that data would only be gathered and included in relation to those who had given explicit consent to presence and participation. The researcher would discard data involving young people who had not consented to active participation: she promised that she would not write field notes about them. Consent was revisited at different stages throughout the fieldwork, for example, when the researcher felt that young people might have tired of her presence or when new young people arrived in the hostel. Some young people who had originally only consented to the researcher's presence, changed their minds and stated that they wanted to be interviewed, perhaps because a relationship with the researcher had developed. Other young people, who had originally consented to presence and participation, subsequently decided that they did not wish to be interviewed but they were still happy for Muireann to spend time in the hostel.

### ***Reflexive questions/considerations:***

When conducting group research, do we neglect the rights of some individuals if we decide that unanimous consent must be obtained from the whole group? In our view, the answer is 'yes', and therefore a different approach must be used. While the consent process in our study was a very complex one, the researchers are of the belief that this complexity was necessary given what they wanted to do: spend time in what was the young people's current home in Ireland. As such, respecting their rights was of ultimate importance. The key in implementing this consent process was time. It was not possible to simply go into the hostel and get consent on a once-off basis. Instead, obtaining consent was considered an on-going process. At the outset, before the fieldwork could begin, it involved several information meetings with the young people, both individually and in groups and the use of various methods (e.g. anonymous comment box; encouraging them to talk to hostel staff or to the researcher) to ascertain their views on the project. Many researchers will say the time spent obtaining consent is a luxury that they cannot afford. Yet, why should this part of the research be rushed or considered a tick the box exercise, when it is of such importance in respecting the rights of the potential participants?

Finally, a question that we continue to ask, a number of years after the research has finished, is the following: Is it ethical to put time into building relationships with vulnerable young people if the primary reason for doing so is to facilitate our research endeavours? In this study, one of the main motivations for conducting participant observation was to build trusting relationships with the young people. These relationships were built, and then, in most cases, they ended once the research had been completed. Is this fair, especially in the case of vulnerable young people who may in many respects be very alone and who may have already experienced multiple losses?

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**Contributed by:** Dr Muireann Ní Raghallaigh, School of Applied Social Science, University College Dublin, Ireland and Professor Robbie Gilligan, School of Social Work and Social Policy, Trinity College Dublin, Ireland.

The research was part of a Ph.D. study which was funded jointly by the National Children's Office, Dublin, and by the School of Social Work and Social Policy and the Children's Research Centre, Trinity College Dublin.

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### **Case study 13: Picturing consent: Using photographs in a visual consent form**

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#### ***Background context:***

The Tiwai Island Wildlife Sanctuary in Sierra Leone is a community-based conservation and eco-tourism initiative managed by the environmental NGO, the Environmental Foundation for Africa (EFA). I conducted my Master's research in the Tiwai communities in 2008-2009 in collaboration with EFA. The study facilitated an intergenerational dialogue about conservation and development using photovoice, a participatory visual method, whereby research participants take photographs to represent their lives, experiences and priorities.

#### ***The ethical challenge:***

As part of preparing my university ethics application, I needed to develop a consent form with an accessible format. Rural Sierra Leone is characterized by relatively low rates of literacy, so a written consent form was inappropriate. Oral consent was considered, however because there was no electricity in the research communities at the time and audio devices were not readily available, sharing an audio recording of the oral consent with participants would be difficult. I needed a consent tool that was low-tech, tangible, and accessible across a range of literacy levels.

It was important that participants received a copy of our agreement to work together that they could understand and refer back to throughout the project. The consent form was an important communication tool between myself, the NGO staff, and the research participants. The form could initiate a conversation about the implications of consenting to participate in the study, document roles and expectations across the research process, and ensure my accountability as a researcher.

#### ***Choices made:***

As I was planning to use photovoice, using photographs in the consent form seemed like an appropriate way to approach the consent process. It also served to begin a dialogue about images. I was probably also influenced by my experiences working in primary schools in Canada with children with special needs. In this work, images were often used throughout the school day, as teaching instruments, as tools to engage learners, as visual cues for school activities, and as expressive tools for emotions.

I began by drafting an oral consent script for the project. I broke the main concepts, ideas and information into segments for which I could imagine a photograph. It was an iterative and creative process - the structure of the consent script shifted as ideas for possible photographs emerged.

In a previous internship in agricultural communities in Sierra Leone, I had noticed that paper resources were scarce. I therefore wanted to limit the visual consent form to one page. Part of breaking the consent script down into segments was balancing how many photographs could fit onto one page while maintaining clarity and readability.

I also decided to include some written words on the form. This decision was partly to help structure my thinking when making the form. Importantly, including written words helped to avoid making broad assumptions about participants' literacy levels and provided an extra method of communication for participants. It had additional benefits of making the purpose of the form clear for the ethics review committee and provided a more concrete guide for my collaborators. The sections included in the form are found in Table 1 below. So that the images on the form reflected the local context, I worked with the EFA staff in Freetown and on Tiwai Island to take photographs for the form. Due to a tight budget, I photocopied the form in black and white. I did not have the opportunity to ask the research participants about the effectiveness of the consent form towards aiding understanding about the research process. I think the form provided a space for the research participants to visualize their potential participation in the project and ask questions about it. Many participants brought the form to each research workshop, and many kept the form - along with the photographs they took - as evidence of their participation in the project.

***Reflexive questions/considerations:***

- **The format of the consent form:** Should there be written text on the form? If so, how much text and in what language? What is the best way for participants to sign? How many pages should the form be? Black and white, or colour? What might a colour booklet, for example, with one photograph per page look like?
- **Who should be in the photographs?** The people photographed on the original form are EFA staff members. The staff agreed to model for the form for in-house use in the research communities around Tiwai Island. At the time, we had no idea about the interest a visual form would generate across the broader academic community. While the staff later agreed to have a digitally-blurred version of the form published in Claudia Mitchell's (2011) book, *Doing Visual Research*, some of the staff expressed discomfort with broader distribution of the form, in particular on the internet. It is becoming increasingly problematic, however, to control what goes on the internet. For example, books often become e-books.
- **Location of photographs:** Where should the photographs be taken? For logistical reasons, we took most of the photographs at EFA's head office in Freetown. Using the form in the Tiwai communities, however, I quickly realized that the concrete infrastructure of the office compound and the urban office wear of the staff looked significantly different from the traditional mud and thatch building materials and rural clothing. It would have been more effective to take photographs in the agricultural context where the research actually took place.
- **Photograph content:** What is the most effective way to break down the process of consent within any particular research context? What additional photographs could be included? For example, in retrospect, I would include a photograph to show how the research might be disseminated, such as presented at a conference, published in a journal or book, or uploaded to a website.



- **Increasing participatory input to the consent form:** What would a visual consent form developed in a participatory way with research participants look like? Many of the decisions informing the design of the consent form were made by me, thereby reflecting my priorities, experiences, aesthetics and imagination. How might the research participants picture the components, ideas, stages and implications of the study? How might other participatory visual techniques deepen the consent process?
- **The consent form as a component of the informed consent process:** What other ethical steps should be taken to ensure the effectiveness of the informed consent process and ensuring ethical research more generally? While including photographs might strive to improve understanding, a consent form is by no means a stand-alone document. The form was conceptualized to be used in conjunction with ongoing dialogue about consent through various stages of the research. I also worked with local structures of authority, presenting the project at a meeting of project stakeholders and hosting public meetings in each community to ensure that permission was granted and that the communities consented to being involved in the project.

**Contributed by:** Jennifer Thompson, PhD candidate, Department of Integrated Studies in Education, McGill University, Canada

**Table 1: Sample sections of a visual consent form**

Topic	Photograph description	Caption
Who is involved and the location of the research activities	A photograph of myself and the field staff who would be facilitating the research workshops, at the Tiwai Island visitor's center where the workshops would be taking place.	I understand who is involved in this research project, and where the workshops will take place.
Purpose of the research	A map of the research area including the wildlife sanctuary, the eco-tourism camp and the surrounding communities.	I understand the purpose of the research.
The research process: Stages of participation that would be required of participants	Photograph of research participants learning how to use cameras in a workshop.	I understand that I will be asked to participate in 2 workshops and potentially 1 interview.
	Photograph of research participants out in the community taking photographs.	I understand that I will be asked to take pictures in my community.
	Photograph of research participants sitting around a selection of photographs and engaged in a discussion about them.	I understand that I will be asked to discuss the photographs that I took.

<b>Topic</b>	<b>Photograph description</b>	<b>Caption</b>
The risks and benefits of the project	A photograph of someone from the community asking a participant holding a camera what they are doing.	I understand the risks and benefits of being involved in this project.
Documentation of the research	Photograph of a voice recorder.	I understand that if my voice is recorded, the cassette tape will be kept private and confidential, and that my photo may be taken. <input type="checkbox"/> I agree to be audio-taped <input type="checkbox"/> I agree to be photographed.
The voluntary nature of participation	A photograph of someone waving as they are leaving a workshop. The researcher and the other participants are clearly smiling in a friendly way.	I understand that my role in this study is voluntary. I can refuse to answer any questions, and I am free to stop participating at any time.
Feeling informed	Photograph of a research participant asking the researcher questions.	I feel informed about this research and have had a chance to ask questions. I understand that I may ask questions at any time.
Consenting to participate	A photograph of a participant holding a consent form and shaking my hand in agreement.	In signing this form, I agree to participate in this study.
Information	No photograph.	Date: EFA staff member: Participant name: Category (elder, youth, etc.): Community:
Signature area	No photograph. The signature area was designed to leave enough space for a thumbprint signature.	Signed: Researcher EFA staff member Participant.

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## Case study 14: Responding to real world ethical challenges when conducting research with young children in Tanzania

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### **Background context:**

This case study describes the ethical dilemmas faced in the conduct of a recent study that sought to answer the question “How do young Tanzanian children experience care?” The study explored the heterogeneous practices that are used by families to care for their children across diverse tribal, lifestyle and geographical groupings. This study was commissioned by an international NGO. An experienced researcher assisted with the design of the study, data analysis and writing the report. People who lived in the communities where the research was conducted collected the data. Technical support and field leads were undertaken by child rights practitioners and a play therapist who had limited qualitative research experience, but significant contextual knowledge of child development and the issues facing children in Tanzania. All parties were challenged to set aside what they deduced about the situation of children from their practical work in the field and to remain truly open to what they may induce from the data and stories of children. All carried prior assumptions about what young children were capable of knowing.

### **The ethical challenge:**

The ethical challenge lay in ensuring that the mechanism to support the data collectors and technical leads to conduct ethical research were actually used in the field. I explore this challenge by examining the choices that were made in negotiating access, aligning expectations, allaying the fears of care-givers and obtaining informed consent from the children and their care-givers. During the design of this research study considerable attention was paid to thinking through the ethical ramifications of conducting research with young children. However, the standards that were set in the design of the study were not always applied during the fieldwork. Why was there this gap between intention and practice?

### **Choices made:**

- Was a formal commitment to child protection made?

The data collectors signed no formal commitment to child protection, even though that was part of the original study design. Rather, child protection was discussed informally during the training of the data collectors and during an initial meeting with the children’s caregivers. In practice, many researchers and study participants do not see the value of making formal statements of commitment; because there is no real liability that accrues to researchers, nor any form of redress for participants should poor ethical behaviour occur in the research process.

- Negotiating access and aligning expectations

Researchers who come into poor communities can often be objects of speculation, be perceived as agents of the government, or as the bringer of services and interventions (Ebrahim, 2010; Morrow, 2009). Thus it is critical to spend time explaining the purpose of the research and the limits of its scope so that the communities’ expectations are not unjustifiably raised. The issue of power dynamics pervades research with disadvantaged communities and children. The ethical symmetry (Christensen & Prout, 2002), where professionals and outsiders who have both social and economic power,

interact with poor research participants is deepened when children are the research subjects and the power differentials of age are considered.

All adult participants wanted to see benefits to children as an outcome of the study. Given that the outcomes of this study are so intangible; namely that it will inform the advocacy initiatives of the commissioning organization, there was no easy response to these adult expectations, and to this day the issue feels unresolved.

The research design took into account the social and cultural positioning of children and strove to find ways to lower the power imbalances (Bergstrom, Jonsson & Shanahan, 2010). They did this by using community insiders who voluntarily run early childhood services for children as the primary data collectors. They sought access to children and parents within the communities via political and traditional leadership and through their contacts with parents and community groups in the area (Ebrahim, 2010). The feeling of the programme officers was that there was more co-operation than challenges in the recruitment of participants and that the main challenge was not accessing participants per se, but the time involved to do so because of the need to use community leaders to mobilize participants.

- Obtaining consent

There is a distinction between the provisional consent that adults and children may give at the outset and the ongoing consent that is then negotiated on a minute-by-minute basis as the research unfolds (Simons & Usher, 2000). This places responsibility on the data collectors to nurture relationships with the research subjects, to be sensitive to the impact of the research on them and to create a non-judgmental space for them to withdraw from the study or not to participate in specific study activities. The data collectors provided the care-givers with clear and precise information about the research in the initial group meeting where they described the study, but this was the only time where adults were able to ask questions. They did not leave additional time in the interviews for the participants to reflect on the experience, even though this had been part of the initial design.

### ***Reflexive questions/considerations:***

- Technical leads and data collectors did not get sufficient opportunity to internalize the seriousness of ethical dilemmas nor to practice reflexivity. There was a gap between what was planned in the research design and its implementation. Data collectors did not use the protocol that had been designed to support daily reflection on the ethical dilemmas that they faced. They only met to consider practical matters of logistics and so forth, but not to engage in conversations that were reflexive in nature. They did not reflect deeply on their posture, on the non-verbal signals that they were getting from the participants; on potential sources of unexpressed resistance amongst the participants; nor on how they managed the power dynamic between themselves and the participants.
- The challenge in building a reflexive practice partly lay in the structural design of the study; which involved multiple parties, each of whom brought different expectations, skill sets and capacities. At the apex was the commissioning organization, which was more concerned with the ultimate research product and the design of data collection tools over the ethical processes that were used to engage with research participants. There is a real tension when doing ethically led research with the need to go slow, listen and think deeply and to continually ask questions about one's own posture as a researcher. Because the NGO and its staff espouse a set of claimed values about putting children's best interests

to the fore, practitioners within these agencies often tend to assume that they know what is best when it comes to engaging with children. There is some resistance towards deeply scrutinizing their own posture when they interact with a child. They struggled to jettison the hat that they wore as advocates and carers for children and to adopt a new hat that would require them to undertake a disciplined qualitative research practice. This involves setting aside preconceptions, listening deeply, creating space for the child to narrate their stories, and not prematurely and partially interpreting the children's stories, namely the essence of a reflexive practice.

- In conclusion, the challenges that an ethical researcher faces start from the moment of contracting with the commissioning organization and the cultivation of shared expectations that good research is ethical research. From the outset everyone has to understand that it takes time to design an ethical study, and that building the mindsets and skills of all parties to engage in reflexive and ethical research is as critical to the success of the study - and to its eventual legitimacy - as conducting fieldwork, analyzing data or writing the research report. The greater the number and the more diverse the people involved, the greater the amount of time and attention that needs to be paid to building a shared understanding, commitment and practice to reflexive ethical research.

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**Contributed by:** Kate McAlpine; Facilitator. Coach. Researcher. Lead Strategist of Caucus for Children's Rights, Tanzania.

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## Case study 15: The challenge of ongoing consent?

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### **Background context:**

When conducting ethnographic or field-based research that involves children with disability, the notion of informed consent requires the researcher to be very thoughtful about what it means to be fully informed across the full range of participants. The school based study in this example involved researchers spending significant time over a year with the same group of students (aged 11-12) and then following some of those students from year to year as they changed classes and schools. There were four researchers in New Zealand

regular schools following seven students with disability. We wanted to understand how school experiences were influencing what it meant to be a student with disability. The following example is based on one researcher's experience with one of the students.

***The ethical challenge:***

Much of the ethical guidance on involving children in research assumes event-based studies, (e.g., taking part in an interview or completing a survey) where the consent is obtained, and data collection follows very quickly after. On the completion of data collection the child has experienced what it is like to participate in research and can form an opinion about whether they would wish to repeat the exercise.

In ethnographic studies the relationships between the students and myself developed over time within the context of classroom participation. The student experience of the research was very much influenced by the developing relationship with myself as the researcher. The children may have wondered to themselves whether I was just another adult who was going to "boss them around". My concerns at the time were: What if a student decided they didn't want to talk with me at a particular time; did that mean they no longer wanted to be part of the research anymore?; how would I check this?

When I stated that, "I want to spend some time in your classroom", they did not necessarily realise that I meant "be there all the time". We are familiar with the idea of participants saying they can withdraw from the research at any time. How was I to check whether this was the case or a student was not having a good day and would be fine tomorrow? My approach was to negotiate what participation might look like and talk about how children can influence what that might mean on a day-to-day basis.

The research information sheets that we provided advised children that they can ask the researcher to "go away" if they are not comfortable about being observed during particular times. However, usual classroom adult-child interactions often do not give children the option of doing this. It is usually difficult for any child to ask an adult not to do something, as this contravenes the usual power relationships in schools. It may be even more difficult for children with disabilities to do this, given the number of extra adults they may have around them.

***Choices made:***

What did this mean when spending time in the classroom? Here are some examples.

As the focus was on the experiences of the student with disability I spoke with Alex and his family first.<sup>xxiv</sup> Thus I spent as much time as was required to give an initial explanation of the study. Once I had their approval to begin I then gained permission from Alex's class. I did not start data collection, that is, writing notes, as soon as I began spending time in the classroom. I wanted students to get to know me first as an adult in the classroom. Over time, many of them were comfortable about asking me to support them in their classroom activities. At the end of the first day I talked with the class about what I was hoping to get from my time in the classroom. I spoke about taking notes and talking with them about their day, but I also gave them permission to talk with me individually or say they would not want to be part of my study.

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<sup>xxiv</sup> Alex is a pseudonym

I provided information sheets about the project, which they could take home and talk about with their parents. I then gave students two more days to raise any questions while they got to know me better (it also allowed me to catch up with any students who might have been away when I spoke with the class the first time).

As I walked past Alex who was doing a writing exercise he leaned over his work and put his non-writing arm over his page making it difficult for me to see. I walked past and talked with another student.

When the class finished for lunch it was often a useful time to review the morning's events with Alex. I was mindful, however, that this meant that he was not spending time with other students. At one point I think he also preferred to spend time with me rather than go out and interact with others. I decided to vary and limit the time I would spend speaking with Alex at the lunch break, despite it being beneficial for the research or the student's preference. Instead, I looked for other opportunities to have these discussions.

Students were used to having adults in the class, but not researchers. Many students wanted to know what I was writing during those times I was in the class. I decided to show them my notes, as they were very messy and I only ever had those for the day with me. (I write my notes in expanded form later in the day.) I showed students my notes and then verbally explained what the 'scrawl' meant. This allowed me to leave out any personal details and reassured the students that my focus was on classroom activities. They did not tend to come back and ask again after the first time.

### ***Reflexive questions/considerations:***

In the context of ethnographic research, the researcher is the experience. Therefore, how children get to know the researcher determines what it means to be informed. This raises a number of questions:

- How will you introduce yourself (or allow others to do it)?
- What opportunities will you give all children to get to know you and what you are doing?
- How much time will you give children before you ask for an initial commitment, and how will you check their views about ongoing participation?
- The criteria for appropriate interactions with a researcher emerge over time. How often do you check that the situation is still okay for the students? In institutions children are not used to challenging adults and they tend to comply with requests. What clues do children give you that they would like things to be different?
- How do you make sure that your relationship with one child does not compromise their relationships with others, such as their peers?
- How will you appropriately reassure children about the nature of the data you are collecting?
- How do you balance the research activities of observing/recording data with participating in classroom activities?

**Contributed by:** Dr Michael Gaffney, College of Education, University of Otago, New Zealand.

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## **Case study 16: Caregiver consent for child participation in research: Reaching and protecting the most vulnerable**

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### ***Background context:***

The Young Carers Study is a national study, designed in collaboration with Universities, the South African government, UNICEF, Save the Children and the National Action Committee for Children affected by HIV and AIDS. The study interviews 6000 children aged 10-17 years using a longitudinal design. It aims to identify the impacts of AIDS-orphanhood and caregiver AIDS-illness, as well as other risks such as abuse, on child outcomes. It also aims to identify services and programming that can help them. See [www.youngcarers.org.za](http://www.youngcarers.org.za).

### ***The ethical challenge:***

Research examining child vulnerability has three – apparently corresponding – ethical requirements. The first is to protect children by ensuring that participating in research is their free and informed choice. This is usually addressed by providing clear written and verbal explanations of the research and its aims, and allowing children time to consider and ask questions about participation. The second ethical requirement is to ensure that it is in each child's best interests to participate in research. Because children are considered to be unable to make this decision alone, this usually requires that the researchers gain permission from the child's parent or legal guardian for the child to participate in the research. The third requirement is to ensure that the most vulnerable children are not excluded from taking part in research, so that the evidence-base on child vulnerability represents those children with the greatest need for assistance.

For a small but worrying group of children, these three ethical requirements are in direct conflict with each other, presenting researchers with a set of ethical dilemmas. In sub-Saharan Africa, the AIDS epidemic has left children living in child-headed and youth-headed households. These are homes where all the adults have died, and the oldest caregiver is a child themselves, or a sibling aged 18-25 years. In these situations there is no parent or legal guardian able to give consent for the child to participate. Our research also identified a group of children who very much wanted to participate in the research, but told our interviewers that their guardians would not let them participate because the guardians themselves were abusing the children, and did not want this to be exposed by the research. Finally, we found a small group of children whose guardians would not let them participate in the research because the guardians were involved in crimes such as drug dealing, and did not want this revealed through the research.

In these situations, gaining guardian consent was either impossible due to a lack of adult caregiver, or because adults were protecting their own interests at the expense of the children in their care. But these children represent some of the most vulnerable groups, and it was essential to include and represent their needs in the research.

### ***Choices made:***

The research team discussed this dilemma with a number of groups: NGOs working with vulnerable children and research ethics committees at Oxford University and South African universities. We also discussed the question with our Teen Advisory Group of South African children who help to make



the research child-friendly. In addition, we reviewed legislation and literature around this area (see the South African Department of Health Research Ethics Guidelines 2004).

For these situations, we allowed children to identify another trusted adult, such as a teacher or social worker (in situations where caregivers were abusing or exploiting children) or an aunt or grandparent (in situations where children had no legal guardian) who could give consent for the children to participate. It should be noted that this approach was never used to get out of guardian consent just because it was convenient, and our research teams were trained carefully in this. If children did report any kind of abuse or exploitation, referrals were made to health and social services for them and with the child's full knowledge and consent.

Within the consent process it was also very important to ensure that children and adults truly understood all the information and expectations of research participation. Consent and information forms were read out in people's first languages, and were written in clear simple language without technical terms. At each stage in the research, children and their guardians or nominated adults were asked again for consent to participate.

***Reflexive questions/considerations:***

- Are there any particularly vulnerable groups of children who you want to make sure are included in your research?
- How can you approach these vulnerable groups without increasing their vulnerability?
- What are the laws about children's participation in research in the country where your study is taking place?
- What are levels of literacy in your research areas? How can you make sure that participants really understand the consent process?
- How can you involve children in planning your research and informed consent processes?
- What services are available in the area to help vulnerable children exposed by the research?

**Contributed by:** Lucie Cluver, Franziska Meinck and Mark Boyes. Young Carers South Africa, University of Oxford.

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## **Case study 17: Maintaining confidentiality of responses and preventing social desirability bias with an innovative method: The polling booth in research on early marriage, including child marriage**

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### ***Background context:***

An impact evaluation, funded by the International Initiative for Impact Evaluation (3ie), of Breakthrough's early marriage campaign in Bihar and Jharkhand, India, is currently being conducted by Catalyst Management Services (CMS). Breakthrough is an international Human Rights Organization that focuses on gender and media strategies. One of the key goals of this programme on early marriage including child marriage is to foster the agency of adolescents when it comes to decision-making regarding marriage. The interventions that Breakthrough has planned include activities through which they expect to reach out to adolescents with the message that early marriage including child marriage violates the rights of the child.

The data that have been collected in this study include indicators that measure knowledge, attitudes, and practices related to marriage. This type of information is usually collected using household surveys and interviews. In addition to the household survey, an innovative method called Polling Booth is described in this case study for both the adolescent and adult participants. The polling booth method allows sensitive questions to be asked that are usually prone to social desirability biases, and which cannot be answered through traditional household surveys. This method adds depth of understanding on the topic of early marriage including child marriage which the household surveys fail to determine. We used the polling booth method at the community level. Some participants may have already been respondents to the household survey. These are voluntary community level respondents who are randomly assigned to this exercise, which ensured deep exploration of sensitive issues. The data is analysed at the village level.

### ***The ethical challenge:***

One of the significant challenges that arose during the inception of the study, and was reinforced at the pilot stage, was that early marriage including child marriage is a sensitive issue and often getting accurate responses on the subject is difficult because it is associated with a social desirability bias. People are reluctant to admit to the practice because of fear of repercussions, since child marriage is illegal as per the Prohibition of Child Marriage Act. This problem is further complicated when adolescent respondents are concerned because accurate answers may elicit punishment from their parents as well.

Sensitive issues that were explored in the research included:

1. Incidence of forced marriage due to religious or financial consideration.
2. Early marriage including child marriage as a legal/social sanction for early sexual activity.
3. Harassment from society for not being married at an appropriate age - institutional sanction of early marriage including child marriage.
4. Early marriage including child marriage due to harassment of religious groups.

**Choices made:**

One of the ways CMS has sought to address this ethical dilemma is by obtaining consent from the parents and guardians and explaining to them the importance of adolescents participating in the survey. CMS also hired an equal number of male and female field investigators so that adolescents may feel more comfortable answering some of the more sensitive questions related to sexuality, sexual harassment, and reproductive health awareness, which were included in the survey.

To address social desirability bias in particular, wherein respondents under-report the practice of early marriage including child marriage, or the pressure to participate in it, CMS has used the polling booth method to obtain responses to sensitive questions. This methodology was initially used by CMS and Mahila Samakhya to collect data on sexual behaviour for studies on HIV/AIDS. The tool was developed to collect information on questions on which it is difficult to get reliable data in the household settings, or where respondents are reluctant to participate in a group setting, such as a focus group discussion. The polling booth method utilises secret voting, where Yes and No questions are read out in the local language, and using a portable polling box, 8 to 10 participants enter green (Yes) or red (No) cards into the box for each question. To maintain privacy and confidentiality of participants' responses, the respondents carry out the exercise separated from each other through cloth partitioning. The booths have physical barriers that prevent access/sight of the responses. The respondents are aware of others' participation in the study, but are completely unaware of others' responses to the questions. The red and green cards are indexed with the question number and after the polling booth exercise is complete the cards are compiled and the responses are logged. The response collecting cups/vehicles are also covered, so that the respondent has complete privacy of their responses. At the start of the secret voting process respondents are also informed about the importance of the study and how their answers to the questions will be kept anonymous.

**Reflexive questions/considerations:**

Due to the positive experience of CMS and Mahila Samakhya using the polling booth method in the survey on HIV/AIDS, CMS has utilised the same method in the survey on early marriage including child marriage. Use of the polling booth method allows for consideration of ethical issues in relation to confidentiality and privacy.

The polling booth method was useful for the following reasons:

1. The nature of participants' responses is anonymous.
2. Social desirability pressures surrounding questions about sensitive issues are addressed.

3. Our experience shows that more depth and divergent responses are achieved when sensitive issues need to be discussed using the polling booth method compared to focus group discussions.
4. Participants' views are represented equitably, giving the most marginalised, or weaker sections of the community a safe space for responses.
5. The polling booth method is not dependent on literacy.
6. The polling booth method has been appreciated by the community as a safe space to vent their concerns.
7. Parents were more comfortable allowing their children to participate in the polling booth method rather than individual questionnaires.

The polling booth tool for this study is still at the design stage and the feedback received from its usage here will inform future studies that CMS undertakes as well.

**Contributed by:** Ms Urvashi Wattal (CMS) and Dr Angela Chaudhuri (Swasti-Health Resource Center), India.

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### **Case study 18: Interviewing children with disability in the presence of a parent**

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#### ***Background context:***

Traditionally, social researchers expected parents or other adults to act as proxies for the authentic voices of children with disability. Such exclusionary approaches to childhood disability research were often grounded in assumptions about the inability of children with disability to have or express their opinions. In recent decades a growing body of participatory research has used a range of creative methods for engaging with children with disability and upholding their right to have their voices heard. When planning to conduct interviews with children with disability, the dynamics of whether or not to have a parent present are an important consideration. In some cases parents assume they should be present because they are expected to provide information on behalf of their child. Parents may also be interested in hearing their child's views or be concerned about their child's safety or support needs. Alternatively, a child may choose to have their parent present as they are a trusted adult who knows them well and who can provide support. The researcher may also wish to have a parent present to provide reassurance for the child or to help understand their child's preferred communication method. However, children with disability should still have the same opportunities as children without disability to express a preference about whether they would like their parent present during a research interview. The views of children with disability are likely to be different to those of their parents and they may prefer to share their views with the researcher without the surveillance of their parent. This case study is drawn from a research study that examined the provision of family support services for children with intellectual disability in Northern Ireland. A key objective of the research was to ascertain the views of children and consult them about their experiences of family support services.

#### ***The ethical challenge:***

The study involved interviews with children with intellectual disability over the course of three visits in the family home. Before visiting children, the

researcher discussed the research process with parents and explained that some children may wish their parent to be present and others may not. The researcher explained that the child would make a decision on this matter, but would also be free to change their mind. On first visits, the researcher consulted each child about their preference of being interviewed on their own or having their parent present. In one case a child indicated a preference to meet the researcher on their own.

The researcher informed the parent of their child's preference and agreed with the parent that they would meet their child alone on the next visit. On the second visit, after welcoming the researcher into the family home, the parent continued to stay in the same room with the child and researcher. The researcher was unsure if the parent had forgotten their earlier discussion about meeting their child on their own or if they still assumed they should remain present. The researcher had to decide how best to address this issue without causing distress for either the child or parent. She was also mindful that her response to this ethical dilemma would send a message to the child about whether the researcher respected and prioritised their views and preferences which could impact on the child's participation in the interview.

The researcher could proceed with the interview and ignore the issue of parental presence unless the child raised it as a problem. This approach would avoid confrontation and ensure the parent did not feel excluded. However, this approach would fail to prioritise the child's preference and could impact on their interview responses as the adults present would be in control of the research process. Instead, the researcher could speak with the parent on their own to explain the research process again and offer them an opportunity to discuss any concerns. However, this may lead the child to believe that the adults are privately discussing their involvement in the research and reaching a decision without including them. An alternative choice would be to address the issue with the child and parent both present. This option may lead the child to feel they have upset their parent by excluding them and to feel pressured to change their mind. However, this approach would ensure that the issue is addressed in a transparent way with both the child and parent.

### ***Choices made:***

The researcher chose the latter option, with both the child and parent present. She took great care to approach the subject in a sensitive and supportive manner. Explaining that the child's views were the main priority for the researcher and reminding the child and parent about the child's expressed preference on the previous visit was a good starting point. The parent explained that they had become accustomed to remaining present during visits from professionals as it was usually assumed that they would provide information on behalf of their child, especially when there were concerns that their child may not be able to answer some questions. The researcher explained the purpose of the research again and emphasised that she was primarily interested in their child's views and it was fine if their child was not able to answer all of the questions or did not wish to answer some questions. The child also advised their parent that they felt comfortable being on their own with the researcher as a range of communication tools were provided to support their participation, including drawing, sentence completion, computer-assisted techniques and sign cards. Following this discussion, the parent was happy to leave the room and for their child to meet the researcher on their own for the next two visits.

### ***Reflexive questions/considerations:***

- Power dynamics between children with disability and parents are an important consideration during interviews in the family home. Parents

can be an important source of support for children with disability and help to facilitate their participation in research interviews. However, they may also dominate the discussion by re-interpreting or correcting their child's responses.

- Researchers need to use creative methods to engage children with disability in the research process and ensure that their views are prioritised whether or not their parent is present.
- Decisions researchers make when presented with conflicting child and adult opinions send a powerful message to children with disability about their involvement in, and control of, their participation in the research process.
- The expressed preferences of children with disability about how to participate in the research process should be respected.
- What could the researcher have done if the child or parent became upset during the discussion about the child being interviewed alone?
- If the parent insisted on being present, what could the researcher do? Would it be appropriate to conduct the child's interview with the parent present knowing it was not the child's preferred approach?
- In cases where children prefer their parent to be present, what techniques could the researcher use to ensure the views of the child are prioritised?
- What are the risks for the researcher when meeting children on their own?

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**Contributed by:** Dr Berni Kelly, Senior Lecturer in Social Work, Queen's University Belfast

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## **Case study 19: Child protection and confidentiality: Surveying children's experiences of violence, abuse and neglect**

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### **Background context:**

In 2008 the National Society for the Prevention of Cruelty to Children (NSPCC) decided to set up a comprehensive UK-wide study of the prevalence and impact of violence towards children and young people at home, in school and in the community. The study was the first ever in the UK to ask children and young people directly about all forms of violence experienced during childhood and within the past year. A UK-wide household survey was conducted in 2009 with 6196 participants, of whom 2160 were parents/carers

of children under 11 years, 2275 were children and young people aged 11 to 17 years and 1761 were young adults aged 18 to 24 years. See [www.nspcc.org.uk/childstudy](http://www.nspcc.org.uk/childstudy) for further details.

### ***The ethical challenge:***

Most ethical guidelines advise researchers to explain to participants that confidentiality is limited by child protection concerns. In the NSPCC study, age appropriate Computer Assisted Self Interviewing (CASI) methods were to be used to ask children and young people privately about their experiences. This meant that parents would not see the questions asked nor the answers given by their child. In CASI interviews, the interviewer also does not see the participant's answers and will not know at the time whether a person has disclosed experiences of abuse. Adults interviewed this way are generally offered full anonymity. The UK does not have a mandatory approach to reporting child abuse. Would it be ethical to conduct a survey giving full anonymity to children reporting their own experiences of violence and abuse? What would happen if a child was in immediate danger of harm? In what circumstances would it be right to breach confidentiality? If confidentiality was to be limited by child protection responsibilities, how would the purpose of the survey and the limits of confidentiality be explained to children and young people and their parents without causing alarm or upset?

The research was conducted in a high income country with relatively well developed child protection and support and advice services. It had been agreed that all participants in the survey would be given a de-brief booklet that gave information on, and contact details for, relevant services so that parents, children and young people could access help or advice themselves if they wished to do so. But what if a child or young person was upset or wanted access to further help? How would they be able to tell us? What help could be offered directly to children and young people who wanted it and how could this be arranged safely in situations where the perpetrator of the violence might be a parent or another person living within the home?

### ***Choices made:***

Consultations were held with child protection and research experts, with parents and with children and young people, including young people who were known to be survivors of child abuse. These confirmed our view that offering complete anonymity would be unacceptable. Research experts recommended limiting confidentiality and developing within the survey a system to identify children likely to be in immediate danger, as well as those wanting further help or support. Young survivors thought it was important that the young person involved should be given a choice of what to do. If the young person did not want to report abuse to authorities at that time then they should not be pressurised or have action taken against their will. Questions were therefore included in the survey at key points to ask if the young person had felt upset or wanted to talk in confidence with a person who knew about keeping children safe.

An alert red flag system and review process was developed so that if a young person asked for support or if there was a combination of answers in the survey indicating a possible immediate risk, a flag was activated when the interview was uploaded onto the data system. This meant that the interviewer and any other person in the household would not know at the time an alert had been activated, only the NSPCC research team would be told about the alert. In case further action was required, in red flag cases participants' contact details were not disaggregated from survey answers until after review. Strict protocols were agreed with child protection experts for managing the alert, review and referral processes. All interviews that were red-flagged, or where

the respondent had expressed the wish to talk to a professional, were sent to the NSPCC on a daily basis and reviewed by two members of the research team. Cases requiring further action were passed on the very same day to ChildLine counsellors or to the NSPCC child protection services to follow-up.

The thresholds for raising red flag reviews were agreed with child protection experts within ChildLine. Some key issues considered included: the severity and frequency of the abuse, whether or not the child had suffered life threatening injury or rape, whether the perpetrator was likely to be abusing other children; any self-harming or suicidal intent; whether the child or young person already had access to help and support; the child or young person's wishes and feelings; potential for a referral against the child's wishes to help or to pose a further threat to the child's safety.

Parents and children were told before agreeing to the interview that the survey was about child safety and victimization. Following advice from consultations, a show card listing the topics covered, including sensitive issues such as sexual abuse, was given to participants when negotiating consent. Participants were also told that their answers would be anonymous unless they gave information that suggested a child was in immediate danger. Children and young people were reminded on screen during the survey that they could choose not to answer and skip questions if they wanted to. Telling parents about the limits of confidentiality did not lower the response rate for the survey. It was 60.4% which compares favourably with other household surveys at the time conducted in the UK. In total 85 of the 191 reviewed cases were referred on, 35 to ChildLine, 44 to an independent counsellor and six to the NSPCC Helpline. In all but four cases the information was passed on with the agreement of the research participant.

Participants were asked during the interview how they felt about taking part. Of the red-flagged participants, 103 (over 54%) said that taking part in the survey had been very or extremely worthwhile; 38 (just under 20%) said they had been upset by the survey (33 young people and five caregivers). Of the 33 young people who reported being upset, 27 also said that taking part in the survey had been at least quite worthwhile. Our experience of conducting this research confirms that young people want to take part and want to express a view about their own experiences of violence, even when this may be upsetting.

#### ***Reflexive questions/considerations:***

- What might be the benefits as well the risks of harm in asking children and young people about their experiences of violence and abuse in the context in which you plan to conduct your research?
- How could you best use the expertise of young survivors and child protection professionals to inform your approach to child protection and confidentiality in research?
- This research was done in the context of a high income country with relatively well developed child protection services. How would you go about identifying appropriate sources of support and help for children and young people when conducting similar research in contexts where services are limited and public attitudes to victims of violence and abuse are hostile?
- If sources of support are very limited, should funders of research be expected to provide some additional resources to help children directly?

**Contributed by:** Lorraine Radford, Professor of Social Policy and Social Work, University of Central Lancashire, Preston, UK.



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## Case study 20: Peer research and young people in and leaving out-of-home care

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### **Background context:**

Care Matters: Time for Change (Department for Education and Skills, 2007) identified the importance of narrowing the gap in attainment between children in and leaving out-of-home care and their peers in the general population. Right2BCared4 was one of the initiatives that was piloted with the aim of improving outcomes for young people making the transition from care to independence. The pilot was based on the following principles:

- Young people should not be expected to leave care until they reach 18 years old;
- They should have greater say in decision-making preceding their exit from care; and
- They should be properly prepared for independent living.

The Centre for Child and Family Research, Loughborough University, in collaboration with the National Care Advisory Service (NCAS), adopted a peer research methodology to promote young people's active participation in the evaluation. This involved training and supporting young people who had experienced care to get involved in all aspects of the research from the development of the research tools to analysis and write up of the findings (see Edwards, 2011; Munro et al., 2010; Munro et al., 2011; National Care Advisory Service and SOS Children's Villages, 2012). Managed well the approach can empower all those involved and provide young people with the opportunity to inform child welfare policy and practice. However, it also raises ethical challenges and critical consideration needs to be given to safeguarding both participants and the peer researchers.

### **The ethical challenge:**

As part of the Right2BCared4 evaluation children in out-of-home care and care leavers were invited to complete a survey. Young people were given the option of completing this independently (online or hard copy) or over the phone with a peer researcher. During one of the telephone interviews a survey participant made inappropriate sexual comments towards a peer researcher. As a consequence the peer researcher terminated the phone call. In line with agreed protocols they notified a member of staff from the local authority about the incident. The support worker then made contact with a member of the research team and suggested informing the survey participant's local authority to notify them who had made these comments. The limits of confidentiality outlined during the informed consent process stated that:

In exceptional circumstances anonymity and confidentiality would have to be broken, for example, if say a child or young person is being hurt by someone, or is likely to be hurt by somebody's actions. In these circumstances advice will be sought from a senior manager from another local authority who will advise the research team as to whether we need to make your social worker aware of what you have told us.

The peer researcher was not distressed by the incident and the research team's view was that the incident was not serious enough to warrant breaching confidentiality and disclosing the information. Moreover, the nature of the

comments would not have prompted action if the young person concerned was not in out-of-home care. The support worker disagreed on the basis that the comment may reflect a pattern of behaviour. S/he took the view that the local authority should be informed so they could assess the situation and take measures to address the matter with the young person concerned.

**Choices made:**

As the support worker and research team could not reach a unanimous agreement about the best course of action it was agreed that advice would be sought from a senior manager from a local authority that was not directly involved in the evaluation (in accordance with CCFR protocols). The independent senior manager advised against contacting the survey participant's social worker on the basis that the incident was not sufficiently serious to warrant this breach in confidentiality. The support worker was informed of this decision, which was accepted.

**Reflexive questions/considerations:**

- Participant and (peer) researcher safety must be of paramount concern throughout the research cycle;
- Research exploring children's experiences of out-of-home care can raise sensitive issues and systems should be put in place to ensure that young people can access support;
- Preparation, training and on-going support is vital to the successful completion of peer research projects;
- Clear protocols establishing respective roles and responsibilities in the conduct of research involving vulnerable groups need to be established;
- Confidentiality should be "honoured, unless there are clear and overriding reasons to do otherwise" (British Sociological Association, 2002, p.5). Perceptions of when information should be disclosed may differ. It is important to ensure that the limits of confidentiality are clearly outlined to all parties and that mechanisms are put in place to ensure the timely resolution of differences of opinion;
- On-going dialogue with gate-keepers is important in the conduct of effective research with vulnerable children.

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**Contributed by:** Clare Lushey (Research Associate) and Emily R. Munro, (Assistant Director), Centre for Child and Family Research, Loughborough University.

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## **Case study 21: Ethical considerations when using incentives in youth research**

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### ***Background context:***

The Queensland Youth Development Research Project (YDRP) used questionnaires to explore the role of youth development programmes in the positive development of young people, aged 12-18 years. We were interested in gaining a better understanding about the programme features which might contribute to positive developmental outcomes and the well-being of young participants. For our research to have sound outcomes we needed a large number of children from diverse backgrounds to take part, thus we needed to gain the interest and consent of young people and parents, guardians, programme leaders and, when a programme was located in a school, school principals.

### ***The ethical challenge:***

We had to decide how we might successfully engage with young people to encourage them to take part in the YDRP. We explored the pros and cons of different incentive options. These ranged from a prize draw with a single or small number of high value prizes or a large number of low value prizes, giving each participant a small pack of nuts or lollies, stickers, pens, pencils, a small token payment and a certificate of appreciation as a reward or 'thank you' for participating. We discussed how we should describe the research project and present information about it so the information would encourage participation (accessible, honest, informative, do-able and appealing) and not act as a disincentive to participation (too much information, too onerous and uninteresting). Above all, we discussed how to make sure our strategy was a balanced one. This involved designing an incentive strategy that would be relevant and attractive to young people but was not coercive, did not apply undue pressure and mediated the differential power relationship between young people and (in the context of this research) adults in their roles as parent, guardian, teacher and programme leader. We discussed how to ensure respect for young people's right to say no or yes to their participation. We debated whether we should keep the gift, payment or reward a secret until each young person finished the questionnaire. We considered how each incentive option might impact on the health, safety and well-being of young people and how different incentives might appeal to particular age and gender groups. How to best encourage and support young people to not skip questions and to complete the questionnaire was also an important consideration in the development of our participation strategy.

**Choices made:**

We chose a strategy that relied on altruism and interest in the project to gain support and consent from parents, guardians, teachers and programme leaders. We hoped young people would choose to participate because they saw the value of the research. However, we decided to use a mix of incentives to encourage young people to take part and to recognise the effort of those who chose to do so. We adopted a multifaceted incentive strategy designed to reinforce rather than replace or undercut the intrinsic altruistic motivation of young people to participate. We revealed all of the incentives at the outset of the research project because we felt everyone involved - young people and adults - needed to be fully informed about participation. Considerable effort was put into providing written and verbal information that was clear, age appropriate, honestly outlined potential risks and benefits of the research and made it clear that participation was voluntary.

We decided not to offer food as a thank you gift because of concerns about exposing young people to the risks of unhealthy or allergy-likely food. Instead, we decided to formally recognise the time young members spent participating by presenting each young person with an individually named certificate of appreciation. We also verbally thanked young people at the time of site visits and wrote visual messages of 'thank you' at the beginning and end of the questionnaire and in the information and consent packages. We gave young people a choice of stickers or temporary tattoos which we hoped included enough design and colour diversity to appeal to both genders and to different age groups.

A key part of our strategy included a financial incentive. Each young person was offered the opportunity to go into a prize draw. We provided a large number of small value prizes (\$20 gift vouchers) rather than a small number of high value prizes. We felt this was a more equitable form of incentive because it was more widely shared. Though each single prize was small in value, the total value in the budget was not insubstantial and young people had a one-in-four chance of winning. The \$20 gift vouchers included iTunes gift cards, movie passes and department store gift cards. Participating youth organizations requested that, based on their duty of care to do no harm, we only offer gift vouchers that were retail store specific and not retail chain specific to reduce the chance they could be used to purchase alcohol.

Motivational props were introduced throughout the questionnaire ranging from "Thank you! That's the first section done!" to "Well done! Keep going!" This was a positive and easy strategy to adopt, and judging by participants' comments, the use of motivational statements worked well. These statements also motivated us when processing the questionnaire data. While our participation strategy was resource intensive, anecdotal evidence and participation data (opt-in rate of 60%, questionnaire completion rate 97%) suggests a high level of efficacy.

**Reflexive questions/considerations:**

Reflecting on our participation strategy vividly illustrated how complex the many layers of considerations are that we must consider when using incentives. There were two main areas where we felt we could have done better. First, we did not spend enough time considering the needs of the adults who we relied on to help facilitate youth participation (e.g., return of consent forms). Too many young people wanted to take part but couldn't because they did not have their signed parental or guardian consent form.

Our research would have been more effective if we had developed a strategy to support the return of consent forms. Second, while we felt the participation strategy we adopted would not lead to young people feeling coerced or pressured to take part we do not know this for sure. This raises two main questions:

1. How do we design components of our research to more actively seek out and document young people's opinion about why they choose to take part or not and what the decision-making process feels like for them?
2. Given the role adults play as gate-keepers and supporters, how do we gain a better understanding about what their needs are and what the research process feels like for them and why they do, or do not, choose to support young people's participation in our research?

### **Reference**

Seymour, K. (2012). 'Using incentives: encouraging and recognising participation in youth research', *Youth Studies Australia*, 31 (3), 51-59.

**Contributed by:** K. Seymour, PhD Candidate, School of Criminology and Criminal Justice, Key Centre for Ethics, Law, Justice and Governance, Griffith University, Australia.

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## **Case study 22: Payment in different contexts: How can payment reflect local considerations?**

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### **Background context:**

Young Lives is an international study of childhood poverty, involving 12,000 children growing up over 15 years in Ethiopia, the state of Andhra Pradesh in India, Peru and Vietnam. Two cohorts of children – a younger cohort who were born in 2001-02 and an older cohort born in 1994-95 – are being followed. A variety of survey and qualitative methods are being used to collect data with children, parents, and others in communities. See [www.younglives.org.uk](http://www.younglives.org.uk)

### **The ethical challenge:**

The decision to compensate or pay research participants raises ethical questions. Payments may be made to reimburse expenses; to compensate for time, inconvenience and possible discomfort; to show appreciation for participants' help; or to pay for people's help. However, payments should not be made to encourage people to take part as an incentive as no persuasion or pressure of any kind should be put on people to become involved with the research (Alderson & Morrow, 2004). Local considerations also impact on how decisions are made regarding payment and remuneration for participation in research, such that different forms of compensation may be needed to suit different locations within the same study.

Ethical dilemmas surrounding payment for research participation are clearly demonstrated in contexts of acute poverty such as the Young Lives study locations. During the first round of qualitative research, the research team noted that people perceived Young Lives as an aid agency and money received as aid. In the second round, researchers paid more attention to explaining that Young Lives does not provide any aid to the community in general and to the research households or children in particular. However, at each round, fieldworkers report that they are frequently asked for help.

(This is not specific to developing countries but happens everywhere). If there are misconceptions about the purpose of research, such as bringing benefit to individual children and/or being perceived as a form of aid, an ethical dilemma in regard to informed consent is also raised. Is consent freely given when the purpose of research and payment is misunderstood?

### **Choices made:**

Each country research team deals with compensation for people's time in locally specific ways, reflecting cultural contexts about the value of people's time, their willingness to undertake research activities for the common good, and the reality of poverty and not having the capacity to miss a day's wages to spend time talking with researchers.

Some country teams pay respondents, including children, for their participation. Others give small gifts as a "thank you". Norms and patterns of reciprocity, notions of community, and/or doing what the government tells you (for example, in Vietnam where government census enumerators are administering the survey) are likely to affect people's participation. However, paying respondents (adults and older cohort children) to compensate them for their time may cause some confusion. For example, in Ethiopia, children were encouraged to use the money to buy school materials.

Other country research teams (Peru, for example) give small gifts as a "thank you", as well as some supplies to local schools. In India, research teams provide some resources to schools (for example) as requested by local community leaders to benefit all children in the locality, and up to 2009, did not make direct payment to research participants. However, in some cases, research respondents consider it unfair that they are giving up their time but benefits are for everyone in the community.

### **Reflexive considerations:**

- The question of remuneration to Young Lives' participants is becoming increasingly important as economies become more market-oriented. For example, in Andhra Pradesh, the National Rural Employment Guarantee Scheme, which pays household members at least Rs.100/- for a day's manual labour, has recently been implemented. Respondents are now aware of the financial value of their time, and are more likely to expect monetary compensation. Thus the decision has been made to compensate respondents for their time in subsequent research rounds.
- Young Lives may run a risk of people refusing to participate in future; fieldworkers report that it is already difficult to persuade people to continue to be involved. This is not to suggest that people should not be paid when they most need it – after all, the duress to accept monetary incentives is created by poverty, not by the incentives. Rather, it is to suggest that care has to be exercised, and awareness that it may be difficult for people living in poverty to refuse requests to participate in the research.

### **References**

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Morrow, V. (2009). *Young Lives working paper*. Available online [www.younglives.org.uk](http://www.younglives.org.uk)

**Contributed by:** Virginia Morrow, Young Lives, University of Oxford.





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# CONCLUSION

The ERIC compendium and website have been designed to provide a rich repository of evidence-based information and resources to guide and improve research involving children.

# CONCLUSION

These resources are  
also available on the  
ERIC website  
[www.childethics.com](http://www.childethics.com)

The content covered in this ERIC compendium is extensive and the issues raised are complex and multi-faceted. Ethical considerations are woven throughout any research endeavour but these merit particularly close attention when such research involves children, either directly or indirectly. The development of ERIC has been premised on the belief that the human dignity of all children must be honoured, and their rights and well-being respected in all research, regardless of context.

To this end, the ERIC project has developed a range of resources, provided in this compendium, for those committed to ethical research involving children, including an International Charter, Ethical Guidance, a collection of case studies, and Questions to guide ethical research involving children. While these resources, also included on the ERIC website ([www.childethics.com](http://www.childethics.com)), have been generated out of extensive research and consultation, their value will be limited unless underpinned by ongoing critical thinking, reflective dialogue, inter-sectoral collaboration and international engagement.

Far from suggesting there are easy answers or clear-cut solutions to the ethical tensions and questions inherent in research involving children, the approach taken in the development of ERIC has been to privilege these tensions and questions. The rationale underpinning such an approach is that those engaged in research are committed to, and capable of, the kind of reflexive practice required to navigate and apply, with skill and integrity, the core ethical principles of respect, benefit and justice in research.

In drawing this ERIC compendium to a close, then, it may be helpful to briefly recap on some of the foundational issues that invite continuing engagement into the future.

## ETHICAL RESEARCH INVOLVING CHILDREN (ERIC) ADVOCATES:

- A reflexive approach in attending to the complex ethical issues that can emerge with research involving children.
- Recognition of children and young people as persons in their own right and as worthy and capable of involvement in research.
- Respect for the rights of children and young people as afforded to them under the UNCRC, including the right to have a say and to be heard, in the context of well-planned, ethical research.
- Awareness of and reflection on the multiple contexts that shape children's lives and experiences, and inform and influence research involving children, both implicitly and explicitly.
- Close attention to the multiple relationships that are formed around the research endeavour.
- Critical engagement with the ethical principles of respect, benefit and justice in decision-making that informs research practice.
- Engagement in dialogue with members of the international research community to foster stronger collaboration.

There is no package of resources or ethics review process that can ultimately mandate and/or monitor the above activities. Instead, the ERIC compendium and website have been designed to provide a rich repository of evidence-based information and resources to guide and improve research involving children, and to provide a platform for further critical reflection, dialogue and collegiality across the international research community, irrespective of geographic, social, cultural, disciplinary, theoretical or methodological context. Further, it is hoped that ongoing sharing of experiences, resources and ideas will support researchers and other stakeholders, across a range of contexts, to further develop, enrich and sustain high quality, ethical research involving children.



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# RESOURCES

Glossary of Terms  
References

Review of Other Ethical Guidelines



# 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.

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# REVIEW OF OTHER ETHICAL GUIDELINES

## REVIEW OF GUIDELINES: HARMS AND BENEFITS

Guidelines on harms and benefits in research involving children include significant emphasis on researchers' responsibilities to justify the inclusion of children in research and protect them from harm, during and after the research, with additional emphasis on children who are particularly vulnerable.

- There should be clear and justifiable reasons why children are being included in the research, with researchers able to substantiate that the information is not readily available elsewhere (WHO, 2011). Children should be protected from both over-research and under-research (Alderson & Morrow, 2011).
- Researchers are responsible for protecting children from any physical, social or emotional harm that might arise from the research (Ennew & Plateau, 2004; Laws & Mann, 2004). Therefore, researchers should do everything possible to anticipate any adverse consequences and ensure that participation will not lead to harm (Alderson & Morrow, 2011; Schenk & Williamson, 2005), including developing strategies to minimise any possible distress and managing context-specific risks (Feinstein & O'Kane, 2008), and protecting children from putting themselves at risk (Ennew & Plateau, 2004).
- Care must be taken if the subject is contentious, disturbing or in any way in advance of what the child or young person may be expected to know or understand (Market Research Standards, 2010).
- Researcher responsibility is further emphasised when the children involved are particularly vulnerable, such as children who are unaccompanied, orphaned or separated from family (Schenk & Williamson, 2005). The research must be conducted in a manner that is sensitive to children in complex situations, such as children with disabilities; children affected/infected with HIV/AIDS; children orphaned or separated from families; as well as children who are distressed or known to have been abused (Mwaipopo, 2006).
- Unaccompanied children and those who have lost their families should participate only in research that will directly benefit them (WHO, 2011).
- Dissemination of findings should not pose risk or stigmatisation to children, young people or their families (WHO, 2011).

Guidance related specifically to research in the health/biomedical sector emphasises the importance of benefits to the participating child or others and the need for follow-up support if needed:

- The participation of a child in research should offer the possibility of direct benefit to his/her health. Where no direct benefit is likely, the results should benefit other children who are the same age or have the same disease, condition or disability, and the child should not be exposed to more than minimal risk (Avard, Amuel, Black, Griener & Knoppers, 2011).
- Research should be conducted in settings in which the child and parent can obtain adequate medical and psychological support (CIOMS & WHO, 2002, 2008).

Guidelines in sectors, other than health/biomedical, also address the need for referral processes if children or families require services as a consequence of their participation in the research process:

- All research should have planned protocols for addressing situations of concern and for making referrals for support or protection (WHO, 2011). Community consultation is important to ascertain organizations or agencies that may be able to offer support (Edmonds, 2005; Schenk & Williamson, 2005).
- Alternative services should be sought if there is an absence of child-focused services (Laws & Mann, 2004).

A number of ethical guidelines address researcher safety with reference to strategies, protocols and researcher training:

- Safety for research staff is essential (WHO, 2011) and should be placed above completion of the research tasks at all times (Laws & Mann, 2004). Researcher safety can be attended to with security plans, back up communication systems, secure transportation and team strategies (WHO, 2007).
- Training programmes should establish professional boundaries and self-care for researchers (WHO, 2011).

Ethical guidelines emphasise the responsibility and obligations of the researcher in protecting children and having intervention plans in place:

- Ensuring child protection is an integral part of planning and implementing the research (Feinstein & O’Kane, 2008; WHO, 2007, 2011). It is the researcher’s responsibility to protect children from putting themselves at risk and to intervene when a child is at risk (Ennew & Plateau, 2004; Mwaipopo, 2006).
- The duty of researchers to protect the safety of children overrides their responsibility to guarantee confidentiality (WHO, 2011).
- Talk carefully with the child before taking any action, be transparent about the steps that will be taken and if possible reach agreement with the child about these (Feinstein & O’Kane, 2008).

- The skill of researchers is paramount in dealing with situations that involve balancing risks and benefits of actions and the need for training is highlighted (WHO, 2007).
- The laws of the country in which the research is taking place should be consulted regarding the obligations for researchers to report to relevant services (WHO, 2011).

The ethical guidance literature also addresses the matter of protecting children from the abusive actions or poor practice of research staff. This includes recommendations to adopt child protection policies and staff conduct codes:

- Some ethical guidelines recommend adopting, or do adopt, a child protection policy and/or an ethical Code of Conduct for researchers (Laws & Mann, 2004). Child protection policies, such as the Save the Children Child Protection Policy (2003), provide clear guidelines for managing concerns about child protection, and conduct codes incorporate guidelines for recruitment, training and ongoing conduct of staff.
- Research staff should avoid actions or behaviour that may be construed as poor practice or potentially abusive (Laws & Mann, 2004).

## REVIEW OF GUIDELINES: INFORMED CONSENT

Existing guidance clearly indicates that children should be required to give consent to participate in research:

- It is essential to have full agreement of children to their participation in research (Schenk & Williamson, 2005).
- Children must be made aware who else consent is being sought from (WHO, 2011). In group settings, individual consent must still be obtained (Shaw, Brady & Davis, 2011; WHO, 2011).
- Consent is usually signified by the written signature of the research participant, but in certain situations the full informed consent process may be carried out verbally by research staff (WHO, 2011).
- Covert research, in which children are not aware the research is taking place and have not given consent for their involvement, is not acceptable (Laws & Mann, 2004).
- Children and young people's consent must always be voluntary (Laws & Mann, 2004). Children should not be enticed, persuaded or intimidated into giving consent (Schenk & Williamson, 2005).

A key topic emphasised in the existing ethics documentation is that children should be provided with information about the research and that researchers should make efforts to ensure that children understand what is involved. This may involve using strategies to encourage and/or ensure understanding, including providing appropriate information, allowing the child time to consider participation and being clear about what the research will and will not provide.



- Consent procedures should be designed with consideration of the child or young person's developmental stage, personal experience and circumstances, and information tailored accordingly (Shaw et al., 2011; WHO, 2011).
- Children must be fully informed to be able to understand and consent to participation in research (Alderson & Morrow, 2011; Laws & Mann, 2004). Information must be child-friendly and age appropriate (WHO, 2007). Steps should be taken to ensure that children understand the research process and what they have consented to do, for example, by asking children questions one-to-one or asking them to summarise what they have been told (Ennew & Plateau, 2004; Laws & Mann, 2004; WHO, 2011).
- It is important that researchers spend time verbally explaining the research to potential participants (Alderson & Morrow, 2011), to help ensure that there are not mismatches in understanding.
- It will not always be appropriate to inform children about all items when seeking consent, as their age or cognitive ability may preclude this. Researchers may wish to seek advice from experts as to what information it is appropriate to impart and how best to do this for younger children or those with learning disabilities (Shaw et al., 2011).
- Children should have sufficient time to consider the information, reflect on their decision, talk to people about it and have any questions answered before giving their consent (Avard et al., 2011; Shaw et al., 2011).
- Special care must be taken in gaining consent to avoid any risks of 'therapeutic misconception' in which individuals do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of any potential benefit (WHO, 2011).

## REVIEW OF GUIDELINES: PRIVACY AND CONFIDENTIALITY

Guidelines on privacy and confidentiality in research involving children emphasise the importance of maintaining confidentiality and protecting participants' identities. However, in some contexts privacy is challenged by other ethical concerns, such as child protection issues, and cultural and social circumstances preventing privacy in the process of collecting information. The tensions that may arise are evident in some of the existing ethical guidelines:

- Confidentiality must be maintained and participants' identities protected (Feinstein & O'Kane, 2008; Laws & Mann, 2004; WHO, 2011).
- Interviews should be conducted in privacy, to the extent that this is accepted in the local community (WHO, 2011).
- An important exception to keep in mind is the recommendation that parents should be given the opportunity to observe clinical/epidemiological research, so as to withdraw the child if the parent decides it is in the child's best interests to do so (CIOMS & WHO, 2002; 2008). [This has relevance with regard to ensuring that children are not harmed through their participation in research.]
- For the researcher's own protection, as well as that of the child, it is important never to be alone in a house or building with the child (Shaw et al., 2011).

- If it is a child's wish (not a parent's wish) that a parent or friend be present during research interviews the researcher should agree to this (Shaw et al., 2011; Laws & Mann, 2004).
- Recent ethical guidelines tend to recommend that confidentiality be breached if the researcher suspects child abuse, has concerns for the child or another person's safety (Schenk & Williamson, 2005; WHO, 2011), or has a communicable or sexually transmitted disease which is required by law to be notified (CIOMS & WHO, 2002, 2008). Researchers are advised to inform potential participants of this during the consent procedure, and have a planned strategy in place if needed (Schenk & Williamson, 2005; WHO, 2011).

Some ethical guidelines advocate developing protocols regarding aspects of confidentiality in data collection and storage processes:

- Confidentiality protocols should be made clear to all the research staff (Laws & Mann, 2004; WHO, 2011).
- Data should be securely stored and protected, especially when it is sensitive (Shaw et al., 2011). Data should be kept separate from identifying information (Laws & Mann, 2004). Personal data should be accessible only by those who need to use it, and sensitive data must be kept in a locked room with controlled access, or kept in a locked filing cabinet or a locked drawer, or in password protected computer files (Shaw et al., 2011). Consideration needs to be given to the transporting and storage of audio or videotapes (Laws & Mann, 2004). Direct identifiers should be removed or destroyed at the earliest possible opportunity (Avard et al., 2011).
- Safeguards adopted to ensure that privacy and confidentiality are maintained should adhere to local law (Avard et al., 2011).

Specific guidance relates to the privacy of the research participants so that they are not identifiable in the dissemination of findings:

- To achieve public confidentiality some researchers omit participants' names, use pseudonyms and remove or disguise identifying information from reports, including aspects of stories in qualitative data while maintaining integrity of the findings (Laws & Mann, 2004).
- As far as possible, researchers should share findings with participants before making them public and seek their consent to plans for distributing publications or communication information, especially photos and video recordings (Ennew & Plateau, 2004). Researchers are advised to discuss issues with children about maintaining confidentiality, especially in assessing the risk in using potentially identifying material in reports (Feinstein & O'Kane, 2008). It is important that researchers avoid giving children and young people written documents or other materials related to the research study to keep if this potentially places them at risk (WHO, 2011).

## REVIEW OF GUIDELINES: PAYMENT AND COMPENSATION

Existing literature points to arguments both for and against the use of payment in research, depending on the form of payment and the context in which the research is occurring. Ethical guidelines tend to advise researchers

against giving incentive payments for participation in research:

- Offering incentives is best avoided, as it may influence participation (Schenk & Williamson, 2005), constitute persuasion or pressure on participants (Alderson & Morrow, 2011), potentially create a sense of obligation, raise expectations or become a form of control (Laws & Mann, 2004). Payment of children should be linked to their attendance and involvement in the research study and independent of their responses and behaviour during the process, including the decision to stop participation or not answer certain questions (Schenk & Williamson, 2005).
- Some organizations' guidelines generally advise against financial payment for research participation (mostly due to concerns regarding incentives) (Edmonds, 2005; Ennew & Plateau, 2004).
- Save the Children guidelines (Laws & Mann, 2004) outline the pros and cons of providing incentives for participation in research. Arguments in favour of incentives for respondents include that it can increase participation levels considerably, especially in poor communities; expedite recruitment and hence save time and resources; recognise the value of respondents' time and contribution; and prevent sample bias by helping to ensure poor people are not prevented from participating. Arguments against providing incentives to respondents include the cost involved; the possibility of compromising voluntary consent by creating a sense of obligation; the possibility of sample bias through encouraging those who want recompense to participate and possibly say what they think the researcher wants to hear; and it can create expectations of recompense for participation in research in the future.

Some ethical guidelines emphasize the importance of taking the local context into account in decision-making regarding payment of research participants. This includes recommending consultation with local and national stakeholders, payment to benefit communities (rather than payment to individual research participants) and consideration of people's livelihoods and local living standards in determining the payment, with a particular awareness of situations of poverty and disadvantage:

- The nature of payment and compensation should be determined by local consultation (Schenk & Williamson, 2005) or national-level deliberation with selected stakeholders (Edmonds, 2005).
- It may be appropriate to give payment to the community for the benefit of the children involved in the research, their families and the community (Schenk & Williamson, 2005). If so, this should be discussed with broad representation of community members and stakeholders to ensure fair distribution.
- Children's participation should be recognised and recompensed, in line with local living standards, cultural and socio-cultural factors, and their contribution (Laws & Mann, 2004; Schenk & Williamson, 2005; Shaw et al., 2011; WHO, 2011).
- Researchers are advised to be transparent about payment or remuneration to avoid fuelling community tensions, particularly in situations of acute poverty (Feinstein & O'Kane, 2008; Hart & Tyrer, 2006).
- The livelihoods of research participants should not be adversely affected by their participation in research (Ennew & Plateau, 2004; Feinstein & O'Kane, 2008)

Some ethical guidance suggests that payment should be addressed in the planning stages of the research, and considered by potential participants and ethics review boards:

- Any payment or compensation should be decided in advance, prior to recruiting participants (Ennew & Plateau, 2004) and discussed during the consent process (Avard et al., 2011). An ethics review board should review the proposed payment plan (Avard et al., 2011).

## ORGANIZATIONS' DOCUMENTATION RELEVANT TO RESEARCH ETHICS

**Avard, D., Black, L., Samuël, J., Griener, G., & Knoppers, B. M. (2012). Best practices for health research involving children and adolescents: Genetic, pharmaceutical, longitudinal studies and palliative care research.**

Centre of Genomics and Policy, McGill University and Maternal Infant Child and Youth Research Network (MICYRN); with the collaboration of the Institute for Human Development, Child and Youth Health, Canadian Institutes of Health Research and Ethics Office, Canadian Institutes of Health Research. Available from: <http://www.pediagen.org/>

Description: These Best Practices provide an overview of international and Canadian ethical norms, reflecting the current situation in Canada regarding health research involving children and adolescents. For a more critical analysis of these norms, please refer to *Pediatric Research in Canada* (D. Avard, J. Samuël and B.M. Knoppers (eds), Les Éditions Thémis, 2009) and *La recherche clinique avec les enfants: à la croisée de l'éthique et du droit* -Belgique, France, Québec (ML Delfosse, MH Parizeau et JP Amann (éd.) PUL & Anthémis, 2009). These Best Practices do not provide specific guidance for research involving the First Nations, Inuit and Métis peoples of Canada. For research involving Aboriginal children and youth, the Best Practices should be used in conjunction with the Tri-Council Policy Statement, Chapter 9, "Research Involving the First Nations, Inuit and Métis Peoples of Canada" (<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>).

**Council for International Organizations of Medical Sciences (CIOMS), & World Health Organization (WHO). (2002). International ethical guidelines for biomedical research involving human subjects. Geneva: CIOMS.**

Available from: <http://www.cioms.ch/index.php/texts-of-guidelines>

Extract from introduction (p. 8): "This is the third in the series of international ethical guidelines for biomedical research involving human subjects issued by the Council for International Organizations of Medical Sciences since 1982. It consists of a statement of general ethical principles, a preamble and 21 guidelines, with an introduction and a brief account of earlier declarations and guidelines. Like the 1982 and 1993 Guidelines, the present publication is designed to be of use, particularly to low-resource countries, in defining national policies on the ethics of biomedical research, applying ethical standards in local circumstances, and establishing or redefining adequate mechanisms for ethical review of research involving human subjects."

**Council for International Organizations of Medical Sciences (CIOMS), & World Health Organization (WHO). (2008). International ethical guidelines for epidemiological studies. Geneva: CIOMS.**

Available from: <http://www.cioms.ch/index.php/texts-of-guidelines>

Extract from introduction (p. 6): "Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to control of health problems' (John Last, Dictionary of Epidemiology, 4th edition). This volume sets forth ethical guidance regarding the first part of this definition, namely, how epidemiologists – as well as those who sponsor, review, or participate in the studies they conduct – should identify and respond to the ethical issues that are raised by the process of producing this information."

**Edmonds, C. (2005). Ethical considerations when conducting research on children in the worst forms of child labour in Nepal. Switzerland: International Labour Office (ILO), International Programme on the Elimination of Child Labour (IPEC).**

Available from: [http://www.ilo.org/ipec/Informationresources/WCMS\\_IPEC\\_PUB\\_1341/lang--en/index.htm](http://www.ilo.org/ipec/Informationresources/WCMS_IPEC_PUB_1341/lang--en/index.htm)

Extract from preface (p. v): "Although there is a body of knowledge, data, and documentation on child labour, there are also still considerable gaps in understanding the variety of forms and conditions in which children work. This is especially true of the worst forms of child labour, which by their very nature are often hidden from public view and scrutiny. ... The ILO has carried out 38 rapid assessments of the worst forms of child labour in 19 countries and one border area. The investigations have been made using a new rapid assessment methodology on child labour, elaborated jointly by the ILO and UNICEF. ... The investigations on the worst forms of child labour have explored very sensitive areas including illegal, criminal or immoral activities. ... I am convinced that the important ethical considerations when conducting research on children engaged in the worst forms of child labour contained in this document will contribute to a well-planned and meaningful research process."

**Ennew, J., & Plateau, D. P. (2004). How to research the physical and emotional punishment of children. Bangkok: International Save the Children Alliance, Southeast, East Asia and Pacific Region.**

Available from: <http://vac.wvasiapacific.org/further-reading/violence-against-children-in-the-home.html>

Extract from preface (p. x): "The important purpose of this Handbook is to encourage sensitive and ethical research on punishment of children, wherever possible directly involving children themselves. It provides an invaluable and practical resource kit for both programme managers and researchers. The aim is to reveal children's experiences and their views. The imperative for prohibiting and eliminating all corporal punishment and other humiliating treatment of children is human rights. The human rights standards are clear, but persuading states to honour their obligations and take the necessary actions – law reform, awareness-raising and public education – is not easy."

**Feinstein, C., & O’Kane, C. (2008). Ethical guidelines: For ethical, meaningful and inclusive children’s participation practice. Oslo: Save the Children Norway.**

Available from: <http://tn.reddbarna.no/default.asp?HMFILE=130232>

Extract from preface (p. 1): “These guidelines have been drawn up to ensure ethical, meaningful and inclusive child participation practice, both with and by children, young people and adults, during the Thematic Evaluation and Documentation process. They draw upon existing Save the Children policies, practice standards and good practice guidelines for involving children in research, consultations, advocacy and so on. ... In particular, these guidelines are underpinned by and should always be used in conjunction with the Child Protection Policy of the Save the Children or partner organization and the Save the Children Practice Standards in Children’s Participation (2005).”

**Hart, J., & Tyrer, B. (2006). Research with children living in situations of armed conflict: Concepts, ethics & methods. Oxford: Refugee Studies Centre, University of Oxford.**

Available from: [http://www.rsc.ox.ac.uk/publications/working-papers-folder\\_contents/RSCworkingpaper30.pdf/view](http://www.rsc.ox.ac.uk/publications/working-papers-folder_contents/RSCworkingpaper30.pdf/view)

Extract from introduction (p. 5): “Research about children’s lives conducted in the volatile setting of armed conflict places particular demands upon researchers. The suggestion that researchers should, whenever possible and appropriate, involve children as meaningful participants in that research may seem unreasonable or inappropriate. However, the production of this paper has been motivated by the conviction that participatory research is especially valuable because of the emergency context. Firstly, such an approach is likely to yield richer and more detailed data than a conventional, adult-led approach. These data can be invaluable to the design of interventions. Secondly, engagement in well-planned research activities can offer direct benefits for young participants by enhancing their skills and awareness. In settings of conflict where the young may be required to play an expanded role in their own protection and in the care of others, their personal development is especially important. Our aim here is to equip researchers to most safely and profitably pursue participatory research with children and, to that end, we explore the specific conceptual, ethical and methodological issues concerned.”

**Laws, S., & Mann, G. (2004). So you want to involve children in research? A toolkit supporting children’s meaningful and ethical participation in research relating to violence against children. Stockholm: Save the Children Sweden.**

Available from: <http://images.savethechildren.it/f/download/Policies/st/strumenti.pdf>

Extract from introduction (p. 7): “This research kit is one part of a series of toolkits produced by the International Save the Children Alliance. This part of the toolkit aims to encourage meaningful and ethical participation by children in research related to violence against children. It promotes research that sees children as active agents in their own lives, not passive victims or research ‘subjects’. There are many ways in which children can be more actively involved in research, both as respondents and as co-researchers. This kit aims to give guidance on ways of approaching this work, on ethical issues to be considered, and on techniques that can be used. Case studies from around the world draw on a rich field of participatory research with children that has developed in recent years.”

**Lobe, B., Livingstone, S., Olafsson, K., & Simões, J. A. (2008). Best practice research guide: How to research children and online technologies in comparative perspective. London: EU Kids Online / London School of Economics.**

Available from: <http://www2.lse.ac.uk/media@lse/research/EUKidsOnline/EU%20Kids%20Online%20reports.aspx>

Extract from Introduction (p. 5): "This Best Practice Guide has been compiled by drawing on the multi-disciplinary and multi-method expertise of the sixty plus researchers who comprise the EU Kids Online network. ... Its purpose is to distil the knowledge, experience and insights of those actively researching children's use of online technologies for the benefit of those entering this domain. It is intended to be useful to new researchers, to experienced researchers new to this domain, to those commissioning or evaluating research on children and online technologies, and to students and interested others. The Best Practice Guide is presented in the format of Frequently Asked Questions, since this how new researchers most commonly express their need for knowledge and guidance."

**Market Research Standards (MRS). (2012). MRS Guidelines for research with children and young people. London: MRS.**

Available from: <http://www.mrs.org.uk/standards/consultation.htm>

Extract from introduction (p. 4): "These Guidelines interpret the market research standards (MRS) Code of Conduct (UK) (revised 2010) and provide additional best practice advice. Unless otherwise stated, Guidelines are not binding. Rules B27 to B33 of the MRS Code of Conduct contain specific mandatory provisions relating to research with children. ... Under the Code, children are defined as those aged under 16 years. These Guidelines also provide additional best practice for research with young people aged 16 and 17 years. There is no recommended minimum age for research among children but it is expected that researchers will involve very young children directly in research only when this is necessary and appropriate to the particular project."

**Morrow, V. (2009). The ethics of social research with children and families in young lives: practical experiences. Oxford: Young Lives Research Project.**

Available from: [www.younglives.org.uk](http://www.younglives.org.uk)

Abstract: A great deal of attention is now paid to the ethics of social research. Research governance has expanded, and a burgeoning literature is emerging that describes the processes, practices and questions that arise in social research with children, families and communities. This paper outlines the approach taken to research ethics within Young Lives, a long-term study of childhood poverty in four developing countries. It describes some of the practical difficulties that Young Lives faces, and emphasises the importance of understanding local contexts in undertaking research with children and families in environments that are dynamic and may change rapidly from one year to the next, economically, environmentally and politically. The paper aims to contribute to current debates about research practices, the ethics of longitudinal research with children and research with communities in majority world contexts, in the spirit of shared enquiry and learning.

**Mwaipopo, R. (2006). Children participating in research. Dar es Salaam: Research on Poverty Alleviation.**

Available from: <http://www.repoa.or.tz/index.php/publications/category/briefs/P30>

Extract from abstract: Research with children is important to reach out to a section of society disadvantaged by age in terms of their representation in societal issues. The traditional method of conducting research with children is to use adult researchers who adapt their mode of communication to suit the children as much as possible. The innovative way is to train young people to conduct the research, involving children in the research process as collaborators, not merely using them in data collection by assigning them roles as passive subjects of research.

**National Children's Bureau. (2003). Appendix V: NCB research department data protection guidelines. UK: National Children's Bureau.**

Available from: <http://www.ncb.org.uk/>

Appendix V of the National Children's Bureau's Guidelines for Research details the steps the research department takes to comply with the Data Protection Act 1998 (UK), which came into force in 2001.

**National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1979). The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. U.S. Department of Health, Education and Welfare.**

Available from: [www.videocast.nih.gov/pdf/ohrp\\_appendix\\_belmont\\_report\\_vol\\_2.pdf](http://www.videocast.nih.gov/pdf/ohrp_appendix_belmont_report_vol_2.pdf)

Summary: "On July 12, 1974, the National Research Act (Pub. L. 93-348) was signed into law, there-by creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. One of the charges to the Commission was to identify the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and to develop guidelines which should be followed to assure that such research is conducted in accordance with those principles. In carrying out the above, the Commission was directed to consider: (i) the boundaries between biomedical and behavioral research and the accepted and routine practice of medicine, (ii) the role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects, (iii) appropriate guidelines for the selection of human subjects for participation in such research and (iv) the nature and definition of informed consent in various research settings" (summary retrieved from <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>).

**National Disability Authority. (2009). Ethical guidance for research with people with disabilities. Dublin: National Disability Authority Ireland.**

Available from: [http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/\\$File/ethicsfootnotes.html](http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/$File/ethicsfootnotes.html)

Extract from Introduction (p. 7): "Research is undertaken to expand knowledge, discover the truth and provide evidence for practitioners, policy-makers and legislators. [1] Research that involves people with disabilities is important in uncovering issues requiring attention; in informing policy; in evaluating programmes and services; and in tracking how social and economic change



affects people with disabilities. The importance of research and data related to disability has been underscored in the Report of the Commission on the Status of People with Disabilities (1996), and in the United Nation's Convention on the Rights of Persons with Disability (2006), adopted in December 2006. [2] Disability research ethics are located within the wider research ethics framework. Ethical principles require that any research involving human subjects is framed and conducted in a way that respects the human rights of the individuals concerned. The UN Convention sets out what recognised human rights principles mean in respect of people with disabilities. Central to the UN Convention's understanding of human rights are respect for the inherent dignity, individual autonomy — including the freedom to make one's own choices — and independence of persons."

**Save the Children. (2003). Child Protection Policy. London: International Save the Children Alliance.**

Available from: <http://resourcecentre.savethechildren.se/content/library/documents/save-children-child-protection-policy>

Extract from introduction (p. 1): "Members of the International Save the Children Alliance have a common commitment to the prevention of child abuse and protection of children. The Child Protection Policy sets out common values, principles and beliefs and describes the steps that will be taken for the Alliance commitment to protect children. The policy was adopted by the International Save the Children's Member's Meeting May 2003."

**Schenk, K., & Williamson, J. (2005). Ethical approaches to gathering information from children and adolescents in international settings: Guidelines and resources. Washington DC: Population Council.**

Available from: <http://www.popcouncil.org/what/ethics.asp#/jQueryUITabs1-2>

Extract from preface (p. iv): "This publication was developed in response to a growing need for practical guidance on collecting information from and about young people. The initial need for such recommendations was identified in the context of activities being conducted among children and adolescents affected by HIV and AIDS. However, they apply equally well to gathering information from young people to address other health and social welfare conditions and difficult circumstances, such as those who have experienced abuse, trafficking, or displacement."

**Shaw, C., Brady, L.-M., & Davey, C. (2011). Guidelines for research with children and young people. London: National Children's Bureau (NCB) Research Centre.**

Available from: <http://www.ncb.org.uk/>

Extract from introduction (p. 3): "These guidelines have been produced for researchers who are contemplating involving children and young people (CYP) in their research project – whether as participants or in a more active role. These guidelines set out the NCB Research Centre's general approach to research with CYP (Section 2); provide practical guidance for the researcher, through all stages of the research process from planning to dissemination: Section 3 focuses on research in which CYP are participants (that is, as sources of data); Section 4 considers other ways in which CYP can be involved in the research process. These guidelines are illustrated throughout with examples from the recent work of NCB's Research Centre."

**Spriggs, M. (2010). Understanding consent in research involving children: The ethical issues. A handbook for human research ethics committees and researchers. Melbourne: Children's Bioethics Centre (Royal Children's Hospital Melbourne / University of Melbourne / Murdoch Children's Research Centre).**

Available from: [www.mcricri.edu.au/media/62539/handbook.pdf](http://www.mcricri.edu.au/media/62539/handbook.pdf)

Extract from 'Purpose of this document' (p. 3): "This handbook together with a project website is an educational resource developed for Human Research Ethics Committees (HRECs) and researchers. The questions in this handbook are based on actual issues of concern expressed in key informant interviews with members of HRECs who review research involving children and young people and researchers who conduct that research. The questions reflect ethical issues that are being encountered by researchers and HREC members and the concerns on which they seek further guidance."

**World Health Organization (WHO). (2007). WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies. Geneva: World Health Organization Press.**

Available from: <http://www.who.int/gender/documents/violence/9789241595681/en/index.html>

Overview: Sexual violence in humanitarian emergencies, such as armed conflict and natural disasters, is a serious public health and human rights issue. Yet, the prevalence of sexual violence is under-reported almost everywhere in the world, and ethical and safety guidelines specific to the particular issues that arise during collection of information about sexual violence in emergencies are lacking. The ethical and safety guidelines (or recommendations) in this document are meant to complement existing internationally-agreed ethical guidelines for research and to inform ethics review processes. Failure to consider ethical and safety issues can result in harm to the physical, psychological and social well-being of those who participate and can even put lives at risk.

**Zimmerman, C., & Watts, C. (2003). WHO ethical and safety recommendations for interviewing trafficked women. Geneva: World Health Organization.**

Available from: <http://www.who.int/iris/handle/10665/42765>

Abstract: The recommendations should be used in conjunction with existing professional standards applicable to the work being conducted. These recommendations provide a set of ten basic standards for interviewing women who are in or have left a trafficking situation. The significance of each issue is explained and examples are offered of how, in practice, each can be addressed. The recommendations should not be taken as a comprehensive guide to working with women who have been trafficked.



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In 2007 in Romania, children jump in a playground in Bucharest, the capital.



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<sup>1</sup> Numbers in bold type indicate the page number in the Glossary of Terms where the term is defined.

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