# Guidance Paper 1: Introduction to The Ethics of Research Involving Children: Common Questions, Potential Strategies and Useful Guidance





This series of guidance papers – *The Ethics of Research Involving Children: Common Questions, Potential Strategies and Useful Guidance* – offers tailored commentary and links to useful resources to assist those undertaking research relating to children<sup>\*</sup> and childhood. The six papers have been developed in conjunction with the University of Liverpool Research Ethics Committee, by academic members of the <u>European Children's Rights Unit</u> (ECRU), an interdisciplinary research unit based within the School of Law and Social Justice with a specific expertise in research involving children. <u>Children and Childhood</u> is a major research theme, led by the Faculty of Humanities and Social Sciences, and spanning the Faculty of Science and Engineering and the Faculty of Health and Life Sciences. Nurturing expertise in child-related research is also a key priority at university level, as part of its <u>Starting Well</u>, Living Well and Ageing Well theme. There are over 150 researchers across the university actively engaged in child-related research, each with distinct disciplinary and methodological approaches, but who share common ethical and methodological consideration points.

These guidance papers address some of these ethical issues and identify strategies to assist researchers in preparing and implementing ethically robust methodologies, particularly when conducting qualitative research with children. They are intended as a basic resource for all researchers at any level who are grappling with different ethical questions, with a view to encouraging thoughtful and rigorous ethics planning and supporting research of the utmost integrity. In that sense, these briefings are not concerned simply with ensuring minimum standards of research ethics; they are about encouraging researchers to **interrogate** established approaches, **innovate** in ways that are appropriate for any given project, and achieve the **highest possible standards** within what are often challenging and unpredictable research contexts. While our focus is on children, the guidance papers should provide useful tips and materials to inform all empirical research with adults generally and potentially vulnerable participants specifically.

"Research ethics is concerned with respecting research participants, partly by adhering to agreed standards. Ethics standards are also designed to protect researchers and their institutions as well as the good name of research." (Alderson and Morrow, 2020:4)

<sup>\*</sup> The term 'children' is used to refer to all research participants below the age of 18.

## Overview

The six guidance papers in this series cover the following themes:

- **Guidance Paper 1:** Introduction to The Ethics of Research Involving Children: Common Questions, Potential Strategies and Useful Guidance (this paper)
- Guidance Paper 2: Obtaining Consent for Research Involving Children Legal and Ethical Framework
- Guidance Paper 3: Putting in Place Appropriate Safeguards for Research Involving Children
- Guidance Paper 4: Digital Methods of Working with Children: Ethics, Rights and Responsibilities
- Guidance Paper 5: Recruiting Children for Research: How, Where and Why?
- Guidance Paper 6: Confidentiality, Privacy and the Protection of Children's Data

To set the scene for this guidance paper series, we begin by setting out some fundamental aspects of our approach to the ethics of child-related research.

#### 1. Researching 'with' rather than 'on' children

As a community of researchers committed to enhancing children's lives, it is crucial that our research promotes children's dignity, protection, inclusion and empowerment. This is not just about striving to achieve better outcomes or impact from our research (in terms of better treatments; better laws or policies; better processes or better products); it is about ensuring that the very design of our research – the framework within which we conduct our inquiry – embraces and evidences these principles. In short, good, ethical research process generally begets good research outcomes.

Children are powerful research resources: their willingness to share their time, their experiences and their insights are often crucial to achieving our outcomes, but with this comes some expectations regarding how they are valued and treated in the process and how they are engaged, not just in providing a sample for our inquiry, but in setting research priorities, identifying the questions we should be asking, and shaping our methodological and ethical framework.

#### 2. Ethical Principles for researching with children

When we think about ethical issues in research with children, it is important that we appreciate that the integral ethical standards for research do not differ from any other population; rather we may need to

think about them in alternative and child-focused ways, as well as considering other obligations we may have towards the welfare of children. Specifically:

- Informed consent must be obtained in order to comply with legal and ethical standards but
  researchers need to think of the overall consent process. Information will be needed for
  participants and, in some cases, for their parents/carers, which needs to be accessible and clear.
  The question of who can provide consent, the child or their parents/carers, has to be addressed
  for any study and even where the child is not competent to provide consent, assent is still integral
  (see Guidance Paper 2).
- The duty of confidence to those participating in research must comply with legal and ethical standards but researchers need to consider specific issues in respect of children's privacy and data. This includes, for example, consideration of whether parents or carers should know about their child participating in a study or ensuring transparency with children about how their information and any data collected will be used and shared (see Guidance Paper 6).
- The welfare of children is paramount and must be considered in all research with children, whereby risk and harm are managed through assessment and appropriate responses to any issues identified. Safety should be well thought out and researchers should be appropriately trained to work with children (see Guidance Paper 3).
- It is a legal requirement that safeguarding measures are in place for anyone working with children. Moreover, if researchers are regulated professionals they have specific statutory regulatory obligations to protect children. Children therefore have a right to know this and to understand when confidentiality may be breached in the context of research for safeguarding purposes (see Guidance Paper 3).
- Participation in research requires time for children, just as it does for adults. Therefore, the issue
  of renumeration or compensation may need to be addressed. Whilst some studies may recruit
  participants on a voluntary basis, researchers need to consider the practicalities and costs of
  participation in research for children and/or their parents/carers. If remuneration or compensation
  is to be provided, researchers need to consider how this will be facilitated (Guidance Paper 5).

#### 3. University Research Ethics Committees: enablers of good practice

It is integral to understand in the first instance that obtaining ethical approval for research is integral to all research involving human participants and personal data, and facilitates and supports good research. The fundamental role of university research ethics committees and processes can be summarised as follows: A properly functioning system of ethical scrutiny is, first, designed to ensure that there is an explicit discussion of fundamental matters of ethical concern before a project might go ahead. Researchers planning a particular project have their own interests in carrying out research. The point about early independent ethical scrutiny is that it submits such plans to some degree of outside scrutiny, raising issues that may require further thought, or expressing concerns that some practices may simply be, on balance, unjustified. **This model sees ethical practice as ineluctably part of a dialogue, in which prevailing social norms of what constitutes ethical practice are open to debate and are in principle justifiable.**<sup>1</sup>

The research ethics approval process is concerned with ensuring the integrity of research through the development of ethical, realistic, and appropriate methods that will add real value to research inquiry and outcomes.

It is also useful to debunk some of the myths that have emerged around the research ethics committee process. Research ethics committees should **not** be viewed as providing a conclusive, incontestable response to proposed methods. Rather, good ethics engagement requires:

- An ability to demonstrate that researchers have invested proper thought and research into the best possible way of conducting projects and into the potential ramifications of a proposed approach
- An ability to respond in an informed and constructive (rather than a defensive) way to any points of consideration raised by the research ethics committee
- A willingness to consider alternative or refined approaches to the research where such alternatives are feasible and promote the rights and interests of the participants in the study.

We should however acknowledge that for some researchers there is apprehension around obtaining ethical approval for their research, particularly when it comes to research involving children. Some researchers may find obtaining ethical approval an intimidating, time consuming and stressful process. One concern is that ethics boards and committees can make it more difficult to conduct research involving children, particularly when the research concerns sensitive topics and/or vulnerable groups of participants. The aim of the ethics committee is not to prevent research but, instead, to facilitate good ethical practice. They should operate as a collaborating but integral part of the research process, enabling researchers to reflect on their methods and ideas to ensure the planned research has identified, considered and planned for all potential risks and to ensure the methodology is the most

<sup>&</sup>lt;sup>1</sup> Anthea Tinker and Vera Coomber (2004), *University Research Ethics Committees: Their Role, Remit and Conduct*, London: King's College London, 52 pp., ISBN 1-872342-22-1

appropriate approach. Researchers should therefore broach ethics applications, particularly those relating to vulnerable groups, in a spirit of openness, dialogue and conscientious reflection. Ethics committees should in turn promote and foster a collaborative approach to supporting the researcher's ethics application.

#### 4. The Importance of a Young Person's Advisory Group

Whilst children are integral to research as participants, it is now widely recognised that the views and experiences of young people as experts are sought in all aspects of research. One way this can be achieved is through advisory groups. In 2018, the University of Liverpool established a university-wide Young People's Advisory Group (YPAG). The primary purpose of this group is to involve children in shaping our research agenda in a more meaningful, comprehensive way. This is consistent with our commitment to moving away from treating children merely as the objects of our research towards engaging them as active research partners, agenda-setters and consultants. The group is composed of up to 20 young people aged 10-18 who are recruited through our partnerships with the Alder Hey Hospitals Children Hospital's Clinical Research Facility, local children's charities, the Liverpool Schools Parliament, local schools and alternative education providers (for young people who cannot, for various reasons, access mainstream school). The group meets up to six times a year to:

- Identify key research priorities and questions from children's perspectives/experiences;
- Advise on the design of methodological tools
- Advise on applications for ethical approval
- Advise researchers on how to recruit young people to research appropriately and on how to work with young people as research partners and subjects.
- Provide feedback on approaches to analysis, work-in-progress or findings;
- Advise on and assist with dissemination plans
- Challenge established patterns of thinking and doing.

The YPAG plays a powerful and unique role in supporting researchers to develop ethically robust research proposals insofar as:

• Child-related projects seeking university research ethics approval can be considered and endorsed by the YPAG before submission to the university research ethics committee.

• The YPAG will also assist with addressing any concerns or questions raised by the university research ethics committee in relation to any given project.

Establishing and utilising the expertise of a YPAG is an integral feature of good research practice. However, the advice or guidance of the Young Person's Advisory Group will not bind the recommendations of a University Research Ethics Committee.

"The Young Person's Advisory Group gave me a chance to discuss my ideas for empirical work with a sample of young people who my research would directly concern. They provided feedback on my methodology and helped to develop my project in a way they felt would best allow for valuable contribution by children and young people." – PhD Student, School of Law and Social Justice

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## Useful resources

Those who are contemplating research involving children will find the following resources a useful starting point:

- The <u>Ethical Research Involving Children (ERIC) website</u> the product of an international collaboration between researchers working in the field of children and childhood. Contains a number of useful articles and resources relating to the ethics of working with children.
- <u>Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). Ethical Research</u> <u>Involving Children. Florence: UNICEF Office of Research – Innocenti</u>, an entire compendium available to download from the <u>Ethical Research Involving Children (ERIC) website</u>. Contains some useful, illustrative case studies that reflect a range of different research priorities and subjects.
- ESRC Research with Children and Young people
- The research ethics guidebook specific section on children

- Alderson, P. and Morrow, G. (2020) The Ethics of Research with Children and Young People: A Practical Handbook (2nd Edition) London: Sage (available electronically through the University of Liverpool library from September 2020 onwards).
- <u>UK Data service guidance on research involving children and young people</u>
- Spencer, G. (Ed), 2021. *Ethics and Integrity in Research with Children and Young People* (Vol. 7). Emerald Publishing Limited.