



# ETHICAL RESEARCH INVOLVING CHILDREN

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and Young People



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# RESEARCHER SUPPORT

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

# RESEARCHER SUPPORT

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

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

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

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

## RESEARCHER SKILLS AND TRAINING

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

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

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

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

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

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

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

## RESEARCHER SAFETY

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

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

## ETHICS REVIEW BOARDS

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

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

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

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

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

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

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

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

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

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

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



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