The Ethical Implications of Involving Children and Young People in Research Related to their Care, Welfare, and Wellbeing

Edited by

Virginia Minogue with Edel Tierney and Caroline Roe

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About the Editors

Dr Virginia Minogue is an independent research consultant and adviser. She had a career of more than two decades in research management in the UK National Health Service (NHS), working at national, regional, and local level. After a degree in Behavioural Sciences, she trained as a probation officer, and worked in many criminal justice environments including residential, prisons, homelessness, substance misuse, and family court welfare. After completing a Masters in Policy Studies, and a PhD, she moved into academia to lecture in community justice. Her PhD explored inter-agency partnerships and mentally disordered offenders. She subsequently moved to the NHS as a research fellow before taking on the role of research and development manager. As well as working in research and development she also had the opportunity to gain experience leading a regional offender health programme and working as a commissioner of services for vulnerable groups. Her final role in the NHS was as the national lead for research. During her time in the NHS, and as an independent consultant, she developed and facilitated many patient and public involvement initiatives and groups both locally and nationally. She has published a number of articles, a co-edited book, several book chapters, in addition to guidance on patient and public involvement. She has provided training on patient and public involvement to potential contributors, and to staff, and facilitated a group in developing its own user led training package. She also has experience of chairing a research ethics committee, of which more than a third of the membership were public members, chairing a charity, and other directorships of charities. She is a qualified coach and mentor and has supported many health service staff in their career development.

Dr Caroline Roe is an Irish researcher whose career spans more than twenty years across the continuum of statutory childcare services. Her work has consistently focused on improving outcomes of children and families through ethical, rigorous research, data-driven decision-making and a strong commitment to participatory practice. She has provided research consultancy and mentoring across a wide range of areas, including service evaluations for partner agencies, inter-agency research initiatives, and projects grounded in Public and Patient Involvement (PPI). Central to her approach is the championing of the voices of children, parents, and seldom-heard groups, ensuring that lived experience meaningfully informs service design, delivery and decision-making.

Caroline earned her PhD from the University of Limerick, where she conducted mixed-methods research exploring the risk factors and patterns of disruption in foster care placements in Ireland. Her academic foundations also include an MSc in Health Promotion.

With a career dedicated to fostering transparency, learning, and collaborative improvement, her work continues to influence policy, practice and the wider conversation about child protection and family support in Ireland.

Dr Edel Tierney is an Irish researcher whose work focuses on advancing knowledge through rigorous inquiry, interdisciplinary collaboration, participation and evidence-based analysis. Her PhD with the University of Limerick explored community participation in primary care teams examining how the voices of marginalised communities are shaping health care service design and delivery. Her Post Doctoral research examined how participation by children and young people could be effectively embedded within service delivery, with particular attention to vulnerable and marginalized groups and using participatory research methods. Her long research career

explores complex social, cultural, and policy-related questions relevant to contemporary society including:

- Children and young people's participation in decision-making, particularly within child protection and welfare services.
- Implementation science exploring how research findings can meaningfully inform practice and national policy.
- Patient and Public Involvement (PPI) in research, especially in engaging socially excluded communities.
- Community participation in primary care and stakeholder involvement in research design and delivery.

She has contributed to research initiatives that seek to deepen understanding of social change, and community development, by listening to the voices of those marginalised in modern society. Her approach emphasises methodological rigour, ethical research practices, and collaboration with both academic and non-academic partners. Her work demonstrates a commitment to translating research findings into meaningful outcomes that can support communities, organisations, and decision-makers and listening to the voice the research serves.

Edel is a co-author of several influential reports and journal articles. Her work has contributed to impactful research. She values accessible scholarship and contributes to conversations that connect academic research with real-world impact. With a collaborative approach, her research aims to expand academic understanding but also support positive social change. Her work reflects a broader commitment to using research as a tool for insight, dialogue, and constructive transformation.

About the Authors

Cían Bermingham became involved in the Building Children's Futures project in 2022 when he was 14 years old. It was his first experience engaging in a project focused on Young People and their rights and it has helped shape the direction of his life since. Cían was a member of the Youth Advisory Group established as part of the project. A highlight for him was being trained through the Youth as Researchers Programme by the UNESCO Child and Family Research Centre. As a co-interviewer, he worked alongside researchers to interview senior decision-makers, gaining rare insight into how government decisions are made. Through this experience, he learned the power of having a seat at the table. Cían is now a 5th year student in Dublin and remains actively involved in youth participation, including his work with Comhairle na nÓg and the National Executive 2024-2026.

Matthew Brown is a member of the Belfast City Youth Council and the RADICAL Children and Young People's Advisory Group. He is currently doing a Law degree apprenticeship at Ulster University. Previously, he was a volunteer youth worker for four years.

Bronagh Byrne is a Professor of Disability and Children's Rights at Queen's University Belfast and Director of the Centre for Children's Rights. Her research interests focus on the implementation of the UN Convention on the Rights of the Child across law, policy and practice, and she has particular expertise in conducting participatory research projects with children and young people with disabilities, including on their right to inclusive education, digital rights, and sign language justice. She has been Principal or Co-Investigator on a range of projects for national and international organisations and is a member

of the editorial board for the International Journal of Disability Studies and Social Justice.

Claire Cassidy is a Professor of Education in the Strathclyde Institute of Education, University of Strathclyde, Glasgow. Her research revolves around three areas: practical philosophy with children and young people; children's rights, and childhood studies; particularly in philosophy of the child. She pioneered using philosophical dialogues as a rights-based research method and has employed this in various projects, including RADICAL and a recent Arts and Humanities Research Council funded project on conceptualisations of care and well-being with siblings of children with life-limiting conditions.

John Larkin is a member of the 40th Belfast Scout group and the RADICAL children and young people's advisory group. He is also a pupil of Saint Malachy's College Belfast.

Mary-Louise Corr is a Senior Lecturer in Criminology at Queen's University Belfast and member of the Centre for Children's Rights. She has extensive experience in designing and conducting participatory, qualitative research on the lives of children and young people, particularly marginalised groups. She has been Principal Investigator or Co-Investigator on a number of research projects involving qualitative methods with children and young people, including on domestic violence and the family courts, young men and masculinities, conflict legacy and child/family homelessness.

Natasha Daniels is a Lecturer in the Discipline of Children Studies, and programme Director of the MSc Adolescent Health in the School of Education, University of Galway. Natasha has interdisciplinary expertise in child and adolescent health and health promotion and in participatory research methodologies with children and adolescents. Natasha has published and presented research widely, working as

part of the Health Behaviour in School-aged Children's team and the UNESCO Child and Family Research Centre, University of Galway. Natasha holds a PhD in Child and Youth Research and a MA in Health Promotion.

Shauna Malone Gill is a research assistant in the School of Nursing, Psychotherapy and Community Health, Dublin City University.

Danielle Kennan is a Lecturer in Applied Social Science in the School of Political Science and Sociology at the University of Galway and a Senior Researcher with the UNESCO Child and Family Research Centre, within the Institute for Lifecourse and Society. Danielle's research examines contemporary social issues affecting children, youth and families from a rights-based perspective, with a focus on policy and service provision responses. She was Principal Investigator of the Building Children's Futures: Using Children's Rights to Recover from the Global Pandemic. She is a qualitative researcher with a methodological expertise in youth participatory action research. Her work includes co-editing the book *Child and Youth Participation in Research, Policy and Practice*, a significant contribution to international scholarship in the field. Danielle is also co-founder of the Youth as Researchers programme, which is central to UNESCO's global strategy for elevating youth voice.

Vanshika Kotaprolu is a member of the Belfast City Youth Council and the RADICAL Children and Young People's Advisory Group. She is also a pupil of Grosvenor Grammar School.

Colleen Kyan is an Okinawan-Irish and care-experienced researcher whose academic interests centre on gender, power, and social control/influence. She serves on Tusla's Independent Research Ethics Committee, where she brings lived experience expertise to ensure ethical practice in research. Deeply committed to equity and social

justice, Colleen is passionate about participatory research approaches that genuinely centre on those most affected by systemic inequities.

Her research experience spans collaborations with academic institutions, non-profit organisations, and NGOs, applying evidence-based methodologies to questions of public health, education, and social wellbeing. Throughout this work, she has championed consent education, advocated for ethnic minority, Indigenous, and youth rights, and worked to dismantle barriers preventing disadvantaged young people from accessing education. Colleen also specialises in scientific and creative communications, translating complex research into accessible, compelling messaging for public bodies and not-for-profit organisations. As an artist, published writer, and poet, she bridges the analytical and the artful, with creative work exploring themes of identity, power, and social justice that echo throughout her broader portfolio.

Honoured with multiple awards for her research and community advocacy, Colleen acknowledges the individuals, communities, and initiatives whose support enabled her educational journey, despite systemic challenges. She works to pay this forward, creating pathways for others who may be navigating similar barriers, and ensuring research meaningfully serves the communities it claims to represent.

Veronica Lambert is Full Professor of Children and Family Nursing at the School of Nursing, Psychotherapy and Community Health at Dublin City University (DCU), Ireland. Her academic journey began in clinical children's nursing, providing a practical foundation that has informed her 20-year career within the higher education sector. She currently leads an interdisciplinary research programme focused on child and family-centred health and wellbeing. Her work primarily explores the lived experiences of children and families managing

long-term health conditions and palliative care, with a specific interest in health communication, shared self-management responsibilities, and the psychosocial impact of illness on the family unit. A significant portion of her work is dedicated to Public and Patient Involvement (PPI). She is the DCU site lead for the Health Research Board funded National Network on Public and Patient Involvement in Health and Social Care Research (PPI Ignite Network). In this capacity, she focuses on building institutional capacity for high-quality health and social care research, working to sustainably embed meaningful PPI into the research lifecycle.

Laura Lundy is an international expert on children's rights and child and youth participation and author of the widely used Lundy model of child participation. She is Professor Emerita of Children's Rights in Queen's University Belfast and Professor of Law at University College Cork. The Lundy Model has been adopted by numerous national governments and public bodies as well as international organisations including the Council of Europe, European Commission, World Health Organisation, UNICEF and World Vision.

Alison MacKenzie is a Professor of Social Justice with interests in child's rights, philosophy of education, inclusion and special needs education. She is the programme director for the Master's programme in Inclusion and Special Needs Education, and joint editor of BERJ (British Educational Research Journal) and associate editor for EJSNE (European Journal of Special Needs Education). Alison is a member of the Centre for Children's Rights, Queen's University, Belfast.

Montserrat Fargas Malet is a Research Fellow in the School of Social Sciences, Education and Social Work in Queen's University Belfast and a member of the Centre for Children's Rights. She has been conducting research in this university since 2005, and has published extensively in a range of areas, including the legacies of the NI conflict;

children's social services, fostering and adoption; and rural schools and their relationship with their communities. Most recently, she was the lead researcher in the RADICAL project. Her research has regularly involved working with children and young people.

Paul Markey is a researcher, academic, and Expert By Experience who specialises in inclusive qualitative social research methods and social policy. He is a Postdoctoral Research Fellow at the Royal College of Surgeons in Ireland on a team developing a methodology to include community perspectives in community health needs assessments as part of Sláintecare reforms, funded by the Health Research Board. Paul studied Sociology and French in Trinity College, Dublin before undertaking a Master's in Human Rights and Social Policy in Maynooth University. He was awarded a Hume Scholarship by Maynooth University to undertake a PhD in Applied Social Studies. His doctoral research investigated the potential, and identified the need for, Expert By Experience inclusion as a discrete stakeholder sphere in Irish mental health social policy development, implementation, and oversight. His work developing emancipatory and inclusive research methodologies for minoritised communities has been published in the International Journal of Qualitative Methods. He served as Vice-Chair of Tusla's Research Ethics Committee for a number of years.

Siobhán McAlister is a Reader in Criminology and member of the Centre for Children's Rights at Queen's University Belfast. She has extensive experience in engaging in participatory research with children and young people, particularly on issues that may be deemed more sensitive. Siobhán was the Principal Investigator for the Economic and Social Research Council funded RADICAL project (Respect and Disrespect in Children's ad Adolescents' Lives), and has

led several other projects on children, young people, violence and victimisation. She is Associate Editor of the Journal of Youth Studies.

Latisha McCrudden is 21 years of age, an Irish Traveller and a third-year law student in the University of Galway. Her role in the Building Children's Future Project was to act as an advisor, as part of the Youth Advisory Group, and to help co-interview the leaders in government departments who made decisions that impacted young people during COVID-19. Outside of college, Latisha has been an Irish activist since she was 14. She focuses on women's rights, domestic abuse, ethnic minority communities, mental health and sport. She has a first Dan black belt in karate. Latisha has sat on many committee groups for organisations including the Irish Traveller Movement, National Women's Council of Ireland, National Youth Assembly of Ireland, Minceirs Whiden and Spunout. One her proudest moments with activism was a podcast she developed with her friend Emma Ward, which Spunout called "Minceirs Paving the Way", and which had over 250,000 listeners. Latisha won a National Volunteer Ireland award. She is privileged to have been listed in the BBC 100 women in the world making a change and has won awards such as a national Garda Youth award, best first year in Ireland, and Irish Tatler woman of the year. Her overall goal in activism is to make Ireland a better and fairer place for all, where those that come from disadvantaged backgrounds don't have to struggle as much and, even if it's not set out for you in life, you can carve your own path with determination and hard work.

John Mitchell is Director of Partnerships at Barretstown children's charity. His career in Barretstown began in 2004 as a student on placement. As an activity leader, John learned about the Barretstown Therapeutic Recreation model and designed and facilitated programmes to meet the needs of children, young people and their

families affected by serious illness. John spent almost ten years as Camp Director managing the day to day running of Barretstown programmes on and off site. As Director of Partnerships, he now leads the development of strategic collaborations that fuel the charity's mission: to rebuild the lives of children with serious illnesses, and their families, through free, medically supported camps and programmes.

With over 20 years' experience in Barretstown's programmes and partnership management, John has been able to forge impactful alliances across the charity, healthcare, and education sectors. Since taking on the role of Director of Partnerships, he has played a pivotal role in expanding the charity's network of supporters, engaging in meaningful research, and driving initiatives that enhance the reach and sustainability of Barretstown's Psychosocial programmes. A champion for growth and innovation, he is dedicated to identifying new partnership opportunities that align with Barretstown's strategic goals. He is also committed to fostering a culture of mutual respect, accountability, and impact, both within the Barretstown team and across all external collaborations. Outside work, John is a passionate advocate for children's wellbeing and inclusion and an active volunteer in his local community. His leadership continues to strengthen Barretstown's capacity to deliver life-changing experiences to children, young people and their families.

Edel Murphy is a public and patient involvement (PPI) specialist with more than a decade of experience advancing meaningful collaboration between researchers and the public. An early champion of PPI in Ireland, she has played a key role in promoting a research culture in which those most affected by research are actively involved in shaping and conducting it.

As National Programme Manager of the PPI Ignite Network for five years, Edel led the development of a dynamic national network that brought together researchers, patients, community partners, university administrators and research funders to strengthen the collective voice for PPI in Ireland. She is passionate about building capacity across the research community and among the public, and experienced in designing engaging, thought-provoking training and knowledge-exchange initiatives that support inclusive and impactful research.

Gail Neill is a Lecturer in Community Youth Work at Ulster University. She is a professionally qualified youth worker with over 20 years' experience in voluntary and community sector settings. Her practice has focused on anti-oppressive approaches, addressing social injustice and supporting youth-led lobbying and campaigning initiatives. Her teaching interests include critical thinking, support and supervision, reflective practice, and gender and diversity in youth work. Her research centres on feminist participatory approaches and qualitative research with young people, particularly those from marginalised groups.

Dirk Schubotz is Professor of Youth and Social Policy at Queen's University Belfast. He is a member of the Centre for Children's Rights at Queen's and a member of ARK, Northern Ireland's Social Policy Hub. Dirk has established and directed Young Life and Times (YLT), an annual large-scale social attitude survey of 16-year-olds in Northern Ireland since 2003. His work spans a range of issues relevant to children and young people. Apart from their rights and participation, this includes community relations, various aspects of education, physical, mental and sexual health, volunteering, social media use and gender-based violence. Dirk is known for this work on participatory research methods.

Zack J.E. Scott is a member of the 40th Belfast Scout group and the RADICAL children and young people's advisory group. He is also a pupil of Methodist College Belfast.

Harry Shier is an Irish activist, researcher, writer, facilitator and commentator on children's rights, participation and play, now retired, who previously worked internationally in a range of community groups, NGOs and research institutions. He is known for his "Pathways to Participation" model from 2001, and his work with child workers in the Nicaraguan coffee sector. He holds a PhD in children's rights from Queen's University Belfast, awarded in 2016 for his study on Nicaraguan children's perceptions of human rights in school. He now lives in Ireland, where he is officially retired, though still involved in a range of children's rights and participation initiatives. His published work from 1984 to the present can be accessed at www.harryshier.net.

Arthur Templeman-Lilley is an independent children's rights and youth participation consultant based in Wales. He is currently 18 years of age and is in his second year studying Social Sciences (Politics) at the Open University. His work focuses on advocating for the implementation of the UN Convention on the Rights of the Child (UNCRC) into policy and practice. He has collaborated with UNICEF, the Diana Award, and the National Youth Agency, supporting them to strengthen their youth participation models and integrate a rights-based approach within their engagement work. He is also the author of Pause, Play, Fast-Forward: The Journey of Children in Wales; an illustrated history of milestone children's rights moments and a call to action for government.

Arthur has been involved in children's rights advocacy since 2019 and has progressed from panel member and volunteer to an active practitioner within this space, working in direct delivery as well as

providing strategic support as an advisor and charity trustee. He has also engaged in a number of research projects, contributing to a report for the UK's UNCRC periodic review in 2023, and leading his own research surrounding accessibility in youth participation, a project which captured the views of young people from over 20 countries globally. Based on these experiences, Arthur has shared his learnings and insights at international conferences, creating guides and delivering workshops to encourage professionals to centre young people's voices within their research.

Introduction

Virginia Minogue

Children and young people (CYP) are current and future knowledge users; they represent the future of research and it is crucial that we include them as partners and co-researchers to ensure they grow up with a culture of understanding and using research evidence. Involving them in their developmental years will enable them to gain skills in research and critical thinking and an understanding of what is involved in creating and undertaking ethical research. Involving CYP as research partners is also crucial to our understanding of their needs and ensures their voices are heard in decisions that may impact on the services they, their families and carers, receive. History tells us that this has not always been the case and failures to protect CYP, amongst others, resulted in the development of ethical principles to protect the dignity, rights, and wellbeing of those taking part in research (World Medical Association 2024; Department of Health, Education, and Welfare 1979).

The involvement of CYP as partners in the planning, design, and conduct of health and social care research is becoming more prevalent. The rights of the CYP to be heard, and to take part in decisions that affect them, is enshrined in the United Nations Convention on the Rights of the Child, 2009. The Council of Europe's (2012) recommendation on the participation of CYP under the age of 18 states that they have:

> "--- the right, the means, the space, the opportunity and, where necessary, the support to freely express their views, to be heard

> and to contribute to decision making on matters affecting them, their views being given due weight in accordance with their age and maturity" (The Council of Europe, 2012).

Meaningful participation should follow the nine basic requirements for the meaningful and ethical participation of CYP as set out in the General Comment on Article 12 of the UNCRC:

1. Participation is transparent and informative.
2. Participation is voluntary.
3. Participation is respectful.
4. Participation is relevant.
5. Participation is child friendly.
6. Participation is inclusive.
7. Participation is supported by training for adults.
8. Participation is safe and sensitive to risk.
9. Participation is accountable.

Despite this right, the involvement of CYP as partners or co-researchers, as with adult Patient and Public Involvement (PPI), is not regulated and no universally agreed standards for involvement currently exist. Some locally agreed standards are in place (e.g. UK Standards for Public Involvement[1]) and international ethical principles provide standards for ethics in research. While ethical principles and research governance and integrity standards relate to the safe participation of research participants i.e. subjects of research, they do not always specify how the CYP acting as a research partner

[1] The UK Standards for Public Involvement were developed by a partnership group, following public consultation, and have been adopted by the National Institute for Health Research (NIHR), Chief Scientist Office (CSO) Scotland, Health and Care Research Wales, and the Public Health Agency Northern Ireland. National Institute for Health Research. National standards for public involvement. 2018.

is also protected from any possible sources of harm. Yet there are responsibilities, ethical and governance issues associated with taking part as co-researchers, project team members, advisory group members, that potentially give rise to significant ethical and governance issues.

However, research is a crucial factor in ensuring children's rights are respected and their voices are heard particularly where the research impacts on the services and care they receive. The involvement of CYP in research that impacts on their lives is critical to ensure that research topics and questions reflect their priorities, lived experiences, and concerns. Nonetheless, concerns have been identified about the ethical involvement of CYP as research partners, the protection of their rights, safety, and wellbeing in the research process, and whether involvement in itself can be potentially harmful. With this volume we have sought to produce a practical textbook on the topic of ethical participatory and partnered research with CYP that will be of value to many different audiences. These include seasoned researchers and student researchers; academics leading health and clinical professional training with a research component; academics leading teaching on the involvement of CYP as research partners; health and social care research centres; research institutes; institutional ethics boards; health and social care research ethics committees; funding bodies; those with responsibility for training and building capacity for CYP in research; and anyone with an interest in good practice in the ethical involvement of CYP.

Defining partnered research involving children and young people

CYP as partners in health and social care research refers to the active involvement of CYP not merely as subjects or participants, but as

collaborators, co-researchers, or co-producers throughout the research process. This participatory approach means CYP help shape research questions, design studies, collect and analyse data, and share findings. This involvement is distinct from traditional "patient and public involvement" (PPI) with adults because it must account for CYP's specific perspectives and rights, potential vulnerabilities, and the legal requirements for protecting those under 18 years of age.

There is no single internationally agreed term for CYP involvement as research partners, collaborators, or co-producers. Terminology developed for adult involvement, patient and public involvement or PPI, is frequently used, particularly in paediatric health research (Preston et al 2024). However, it is rarely used in social care, social work, education, and child and youth service research, where references are usually to participatory research, co-research, or co-production. PPI does not always capture what is involved when CYP engage as partners and co-researchers in health and social care research. In addition, there may be circumstances where CYP may be unable to contribute directly because of age, vulnerability, or the risk of being made more vulnerable by increased visibility in the research process. In these cases, their contribution may be supported by an advocate or someone who has a strong relationship with them and understands the care and support they need and receive. For these reasons, definitions of partnered research with CYP are often broader than definitions of PPI in health research.

Organisations such as the World Health Organisation (WHO) and UNICEF have published definitions relating to the involvement of CYP in participatory activities, including research. The WHO (2018) refers to:

> "—inclusive, intentional, mutually respectful partnership between adolescents, youth and adults whereby power is shared, and respective contributions are valued—".

UNICEF (2021) similarly describes meaningful partnership as:

> "—grounded in mutual respect, shared power, and a reimagining of intergenerational relationships."

In the health and social care context, the National Institute of Health and Care Research (NIHR) (2021) uses the definition produced for adults engaged in patient and public involvement, "doing research 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them". This involvement may include setting research priorities, designing studies, carrying out research, analysis, reporting, and dissemination. The NIHR emphasises involvement should be meaningful, collaborative and not tokenistic. Tusla[2] Child and Family Agency (2023) have developed a definition focused on the active involvement of CYP in research that also recognises the role of advocates where there are particular circumstances that may mean the CYP cannot exercise their own agency (see Box 1.0).

The common factors within these definitions are the involvement of CYP as active contributors to research which:

- Embraces an ethos of partnership
- Is active and meaningful
- Takes a rights-based approach
- Emphasises agency and voice
- Is flexible

[2] Tusla is the Irish Child and Family Agency, the dedicated State agency responsible for improving wellbeing and outcomes for children. www.tusla.ie

- Recognises the need to provide support and to protect and safeguard the child or young person's interests.

Box 1.0: Defining the involvement of children and young people as partners, co-researchers, and co-producers of research

> 'By patient and public in this context we mean everyone: children and young people, those attending Tusla services including potential users of services. We also include parents, carers, guardians staff members or anyone involved in the care and protection of children and young people. By 'involvement' we mean the active involvement between children and young people/people who use services/ parent/guardians/carers/staff/
> the general public and researchers. It does not include the use of people as participants in research (or as research 'subjects') and does not generate data for individual research projects.'
>
> (https://www.tusla.ie/research/tusla-research-office/public-and-patient-involvement/).

Throughout this book the terminology used to describe the involvement of CYP as active collaborators and co-producers of research will be research partners in participatory and partnered research.

This book presents the reader with a practical understanding of how to ensure the ethical involvement of CYP as partners and co-researchers in health and social care research that has an impact on their lives. The aim is to provide a reference point and guidance in a field that is still growing and developing in its intention to include CYP in a meaningful and ethical way and to give them 'space, voice, audience and influence' (Lundy 2011). Authors discuss key areas of ethical and meaningful involvement including:

- What is ethical practice in involving CYP as co-researchers and research partners.
- The importance of adopting a rights-based approach to involvement and approaching the process with respect and sensitivity to power dynamics.
- Understanding the presence of power imbalances and addressing those dynamics through self-awareness and reflexivity in order to change the way we work and communicate.
- The creation of safe spaces and meaningful partnerships with CYP whilst understanding their support needs and safe-guarding their interests.
- Consideration of when ethical approval and consent/assent is needed to engage CYP as research partners and whether involvement of this nature is seen primarily as beneficial or potentially placing them at risk.

The book is a practical resource for people who want to involve CYP as research partners in health and social care, and who want to do so ethically, with CYP's best interests and safeguarding at the centre. It helps readers to explore key ethical considerations in CYP involvement, including power dynamics, working with an ethos of respect, meaningful inclusion (particularly of diverse voices), relationship building, and differing interpretations of vulnerability. Three chapters foreground CYP voices and are written from the perspectives of those who have engaged in research and those with care experience or lived experience of CYP services. These chapters offer unique insight as CYP share what they have learned about navigating power differences and systemic exclusion. Using a rights-based approach, the book shows how successful partnered and participatory research can amplify CYP voices.

Chapter one sets the scene by outlining key ethical issues to be considered when working with CYP as partners, collaborators and co-producers of health and social care research. It sets out the unique ethical considerations of involving CYP and the implications of doing so. It discusses the creation of the foundations for meaningful partnerships and how to enable CYP to make an active contribution. It explores the value of the various ethical approaches and models centred on a rights-based and values-based approach to involvement and the benefits and challenges of this approach.

Chapter two considers questions of power and empowerment in partnered and co-produced research with CYP. It explores the three faces of power: direct, indirect and ideological, that adults hold over CYP but also addresses disparities of power among CYP themselves. These disparities are often linked to stereotyping and stigma and can lead to some groups and minorities becoming marginalised and disadvantaged and their voices not being heard. The author provides tools, based on their own experience, that can be used to understand and address power imbalances.

Chapter three reflects on how the framework for a rights-based ethical approach to working with CYP, provided by the UN Committee on the Rights of the Child (2009), can be applied to collaborating with them in the research process. Using the learning from a collaborative research study, the authors explore how to embed the promotion and protection of the rights of CYP in decision making. They examine the different requirements of the UN Committee on the Rights of the Child ethical framework and map how the project sought to achieve those elements. The chapter also includes the reflections of young people who participated in the project.

Chapter four also focuses on the experience of CYP and discusses the ethical considerations involved when Children and Young People's

Advisory Groups (CYPAGs) are engaged in the design and conduct of research. This chapter utilises a participatory rights-based approach using the Lundy Model (Lundy 2011) to explore the experience of the CYP and their understanding of respect and disrespect.

Chapter five provides a personal reflection and valuable insight from a young person, illustrating what participation looks like for a CYP. Shaped by their experience as a research participant, advisor, peer researcher and facilitator of youth-led projects, the author explores the opportunities and tensions that can arise. They offer an approach to participation and practical recommendations for researchers who want to engage in the meaningful and ethical involvement of CYP.

Chapter six examines the inclusion of CYP with lived experience of child and family services, and specifically with care experience, as voices in Research Ethics Committees as well as research partners. Drawing on the authors lived experience, it demonstrates how the unique experiential knowledge and meaningful involvement of those with lived and care experience is essential for improving ethical integrity and scientific rigour in research. As with earlier chapters it explores concepts of power, inclusion and systemic change. It also points to how Research Ethics Committees can adapt their structures and processes to make them more inclusive, and address issues of representation and lack of diversity.

Chapter seven also focuses on those who have care experience or lived experience of child and family services. Many of those CYP may also be involved in research as participants or co-researchers and are motivated by their experience to utilise it to undertake research aimed at improving service delivery and the user experience. This chapter explores the journey from childhood care or lived experience to a career as a researcher or academic and the navigation of the ethical

considerations that arise. It examines the potential emotional impacts of research and the use of reflexivity in managing their unique position.

Chapter eight explores ethical approaches to involving CYP experiencing mental health issues and distress as partners in research that affects their care, treatment, and wellbeing. The chapter examines and challenges the perception of some researchers that CYP, particularly those experiencing mental health issues, are vulnerable and require additional safeguarding. It also looks at some of the challenges and barriers to meaningful engagement and outlines how partnered and collaborative research can improve the quality, relevance, and representativeness of mental health research for CYP.

Chapter nine examines the evolution of Artificial Intelligence (AI), its role in CYP research, and the potential impact on partnered and participatory research with CYP. It points to the need for additional reflection on the harms those young people may experience when using AI, building awareness of and mitigating the risks, and the requirement for good governance and safeguarding (World Health Organisation 2024; NSPCC 2025; Hashem et al 2025; UNICEF 2025). The chapter explores the potential benefits of AI in participatory and partnered research with CYP, the impacts, and the ethical concerns.

Chapter ten focuses on capacity building for the involvement of CYP as research partners. It explores a Network approach to building capacity and draws on the learning from the development of the Patient and Public Involvement network (PPI Ignite Network) in Ireland. The author sets out what is required to build a network of organisations focused on supporting, and building capacity for, high quality public involvement. It shares the learning and experience of those who created resources and facilitated the involvement of CYP across a network of universities, health and care organisations, and the charity and voluntary sector.