ETHICAL RESEARCH INVOLVING CHILDREN
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

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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.
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).

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.
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.

**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).**

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 (Nyambetha, 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**

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

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
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 Lauvers, including the impact on participating children’s relationships of sharing previously unknown information.
Case study 4: The impact of shared information in focus groups on children’s relationships, by Hilde Lauwers (see Case Study section p.121).

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. 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. Fosheim, 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.

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 (van & 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.

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).

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.
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
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.

**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).**

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

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

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 of 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).

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.
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.

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

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.
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.

**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).**
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’ 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**
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.x

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).

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).

x 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 ‘children 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.

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

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?