

**ETHICS AND INTEGRITY IN
RESEARCH WITH CHILDREN AND
YOUNG PEOPLE**

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ADVANCES IN RESEARCH ETHICS AND INTEGRITY,
VOLUME 7

**ETHICS AND INTEGRITY
IN RESEARCH WITH
CHILDREN AND YOUNG
PEOPLE**

EDITED BY

GRACE SPENCER

Anglia Ruskin University, UK



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INVESTOR IN PEOPLE

For Harry, Emily and Oliver, and all the incredible children and young people that have inspired the chapters in this volume and my broader programme of work.

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CONTENTS

<i>List of Tables and Figures</i>	<i>xi</i>
<i>List of Contributors</i>	<i>xiii</i>
<i>Series/Volume Editors' Biographies</i>	<i>xix</i>
<i>Series Preface</i> <i>Ron Iphofen (Series Editor)</i>	<i>xxi</i>
<i>Acknowledgements</i>	<i>xxv</i>

Introduction: Ethics and Integrity in Research with Children and Young People <i>Grace Spencer</i>	<i>1</i>
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PART I

CHILDREN AND YOUNG PEOPLE'S PARTICIPATION IN RESEARCH – NAVIGATING TRICKY ETHICAL MOMENTS

Chapter 1 Beyond Agree or Disagree: A Consent Story and Storytelling for Indonesian Children <i>Fitri Arlinkasari, Debra Flanders Cushing and Evonne Miller</i>	<i>13</i>
Chapter 2 Assent or Consent? Engaging Children in Ethnographic Study <i>Ruth Barley</i>	<i>29</i>
Chapter 3 Negotiating Youth-centred Research: Ethical Reflections on Research with Young People in Rural and Urban Spaces in Nigeria <i>Chikezie E. Uzuegbunam</i>	<i>43</i>
Chapter 4 Ethically Sensitive Research with 'Children' and 'Adults' in Custody <i>Jayne Price</i>	<i>57</i>
Chapter 5 Ethical Considerations for Doing Research with, and in Relation to, Disabled Children <i>Gillian Parekh, Kathryn Underwood and Abneet Atwal</i>	<i>73</i>

**PART II
ADULT/CHILD POWER RELATIONS
AND POSITIONALITY – ETHICS, EMOTIONS AND
THE BUILDING OF TRUST**

- Chapter 6 Ethics of Positionality in Capturing Adivasi Youth ‘Voices’ in a Village Community in India**
Gunjan Wadhwa 89
- Chapter 7 A Balanced Approach to Ethics in Ethnography**
Emma Davidson and Christina McMellon 105
- Chapter 8 Research with Child Street Traders: Building Trust and Sensitivity**
Sarah Burch and Abiodun Blessing Osaiyuwu 121
- Chapter 9 A Spy in the Family: Trust in Sensitive Research with Children**
Sofie Henze-Pedersen 135

**PART III
CHILDREN AND YOUNG PEOPLE AS KNOWLEDGE
PRODUCERS AND THE ETHICS OF REPRESENTATION
AND RESEARCH DISSEMINATION**

- Chapter 10 Children as Co-researchers: A Transdisciplinary and Participatory Process**
Zoé Moody, Frédéric Darbellay, Sara Camponovo, Ayuko Berchtold-Sedooka and Philip D. Jaffé 151
- Chapter 11 Conducting Research with Children, Ethically and Effectively, to Inform Public Policy**
Penelope Carroll, Karen Witten, Melody Smith, Victoria Egli, Suzanne Mavoa and Marketta Kytta 167
- Chapter 12 Children and Young People Who Migrate – Representing and (Re)producing Vulnerabilities through Research**
Grace Spencer, Ernestina Dankyi, Stephen O. Kwankye and Jill Thompson 183
- Chapter 13 Ethical Considerations in Drama-based Research with Children and Young People**
Abigail Shabtay 199

Chapter 14 A Meta-critical Reflection on Academic Writing with Child Researchers <i>Justyna Deszcz-Tryhubczak and Mateusz Marecki</i>	213
Conclusion: Meeting the Ethical Challenges in Research with Children and Young People <i>Grace Spencer</i>	229
<i>Index</i>	233

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LIST OF TABLES AND FIGURES

TABLES

Chapter 11	Table 1.	Eight Research Projects Working with Children.	174
Chapter 12	Table 1.	Critical Ethical Questions in Research with Child Migrants.	193

FIGURES

Chapter 1	Fig. 1.	A Quote from One of the Stories Explaining the Child-led Tour Activity.	19
	Fig. 2.	Children and the Lead Researcher in a Storytelling Session Discussing the Proximity of the Children's Homes to the RPTRA Sites Using a Neighbourhood Map.	21
	Fig. 3.	A Drawing by Moon (9 Years Old) Representing Her 'Mental Picture' of Her Front Door ('pintu') and Her Bedroom ('kamar'), as per the Scenario in the Door Story.	23
Chapter 2	Fig. 1.	Children's Consent Form.	35
	Fig. 2.	Extracts from Fieldnote Book	37
Chapter 10	Fig. 1.	Basis for <i>Diamond Ranking</i> Activity.	154
	Fig. 2.	Third Session: Analysing the Data from the Photographs Classification Activity.	159
Chapter 13	Fig. 1.	Youth Participants Presenting Memories on Stage in the Play <i>Motivation and Justice</i> .	202
	Fig. 2.	Youth Participants Portraying Feelings of 'Stress' Through Embodiment.	202

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SERIES PREFACE

By

Ron Iphofen (Series Editor)

This book series, *Advances in Research Ethics and Integrity*, grew out of foundational work with a group of Fellows of the UK Academy of Social Sciences (AcSS) who were all concerned to ensure that lessons learned from previous work were built upon and improved in the interests of the production of robust research practices of high quality. Duplication or unnecessary repetitions of earlier research and ignorance of existing work were seen as hindrances to research progress. Individual researchers, research professions and society all suffer in having to pay the costs in time, energy and money of delayed progress and superfluous repetitions. There is little excuse for failure to build on existing knowledge and practice given modern search technologies unless selfish ‘domain protectionism’ leads researchers to ignore existing work and seek credit for innovations already accomplished. Our concern was to aid well-motivated researchers to quickly discover existing progress made in ethical research in terms of topic, method and/or discipline and to move on with their own work more productively and to discover the best, most effective means to disseminate their own findings so that other researchers could, in turn, contribute to research progress.

It is true that there is a plethora of ethics codes and guidelines with researchers left to themselves to judge those more appropriate to their proposed activity. The same questions are repeatedly asked on discussion forums about how to proceed when similar longstanding problems in the field are being confronted afresh by novice researchers. Researchers and members of ethics review boards alike are faced with selecting the most appropriate codes or guidelines for their current purpose, eliding differences and similarities in a labyrinth of uncertainty. It is no wonder that novice researchers can despair in their search for guidance and experienced researchers may be tempted by the ‘checklist mentality’ that appears to characterise a meeting of formalised ethics requirements and permit their conscience-free pursuit of a cherished programme of research.

If risks of harm to the public and to researchers are to be kept to a minimum and if professional standards in the conduct of scientific research are to be maintained, the more that fundamental understandings of ethical behaviour in research are shared the better. If progress is made in one sphere everyone gains from it being generally acknowledged and understood. If foundational work is conducted everyone gains from being able to build on and develop further that work.

Nor can it be assumed that formal ethics review committees are able to resolve the dilemmas or meet the challenges involved. Enough has been written about such review bodies to make their limitations clear. Crucially, they cannot follow researchers into the field to monitor their every action; they cannot anticipate all of the emergent ethical dilemmas nor, even, follow through to the publication of findings. There is no adequate penalty for neglect through incompetence, nor worse, for conscious omissions of evidence. We have to rely upon the virtues of the individual researcher alongside the skills of journal reviewers and funding agency evaluators. We need constantly to monitor scientific integrity at the corporate and at the individual level. These are issues of quality as well as morality.

Within the research ethics field new problems, issues and concerns and new ways of collecting data continue to emerge regularly. This should not be surprising as social, economic and technological change necessitate constant re-evaluation of research conduct. Standard approaches to research ethics such as valid informed consent, inclusion/exclusion criteria, vulnerable subjects and covert studies need to be reconsidered as developing social contexts and methodological innovation, interdisciplinary research and economic pressures pose new challenges to convention. Innovations in technology and method challenge our understanding of 'the public' and 'the private'. Researchers need to think even more clearly about the balance of harm and benefit to their subjects, to themselves and to society. This series proposes to address such new and continuing challenges for both funders, research managers, research ethics committees and researchers in the field as they emerge. The concerns and interests are global and well recognised by researchers and commissioners alike around the world but with varying commitments at both the procedural and the practical levels. This series is designed to suggest realistic solutions to these challenges – this practical angle is the *unique selling proposition* (USP) for the series. Each volume will raise and address the key issues in the debates, but also strive to suggest ways forward that maintain the key ethical concerns of respect for human rights and dignity, while sustaining pragmatic guidance for future research developments. A series such as this aims to offer practical help and guidance in actual research engagements as well as meeting the often varied and challenging demands of research ethics review. The approach will not be one of abstract moral philosophy; instead it will seek to help researchers think through the potential harms and benefits of their work in the proposal stage and assist their reflection of the big ethical moments that they face in the field often when there may be no one to advise them in terms of their societal impact and acceptance.

While the research community can be highly imaginative both in the fields of study and methodological innovation, the structures of management and funding, and the pressure to publish to fulfil league table quotas can pressure researchers into errors of judgment that have personal and professional consequences. The series aims to adopt an approach that promotes good practice and sets principles, values and standards that serve as models to aid successful research outcomes. There is clear international appeal as commissioners and researchers alike share a vested interest in the global promotion of professional virtues that lead to the public acceptability of good research. In an increasingly global world

in research terms, there is little point in applying too localised a morality, nor one that implies a solely Western hegemony of values. If standards ‘matter’, it seems evident that they should ‘matter’ to and for all. Only then can the growth of interdisciplinary and multi-national projects be accomplished effectively and with a shared concern for potential harms and benefits. While a diversity of experience and local interests is acknowledged, there are existing, proven models of good practice which can help research practitioners in emergent nations build their policies and processes to suit their own circumstances. We need to see that consensus positions effectively guide the work of scientists across the globe and secure minimal participant harm and maximum societal benefit – and, additionally, that instances of fraudulence, corruption and dishonesty in science decrease as a consequence.

Perhaps some forms of truly independent formal ethics scrutiny can help maintain the integrity of research professions in an era of enhanced concerns over data security, privacy and human rights legislation. But it is essential to guard against rigid conformity to what can become administrative procedures. The consistency we seek to assist researchers in understanding what constitutes ‘proper behaviour’ does not imply uniformity. Having principles does not lead inexorably to an adherence to principlism. Indeed, sincerely held principles can be in conflict in differing contexts. No one practice is necessarily the best approach in all circumstances. But if researchers are aware of the range of possible ways in which their work can be accomplished ethically and with integrity, they can be free to apply the approach that works or is necessary in their setting. Guides to ‘good’ ways of doing things should not be taken as the ‘only’ way of proceeding. A rigidity in outlook does no favours to methodological innovation, nor to the research subjects or participants that they are supposed to protect. If there were to be any principles that should be rigidly adhered to they should include flexibility, open-mindedness, the recognition of the range of challenging situations to be met in the field – principles that in essence amount to a sense of proportionality. And these principles should apply equally to researchers and ethics reviewers alike. To accomplish that requires ethics reviewers to think afresh about each new research proposal, to detach from pre-formed opinions and prejudices, while still learning from and applying the lessons of the past. Principles such as these must also apply to funding and commissioning agencies, to research institutions and to professional associations and their learned societies. Our integrity as researchers demands that we recognise that the rights of our funders and research participants and/or subjects are to be valued alongside our cherished research goals and seek to embody such principles in the research process from the outset. This series will strive to seek just how that might be accomplished in the best interests of all.

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There are a number of people that have made this volume possible and I am grateful for their support and ongoing commitment to the book. First, I would like to thank Ron Iphofen, Series Editor for *Advances in Research Ethics and Integrity*, for inviting me to be Editor for this important volume on ethics and integrity in research with children and young people. I am immensely grateful for Ron's timely guidance and support throughout the process of preparing the manuscript and its final publication. I would like to thank the full team at Emerald Publishing for their assistance and meticulous work on preparing the final volume. I am especially thankful to all the authors of the book for their considered and critical engagement with the volume and ethical issues. Their contributions and hard work have resulted in an exciting addition to the field of research ethics with children and young people. I am also hugely appreciative to all of those who participated in the peer review process. I am grateful to all my colleagues at Anglia Ruskin University in Cambridge, particularly Roxana Anghel, and Jill Thompson from the University of Sheffield, for their ongoing support and review of the final manuscript. Finally, warm appreciation goes to my close friends and family who have supported me unreservedly from afar during the preparation of the volume and at the exceptional time of the COVID-19 pandemic.

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INTRODUCTION: ETHICS AND INTEGRITY IN RESEARCH WITH CHILDREN AND YOUNG PEOPLE

Grace Spencer

The expansion of research with children and young people in recent times has offered important opportunities for researchers, practitioners and policy-makers to understand better children's perspectives and everyday lived experiences. In line with Article 12 of the United Nations (UN) Convention on the Rights of the Child (UN, 1989), young people's meaningful participation in research signals an important step towards their rights to participate in matters that affect their lives. Examples of research conducted with children and young people can be found across many academic disciplines including the health and social sciences, psychology, arts and humanities, international development and economics. Children's views on areas such as health and education, family life and friendships, and broader global and political challenges including climate change and more recently, the COVID-19 pandemic are now frequently sought as part of enhanced efforts to inform policy and practice areas directly relevant to young lives (Alderson & Morrow, 2020). Crucially, the growth of research with, on and for children and young people acknowledges that children may have different ideas and experiences from adults and are, thus, the best informants on their own lives.

The development of childhood and youth-focussed research has called for new ways of thinking about and doing research with young people. Maximising children's engagement in research, and in ethically sensitive ways, has sparked new debates about the range of 'appropriate' methodologies and methods best suited to the investigation of young lives (Christensen & James, 2008; Fargas-Malet, McSherry, Larkin, & Robinson, 2010; Green & Hill, 2005; Punch, 2002). Traditional research methods such as interviews, focus groups and observation techniques offer particular ways to generate insights into young lives and have

been championed (to varying degrees) for their abilities to support the building of research relationships and rapport with young participants. Yet, such approaches are also used cautiously because of the ‘dangers’ of exacerbating the inherent power disparities that exist between adult researchers and younger participants (Davidson, 2017; Holland, Renold, Ross, & Hillman, 2020; James, 2007; Spencer & Doull, 2015) – and as many of the preceding chapters illustrate. Indeed, children’s participation in research is often mediated via adult gatekeepers including parents, carers and teachers who make decisions on children’s behalf.

Efforts to minimise the impacts of adult/child power relations have, thus, prompted new methods of enquiry. A range of child and youth-centred methods now exist, which aim to foreground children as active social agents and knowledge producers. Often informed by contributions from the sociology of children (James & Prout, 2015), these approaches seek to challenge dominant deficit discourses that typically privilege ideas about children’s (im)maturity and (lack of) competence, thereby readily overlooking young people’s views as legitimate ways of knowing and experiencing the world. Examples of such methods are featured in the contributing chapters and include photo-elicitation, creative and arts-based methods, online platforms and digital technologies, and performative and participatory methods. These methodological tools can enhance the opportunities for young people to participate in research and (in part) counter the adult-centric focus of much research.

Despite the methodological advances afforded by these, and other approaches, conducting research with children and young people presents a range of tricky ethical complexities and sensitivities. The ethics and integrity of research with children and young people is now receiving greater critical attention and a growing body of literature explores the ethical difficulties researchers encounter (see Alderson & Morrow 2020, and Ethical Research Involving Children available at www.childethics.com). Research ethics frameworks and related guidance provide useful toolkits to help researchers with their ethical decision-making (see Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013; INVOLVE, 2016; Nuffield Council on Bioethics, 2015). In line with these guidelines and perspectives, Research Ethics Committees (RECs) and Institutional Review Boards (IRBs) typically foreground key ethical principles such as informed consent and assent, confidentiality, privacy and anonymity, and the minimisation of any possible harms or risks stemming from the research. In childhood research, RECs take a particular focus on safeguarding concerns, calling upon researchers to identify and put in place ‘appropriate’ measures to protect the wellbeing of children as part of ethics approval processes.

Whilst offering important and necessary ethical safeguards and standards, formal ethics review processes are usually informed by adult views and ways of thinking about research and research ethics. Rarely have children and young people’s views on research ethics and related processes been sought (an exception includes Spencer, Boddy, & Rees 2014). Children and young people’s views on research ethics and the implications of their participation may well differ from adults, reflecting the different priorities or frames of reference children might have and may highlight alternative or unforeseen ethical consequences. Tolich (2016)

reminds us about the difficulties of pre-empting the full range of ethical issues that can and do arise in the field. In contrast to a focus on procedural research ethics, Tolich (2016) and others (Ebrahim, 2010; Guillemin & Gillam, 2004), call for a closer and critical engagement with the everyday ethical moments that emerge in practice. This situated approach highlights the importance of developing a critical ethical reflexivity to aid ethical deliberations and decision-making in context. By drawing close attention to the (unforeseen) issues that can and do arise in the field, researchers can better expose how they managed such tricky moments and the subsequent impacts on the research and participants.

In response to these calls for developing an enhanced ethical reflexivity, this multi-disciplinary volume offers a series of critical accounts on some of the everyday ethical issues that can and do emerge in research with children and young people. Drawing on research from across the globe, the chapters that follow expose some of the delicate ethical moments and deliberations the contributing authors have experienced and grappled with in their day-to-day research practice. The volume brings together international examples of research with children and young people of different ages, backgrounds and experiences – reflecting the diversity of young lives and the multiple socio-cultural positions children and young people occupy (Lundy, 2007). The studies reported in the proceeding chapters make use of different methodologies and techniques (questionnaires, interviews, focus groups, observation, visual and creative methods) to support children and young people's engagement in research, each of which come with their own ethical challenges and considerations. Despite contextual and methodological variations, each chapter shares a common commitment to the meaningful and ethical engagement of children and young people in research and the authors offer helpful guidance, suggestions and critical questions to aid researchers with their own ethical deliberations and decision-making.

The volume is set out in three main parts to reflect the different ways and stages ethics enter into our research intentions, processes and outcomes. Part One of the volume tackles some of the everyday ethical issues in research with children and young people including the processes of informed consent, minimising harms and vulnerabilities, and conducting research on 'sensitive' topics and with marginalised or 'hard to reach' children. Part Two takes-up a focus on the researcher's positionality to highlight how adult/child power dynamics impact on the ethics and integrity of research, including the role of emotions and trust in building research relationships with young participants. Part Three of the volume unpacks issues of representation, including how the active involvement of children as co-researchers and research dissemination methods trigger complex issues about children's expertise and how they become defined and represented through, and in, differing research processes and outputs.

CHILDREN AND YOUNG PEOPLE'S PARTICIPATION IN RESEARCH – NAVIGATING TRICKY ETHICAL MOMENTS

In Chapter One, Arlinkasari and colleagues explore the issue of children's informed consent. Drawing on a study with children living in a low-income

context in Indonesia, the authors reflect on their use of story and story-telling methods to engage children in consent processes. Arlinkasari et al. highlight the importance of understanding cultural variations and nuances that shift the meaning and use of commonly used terms such as confidentiality, privacy and rights to withdraw from research. The authors highlight the need for researchers to move beyond imparting study information and instead, offer alternative and creative opportunities for children to explore what their participation might mean for them. This includes developing techniques for children to express their rights *not* to participate and withdraw from research – areas that can be overlooked in efforts primarily aimed at encouraging their participation.

Barley takes forward the issue of consent and opportunities for children's dissent in Chapter Two. Drawing on a longitudinal ethnographic study with young school children in the UK, Barley highlights the importance of viewing children's consent as an ongoing, dynamic process (Morrow, 2008). In this chapter, informed consent processes extend from the planning and data collection stages through to data analysis and data protection and dissemination activities. Barley offers useful examples of the ongoing negotiations held with children, and using a range of techniques over a period of several years. Recognising children's expressions of dissent necessitated the careful 'reading of' children's cues, which reflected their decisions to (temporarily) withdraw from the study, or particular research activities at a given time. By viewing consent (and dissent) as an ongoing process, Barley highlights how children's participation in research must be continuously negotiated and decided by them.

In Chapter Three, Uzuegbunam takes us through a number of tricky ethical issues encountered in a study on young people's use of digital technology in Nigeria. The difficulties of conducting school-based research and using group based methods with young people are especially pronounced in contexts where young people occupy subordinate positions to adults, such as the school setting (Allen, 2008; David, Edwards, & Alldred, 2001; Spencer, 2016) – and, in this case, in Nigerian society. Negotiating access to school-based participants via adult gatekeepers, and encouraging their participation, without any undue adult influence reflects how power relations often impact on young people's decisions to take part in research (Allen, 2008; David et al., 2001; Spencer, 2016). In low-income contexts, the ethical sensitivities surrounding financial reimbursements for participation can be heightened and may further contribute to some young people's discomfort and feelings of shame or embarrassment because of their lack of access to material resources. The latter is particularly problematic when research takes a focus on young people's use of, and access to, material assets such as digital technologies and mobile phones.

Price continues in Chapter Four with a focus on the difficulties of negotiating access to young people via adult gatekeepers. Her research in the prison context highlights the ethical challenges of conducting research with marginalised young people deemed to be 'doubly vulnerable' – including the range of emotions this can trigger for both the researcher and participants. The careful navigation of informed consent in a highly controlled environment such as youth offenders' institutions highlights how the research context can inadvertently contribute to

the reproduction of dominant power relations. Price illustrates how issues of privacy and confidentiality are particularly pronounced in contexts where young people have little control or autonomy, and where adults make decisions on young people's behalf.

In Chapter Five, Parekh and colleagues extend the discussion of 'doubly vulnerable' children through an exploration of the ethics of research with disabled children. Children with disabilities are often 'left out' of studies because of the assumed complexities of involving these children in research (Alderson & Morrow, 2020, p. 2) – or are otherwise characterised or depicted in a particular way that contributes further to their disablement. This critical chapter exposes how particular definitions of disability, and related research methods and techniques, can exacerbate the stigmatisation and marginalisation of disabled children. Parekh et al. highlight the importance of methodological flexibility and the building of relationships with families and children to enable their full inclusion and representation in, and through, research.

ADULT/CHILD POWER RELATIONS AND POSITIONALITY – ETHICS, EMOTIONS AND THE BUILDING OF TRUST

Part Two of the volume unpacks some of emergent ethical challenges that come from the researcher's positionality and specifically, the navigation of adult/child power relations. By engaging with the effects of power, the chapters in this part of the volume each offer a critical reflection on some of the unintended consequences of our research processes, including the difficulties of building trusting relationships with children and young people and the related emotional responses.

In Chapter Six, Wadhwa reflects on her positionality in research with Adivasi youth in India. Reflecting on her own background and position of power, Wadhwa exposes the ways in which deficit discourses about young people are (re)produced through procedural ethics processes. The chapter highlights how our language and research practices can support particular representations of young people and, in this context, uphold dominant discourses about young people's assumed vulnerabilities and deficits. Caution and criticality are thus needed when examining the effects of the researcher's positionality and power on young people's involvement in research.

Davidson and McMellon offer an honest and critical account of the role of emotions in ethnographic research with young people in Chapter Seven. The authors share how their own emotions shaped their research processes and experiences and triggered a number of ethically sensitive moments. Drawing on two contrasting research projects in the UK and Laos, the chapter highlights how the building of research relationships cannot be readily untangled from the emotional aspects of research with young people. The authors call for greater transparency and reflexivity when reporting on the tricky ethical moments and deliberations that arise in practice, including how these shape research relationships and power dynamics with young people.

Similarly in Chapter Nine, Burch and Osaiyuwu highlight how the researcher's positionality and emotions can yield ethical consequences. Osaiyuwu's former position as a trade worker offered a shared understanding about the everyday experiences of child traders in Nigeria and aided the building of trust with participants. Yet, such commonality and trusting relationships also revealed the ethical dangers of 'being too close' to participants (Spencer, 2016). The assumption that informed adults can readily 'step into' children's live worlds, without due attention to issues of power and positionality, reminds us of the need to proceed cautiously when developing trusting relationships. Burch and Osaiyuwu illustrate the importance of acknowledging that adult/child power disparities cannot be entirely eradicated.

The final chapter in Part Two offers a sensitive account of the researcher's positionality in the highly complex context of family domestic violence. Henze-Pedersen reflects on her positionality (and related decision-making) as an adult researcher participating in children's everyday live worlds at a women's refugee. Navigating trust with children (and their mothers) revealed the ethical complexities tied to the building research relationships, particularly when trust can be compromised or undermined. Henze-Pedersen shares her experiences of managing different research relationships, and how these supported or undermined children's participation, privacy and confidentiality.

CHILDREN AND YOUNG PEOPLE AS KNOWLEDGE PRODUCERS AND THE ETHICS OF REPRESENTATION AND RESEARCH DISSEMINATION

Part Three of the volume draws on examples of children as knowledge producers and co-researchers. The chapters in this final section offer important ethical reflections on issues of representation and the involvement of children in research dissemination activities. The ethics of representation and dissemination activities are often overlooked, with limited critical reflection on how the 'translation' of children's voices, perspectives and experiences may contribute to the silencing and misappropriation of (some) children's perspectives (Spencer, Fairbrother, & Thompson, 2020; Spyrou, 2016). This section highlights some of the ethical and methodological difficulties of representing children and childhood on the basis of age-related categories and assumptions about their (lack of) competence – including the tendency for adults to 'step in' and represent children's perspectives on their behalf.

Chapter Ten draws on a participatory study involving children as co-researchers and knowledge producers about their school journeys in Switzerland. Moody et al. question the notion of 'expertise' in research to demonstrate how children's contributions can hold effective influence. The authors highlight the range of tensions that can emerge when seeking to uphold children's contributions to the design and delivery of research design, along with academic conventions and 'scientific' knowledge about how best to conduct research. Developing co-expertise is ethically challenging and necessitates critical reflection on what gets counted as 'expertise' in research.

In Chapter Eleven, Carroll and colleagues synthesise the ethical and methodological insights drawn from a series of quantitative and qualitative studies seeking to engage children and young people in policy processes in New Zealand. This chapter usefully highlights the importance of flexibility and adaptation of methods and approaches to ensure children's meaningful and ethical engagement in research that specifically aims to inform policy. The authors remind us of the need to attend to the ways in which children are differentially represented through different research processes and methods – including our final dissemination and impact activities.

Spencer et al. continue the focus on the ethics of representation in Chapter Twelve and through a critical reflection on how differing socio-cultural constructions of age and childhood status can trigger complex issues around consent and assumed vulnerabilities of migrant children in Ghana. The chapter illustrates the ambiguities of these children's 'adult-like' status as they independently navigate their lives and livelihoods, and in highly precarious circumstances. Migrant children often display their autonomy in the absence of parental or adult figures, yet their participation in research remains mediated by adult gatekeepers largely unknown to them. Spencer et al. illustrate the difficulties of establishing the exact ages of young migrants and what this means for their participation. The tricky issue of financial compensation for young participants comes to the fore when children take on 'adult-like' roles and responsibilities.

Chapter Thirteen explores some of the ethical issues that emerge with the use of drama-based methods with children and young people. Performative methods are increasingly being used for data collection and dissemination activities and offer an opportunity for young people to participate directly in the generation and sharing of research data and findings. Yet, performance requires particular skills and interpretive work to convey messages to an audience and can expose the identities of young people involved. Shabtay carefully charts some of the opportunities afforded to young people through drama-based approaches and how they can take ownership of the process and outcomes, all the whilst drawing our attention to the possibilities for these young people to be exposed to stigmatisation because of the limits to anonymity. Carefully navigating young people's consent in drama-based research thus necessitates an open discussion of the implications of, and risks involved with, (limits to) confidentiality and anonymity.

The final chapter in the volume examines children's roles in academic writing and study outputs. Deszcz-Tryhubczak and Marecki draw on their experiences of co-authorship with child researchers to highlight the ethics of representation and the tendency for adultism to prevail in academic outputs. Through their reflections on co-producing texts with children, the authors illustrate how the rigidity of academic writing can hinder children's participation in the development of research outputs. Whilst the notion of children's voices has been (uncritically) championed in recent times as evidence of children's participation in research, the chapter exposes some of the ways in which children's expressions become sanitised in final reporting or reflect the 'voices' of more articulate or academically inclined children (see [James, 2007](#); [Spencer, Fairbrother, & Thompson, 2020](#); [Spyrou 2016](#)). Such processes call into question the meaning of children's

participation in research as knowledge producers, and the ethical responsibilities researchers hold when generating outputs on, with and about children.

The chapters in this edited collection expose some of the everyday challenges and opportunities for enhancing the ethics and integrity in research with children and young people – offering new thinking and techniques to help guide researchers and practitioners with their own ethical reflexivity and decision-making.

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