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Ethical Research Involving Children: Encouraging Reflexive Engagement in Research with Children and Young People

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Abstract:

Research involving children raises complex and well-documented ethical questions and challenges that extend far beyond the reach of formal review and governance systems, where these exist. However, researchers collectively have a wealth of knowledge and experience in applying universal ethical principles in diverse social, cultural and methodological settings, which offers much potential for understanding how ethical concerns are responded to in situ. Through extensive consultation and research, the Ethical Research Involving Children (ERIC) project, discussed in this article, has drawn on this collective knowledge in generating evidence-based resources that highlight best practice while grounding ethical decision-making in lived experience.

Introduction

The importance of involving children¹ in research has been well-documented over recent years, in this journal and other publications. Such research holds significant potential for strengthening laws, policies, programs and services targeting children and families, while promoting their human dignity, rights and well-being. It signals respect for children's rights to participation and expression of their views, as recognised in the United Nations Convention on the Rights of the Child (UNCRC). Developments in the ways in which children and childhood are viewed have led to increased emphasis on accessing and listening to children's views in order to better understand their experiences (Hill and others, 2004; Pufall and Unsworth, 2004; Woodhead, 2009). Researchers working in various international contexts, sectors and disciplines can now access a wide range of well-documented research methods and tools to engage children in research.

Much has also been written about ethical issues in research involving children (Powell and others, 2012), and systems and procedures are now in place in many contexts to govern how these are attended to. Explicit compliance requirements provide some clarity around what researchers have to do, but are generally not sufficient to guide decisions about what researchers ought to do, especially in the ‘microethical’ moments within research that require ‘right here, right now’ responses (Ebrahim, 2010; Gildersleeve, 2010). Further, little is known or shared about the specific nature of dilemmas encountered in situ, the decision-making processes involved, the actions taken, and the affective responses to these. Such ‘re-personalising’ of the moral dimensions of research (Bauman in Moss and Petrie, 2002, p.45) can leave some researchers feeling uncertain, threatened or isolated, particularly in globally diverse contexts where there may be unequal access to information, guidance and mentoring.

In this article, we share the story of a recent project which sought to explore some of the complexity around the ethics of research involving children, while harnessing the best evidence and expertise internationally, and generating resources that might be useful across a range of social, cultural, methodological and disciplinary contexts. Underlying the extensive print and web-based resources that have emerged out of the Ethical Research Involving Children (ERIC) project is a strong dialogical intent to open up a space for more reflexive and collaborative international engagement in helping to ensure the human dignity of children remains paramount in any research involving them. In the discussion that follows we briefly outline some of the concerns and complexities in relation to ethical research before introducing the ERIC project. We provide an overview of the background, rationale and philosophy underpinning the ERIC approach, not in the interests of a ‘show and tell’ exercise, but rather to invite deeper international engagement around some of the questions, issues, tensions and challenges that embody our individual and collective research efforts.

Complexities inherent in ethical research involving children

Irrespective of the purpose, research involving children will invariably be shaped by the cultural, social, political and economic milieus in which it takes place. Notions of ‘ethical research’ cannot be uncoupled from the particular understandings of children and childhood that shape the research encounter since these invariably influence and inform both methodological and ethical choices (Christensen and Prout, 2002; Punch, 2002). Indeed, it might be argued that it is the attitudes, values, beliefs and assumptions of the different stakeholders, including members of the research team, that ultimately shape the research experience, much more than any ethics checklist possibly could.

Children’s involvement in research is ‘nested within [these] broader discourses about the nature and status of childhood’ (Munford and Sanders, 2004, p.471). The emphasis has shifted in social science research over recent years from a predominantly protectionist focus, which positioned children as vulnerable and requiring safeguarding, to an emphasis on recognising children’s agency, competency and right to participate in research (Alderson and Morrow, 2011; Hill, 2005). Tensions between protectionist and participatory standpoints often appear to be at the core of ethical dilemmas and decision-making (Powell and others, 2011). Rather than seeing these in oppositional terms, children’s protection and participation can be 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’ (Graham and others, 2013, p.14).

The understandings and meanings attached to ethics add to the complexity. The ‘notion of ‘ethics’ is a complex construct ... imbued with particular values and beliefs that influence how we approach

research' (Graham and Fitzgerald, 2010, p.134). It can signify underpinning philosophies and principles, or mechanisms for promoting conduct and compliance. Guillemin and Gillam (2004) further distinguish between '(a) procedural ethics, which usually involves seeking approval from a relevant ethics committee to undertake research involving humans; and (b) "ethics in practice" or the everyday ethical issues that arise in the doing of research' (p.263).

Procedural ethics, such as ethical guidelines, codes of conduct and ethics review processes, can offer important support and guidance, as well as helping to prevent poor research and to safeguard research participants (Alderson and Morrow, 2011). However, while ethical codes can be aspirational, reflecting the highest ethical stance sought (Lahman and others, 2011), it is difficult for specific ethical rules to address the breadth and complexity of research endeavours (Gabb, 2010). Hence, researchers have increasingly questioned the assumptions that ethical philosophies can be reduced to codified sets of principles, which when followed systematically will make research more ethically sound (Gallagher, 2009). Many complex ethical issues emerge throughout the research process, persisting long after gaining clearance from institutional ethics committees (Alderson and Morrow, 2011; Hill, 2005; Morrow and Richards, 1996). With bureaucratic regulation of research ethics and an increasingly evident disconnect between procedural ethics and ethics in practice, there are concerns that researchers may, without any critical insight, become expert at meeting institutions' requirements (Halse and Honey, 2007), abdicate responsibility to ethics review committees (Alderson and Morrow, 2011) and not further develop understanding of ethical decision-making in specific contexts (Gallagher and others, 2010). Procedural ethics alone cannot foster or mandate the thinking and action required, throughout the entire research process, to ensure research is ethical. The landscape is more complex than this.

The Ethical Research Involving Children (ERIC) project

The ERIC project is a collaborative partnership between the Centre for Children and Young People at Southern Cross University, Australia, UNICEF's Office of Research Innocenti, the Childwatch International Research Network and the Children's Issues Centre at the University of Otago, New Zealand. The project emerged out of concerns that while some countries are becoming increasingly adept at managing research 'risk' through increased governance, other countries are calling for more dialogue, support and guidance to ensure research being undertaken in important areas of children's lives promotes their dignity, rights and well-being. Over a 2-year period of research and consultation with the international research community, a wide range of views and perspectives were identified about the type of resources that might help guide different research stakeholders, as well as how these might be applied to questions and concerns in particular settings.

Our initial activities included an international survey involving 257 researchers across 46 countries, providing insight into ethics-related issues and constraints in research with children (Powell and others, 2011) and an exhaustive literature review, which found that the ethical issues most frequently arising are informed consent, protection of children, privacy and confidentiality, payment and power dynamics (Powell and others, 2012). This preliminary work drew attention to the perceived isolation of researchers and limited access to available resources. It also provided stimulus for engaging with members of the international research community and fostering dialogue around the ethical issues, gaps and concerns that require ongoing attention. A subsequent forum was convened in London, involving 17 child and youth research experts, to discuss the evidence from the literature review and international survey and to identify possible implications for existing and future ethical guidance, governance, training and accessibility of resources. A significant outcome of the meeting was the establishment of a funded, international partnership to progress identified

priorities, particularly the development of an international charter and clear, evidence-informed ethical guidance that could be applied in research involving children, in any context.

An expert project advisory group was established and an exhaustive consultation process followed, involving nearly 400 researchers and other stakeholders in a wide range of international regions and organisations. Other activities included detailed mapping, analysis and collating of existing ethics Charters and Guidelines; identification of promising or ‘lighthouse’ ethics initiatives, training programs and resources in different countries; and a review of relevant philosophical ethics and governance practices in different local and disciplinary contexts.

The research and consultation process culminated in a range of resources which include: an International Charter for Ethical Research Involving Children;

- a collection of Case Studies around ethical challenges and dilemmas in a wide range of social, cultural and methodological contexts;
- structured questions, Getting Started, to encourage reflexive engagement with ethical considerations throughout the research process, from conceptualising the research focus through to its post-dissemination impact;
- an online Resources library, which is regularly updated; and
- a monitored Forum providing a platform for discussion and debate.

These ERIC resources are freely available in print-based compendium form and as an open-access website (childethics.com).²

Ethics charter

The International Charter for Ethical Research Involving Children (see Box 1 below) is an aspirational statement of seven key commitments, reflecting the ERIC philosophy and aimed at elevating the status, rights and well-being of all children involved in research.

The realisation of the aspirations embedded in this Charter requires a particular approach that is briefly outlined in the following section.

The ERIC approach

The underlying philosophy of the ERIC approach seeks to ensure the human dignity of children is honoured, and their rights and well-being are respected in all research, regardless of context. Hence, the ERIC Compendium and associated website (www.childethics.com) are founded on the belief that ethics is more than procedural compliance. The initiative is concerned with ‘higher aspirations’ than laws (Masson, 2004, p.43), which, while important, frequently only set minimum standards to prevent bad practice (Alderson and Morrow, 2011).

The ERIC approach is underpinned by well-established, accepted ethical principles, including autonomy, beneficence and non-maleficence, and justice. Respect for autonomy gives potential research participants the freedom to choose and act without being constrained by others, including informed choice about participation in research. Beneficence and non-maleficence means that

researchers have an obligation to assess the potential harms from research and work assiduously to minimise or eliminate them. Justice requires that all research participants are treated fairly. These principles are supported by three pillars, which are connected and critical to the ERIC approach — reflexivity, rights and relationship.

Reflexivity

Reflexivity refers to the capacity of people to be conscious of, and give account of, their actions (Phillips, 1988). As such, it fosters a kind of ‘ethical mindfulness’ (Warin, 2011) or ‘intellectual introspection’, somewhat akin to Bourdieu’s notion of examining the ‘epistemological unconscious’ (Kenway and McLeod, 2004, p.528). While reflexivity may be facilitated in various ways (formal and informal, conducted alone or with others), it is perceived by some ‘as an attitude or ‘way of being’ during the research process’ (Probst and Berenson, 2013, p.8), rather than a set of prescribed techniques. Reflexivity requires self-awareness in relation to matters such as one’s own childhood experiences and engagement with children as an adult (David and others, 2005); personal biases and how these impact on the study (Lobe and others, 2007; Moore, 2012); the influence of academic paradigms and non-academic life-based experiences (Davis, 1998) and the choice and implementation of research methods (Punch, 2002). Recently, researchers have argued for approaches to research ethics that take the social and cultural context into account, and foreground flexibility, reflexivity and dialogue as key aspects of ethical research (Ebrahim, 2010; Skovdal and Abebe, 2012; Pain, 2008; Warin, 2011). Ideally, ethical guidelines need to be iterative and responsive, but such processes do not generally fit standard ethical review requirements, which assume knowing in advance what will happen and how it will be managed. Therefore, specific components of ERIC are framed by questions, dilemmas and exemplars that have the express intent of promoting and guiding reflexive thinking.

Rights

Rights refers to the fundamental human rights that all children are entitled to, along with particular rights relevant to their care and protection as minors. The ERIC project is explicitly founded on the belief that researchers have a responsibility to respect the rights, wellbeing and human dignity of all children, in all research, regardless of context. Although the UNC- RC does not refer specifically to research, it is a central starting point, asserting a full range of rights for children and, in effect, being ‘a legal articulation of a broader philosophical perspective’ (Lundy and McEvoy, 2012, p.77). The Articles in the Convention open the way for more critical engagement around children’s involvement in research (Lundy and McEvoy, 2012; Ennew and Plateau, 2005). Some researchers advocate for the rights afforded to children in the UNCRC to be translated into workable ethics for research practice (Bell, 2008; Robson and others, 2009). Ennew and Plateau (2005) usefully articulated children’s ‘right to be properly researched’, combining four articles of the UNCRC, and merging children’s right to protection with their right to participation. Importantly, the UNCRC contributes to reflex- ive practice insofar as it ‘locates axes along which a child’s rights are defined and urges researchers, among others, to account for the impacts of their own choices’ (Aitken and Her- man, 2009, p.19), potentially influencing the creation of more ethical research practices. Hence, the ERIC resources draw attention to a range of UNCRC articles that are useful in guiding ethical decision-making across different research contexts.

Relationships

Relationships refers to the many connections between people involved in the research context. The ERIC approach recognises that research involves multiple relationships, even when these are not explicitly identified, and that ethical issues implicate not only the researcher and the children, but also others closely or tangentially involved. These relationships involve members of the research team; governance and funding bodies; children and young people; family members and/or

significant adults/gate-keepers; and local communities. It takes considerable awareness, respect, skill, creativity and expansiveness to ensure children's wellbeing, dignity and rights remain a shared, paramount interest throughout the research endeavour (Graham and others, 2013) and this invariably involves others, not least of all the children. The kind of reflexivity discussed above assists researchers to develop more nuanced insights into research relationship dynamics (Solberg, 2014), provoking 'an alertness or heightened sensitivity to understanding the relational aspects of the research process: an interdependent awareness of how I, as a researcher, am influencing my research participants' perceptions and a simultaneous and interdependent awareness of how they are influencing me' (Warin, 2011, p.810).

By emphasising the relational potential of research ethics, the ERIC approach also opens the way for increased dialogue between researchers as they engage critically with the content and take up the invitation to share their experience, questions, concerns, stories and resources online.

Guidance for ethical research involving children

The extensive Guidance provided with the ERIC resources has built upon the foundational pillars of reflexivity, rights and relationship, ensuring these are the starting point for researchers' further engagement with particular ethical considerations and issues in their own research contexts. Rather than offering formulaic 'one-size-fits-all' guidelines (which clearly do not and cannot 'fit all'), the ERIC approach offers a framework for guiding researchers through key ethical considerations. The Guidance sections summarise the wider academic debates in core ethics areas, considering key issues in light of the '3 Rs'. Case studies from a range of international research contexts are linked to this Guidance, offering insights into the real, lived experience of researchers in different social, cultural, disciplinary and methodological contexts. These case studies exemplify the reflexive engagement required by researchers as they navigate and problem-solve around complex ethical challenges. As flagged above, reference is made to relevant UNCRC articles to further inform and guide ethical decision-making, and reflective questions are posed throughout to prompt researchers to examine the assumptions and beliefs that guide their research practice.

We turn now to a brief overview of the key ethical areas covered in the Guidance sections of the ERIC compendium and website, highlighting challenges that may be encountered by researchers as they engage with the complexities of research involving children. Consideration of these challenges draws attention to the central role of reflexivity, rights and relationships in negotiating an ethical research pathway.

Harm and benefits

Researchers are responsible for protecting participants from any physical, emotional or social harm that might result from the research and anticipating any potential adverse consequences. The principles of beneficence and non-maleficence underlie the ethical issue of protecting children from harm, emphasising the importance of researchers balancing children's rights to protection from the potential harms of research, with their right to participate in research and benefit from the results. Identifying benefits and harms is not always straight-forward (Spriggs, 2007), particularly in social research where harm can be difficult to predict or detect, complicated by different viewpoints as well as short- and longer-term outcomes (Alderson and Morrow, 2011). Benefits can be similarly hard to define, assess and know in advance, with causality difficult to determine.

In considering harms and benefits in research involving children researchers need to engage with questions such as:³

- How are potential harms and benefits assessed in research involving children?
- How can harm be minimised or eliminated?
- What are researchers' responsibilities if children show signs of harm or distress?
- What if there are not appropriate follow-up services to refer children or parents to?
- How can researchers ensure that children's participation in research is equitable?

Potential harm can be minimised from the very outset of the project, and throughout its implementation, through critical reflection and strategic research design and implementation (provided in the Getting Started section of the ERIC resources). Children who are considered especially vulnerable may require additional safeguards to protect their welfare, with integration into the research design of specific methods to ensure protection and care, and researcher support (Gorin and others, 2008; Mudaly and Goddard, 2009).

The role of parents and significant adults is of critical importance in decisions related to harms and benefits. A hierarchy of gatekeeping, for example, can function to protect children from harm. However, it also increases barriers to children's participation in research (Hill and others, 2004; Masson, 2004; Morrow and Richards, 1996; Powell and Smith, 2009). One issue for reflection, therefore, might be how best to include or inform parents or care-givers in ways that enable them to support and safeguard their children, as well as understand the importance of them being involved in the research (Baker, 2005). Conversely, harm to children, may come from within households, in the form of reprisal or retribution as a consequence of children being included or excluded from the research, and ensuring confidentiality may be critically important. Consideration of harms and benefits is thus integrally linked with awareness of and engagement in wider relationships.

Informed consent

Obtaining consent is the cornerstone of the research relationship and a routine practice, demonstrating respect for the individual research participant's autonomy and dignity. However, the ethical issue of consent has probably generated the most debate in regard to research with children (Alderson and Morrow, 2011; Morrow and Richards, 1996). The literature indicates that informed consent rests on four core principles — 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, including the risks and potential benefits; 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 principles raise a number of issues for researchers engaging with children, including:

- Are all children capable of providing consent?
- Is parental/adult consent always required in research involving children?
- How can researchers ensure that children are fully informed?
- How can researchers ensure that children's consent is freely given?
- How can children's dissent to take part in research be respected?

There are unique ethical complexities in gaining consent for children's participation in research, including those related to the usual requirement to seek parents' 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 and Sanders, 2004). Researchers are also 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) before children can be approached about participating in research. It can be difficult to ascertain that children's consent to participate in research is given freely (Ahsan, 2009; Coyne, 2010; David and others, 2001; Nyambedha, 2008; Valentine, 1999) and, in some cultural and social contexts, the right to consent may be a collective rather than individual concern, involving the wider family and community (Suaalii and Mavoa, 2001). Standardised research consent processes are generally not equipped for managing the complexities encountered in gaining consent for children's participation in research.

Privacy & confidentiality

Privacy is a basic human right and a key factor in ethical research practice, of particular importance in some cultures (Gabb, 2010) and when research topics are sensitive or potentially stigmatising (Clacherty and Donald, 2007; Hunleth, 2011; Langhinrichsen-Rohling and others, 2006; Valentine and others, 2001). However, ensuring children's right to privacy is upheld can present significant challenges to researchers, including:

- How can privacy be provided for children if this is not the usual social/cultural practice?
- Which location best supports privacy for children in research?
- How can confidentiality be respected in research with focus groups?
- What are the limits to confidentiality when there are safety concerns?
- What if children (or parents) do not want to be anonymous in dissemination of research findings?
- What are the privacy and confidentiality challenges related to technological developments?

These challenges point to the impact of research location and methods on the privacy of the participant and the confidentiality of the research information collected. Frequently, research with children takes place at school or home where confidentiality can be compromised, through difficulties finding private space (Gorin and others, 2008; Kellett and Ding, 2004; Sime, 2008; Valentine, 1999) and parents', or others', curiosity and concern for the child (Bushin, 2007; Fargas-Malet and others, 2010).

A particularly contentious issue is the dilemma concerning limits of confidentiality when researchers suspect unsafe or criminal activity, such as a child being harmed or threatening to harm her/himself or another person (Schenk and Williamson, 2005); or having a communicable or sexually transmitted disease requiring notification (Avard and others, 2012). Opinions and practice about breaching confidentiality to report suspected child abuse are divergent (Cashmore, 2006). Respect for the child's autonomy and right to confidentiality may directly conflict with the researcher's ethical responsibilities to ensure children's protection or comply with mandatory reporting requirements. These challenges and dilemmas underline the need for reflexive ethical practice both at the outset and during the research process.

Payment and compensation

There is no clear consensus on whether children should be paid for participation in research (Kellett and Ding, 2004) or what kinds of rewards are appropriate (Gallagher, 2009). However, the ethical 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. Four types of payment in research have been identified: reimbursement, compensation, appreciation and incentive (Avard and others, 2012), and each of these have ramifications for ethical practice. Incentive payments are the most contentious, with some researchers arguing that small incentives to improve recruitment levels are ethically acceptable where research involves low or negligible risk (no more than discomfort), whereas offering incentives to secure the involvement of children in risky research is exploitative and undermines public trust and support for research involving children and young people (Spriggs, 2010). Considerations related to payment include:

- When will participants be given information regarding payment?
- How can payment of research participants be addressed in locally specific ways?
- What are the additional considerations related to payment in situations of acute poverty?
- What are the implications within the community of payment to research participants?

Cultural context influences perceptions of research payment, and consideration of the local contexts is critical in determining the nature of any payment for children's participation in research. This might include consideration of children's role in the economic wellbeing of the family, the ethical implications of payment in contexts of poverty or the appropriateness in some situations of forms of compensation other than monetary, such as certificates of recognition, gifts or vouchers (Morrow, 2009; Seymour, 2012; Sime, 2008). Decision-making regarding payment is thus enhanced by reflexive practice, with cognisance of rights and the multiple relationships influencing and being influenced by particular aspects of the research process.

Conclusion

The print and web-based ERIC resources harness the expert knowledge, commitment and goodwill of the international research community to provide a framework for approaching ethical research involving children that takes account of universal ethical principles and explores how these might be applied in unique and diverse research contexts. A key challenge has therefore been ensuring the relevance of ERIC for these different social, cultural and methodological settings and, more recently, responding to requests for translation into languages other than English. The ERIC resources are not intended to be, and indeed never could be, all-encompassing. They cannot possibly resolve the myriad challenges associated with ethical child research nor provide neat answers or 'one-size-fits-all' solutions. Rather, ERIC offers an approach that: foregrounds the human dignity of children as paramount; incorporates reflexivity, rights and relationship as essential elements of ethical research; provides extensive evidence-based guidance that features best practice while grounding the discussion of issues and challenges in the lived experience of research; engages researchers in critical questions to guide their decision-making; and invites further dialogue and sharing of ideas, experiences and resources. Our hope in producing these resources is that they be viewed as a stimulus for continued collaboration internationally in affirming, connecting, challenging and improving our respective research efforts with children.

To download the Compendium, browse ERIC or share your experiences visit: www.child-ethics.com.

Notes

1 In this article, children are defined in accordance with Article 1 of the UNCRC, as ‘every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier’. However, we acknowledge in conjunction with this, that definitions of children and youth vary according to law, culture and custom.

2 The website was specifically developed to act as a rich repository of evidence-based information, providing additional resources and links to journal articles to guide and improve research involving children, and to provide a platform for further dialogue within the international research community.

3 These and other questions are the focus of detailed discussion in the Ethical Research Involving Children compendium.

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