# Being Participatory: Researching with Children and Young People

## Co-constructing Knowledge Using Creative Techniques

Imelda Coyne
Bernie Carter
*Editors*

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# Preface

The need for a book on participatory research arose from many conversations and debates about children and research between ourselves, our colleagues and our students and, of course, with the children and young people with whom we have worked. The book is a collaborative creation as we believe that understanding, respecting and incorporating different theoretical perspectives is necessary since children's and young people's lives are complex and multifaceted. Our contributors are leading international researchers, practitioners and academics who represent different disciplines and traditions including nursing, health, ethics, sociology, anthropology, human geography and education.

In this book we have two main objectives. The first is to examine the theories, principles and ethical issues in participatory research with children and young people. The second is to provide examples of how researchers from a variety of disciplines have set about conducting participatory research with children and young people. Our aim is to provide detailed guides and worked examples on a range of participatory research methods/techniques used with children and young people which will have relevance for students, practitioners and researchers from health and social sciences.

With an increasing focus on children and young people's participation in matters that affect their lives, this textbook aims to explain why and how children's and young people's voices can be elicited using a variety of participatory techniques. Our intention is to advance thinking and knowledge on participatory research methods and to show how these can be used and developed. This book focuses on both the theory and practice of participatory research, and we hope that researchers will find the top tips and guidance helpful in their research with children and young people.

Many times in our respective workplaces, we are asked by our students to recommend or direct them towards one research book that addresses a variety of participatory research techniques. Although there are many good research textbooks on the market, most usually just include one chapter on participatory research techniques. Therefore, our intention with this book was to provide examples of participatory research studies, exploring how the studies happened and what the researchers would have done differently as research occurs in the real, sometimes 'messy', world. Our detailed description of the methods/techniques, guidance, top tips and ways to avoid problems and potential pitfalls aims to address some of the challenges faced by researchers. So, we have targeted this book at researchers, academics and practitioners who need guidance on what techniques are available, how the techniques can be used, the various advantages and challenges and how best to involve children and young people in all stages of research. There is increasing interest in involving children and young people as coresearchers but little guidance on how this can be done. This book provides several examples of how to engage and support children and young people to have an active participatory role in research. We hope this textbook will be a valuable resource not only for researchers thinking about or embarking on research with children and young people but also for experienced researchers who wish to explore participatory approaches and enhance their thinking and use of creative techniques.

As editors we started this book with a number of core principles in mind. First, research needs to be carried out *with* rather than *on* children, thus recognising children as active contributors to rather than objects of research. We have the firm belief that children and young people have the right to express their views and opinions on all matters that affect their lives such as education, health, welfare and social care. The growth of legislation nationally and internationally emphasising user involvement coupled with a participation agenda has led to increasing need for participatory research with children and young people. The participation agenda has made it imperative that users' views and experiences are included in government policies, reports and guidelines. In addition, new political and funding pressures strongly advocate and require research that actively engages user groups (including children) in all stages of research, from inception to implementation and beyond.

Second, we view participatory research as being theoretically positioned within a strengths-based perspective of children's and young people's agency and capabilities. Thus, we are interested in a diverse range of techniques that respect and maximise children's and young people's agency and capabilities and which accommodate and maximise children's and young people's diverse ways of communicating and participating. As a result, the chapters in this book illustrate a range of creative, participatory methods, tools and involvement strategies to reveal children's and young people's competencies. The focus is on creative participatory techniques that can enable and promote children's and young people's ways of expressing their views and experiences. Researchers need to recognise the power differential in the adult-child relationship and adopt a stance of coresearcher and colearner in the co-construction of meanings and understanding.

Third, we were keen to illustrate not only the advantages but also the challenges associated with participatory research techniques so that researchers can make informed decisions about their choice of methods, research design and other factors.

Both editors of this book are children's nurses who actively engage children and young people within participatory research. We do not just talk and write about participatory research; we have been undertaking participatory research with children and young people for many years. Prior to beginning this book, we were surprised at the lack of worked examples and descriptions of participatory techniques in published research and research textbooks. We hope that this book will provide researchers with the knowledge to conduct truly participatory research with children and young people. In addition, we hope this book will equip researchers with the knowledge to choose techniques tailored to individual children's and young people's strengths, their particular situations, contexts and cultures as well as the focus of the research. We hope that researchers across a range of different disciplines will find this book useful.

## An Overview of This Book

Drawing on a rights-based and strengths-based approach, this textbook provides detailed worked examples of participatory research techniques that have empowered and actively engaged children and young people in the research process.

The book is broadly divided into two parts: In Part I, we set the scene for participatory research considering the theoretical and conceptual ideas underpinning the field. Chapter 1 provides an overview of participatory research and a rationale for conducting participatory research with children and young people. In Chapter 2, a detailed and theoretical consideration of the principles of participatory research is presented. The ethical issues in participatory research and their implications for researchers are critically considered in Chapter 3. The final chapter in this section explores ways of involving children and young people in participatory research.

In Part II, four chapters provide detailed discussions of the key participatory research methods—play, interviews, photovoice and e-technology. The final chapter provides a final consideration of the positioning of participatory research. Each of the four chapters about methods includes an example of how the research technique was used in a research study. This is followed by a discussion of the advantages and challenges associated with each technique. Each chapter includes a list of 'top tips' which represent key advice for researchers contemplating using the particular method. Chapter 5 opens this section by focusing on 'being participatory through play', and within this chapter different methods of engaging children and young people are presented and explored. These methods include drawing techniques, collage, body mapping, toys and games, puppets, storytelling and creative writing. In Chapter 6, the focus turns to the use of focus groups, peer-to-peer interviews, interviewing children with learning disabilities and interviewing adolescents. In Chapter 7, we focus on participatory research using photo-based images including auto-driven photo-elicitation, researcher-driven photo-elicitation and visual storytelling. In Chapter 8, the use of mobile technological tools is considered and the techniques for implementing app-based research with children and young people are critically examined. In the final chapter, Chapter 9, we raise questions about the current positioning of participatory research, the extent to which the claims that even committed researchers and academics make about participatory research are authentic and whether participatory research is a genuine extension of the sphere of children's and young people's participation.

Note: the editors and publishers have been assured by the authors that they received from parents their written and signed permission for the image of their children to be published and disseminated.

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# Participatory Research in the Past, Present and Future

# 1

Imelda Coyne and Bernie Carter

## 1.1 Introduction

Within the last decade, in particular, there has been a huge surge in research with children and young people about matters that affect their lives, ranging from education, health, care, wellbeing and social care. The surge in research has mostly been in Western, developed countries and not so much evident in many other countries. Although talking about children's rights advocacy, Häkli and Kallio [1] note that 'different parts of the world constitutes a diversified and uneven field of thought and action' (p. 308). The increase in research with children has been promulgated and supported by other factors. Firstly, by the growth of legislation in many countries internationally that supports and values the voices of children in all matters that concern them. Secondly, for those countries whose focus has shifted to an active participation agenda, the inclusion of users' views and experiences in governmental policies, reports and guidelines is now considered essential, even when rhetoric outstrips reality. Thirdly, and more specifically to the focus of this book, the political and funding bodies of an increasing number of countries now strongly advocate for research studies that engage user groups (including children) in all stages of research, from inception to implementation. In many cases, funding is contingent on at least some degree of service user involvement; this has led to increased interest by researchers in how to actively involve children and young people in research and participatory methodologies.

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Participatory research with children and young people can mean many different things [2]. In this textbook, we view participatory research as taking a person-centred participatory approach to represent children's and young people's voices faithfully, by building understanding from an interactive, reflexive and engaged position [3]. We view participatory research as being theoretically positioned within a strength-based perspective of children's and young people's agency and capabilities [4]. Participatory methods are a diverse range of techniques that aim to accommodate and maximise children's and young people's diverse ways of communicating and participating [5]. Participatory research involves using creative participatory techniques that facilitate and promote children's and young people's active engagement in the research so that they are active participants in telling their stories and sharing their meanings and experiences of their world. Participatory research is about the co-construction of meanings and understanding [6]. It requires the adult/professional researcher to become a co-learner and the children and young people to become co-researchers; together each individual (child, young person or adult/professional researcher) play an active role in knowledge construction [7]. This active role ranges from the involvement of children and young people in some or all aspects of a research project. Typically, this ranges from the identification of the problem and involvement in the research design to a much more embedded and sustained involvement in the methods, analysis and interpretation of the data, dissemination and implementation of changes. The key issues in participatory research are participation, choice, co-construction, reflexivity, flexibility, time, space and relationships [2, 3, 8, 9]. All of these issues will be addressed throughout this book at varying points.

This book takes the theoretical viewpoint that children and young people are 'experts in their own lives' and that we as researchers need to find ways to work with them to help co-discovery of their unique insights. Methods need to be tailored to individual children's and young people's strengths, their particular situations, contexts and cultures as well as the focus of the research. Thus, the researcher needs to work closely with the children and young people to find the most appropriate means that will help them to communicate their perspectives. To be effective in research with children and young people, researchers must be prepared to try to step into another world; albeit as researchers we can never really gain entry into a child's, young person's or, for that matter, another adult's lifeworld [10]. The lives of the children and young people who participate in our research are a long way away from the world we inhabited when we were children. We should not presume to think that we can guess their perspectives. Instead, children and young people must be allowed to convey their perspectives as best they can, and the researchers need to be receptive to their views. Children and young people are the most important source of evidence on how their lives are lived and experienced, although this stance was far from evident in the past.

## 1.2 Past Views of Children and Childhood

In the past, children's and young people's perspectives were marginalised and in many cases silenced. Research was done *on* children, rather than *with* children [11, 12]. The adult's view of the child's perspective was often sought in research about children's and young people's issues. This reflected a developmental perspective that viewed children as being unable to understand and describe their world and life experiences due to developmental immaturity [13]. There was a widely held belief that children were not capable of providing accurate accounts of their experiences and were unreliable informants on their lives [14]. Parents or carers were seen as knowing the child sufficiently well so they were capable of relating child's thoughts and preferences. This meant that information about children's views was most often obtained through objective measures and/or from proxy accounts by adults (parents, carers, teachers) who were thought to know the child best [15]. It was also assumed that adults could extrapolate memories from their childhood and identify the concerns of children in present-day realities. It was also commonplace that interventions developed for adult populations were applied to children without consideration of work or fit [16]. Generally children's views represented a rich source of data which was largely unexplored from the child's own perspective [14].

Apart from the stance that adults were able to provide robust and authentic proxy data about children, there were many ethical and organisational hurdles to overcome for even the most committed researcher. Gaining ethical approval was usually a lengthy process without the assurance that ethical approval would always be obtained as ethics committees tended to be risk averse and highly protectionist about any research involving children [10]. Researchers required high levels of patience and time to gain access to CYP as approval from ethical committees was never certain, and long delays were inevitable [17, 18]. Even with ethical approval, some research studies could be derailed due to the challenges with negotiating access to CYP via multiple gatekeepers [19] and requirement of parental written consent for all children aged up to 18 years [20].

It was in the 1990s that the lack of research *with* children became increasingly recognised by researchers [13]. Around the same time, leading sociologists wrote about a new paradigm for childhood studies [12] where they challenged assumptions and outdated beliefs about children and their childhoods, and these publications became seminal texts. This new sociology of childhood offered an alternative understanding of child development and was a reaction towards the perspective that childhood was a period in which children were socialised into adulthood. These sociologists challenged the notion of the child as an object and made strong arguments about children as actors and agents in the social world. They also pointed out how childhood was historically and culturally created in and through discourse and how constructions of childhood are continually evolving and being constructed. The new sociology of childhood represented a major paradigm shift and provided a new lens through which to view and think about children and childhood. Children were no longer theoretically regarded as objects of concern; instead, they were positioned as beings, social actors and competent co-constructers with others in everyday social relations [21].

Recognising children's agency and capacity to be active contributors to research about their lives was a significant paradigm shift in the new social study of childhood and raised the importance of conducting studies *for* and *with* children. Around the same time, the United Nations Convention on the Rights of the Child (UNCRC) was published which asserted children's rights to participate in all matters that affect their lives in 12 articles [22]. The UNCRC advocated the right of every child to self-determination, dignity, respect and non-interference and the right to make informed decisions. In the Convention, Article 12 states that 'States shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child will be given due weight in accordance with the age and maturity of the child'. In the Convention, children's rights are seen as encompassing the fundamental principles of protection, promotion and rights of participation which are key elements in child-centred care and participatory research [4]. Over time, the gradual acceptance of children's rights by key stakeholders in research coupled with the changing views of childhood led to increasing recognition of children as active contributors rather than objects of research. This in turn has led to new ways of engaging with children and young people and increasing emphasis on participatory research with them to uncover the richness of their worlds.

## 1.3 Contemporary Views of Childhood and Young Adulthood

With the 'new' sociology of childhood and the UNCRC now into their third decade, their influence has resulted in an increased demand for research on children's and young people's lives and increased requirements for children's and young people's participation in research that can inform policy and service delivery. Giving children and young people a voice is seen as essential for improving service delivery and planning. Increasingly researchers are recognising the importance of recording children's and young people's own perspectives in order to understand their lives in their own terms. Key to this is balancing requirements for protection with the desire for participation so that children and young people are provided with a choice as to whether and to what extent they want to take part. The perception of children and young people as vulnerable and unable to contribute has been challenged by research which clearly demonstrates that children have a contribution to make [23] and research which illustrates children's and young people's competence and abilities [24] and the valuable contributions to research as co-researchers that children and young people can undoubtedly make [25].

As Carter [10] points out the 'notion of vulnerability is all too often seen as interchangeable with the notion of lacking competence and these two concepts need to be unshackled' (p. 861). Carter makes an important point that the practice of framing children within a discourse of vulnerability and seeing research with children as inherently risky inevitably positions researchers as 'dangerous' and requires reviewers to take an overcautious approach to any research involving children. It is important that researchers uphold ethical standards, but at the same time children and young people's voices need to be heard [26]. It is a case of balancing protection and participation so that children and young people are given the opportunity to convey their views about matters that affect them directly [27]. At the same time, it is of course important that children and young people are not exploited in the process. For example, seeking children's and young people's views about what they would like to change but then failing to activate change because the researchers have moved on to their next research project.

### 1.3.1 Strength-Based Perspective

The view of children as passive, incomplete and incompetent has been replaced with a view of children as active, social actors and beings in the world. The child's or young person's perspective as an agent in a situation represents how they experience, perceive and understand the context in relation to themselves and their situation [4]. Taking a child's or young person's perspective means that they are seen as both a subject and agent and possessing competencies [21]. We know that children and young people are the best persons to relate how they feel, how they experience things and what their views are on a range of matters. Even very young children from about 2 years of age and upwards can convey their views provided researchers use appropriate tools that play to their capabilities and strengths. Although essentialist criterion, such as age, may be used to demarcate competency, it is now more commonly acknowledged that age is not the most important marker for children's competency or cognitive abilities; instead experience is much more relevant as children are not a homogeneous group. However, despite this, age perhaps because it is such an easily measured metric is still presented in applications for funding or to ethics committees, to reflect competence and capacity.

Taking a child's or young person's perspective means that children are viewed as having competencies and agency in specific settings and different social processes [28]. Children are involved and actively contribute towards a negotiated set of social relationships within families [29]. There is a changed emphasis in childhood research towards viewing children and young people from a strength-based rather than a deficit-based perspective. Standpoint matters in all research. It means viewing children and young people as agentic, capable of social action and socially active. So, the best people to provide information on the child's perspective are children themselves. It requires a sensitivity to children's and young people's standpoints and using creative, participatory methods, tools and involvement strategies to maximise children's and young people's competencies and strengths.

### 1.3.2 Range of Participatory Techniques

There is a growing body of participatory research techniques which utilise creative ways of accessing children's and young people's experiences, for example, storytelling, puppets, photovoice, drawing, painting, role play, model-making, collage, games, music, dance, drama, cameras, mapping exercises, child-led tours, blogs, videos, television, radio productions and digital technologies. Other structured activities include worksheets, vignettes, diaries, sentence completion and spider diagrams that are used in addition to more traditional qualitative methods like interviews and observation. Many participatory techniques are creative and visual which attempt to make it easier for CYP to convey their understandings of their experiences [30]. To play to CYPs strengths, researchers needs to use a multi-method approach as it is unlikely that any one tool will be accessible to all CYP with different skills, cultural background and personalities [31].

These techniques help to expand the modes of expression available to children and young people and cater to different preferences and strengths [5]. For example, some children may enjoy using arts-based techniques, while others may prefer storytelling. The techniques frequently help to create a relaxed environment where children and young people may be more at ease and feel more able to express themselves freely, without worrying about giving the right answer. Participatory techniques must be framed in such a way to allow children and young people to take the lead [21]. So, it is about giving children and young people greater control over the research process and space to talk about their experiences and express their views. Arts-based techniques can enable dialogue with children and young people about complex and abstract issues, help with sensitive interviewing and work well with children of different ages and varied literacy [5]. It also can provide children and young people with a sense of ownership of their contributions, ideas and materials. Participatory techniques can also introduce a fun element into a potentially 'serious' endeavour [32].

There can be a tendency to misconstrue participatory methods as being 'childish' or less rigorous than the more traditional forms of data collection such as the written word. Instead we would see these data collection techniques as being more child-oriented because to use them, researchers need to take account of children's and young people's skills, capacities and preferences [5]. Participatory techniques, arguably, can be used equally well with adults and those with communication difficulties. We used a card-sorting exercise with adult participants (healthcare professionals), and although some individuals thought it was unusual, all willingly participated and enjoyed the process [33]. The exercise proved very useful for stimulating more discussion, reflection and new insights in the research study.

### 1.3.3 Relationships and Co-construction of Meanings

A participatory approach that seeks to facilitate recognition of children entails much more than listening to their voices. It is also not simply about the mechanical application of a particular technique. It is instead a process of developing relationships, encouraging dialogue, joint learning that is geared towards children's and young people's self-understanding and agency as well as to the self-understanding of the researchers involved [34]. Researchers need to allow sufficient time to build rapport and relationships with children and young people in order to access deeper layers of their voices. It is about handing over the agenda to the children and young people so that they can control the pace and direction of the conversation, even if this can be discomforting for some researchers. It is an active process of communication involving listening, hearing, interpreting and constructing meanings [2].

Clearly researchers need to be flexible in the methodology they use as children, and young people are not a homogeneous group. Spyrou (2011, p 162) reminds us that children's worlds are complex and 'messy, multilayered and nonnormative' in character. Researchers need to be constantly aware of the varying reactions of children and young people as one method does not suit all. Not every technique is appropriate for every child or young person in every situation. Researchers need to be intuitive, reflective and flexible so that they can adapt methods/techniques during the research process to reflect situational contexts, social relationships and children's and young people's preferences [30]. Participatory research techniques should be flexible enough to take account of differences in age, cognitive development, individual personalities and interests, context and preferred form of communication. Many studies now incorporate a variety of techniques recognising that children and young people have differing preferences for ways of communicating. The matter of context needs to be taken into account since children's and young people's participation agency may be influenced by many factors including social class, family structure, family dynamics, ethnicity, culture, parents' age and education. It should not be assumed that children and young people within certain age groups or certain cultures will all behave in a certain way. Likewise, it may not be assumed that all children and young people will actively enjoy and embrace participatory techniques or wish to participate in the first place.

The adoption of participatory methods changes relationships and power status. It does not mean that power is shared equally, but it should mean that the power differential is better balanced so that the child has an active input into the co-construction of knowledge. Bjerke (2011) and Moosa-Mitha [35] talks about this power sharing as things being 'differently equal'. Participatory research is not about extracting information in a one-way event as it involves children and young people and adults discussing meanings and then co-constructing meanings and knowledge. So, participatory research is about the development of shared understandings from sustained interactions within a safe environment. It is also about researchers relinquishing their roles as controllers and knowledge owners, thus requiring a fundamental shift in research approach. Using a variety of participatory techniques within a relationship of trust may encourage children and young people to express themselves more openly, help them to feel more at ease, make the research fun or more pleasurable and may balance the adult-child power differential. Participatory techniques are seen as potentially producing more 'authentic' knowledge about children's and young people's subjective realities [36]. Participatory techniques, therefore, may contribute towards a more approximate representation of children's and young people's worlds than those accounts obtained solely from interviews and questionnaires.

However, these claims are subject to challenge from researchers particularly within children's geographies and cultural studies. Researchers have raised concerns about privileging children's and young people's voices as the most authentic source of knowledge about themselves and their lives and challenged the assumption that knowledge produced by children and young people about children's and young people's experience provides a better understanding of these experiences than that generated by adult researchers [37, 38]. Lomax concluded from her research that used child-led visual methods that it produced different rather than superior knowledge about the children's lives. She concluded that children's voices are differently and unequally heard in the research which challenges the premise of a singular children's voice in the literature [38].

The assumption that participatory research techniques may reduce the adult-child power differential has been challenged also. Gallagher [39] provides an interesting account of how some primary school children resisted participation in a participatory technique (model-building) and focus groups, and other children used the time to indulge in fun activities, which generated chaos. He concluded that power cannot be 'given' to children and young people through participatory techniques; instead children and young people may 'exercise power by resisting, redirecting, or subverting these very techniques' (p. 146). Gallagher suggested that participatory techniques should be framed in terms of tactics and strategies within complex pre-existing relations of power. This means we cannot assume that participatory techniques are necessarily liberating or that they will be used in a liberating way. Likewise, researchers cannot assume that all children and young people want to exercise their agency and participatory rights. Children and young people have the right not to participate and should also be able to choose whether they want to exercise their agency. In the same way that adults like their individuality to be respected, children should be accorded similar respect.

## 1.4 Where We Need to Go

Researchers continue to push boundaries and challenge assumptions with regard to being participatory with children and young people in research matters. But there is more work to be done with regard to promoting choice, enhancing agency and employing empowerment strategies that will enable children and young people to share their views on matters that affect them and to share their worldview with adults. We need to move away from thinking that we, as adults, can know what it is like to be a child or young person in the twenty-first century. We need to do more to involve children and young people as co-researchers in all stages of a research project, e.g. from identifying the research question, deciding on design and methods, collecting data, analysing, interpreting and disseminating the findings. Children and young people can offer new perspectives as they are 'insiders' to a peer culture where adults are ‘outsiders’. Involving children and young people in designing and carrying out their own research has been limited in the past, but the situation is changing gradually. More researchers and policymakers have begun to explore how to involve children in setting research priorities and building their capacity to be co-researchers on many issues that impact their lives [25].

Although there are many advantages to involving children and young people as co-researchers right from the start of the research, we cannot assume that this approach to research (children as co-researchers) will always result in better or more authentic research since children’s and young people’s voices are produced within specific institutional contexts, e.g. schools, hospitals, social services and communities. Given children’s and young people’s position in families and society, it is clear that their positioning and agency are subject to similar constraints, cultural and social norms as adults [6]. So children’s and young people’s relations in the social world are constrained and coordinated in a systematic way. Holland et al. [3] suggest that although research may be labelled as creative and participatory, in many cases, it is in fact a highly managed encounter between adult researchers and children and young people that is driven by adult research agendas, time frames and priorities. Endeavouring to be creative and participatory does not mean that the children and young people will actually experience the process as participatory. This means that researchers need to be critical and self-reflective on the processes which produce children’s and young people’s voices in research, the power imbalances and the ideological contexts that shape them and which influence representation.

More needs to be done in participatory research to reach out to marginalised children and young people whose views are seldom reported due to challenges associated with access, ethics and gatekeeping structures. Participatory research methods need to be more encompassing of the diversity of children and childhood. There is no single universal childhood, but yet there is a preponderance of studies conducted with white middle-class articulate adolescents [40]. From a review of 320 empirical research articles published in three journals, McNamee and Seymour found that there was an overfocus on a particular age, namely, those aged 10–12 years, and concluded that not all children’s and young people’s voices are being heard. Although there has been a proliferation of participatory research with children and young people, there are fewer studies being conducted with children and young people with disabilities and those from different cultures and countries, from marginalised backgrounds and from hard to reach populations (e.g. drug users, homeless children) and those facing global adversity [41]. In particular, children and young people with diverse cognitive, physical and communication impairments are often overlooked as research participants or researched by-proxy.

The assumption that participatory research is not possible with certain groups of children and young people due to perceived incapacity needs to be dispelled as researchers need to find ways to involve children with diverse capacities. The prejudicial assumptions about competency are being challenged by a body of studies which clearly illustrate how child-centred participatory methods can enable children and young people with physical and cognitive disabilities to have their views heard [7, 42]. These studies show that *all* CYP are able to participate in research when their circumstances and needs are considered, and their voices are accessed through appropriate research techniques [43]. There is no one single perfect research method; instead methods need to be found and used to help children and young people of any age, gender, ethnicity, and background to express their opinions and views freely.

Although there is increasing involvement of children and young people in research, it is important that we do not become complacent and assume that the participation of children and young people is optimal and always successful. For some researchers, the participation of children and young people may be just another tick box to ensure that the research project meets the criterion of service user engagement (patient and public involvement) to meet a criterion for funding. It is important that participatory research does not become a 'means to an end' to meet the requirements of the prevailing service user engagement paradigm. If this were the case, 'means to an end' tokenistic research could be done under the auspices of 'participatory' while actually reinforcing rather than challenging hierarchical power relations. It is very clear that involving children in participatory research needs to be done authentically so that it does not become tokenistic.

We need to do more with the results of participatory research in relation to dissemination, developing interventions and following through on actions and change. Increasingly researchers are using participatory techniques and tools to share research findings more collaboratively with children and young people, stakeholders and funders and as a form of intervention [41, 44]. These range from blogs, zines, videos, websites, theatre, drama, role play, music, songs, digital storytelling and technological applications. With the advent of diverse multimedia tools and a wide variety of social network platforms, there are many more ways to access children's and young people's views and equally greater opportunities for them to share their experiences. For example, Stålberg et al. [45] developed an interactive application through a participative iterative process to facilitate young children's participation in healthcare situations. They showed how the young children (aged 3–5 years) were able to contribute their own perspectives on the usability, content and graphic design of the application, which substantially improved the software and resulted in an age-appropriate product. D'Amico et al. [41] illustrated how participatory visual methods (photovoice, drawing, image theatre and digital storytelling) have been used with children and young people facing global adversity both to reflect their lived realities and also as a form of intervention. They noted that participatory visual methods actively engage children and young people by producing a representation of their experiences while also examining the meaning of the representations and how they may contribute to social change. Other researchers have illustrated how they collaborated with children and young people to codesign a knowledge-translation intervention (website, resources, videos, podcasts), which resulted in co-construction of meanings and a more accessible medium for young people [46].

There is now more emphasis on knowledge dissemination and implementation science as this has not been done well in the past. Successful collaboration of children and young people and stakeholders around agreed action from research outcomes is challenging. It requires dedicated commitment from the research team and stakeholders as it involves time and resources. Building a culture of participation between children and young people and adult stakeholders is not easy. However, ensuring space and time to come together to discuss and reflect on findings of participative research is integral to meaningful participation. Research suggests that when children and young people see that their views are taken into account and that there is tangible evidence that action and/or change has occurred, they feel valued and are more engaged in supporting planning and development.

## 1.5 Conclusion

It is commonly accepted now within the research community that researchers need to incorporate more participatory techniques along with the more traditional adult-oriented research tools (e.g. interview and questionnaire) if they wish to successfully obtain children's and young people's views. This has led to a growing body of knowledge and expertise in using participatory research methods, particularly visual and arts-based methods with children and young people. There is, however, a deficit of published literature in this area and a lack of detailed information on participatory methods suitable for researching children in various settings. Researchers have commented upon some methodological and ethical dilemmas in researching children and young people and noted the deficit of published guidance in this area. Similarly, others have noted the lack of information on the methods and techniques involved in participatory research. Carter and Ford [5] note that some of the arts-based techniques are not yet fully established or fully accepted as valid research techniques among researchers, and this needs to change. It is, therefore, important that researchers share their experiences and accounts of using participatory techniques so that we can learn from each other and build upon the body of knowledge and expertise in this area. As more researchers share their experiences with participatory research techniques, this will contribute to the development and promotion of more participatory research with children and young people.

Experience in involving children in participatory research is still relatively new and raises many questions about what is the most appropriate method or technique to use and how to use different methods, associated challenges and potential solutions. It is important that methodological issues are shared to provide clear guidelines for future researchers to promote respect for children's and young people's rights as research participants. Researchers need knowledge about creative participatory techniques that can enable and promote children's ways of expressing their views and experiences. They need guidance on appropriate techniques that reduce the power differential in adult-child relationship and which optimises children's and young people's abilities to participate in research. As children and childhood are constantly evolving, participatory research methods need to keep evolving to keep abreast of changes and new technologies.

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# Principles of Participatory Research

# 2

Catherine Wilkinson and Samantha Wilkinson

## 2.1 Introduction

Since the 1990s, research with children and young people has witnessed significant changes in methods and epistemologies that have challenged traditional research methods [1] and have endeavoured to dismantle conceptions of children as mindless and deviant (see [2]). The literature has witnessed a surge in children-centred and, less so, young people-centred research methods. Such methods endeavour to remedy power inequities by supporting young people to choose their own methods of communication [1]. This is in line with the emphasis within social sciences upon young people's agency (e.g. [3]). Alongside this movement, participatory research has gained increasing popularity [4] and can be seen as an effective, and more inclusive, way of engaging hard-to-research populations in the research process.

At its most basic, participatory research involves those conventionally 'researched' in the different phases of a study, for instance, in the construction of data [5], presentation of research findings and dissemination [6], and pursuit of follow-up action [7]. Though ostensibly related to ethnographic research, participatory methods are positioned as less invasive than traditional ethnographies, as participants assume an active role in the research process. Ideally, participants not only provide, collect, analyse and interpret data gained through participatory research, but they take action on issues and problems that arise [8]. At their best, participatory research methods work with participants to produce change [8]. It is for this reason that many authors (e.g. [9, 10]) support participatory research, believing that when

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children and young people are involved in research, they have greater opportunities to influence decisions that concern their lives.

This chapter details the participatory approach, with an emphasis on active participation. It then provides an overview of different 'types' of participatory research, before discussing shared meanings and co-construction through participatory approaches to research. This chapter then turns to discuss social mores and power structures, and then choice and agency in participatory research with children and young people. It then offers key advice to researchers and practitioners considering implementing a participatory design; in doing so, it problematises the alleged emancipatory potential of participatory research. After concluding, the authors provide some useful resources for participatory researchers and practitioners.

## 2.2 Participatory Approach: Active Participation

The emergence of the sociology of childhood has contributed to a reassessment of the inclusion and role of children in research [11]. Children's right to participate in decisions that affect them (outlined in Article 12 of the [12] *Convention on the Rights of the Child*) gives momentum (both political and quasi-legal) to the promotion of research which engages children and young people, particularly in studies about their lives [13, 14]. Adopting the view that children are competent and have an entitlement to participate has challenged researchers to (re)consider the most appropriate ways to enable and support their participation [13]. Whilst the United Nations [12] *Convention on the Rights of the Child* does not refer specifically to research, it is applicable considering children's competence and ability to participate more generally.

Participation, according to Vromen [15, p. 82–83], is 'acts that can occur, either individually or collectively, that are intrinsically concerned with shaping the society that we want to live in'. In the context of research, participation is concerned with who is involved throughout the research process (e.g. academic partners, organisations, children/young people), to what extent they participate and to what end [16]. The term 'participatory research' originated from Tanzania in the 1970s and is entrenched in work with marginalised, hard-to-reach and oppressed people living in developing areas. Participatory research has since been developed and has been employed in a number of settings including healthcare, community development and education, and has been adopted and appropriated by scholars in a range of disciplines including anthropology, sociology, geography and nursing. Participatory approaches are now widely employed by child rights advocates, critical educators, youth workers and community organisers.

Researchers are faced with a challenge to maintain academic rigour throughout their research, whilst ensuring their research, and the emergent findings, is relevant to the real world [17]. Participatory research has been positioned as one way to achieve this social relevance and rigour. This is because participatory research is conducted in partnership with the individuals or community of interest, that is, *with* them and not *on* them [18]. The bedrock of participatory research is that it involves those conventionally ‘researched’ in specific aspects of/all stages of research, from the definition of a problem or issue through to dissemination and follow-up action [6]. It is an orientation to research focussed on the co-construction of knowledge through partnerships between researchers and those affected by/involved in the phenomenon under study [19]. In participatory research, then, the researcher is not responsible for producing knowledge; they must facilitate project partners to produce knowledge about themselves and their lives [5]. There are different levels of engagement within participatory research, varied both in methodological approach and scope. Franks [20, p. 15] proposes the idea of ‘pockets of participation’, to refer to the different participatory elements that may comprise a project which children and young people can opt into.

Whereas children and young people were previously considered passive, or at best marginal, in research encounters, participatory research positions them as co-creators of knowledge. As Foth and Axup [17, p. 93] put it, ‘the core idea of participation is to shorten the communicative distance between research activity and real world activity, between researcher and researched’. Participation has become a label that is haphazardly used and is being implemented in a proliferating fashion in a number of domains across the world [21], for instance, ‘public participation’, ‘participatory budgeting’, ‘participatory culture’. However, the widespread use of this word is accompanied with a caution that participation is being used to co-opt people into the agendas of others (potentially researchers, universities or governments) or to justify short-cut research with a top-down approach (see [22]). This is problematic as participatory research should enable people to discover their own solutions according to their own priorities.

Participatory research is an approach to research (as opposed to a method per se). A variety of qualitative and quantitative methods can be employed within this approach, typically determined by the research context and discussions with project partners. Examples of methods used in combination with a participatory approach include, but are not limited to, participant observation, interviews, focus groups, surveys, child-led photography, child-led tours, theatre, map making, map labelling, diagramming and drawing. Participatory researchers may adapt and appropriate methods, using them in new contexts and in new ways or attempting to ‘make them’ participatory or relevant to bottom-up research. To provide an example, although a survey may not immediately be considered a participatory method, the design of the survey with project partners, including thinking up questions, undertaking the dissemination of the survey and analysing the results, can be undertaken in a participatory fashion. Likewise, project partners can be involved in peer interviewing and facilitating focus groups.

For participatory research with children and young people, often methods are employed to draw on skills possessed by the age group. For instance, older children may be involved in methods such as completing diaries and story-writing, whilst younger children may be invited to participate in drawing activities. Accommodating different skill sets is important as young people are a highly differentiated group, and approaches that are appropriate for children may be unsuitable or unacceptable for teenagers and vice versa. This emphasises the importance of a ‘mosaic approach’ developed by Clark and Moss [23] to elicit the perspectives of young children about their day-care experiences. This multi-method approach supports the use of both traditional and participatory tools to listen to children's views (each method or each person's perspective representing a tile in the mosaic). Multiple methods allow researchers to be as inclusive as possible and 'play to' children's strengths [11, p. 118]. A further example of this is that, in research with young people, methods are often selected based on the assumption that young people are digital natives. However, there is evidence that young people involved in research do not always prefer the methods that adult researchers assume they will. For instance, in Wilkinson's [24] research into young people's alcohol consumption experiences, the researcher presented young people (aged 15–24) with the option of completing an audio or written diary. She anticipated that the young people would opt for the audio method, believing that they may perceive the written diary as a form of homework. Further, Wilkinson [24] considered that the audio diary was in line with young people's typical confidence in using technology. Much to her surprise, all young people opted for the traditional paper-based diary, contending that they 'don't like the sound of their own voice', and described the prospect of using the audio-recording device as 'scary', fearing they may accidentally delete something. Having a palette of methods that participants can opt into thus acknowledges that any one research activity or tool will not be accessible or appealing to all children and young people with different skills, cultural backgrounds and personalities.

Further, as Crivello et al. [9, p. 56] reflect, selecting methods for children often takes into consideration the 'fun factor' of these methods, acknowledging that children may have lower attention spans for research than do adults. This 'fun factor' runs alongside the idea that early childhood research has been at the front of participatory approaches intended to ensure that children's involvement in research is appropriate, safe, *enjoyable* and meaningful [13]. As Pinter and Zandian [25] point out, creative participatory methods can provide heightened opportunities for enjoyment, education and a sense of empowerment. Importantly, however, though potentially enjoyable, adopting creative participatory methods does not guarantee that young people have genuine opportunities to develop and perform agency throughout a research project [26]. To explain, the success of the implementation of these methods is, in part, related to the positionality of the adult researcher. There are arguments that researchers should adopt the 'least-adult' role (see [27]) and debunk children's impressions of the powerful and 'potentially dangerous' researcher (see [28, p. 85]). However, others (e.g. [29]) caution that equal research relationships are impossible. There will be more discussion of this in the Social Mores and Power Structures section later in this chapter.

Just like traditional research projects, participatory research requires significant levels of energy prior to the commencement of the project, including responding to a funding call or proactively writing a funding application. As an outline of the study and research questions are typically necessary parts of a funding application (to demonstrate to the funder what, precisely, the project will seek to undertake), most often children and young people/other project partners are not involved in the early stages. An exception to this is health research which often does involve patients and public in setting research priorities and also in developing bids, designing tools and influencing the aims of studies (see [30]). In many other disciplines, writing the funding bid and applying for funding are undertaken by the adult researcher(s). This is perhaps because adult researchers are aware of the competitiveness of funding and the strict criteria that must be met and have learnt from experience/training what precisely to include/address within a written bid. In this sense, most studies only become participatory once the project has been approved by a funder [31]. This begs the question, then, to what extent is participatory research a tokenistic gesture? Further, is participatory research really addressing the concerns of those at the centre of the research or the researcher's own agenda?

Considering the extent of children and young people's participation in research, Hart [32] developed a 'ladder of participation'. The creation of the ladder was part of a global drive for participation [33] and has been adopted by groups and institutions that use it to think about how they work with young people, including youth workers, scout leaders and health professionals. Hart's [32] ladder presents participation as a continuum, reflecting that children may participate to varying degrees at different stages of a project. The ladder is comprised of eight rungs, ranging from three types of 'non-participation' including manipulation, decoration and tokenism through to five types of participation. At the top of the ladder is child-initiated shared decisions with adults, where children have ideas, set up the project and invite adults to join with them in making decisions. See Fig. 2.1.

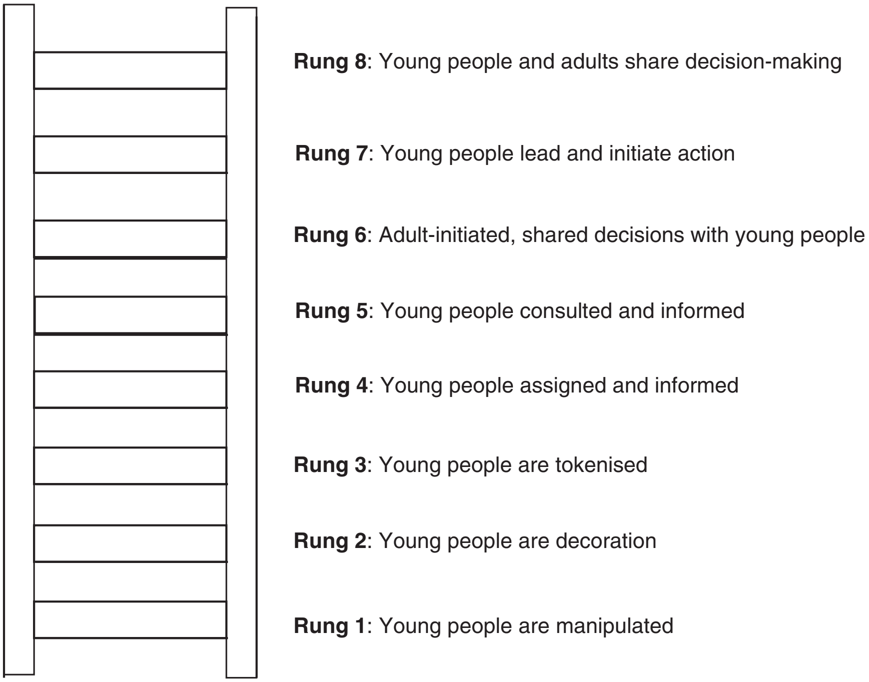

**Fig. 2.1** Ladder of participation (Adapted from [32])

Though useful, the ladder of participation should not be used as a measuring stick of the quality of any research project. As Hart [34] recognises, the ability of a child to participate varies greatly with his/her development: a preschool child may be only capable of carrying materials to a playground building site, whereas an adolescent might be able to oversee the entire building operation. Further, it is not necessary that children always operate on the highest rungs of the ladder. This relates to a critique that the ladder structure is hierarchical [35], which is likely to lead to participatory activities being unfairly and misleadingly judged against particular levels. Gristy [36, p. 371] tells how the project she was involved in was defined as 'participatory' in its early phases, but this position changed as the project developed, with 'the contingent shifting relations with, within and between the project, the young people involved and the researcher'. Gristy's [36] aim was for young people to be involved in every element of the planning and implementation; however she later began to question her motivations and the appropriateness of a participatory approach, recognising that the young people in her research project wanted action quickly, which the participatory research process did not lend itself to. This emphasises that different young people, at different times, might prefer to perform with varying degrees of involvement or responsibility.

Moving on from Hart's [32] ladder of participation, Treseder's [37] model of participation reworks the five degrees of participation in two ways. Firstly, it aims to communicate that there is no progressive hierarchy or particular sequence in which participation should be developed. Secondly, there is no limit to the involvement of children and young people, but children and young people must be empowered adequately to enable full participation (see [37]). An alternate model is Shier's [38] Pathways to Participation, intended as a practical planning and evaluation tool to be applied in situations where adults (typically teachers/schools) work with children. The pathway's framework, like Hart's [32] ladder, highlights the relationships between different levels of participation and the stages within each. Its purpose is to help adults to identify and enhance the level of children and young people's participation in line with the five levels of participation. At each level, adults may have differing levels of commitment to the processes. The levels of participation range from when children are listened to, to children sharing power and responsibility for decision-making. Three stages of commitment are identified across the top of the matrix: openings, opportunities and obligations (see [38]). Pathways to Participation makes no suggestion that young people should be pressured to participate in ways and levels they do not want or that are inappropriate for their level of development and understanding [39]. However, some commentators (e.g. [40]) argue that the hierarchical nature of Pathways to Participation pushes teachers and schools to move relentlessly from the lower levels to the higher, and thus it has the same trappings as Hart's [32] ladder of participation.

Having provided an outline of the participatory approach, this chapter now turns to detail different types and purposes of participatory research.

## 2.3 Types and Purposes

Participatory research is an umbrella term referring to a range of methodologies and epistemologies that aim to produce or inspire change for, and importantly *with*, project partners [8]. A number of research methodologies have been created or adapted to encourage participation [17], and the diversity of participatory approaches is growing. Approaches used within the participatory paradigm include community-based participatory research (CBPR), participatory action research (PAR), participatory rural appraisal, user-centred design and theatre for development, amongst others. As the most commonly employed approaches, CBPR and PAR will now be detailed, respectively, with a discussion of how they 'fit' with the ideal of participation.

### 2.3.1 Community-Based Participatory Research (CBPR)

CBPR is an orientation to conducting participatory research, not a research method [41]. It involves conducting research equitably through partnerships between researchers and communities of people directly affected by, and thereby knowledgeable of, the context and culture that impact an identified subject, problem or concern [41]. This collaborative approach involves all partners in the research process and recognises the unique strengths that each brings to the process of knowledge production [41]. Horowitz et al. [41] argue that in CBPR, the starting point is a topic of importance to the community, and this orientation aims to combine knowledge with taking actions, including social change. Researchers and funding institutions have requested increased attention to the issues that affect the health of children living in communities and have called for greater community involvement in processes that shape research and intervention approaches through CBPR partnerships amongst academics, health services, public health and community-based organisations [42].

The term 'community' in CBPR is typically interpreted broadly, considering anyone who will be affected by the research; it could be geographic, virtual, identity-based, community of interest or another type of community [41]. Community participation in research is useful for ensuring that the aims and objectives of the study are relevant to the community and that the means of accomplishing them (including methods, timeframes and resources) are realistic [41]. However, fostering meaningful community-based participatory relationships between researchers and the community can be challenging [43]. Often such relationships can become muddled, and it is not uncommon to hear of CBPR 'gone wrong' [44, p. 69]. Tucker et al. [43] argue that relationships between researchers and the community cannot be forced and that they must be allowed to develop organically, much like a social relationship, thereby fostering trust. If successfully developed over the long term, equitable partnerships can lead to a number of benefits, including the sustainability of these relationships, generating spin-off research projects, cultural shifts and the implementation of new policies [45], as well as giving rise to rigorous processes and yielding rich data [44]. Importantly, young people are less likely to be included as partners in CBPR, owing to a belief that young people seldom feature as leaders of communities, groups or organisations [46]. However, this discredits or ignores the important roles that young people play as leaders in youth advisory groups and youth councils, for instance.

According to CBPR best practice, findings should be disseminated by, and to, all partners. Academic and nonacademic project partners learn how to communicate effectively with each other's audiences, expanding their competences and skill sets, further strengthening relationships and opening avenues for collaboration and the sharing of ideas [41]. Strategies for dissemination at the local level include discussions within town hall meetings, presentations at local venues and through community newsletters [41]. It is also typical for the findings of CBPR to be translated into practice and policy. Furthermore, it is not unusual to see collaborators of CBPR projects (including children and young people) presenting at academic conferences.

Challenges include that CBPR is typically more time-consuming than traditional research, and therefore conducting research within a traditional research timeframe may not be possible or may lead to compromise; partners may differ in their emphasis on project objectives and perspectives; there may be financial inequities, such as the difference in academic salary versus project partner 'incentives'; and involvement may be marginal or tokenistic [41]. The CBPR approach is recommended to researchers who would like to increase the relevance, rigour and results of their community-based work [41]. CBPR is not, however, all about the outcome; advocates of CBPR (e.g. [47]) argue that the very process of meaningful participation can be transformative for project partners.

### 2.3.2 Participatory Action Research (PAR)

PAR arises from two research approaches: participatory research and action research. PAR is often used interchangeably with these two approaches, although the three should be understood as distinct approaches (sharing some commonalities). The main objective of PAR is social change [7]. As such, it is the 'action' that differentiates PAR from methodologies which primarily set out to 'investigate'. There has been a close relationship between PAR and marginalised and disenfranchised groups and also of political and pedagogical projects. PAR is gaining increased attention in community and public health research [48] and can involve qualitative, quantitative or combined data gathering methods, depending on the issue under investigation.

In PAR there is a commitment to research contributing to communities/groups and 'giving back' to collaborators [6]. The overarching aim of PAR is to 'give power to' groups of people/individuals who are seeking to improve their situation. To this end, PAR involves collaboration between researchers and stakeholders in the co-production of knowledge [49]. Baldwin [49] describes how researchers and stakeholders join together to produce new knowledge to inform practice and solve identified problems. Thus, more than just being *in*formative, PAR can be *trans*formative [49]. As an epistemological choice, PAR is most closely aligned to social constructivism and critical theory [50], maintaining the belief that all knowledge is socially created.

One of the ideals of PAR is that the beneficiaries should be directly involved in conducting the research. PAR may involve participants in any, or all, of the following: helping to formulate/identify the problem, assessing the problem, determining an intervention and assessing the intervention [50]. PAR requires researchers to be more reflective, reflexive and transparent about their respective standpoints, vulnerabilities and the limits to different theories, methods and analytical strategies that they adopt [51]. Reflexivity is an awareness of how the researcher and objects of the study affect each other mutually throughout the research process [52]. Warin [53, p. 810] tells that it is necessary to develop ‘an interdependent awareness’ of how the researcher influences research participants’ perceptions and also of how participants influence the researcher. Further, reflexivity provokes researchers to remain open to that which is not yet known, trying to avoid bringing their own epistemologies to bear on the data [13]. This is further complicated as the ‘researcher’ in PAR projects is not a lone investigator but an individual in a collective. PAR is therefore a process augmented by the multiple perspectives of several researchers (academic and non-academic) working together [54]. The intimacy of a PAR approach has brought its own problems; PAR researchers have reflected on their positionality and the blurring between researcher and friend (e.g. [51, 55]) in building relationships with project partners.

Despite a number of differences in participatory research designs, many key facets are similar, mostly linked to co-production. Before moving on to unpack participatory research further, it is important to remember that participatory approaches are not appropriate for all types of research (see Gristy’s [36] discussion of ‘moving on’ from participatory research). The suitability of any one methodology depends on the purpose of the research. Having detailed some of the different types of participatory research, this chapter now turns to unpack shared meanings and co-construction which characterise a participatory research approach.

## 2.4 Shared Meanings and Co-construction

As discussed thus far in this chapter, the defining characteristic of participatory research is not so much the methods and techniques employed but the degree of engagement of participants within, and beyond, the research encounter [8]. Participatory research is characterised by shared meanings and the co-construction of knowledge, and thus the emphasis is on research *with*, as opposed to *on*, participants.

It is appropriate here to draw on Chávez and Soep’s [56] exploration of the collaboration amongst young people and adult participants at Youth Radio, a broadcast training programme. The authors introduce the concept of ‘pedagogy of collegiality' to describe how young people and adults at the training programme are mutually dependent on one another's abilities, viewpoints and combined efforts to engender original, multitextual, professional quality work. Though not discussing participatory research specifically, Chávez and Soep's [56] concept of pedagogy of collegiality is certainly relevant to the more nuanced analysis that can be produced through the relationship between young people and adults in participatory research. Collegiality is a relationship of shared collective responsibility. Collegial pedagogy, then, characterises situations in which young people and adults jointly identify the area of focus and undertake projects in a relationship marked by interdependence, where both young people and adults are hands-on and applied in their contribution [56]. In particular, striking similarities can be seen between collegial pedagogy and PAR, as outlined in the previous section.

However, caution must be exercised when using the term 'collegiality' because it can suggest a utopian view of joint production, whereby young people and adults are equal co-producers, democratically creating work together [56]. Chávez and Soep [56] argue that the mutual engagement, investment and vulnerability between young people and adults that underpin collegial pedagogy do not nullify the institutional and historical forces through which power travels in any collegial and pedagogical relationship. Participatory research, just like collegiality as described by Chávez and Soep [56], involves the mobilisation of the skills, competences, knowledge and resources of project partners. In participatory research, children and young people are often employed as peer researchers because they possess skills that adult researchers do not; they speak the same language as their peers; they have access/membership to hard-to-reach groups, and they have first-hand insight into matters affecting their age group [31]. Essentially, they are experts in their lives [57], capable of defining, exploring and finding solutions to their own problems. Thus, the knowledge produced from participatory research with children and young people can be considered more authentic, richer and more reliable than that produced through traditional top-down practices.

This joint production/co-construction is complicated, however, as children and young people often do not possess the same level of data collection and analysis skills as researchers, who may have spent several years at university honing their skills. Enabling children and young people to develop the knowledge, skills and responsibility to co-construct research signals the 'conscious exchange of power' [31, p. 10] between adult researchers and children/young people. Participatory research, then, increases children and young people's capacity to identify and solve problems affecting them. However, this is not without critique, and some authors have condemned such 'teaching' as implying that project partners would benefit from 'superior' knowledge (see [29, p. 103]). Others instead argue that participatory research is a process of mutual learning [58]; whilst children and young people may be trained as peer researchers, developing skills in interviewing and facilitating focus groups (see, e.g. [7]), researchers become co-learners in their everyday lifeworlds [59]. Participant researchers have a role in data gathering and analysis (although less occasionally the latter). They can also influence how research findings are subsequently disseminated, and this is often in culturally credible ways. In sum, each person in the research partnership is considered to bring unique strengths and skills.

This intergenerational learning, where children and young people learn research skills through guided participation and active engagement [50] and adults learn about young people’s lifeworlds, can produce robust research. Further, the collaborative ethos of participatory research is significant for mutual capacity building. Self-confidence is a reported outcome of participatory engagement with children/young people, as well as increased awareness and knowledge of the research topic, and social development related to working in a team (see [10]). Importantly, undertaking participatory research with children/young people does not mean that adult researchers are abandoning their research roles but allowing flexibility for the changing nature of their roles, with new opportunities for the co-construction of knowledge [11]. It is important for adult researchers to be willing to allow this transformative process. It has been argued that in participatory research, guidelines can, and should, be developed to protect research (and researcher!) integrity (see [48]). Such guidelines would pertain to aspects such as research design, individual roles and responsibilities within the research project, ownership and authorship, and dissemination [48]. Clearly, there is a difference between participation (taking part in) and effective participation (co-construction). This chapter now turns to consider social mores and power structures within participatory research with children and young people.

## 2.5 Social Mores and Power Structures

In traditional research, the researchers are powerful, because they determine the aims and objectives, methods and data collected and therefore the knowledge produced [5]. It is argued that to progress beyond this unfair situation, some power must be taken away from adults and given to children/young people, so that power is distributed equally [5]. Participatory research is often suggested as a strategy to overcome power imbalances between researchers and research ‘participants’ because it values equally the knowledge of each individual who participates in the project [60]. Thus, participatory research with children and young people is characterised by a shift from the typical power dynamic inherent, to include children and young people as active researchers in one or more phases of the research process.

As has been argued so far throughout this chapter, participatory methodologies provide opportunities for children and young people to present their experiences and knowledge that is less likely to be mired by researchers’ concerns [61]. Participatory research attempts to minimise the ‘us and them’ dichotomy between academic researcher and participants [6, p. 656]. However, owing to the collaborative nature of the participatory process, power dynamics can be difficult to negotiate. DeLemos [62] recognises the problems associated with renouncing total control in research. The author highlights the shifting power scales from research *on* communities to research *with* and *for* communities. By researching *with* children and young people, participatory research endeavours to break down the hierarchies of knowledge and democratise the research process, as Cahill [63, p. 16] puts it, to move beyond the 'privileged perspectives of the ivory tower'. The multiple reported benefits of engaging children and young people in research have served to redistribute power within the research process and build the capacity of children and young people to not only analyse, but importantly to transform their own lives, and become partners in the building of more sound, democratic communities [63]. As is clear from this, power and empowerment are central concepts in participatory research in reversing conventional assumptions about who owns and benefits from research [6] and in promoting inclusion within the research encounter.

Certain authors have discussed how they attempted to 'divest power' so that project partners could 'take control of the research process' [60, p. 200], in a bid to move towards participatory research. However, this can lead to feelings of the loss of expert status for the researcher and adopting a role of observer and facilitator [60]. There is a need to bridge participatory epistemologies with methods that support the transgression of power relations in research with young people. This rebalance promotes children and young people in a position of competence and power and compels researchers to abandon the traditional views of children/young people as vulnerable and incompetent [64]. This requires researchers to reflect on their own subjectivities and the discursive relations of race, class, gender, sexuality, religion and age [61]. More than this, it requires researchers to reflect on other more movable aspects of their positionalities—including education, social position, occupation and also their personality and appearance (see [55]). Exercising this reflexivity will enable power relations to be properly understood and negotiated. Some researchers (see [29]), however, have argued that power will always be present in the research relationship and that adult researchers cannot avoid being in control of research agendas.

Participatory research is dependent on stakeholder input to obtain its applauded benefits of improved social significance, validity and actionability of research outcomes [21]. An often understated issue is that, for a number of reasons, children and young people may choose not to participate in a research project. Put more bluntly, the desire to participate in research must not be assumed. The meaning of participatory in 'participatory' research, then, should be determined in communication with the participants in one's proposed study; only then can such research be considered truly participatory. This chapter therefore argues that the degrees of expected participation should be negotiated at the outset, rather than imposed. Researchers and participants should communicate about precisely in what ways participants will be involved [21]. As Cahill [63] has argued, the term 'participation' has been used indiscriminately, and there is a need to be wary about such broad applications so that it is not used as a tokenistic gesture. Related to this is how the use of the word 'participation' plays out in expectations, that is, the expectations from researchers of participants and vice versa. Perceptions of degrees of participation may vary between different actors. Barreteau et al. [21] argue that disappointment experienced by participants can be avoided by being forthright about how participation will be implemented and what kind of involvement (and how much) is expected. Thus, it is all about finding 'appropriate and desirable levels of involvement' that give participants meaningful voice (if they so desire it) without overloading them or diverting them from other duties in their lives [47, p. 84]. The extent of collaborative involvement may vary over the duration of the project and from one project to the next, determined by the nature of the project [65]. Equally, children and young people may have more time/desire to participate at one stage of a project than another, and this should be accommodated.

On the flip side to the overburdening of participatory research as described above, some children and young people may wish to participate in a research project further than the remit outlined by researchers allows. Barreteau et al. [21] question whether participants will become sceptical after experiencing participatory processes that did not allow them to participate in the ways that they expected and, this chapter adds, to the extent they wish to participate. Thus, people who are disappointed whilst participating in a research project may be disinclined to continue, or reluctant to participate in future projects [21]. Hence, Barreteau et al. [21] argue that, when explaining the aims and approach of a potential participatory research project to prospective partners, and what their participation will entail, special attention must be given to who, ultimately, has control over the research process.

There are a number of obstacles relating to power and communication that encumber the task of involving children and young people as active participants in the research process. One, as challenged by Kellett et al. [66, p. 330], is the 'competence barrier'. Clark [11] reports that the age and stage of development of a child (something touched upon previously in this chapter in relation to the choice of methods and also Hart's [34] ladder of participation) can place emphasis on the power differences between (adult) researcher and child/young person research participant. This stance is taken from a developmental psychology perspective and is intrinsically related to age. For instance, Clark [11, p. 116] reports that young children can be seen as presenting 'communication difficulties' in a research context due to their nonliterature status. This power gap can be widened further if the child/young person belongs to other marginalised groups, taking into account gender, class, ethnicity and disability. However, this dated view is being replaced (see [67]) with the idea that social experience should be a more reliable marker of competence than age.

In summary, it is often assumed that participatory research is a positive ethical and political framework for approaching research with children and young people. Above, we have demonstrated how arguments that suggest that power differentials between adult researcher and children/young people participants can be eliminated through participatory research are problematic [8]. This chapter now moves on to consider the related topics of choice and agency in participatory research.

## 2.6 Choice and Agency

Locating children and young people as active social agents via participatory methods to facilitate 'voice', 'agency' and 'empowerment' has been highlighted as influential in the early wave of childhood research [14]. In the participatory research literature, there has been a tendency to theorise agency almost as an attribute that children/young people can 'have' and that is enabled, promoted or 'given' by the adult researcher [68]. This relates to a critique (e.g. [33]) that some participatory research projects involve children and young people as tokens, resulting in low levels of self-advocacy and empowerment. Thomson [69] highlights how child-centred participatory approaches can cause harm if children's voices or perspectives are rendered inauthentic or meaningless, due to unacknowledged personal assumptions of the researcher; this resultantly keeps children 'in their place'. As Ansell [29] argues, choices must be made by the researcher, and although the consequences of these choices cannot be fully controlled, nor fully known, some responsibility must be assumed for the potential outcomes.

As discussed above in this chapter, research should be a positive and empowering experience for children and young people [64]. By involving children and young people in the research process, it is argued that they 'cease being data mules in the carriage of other people's academic careers' [70, p. 17–18], and instead are realised as competent actors in their own lifeworlds. Participatory research is not, as this chapter has begun to unpack, without its flaws. One argument is that, despite children and young people assuming a more active role in participatory research, the process can still be configured as adult-controlled [64, 71]. For instance, Gallacher and Gallagher [72] recognise that, whilst some participatory research does provide choice for children and young people, and opportunities to exercise their agency, much is highly managed by researchers. For instance, children and young people are often instructed on what to research, how many photographs to take and of what subjects [72]. An exception of this is the work of Kellett et al. [66, p. 332] whereby children were given 'completely free choice' in what they wanted to research and what methods to use; many children chose areas related to their interests.

Further, Mohan [73, p. 51] is concerned that 'despite replacing a monologue with polyphony there are still the questions of who writes up, who publishes the material and whose career benefits?' Mohan's [73] account demonstrates the extent to which children and young people are often not given the choice to participate after the data gathering stage. Reflecting on a project that attempted to engage young people with an intellectual disability in participatory research, Dorozenko et al. [60, p. 200] argue that, as academic researchers, their team had 'certain skills and expertise that lent itself to research'. The authors explain that they are experienced at undertaking literature reviews, analysing qualitative data and publishing research reports, and they felt it would be 'self-effacing (and dishonest)' to deny their contribution to this part of the research project [60, p. 200]. Muhammad et al. [74, p. 1055] support this, stating that, in the writing and representation of data, 'academic power and privilege can become omnipresent', as academics have the training and experience to produce peer-reviewed articles, whereas project partners may have distinct expectations (for instance, school/work) that preclude additional tasks. However, in 'true' participatory research, though possibly a utopian view, children and young people should be given the choice as to whether they wish to participate in these later stages of a project. There is much to be commended in Mary Kellett's decision to include three young people (Ruth, Naomi and Simon, aged 10) as co-authors in an article published in *Children & Society* about empowering children as active researchers (see [66]). Kellett enables children in this project to take ownership of their own research agendas and challenges the status quo.

Discussions of choice and agency in participatory research speak to two main problems as identified by Gristy [36]: the problem of representation and the problem of speaking for others. Any written reports emerging from the research activity that involve people will implicitly require representation. Further, Gristy [36] argues that representation in a discursive context, such as communication of the findings of a project, is a political act. This is especially so when considering the different editorial decisions involved in publishing journal articles and book chapters, for instance, choice of the venue to publish, word limits, restrictions to lengths of quotations, etc., that ultimately rely on the researcher to make decisions.

However, it should not be assumed that all young people are as ‘hung up on’ their representations as some researchers are on their behalf. Wilkinson [75] undertook a participatory research project with young people at a community radio station, which involved the co-creation of an audio documentary and a radio series. She reflects how, in preparing for the audio documentary and radio series, conjuring up key themes and thinking about songs and particular lyrics to be included, the young people were eager to participate. They were also forthcoming in volunteering their time to be interviewed and assisting with the use of the recording equipment. However, when it came to editing the audio clips, the young people seemed reluctant. Also discussing the co-production of an audio documentary, Noske-Turner [76], too, reflects that editing, the phase that she had predicted as being crucial for participation in meaning-making, was met with the most ambivalence by participants. Considering that she desired to facilitate the presentation of youth voice and to promote agency, Wilkinson [75] was wary of making editing decisions independently. Aware of the potentially manipulative and exploitive editing process, accurately representing the young people was something that she aimed for. However, Wilkinson [75] was surprised that the rare occasions that young people requested the deletion of an audio clip were because they had made a slip of the tongue or stuttered over speech and were embarrassed by this being broadcast. In other words, editing was only requested for issues surrounding delivery, as opposed to content. Thus, Wilkinson [75] concludes that her desire for the young people to have agency over their representations was greater than (or perhaps more accurately different to) theirs.

Also challenging the participation agenda, and perhaps on the flipside of the above argument, Lushey and Munro [77] argue that co-producing research can be a burdensome and undesirable task and consider it an unethical demand to expect unsalaried young people to have equal involvement in the project. Thus, although some scholars criticise participatory research as it does not devolve control of the research entirely onto participants, it should not be assumed that participants would want this control or responsibility. Involvement in any research project can be time-consuming, and participatory research, due to the process of co-production, can be even more burdensome. Thus, by insisting upon participation, in the belief that it constitutes empowerment, researchers may actually be reproducing the regulation of children and young people [5]. Researchers must be prepared for the ways in which children and young people may utilise their choice and agency (granted to them by unsuspecting researchers) to exploit, appropriate, redirect, contest or refuse participatory techniques [5]. For instance, in Ansell's [29] research which was concerned with producing knowledge about Third World Women, students in a Zimbabwean secondary school resisted her attempts to enrol them as researchers in her project. After co-operating in the preparatory phase during school time, none of the students conducted research out of school, and some even fabricated results/analysis to appease her. Ansell [29] reflects how an exercise she considered empowering of the students was perceived by them as an unreasonable imposition on their time. Ironically, this exercise did allow the students to assert their agency though not in the way that Ansell [29] had hoped (arguably, school is a setting where children are least able to exercise their participation rights [66]). There is also the issue that what may be interesting to researchers might be 'boring' or too challenging (emotionally or intellectually) for young people or any lay participants [14]. There is a weak empirical base of what children and young people think and feel about being involved in participatory research [78], despite an abundance of writing stating involvement in participatory research is 'good for them'. This emphasises the importance of allowing choice in the ways in which/the extent to which children and young people participate. This chapter now turns to offer some key advice both taken from the literature and also that the authors have learnt from their own engagement (to varying levels of success) in participatory research.

## 2.7 Key Advice

1. Participatory research is a process of mutual learning, and researchers must become co-learners in young people's everyday lifeworlds.
2. Project partners must agree on the missions, goals and outcomes of participatory research at the outset.
3. The meaning of 'participatory' in 'participatory research' should be determined in communication with the children/young people in one's study.
4. Participatory research should not be expected to eradicate power differentials; rather if successfully undertaken, it should minimise them.
5. Sharing honest accounts of practice enables dilemmas in participatory research to be considered, thereby contributing to researcher learning.

## 2.8 Conclusion

Participatory research has been touted as a more empowering and equitable approach to research with different groups, including children and young people. Part of the charm of participatory research is that it is a process of mutual learning [58], whereby researchers become co-learners in children/young people's everyday lifeworlds [59], and children and young people become knowledgeable about social research methods, thereby developing their capacity and competence [65]. Despite the benefits of participatory research, however, the unresolved challenge of creating complete research equity has several consequences.

Throughout this chapter, the alleged emancipatory potential of participatory research has been problematised. It has been argued that participatory research should not be considered as a cure-all for adult-dominated research processes. Particular concerns are centred on who benefits most from the undertaking of the research (i.e. the adult's career or the child/young person's?). Further, there is the potential for the reproduction of power differentials throughout the research process. As interest grows in collaborative research, it is important to support the development of new partnerships in line with the desire for more equitable forms of knowledge production.

The concerns documented throughout this chapter do not devalue the important role a participatory approach can play in knowledge exchange and action. However, it emphasises that this should not be without careful implementation. Efforts to increase the participation of children and young people in participatory research should be measured against their will to participate at different phases of the research. New understandings and appreciations of 'participation', and in particular *meaningful* participation, can bring exciting possibilities for research agendas.

## 2.9 Useful Resources

- The Participatory Research Hub at Durham University hosts free events and training sessions, as a way to share knowledge about 'doing' research that brings more equitable benefits to all involved. The website has free resources and toolkits that the hub has developed over the years with a range of community partners. Participatory Research Hub at Durham University: https://www.dur.ac.uk/esrciaa/test/researchingtogether/hub/
- The Participatory Research Group (PRG) is a network of organisations committed to bringing knowledge from the margins into decision-making at every level of society. The website lists publications, including synthesis reports, research reviews and policy briefs, which draw together the findings of the PRG's research in 29 countries. It also showcases outcomes from creative participatory approaches, including visual research such as digital storytelling and participatory video. Participatory Research Group: http://participate2015.org/prg/
- PyGyRG is a collective whose members aim to raise the profile/perceived value and further the understanding and use of participatory approaches, methods, tools and principles within academic geography and beyond. Participatory Geographies Research Group (PyGyRG): http://www.pygyrg.co.uk/

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# Ethical Issues in Participatory Research with Children and Young People

## 3

Tineke Water

## 3.1 Introduction

Participatory research with children and young people has been offered as one methodological approach that seeks to overcome many of the issues of power and exclusion that may arise in research with children and young people, through actively involving them in the research process and viewing them as experts on their own lives. It is envisioned that supporting children's and young people's agency and addressing power issues inherent in the researcher-child/young person relationship will resolve some of the ethical issues researchers have grappled with when undertaking research with children [1]. However, participatory research still brings with it other challenges that need careful consideration, negotiation and renegotiation [2].

One of the central arguments to any ethical research with children and young people is balancing their rights to protection along with their rights to participation [3]. Children's and young people's real and potential vulnerability requires researchers to carefully think through issues of assent, consent and dissent, competency and dependency, privacy and confidentiality as well as power dynamics between the researcher and child/young person and possible benefit and harm from participating in the research [4]. Powell et al. [5] argue that questions around children's and young people's vulnerability and need for protection should not limit their participation in research. Rather, it should inform methods of research and how children and young people will be included. Therefore, participatory research offers a methodological approach that takes an ethical standpoint in valuing the agency and right of children and young people to have a voice in things that matter to them, whilst also recognising their developing competency [6]. Participatory research offers a

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deeper way of engaging with the life world of children and young people whilst also engaging with underlying ethical issues [4].

Engaging in the life world of children and young people means that participatory research is inherently less rigid, more fluid and takes place in the 'messy, unpredictable, real world of children's [and young people's] lives' which calls researchers to think about the ethical issues in planning a study, but also be open and able to respond to ethical issues that arise as the study takes place [5]. Aspects of procedural ethics such as planning the study, gaining ethical approval from ethics committees, engaging with stakeholders and formalised processes for assent, consent and dissent require careful consideration when undertaking any research with children and young people [3]. However, using a participatory approach may give rise to different challenges, such as cautiousness on the part of ethics committees and gatekeepers, and gaining access to the field. The longitudinal and dynamic nature of participatory research also means that children's and young people's assent, consent and dissent becomes a process of ongoing negotiation that can challenge notions of what participation is. Situational ethics, or the everyday ethics that arise whilst undertaking a study with children and young people, requires reflexivity on the part of researcher to carefully consider the implications of how to address these issues and how the researcher themselves may mitigate or contribute to ethical issues [7].

The call for reflexivity on the part of researcher means considering their role in the research, the relationship and dynamic between them and the participants, how the research processes may impact on the findings and the eventual outcomes or benefits for the participants [8]. Phelan and Kinsella [9] argue that researcher reflexivity is critical in conducting ethically sound research with children and young people to ensure their safety, dignity and voice. This chapter encourages researchers to think reflexively around ethics when planning and undertaking participatory research with children and young people and poses both procedural and situational questions for researchers to consider.

### 3.1.1 Children and Young People as Co-researchers

Participatory research with children and young people leading and controlling the research process is offered as an approach that can overcome issues of diminished agency, lack of voice and unequal power relations between adult researchers and children and young people. Child/young person-led participatory research involves active participation in all aspects of the study from framing the research interest/questions to data collection methods, analysing the data and deciding how to disseminate the research findings.

One of the primary ethical and methodological positions of participatory research is promoting the agency of children and young people as experts on their lives and with rights to have a say on things that matter to them [1]. This view supports the 1989 United Nations Convention on the Rights of the Child (UNCRC) [10] which states that children should have the right to have a say on things that concern them, for their opinions to be taken into account in a way that supports their developing competency (Article 12) and to be able to share information in a variety of ways which may include verbally, in writing or through various art forms or medium of the child's choice (Article, 13). UNCRC clearly argues for the need for equity and visibility of children's and young people's views and opinions [10]. One way that children's and young people's views may be rendered invisible is by adults who work with children and young people making assumptions around what they think is best for them. This can contribute to a lack of input from children and young people on matters that are important to them [11]. Assumptions around what is best for children and young people may be based on a perceived role of the need to advocate for children. However, advocacy should also include promoting children's and young people's agency and expression of views.

When embarking on a research project, perhaps one of the first questions for researchers using participatory research is 'who sets the research agenda'? Is it the funders, organisations, researchers or children and young people? All research is influenced by certain agendas, vested interests and stakeholder groups, which will influence the scope of the research and the research outcomes. The interests or agenda of an organisation, researcher and children and young people may be very different and have different implications for outcomes for each group. At the beginning of a participatory study, it is important to consider who will be involved in setting the research agenda and to what extent will they be involved in shaping the design and direction of the research. Importantly, involving children and young people right from the beginning is a way to ensure the research is participatory and child/young person-led. However, it is important to keep in mind that even though the research agenda may appear to have been set at the beginning of the project, children's and young people's priorities and interests may change over the course of the project, and researchers need to remain alert and responsive to this. An example of this is from Cahill et al. [12] study 'the role of blue scapes play – fun things to do at the beach', where children's initial agenda and incentives for taking part in on a study (having fun) were overtaken by children trying to keep the study going. Here the researchers had to balance the children's wishes to enjoy participating in the project whilst also supporting children's motivation to stay on track to complete the research project. Balancing different agendas and anticipated outcomes meant negotiating and renegotiating priorities throughout the research process.

Advisory groups comprised of children and young people are one way to help guide the research agenda from topics for research to research design and future benefits of the research for children and young people. These groups are not only helpful at the outset of the project, but they also inform and give feedback on the project and findings as the study progresses. In many countries, advisory groups are well established and are included in the research budget. These groups may already be formally established through national ministries of health or education, organisations (private and public) or special interest groups. Researchers may also seek to establish their own advisory group so that the membership of the advisory groups reflects the demographics (such as age, gender, ethnicity, social experience or context) of the potential study. Although advisory groups have been beneficial for many projects, caution needs to be applied as the advisory group may not represent all the groups participating in the research. For example, well children in the community may offer great insights, but not capture all the perspectives of sick children in hospital related to aspects of the study design [13].

Another question for researchers to consider is whether the planned methods will help to highlight children's and young people's perspectives or just make less transparent approaches that reinforce adult world views. Some studies claim to be participatory, but children's and young people's participation is limited to the activities that produce data, with little or no involvement in planning or data analysis [14]. There are also assumptions that the use of certain methods will make the study more participatory. In particular art-based methods such as draw and tell, photography or video making are associated with increasing children's and young people's participation in research. Although these methods certainly can increase children's and young people's agency and decrease issues of power and increase engagement in data collection [15], attention needs to be given to what extent children's and young people's involvement goes beyond this [16]. The methods chosen also need to be fun and meet the interests of the children and young people (otherwise why would they want to take part), and complicated methods can 'bore' children or even worse exclude or marginalise them [1].

Limiting participation to only certain aspects of the research study can contribute to 'tokenistic' approaches to participatory research that limits opportunities for children and young people to be active researchers/co-researchers at each stage of the research process. However, equal participation should not be viewed as an 'all-or-nothing' approach, as under different circumstances, different levels of participation may be more appropriate. Hart's [17] model of the ladder of participation has been offered as one way to explore the degree and extent of how children and young people participate in research moving from tokenism to citizenship. As children's and young people's participation increases, they also move further up the rungs of the ladder. Hart's ladder of participation was never intended to be hierarchal; however it has contributed to studies being judged whether they reach the highest level of participation [16]. Ergler [16] suggests that children's and young people's engagement should be appropriate to their interests, time and capabilities and that children should be free to decide their own level of engagement over the course of the research. This may include them moving between passive and active participants at different stages of the research project. Ergler [16] found that at times children were overwhelmed by the time and effort needed to complete the study and wanted to privilege having 'fun' over being the 'researcher'. Children wanted a more cooperative and flexible approach where they could climb up and down the ladder [16].

The question of how much children and young people can or will participate is also linked to how well they will be prepared to be a researcher/co-researcher. It is argued that not providing children and young people with training, yet expecting them to fulfil a role, is unethical [18]. Careful thought needs to go into what capacity and competency children and young people already have to undertake the role of researcher/co-researcher and what sort of comprehensive training they should receive. Any research training should be tailored to the project and the knowledge required by children and young people. One of the problems of participatory research training is that it can be challenging and requires time and adequate resources [19]. However, once children and young people are trained they can also participate in training other child/young person researchers [20]. Alongside training, remuneration is seen as a contentious issue. Bradbury-Jones and Taylor [19] argue children should be compensated for their time the same way adults are. How children and young people are compensated (e.g. cash or vouchers) may depend on the local context where the research is to take place. Some ethics committees may potentially see cash as a form of inducement rather than a form of acknowledgment or compensation.

How much the researcher will participate is also a question that needs careful thought. One of the main responsibilities of a participatory researcher is to act as a facilitator whose role is to support the participants to produce knowledge [14]. One of the issues Gallagher raises is 'keeping the research on track', balancing children's and young people's agency and autonomy whilst also trying to stay with the research agenda. He describes how the children in the study he undertook? were having fun, 'but I felt the session had degenerated into chaos and I was not sure what to do' (p. 142). Gallagher and others' experiences raise the issue of 'freedom versus policing' and how to meet the challenge of maintaining momentum of the research project whilst staying true to the participatory nature. Paradoxically, it is the power issues related to controlling the research that participatory research seeks to diminish that may also contribute to a more unpredictable and dynamic research environment.

Alongside promoting children's agency, participatory research seeks to address the unequal power dynamics between the researcher and children and young people and shift the balance in favour of children and young people. It is argued that participatory research overcomes issues of power and exclusion that are a feature of non-inclusive child-/young people-focused research [19]. Although the more collaborative and reciprocal nature of the relationship between the researcher and co-researchers can flatten out hierarchal structures, Gallacher and Gallagher [21] caution that researchers should not automatically assume this will lead to empowerment (or disempowerment)—as power is multilayered.

For Foucault, power is not good or bad, it just exists. Rather than seeing power as something that someone has or not, Foucault sees power as something that is exercised and provides sites for resistance. Therefore, power is not something that is handed over in participatory methods; instead children may exercise power by 'resisting, redirecting, and subverting these very techniques' ([14], p. 146). Gallagher gives an example of children ticking both the male/female gender boxes, taking the researchers notebook to write their own comments on his notes and in some cases adding graffiti over them. Here children and young people are exercising their own agency by challenging authority and power and may not be as powerless as initially thought.

There are also power relationships between children and young people, where children and young people who have had the research training may have an elevated status, where participant voices may be mediated by 'cool' hierarchies and more articulate children and young people and where some children and young people may be intentionally or unintentionally excluded [19]. Therefore, although involving children and young people as researchers/co-researchers changes power dynamics, it does not remove them, and the researcher needs to consider how much they may moderate this.

Researchers also need to consider the wider context of power that the research takes place in. This includes power relations in the classroom, year group, school and the wider social relations children and young people are embedded in [14]. Children's and young people's world is still mostly mediated through an adult-centred society; therefore the potential to participate is contextual and very much negotiated [22]. Questions of agency, power and involvement in research are influenced by contextual factors including the child/young person's experience, development and social background. Therefore, considering how children's and young people's participation in research is fostered, is an ongoing process or negotiation, renegotiation and reflexivity on the part of the researcher.

### 3.1.2 Protection and Participation: Questions of Vulnerability, Capacity and Development in Participatory Research

Research with children and young people has often been framed within discourses of protection and participation. The discourse around protection stems from a view of children as vulnerable and therefore needing protection, whilst the discourse on participation stems from a view of children as competent social actors [3]. These views are not mutually exclusive, as participatory research values children's and young people's participation in having a voice on things that matter to them, whilst also being aware of protecting children and young people from potential harm as a consequence of taking part in the research. However, the view of children and young people as 'vulnerable' has continued to contribute to notions that research with these groups is 'risky' research [6]. The younger the child, the more vulnerable they are perceived to be and the more 'risky' the research is perceived to be by researchers, ethics committees and gatekeepers. This means researchers often favour research with 'almost' adult young people, as this is seen as less uncertain and more likely to gain ethical approval from ethics committees [6]. The consequence of this is that whilst it may protect children and young people from any real or perceived risks related to taking part in research, this also limits their choices and ability to participate in research, in effect silencing and excluding their voice in things that matter to them [6]. The desire to protect children and young people from taking part in research may restrict their agency and autonomy and make invisible their perspectives, thereby making them even more vulnerable [23]. For participatory researchers, there are questions around factors that contribute to children's and young people's potential vulnerability and how participatory research might address or mitigate these.

### 3.1.3 What Does Vulnerability Mean and What Makes a Child or Young Person Vulnerable in Participatory Research?

Vulnerability is defined as the degree to which a person is susceptible to physical or emotional harm and often linked to belonging to a particular group such as children and young people and therefore by default considered ‘vulnerable’ [24]. The assumption that children and young people are vulnerable has been reinforced by social and historical discourses that position children and young people as lacking in competency and capacity and children as ‘less-than’ or not quite yet adults [6]. These views suggest that all children and young people are vulnerable and lack capacity or competency until they reach adulthood.

Another view of vulnerability and capacity/competency is that these are more contextual than linked to a particular category. Everyone, not just children, will over their lifetime have times when they will be more vulnerable and when their capacity or competency to deal with a situation may need support from others. For children and young people, unequal power relations and dependence on adults may also contribute to increased vulnerability. Equally, however, when children and young people are valued and supported, such as in participatory research approaches, this has the potential to increase their autonomy and decrease their vulnerability. Therefore, although children’s and young people’s vulnerability may increase in particular situations, it may also decrease or be mitigated by supportive contexts and support from others.

Children’s and young people’s potential vulnerability do place an ethical obligation on adults and researchers to protect them from possible harm. One of the questions that arises is if children and young people are then dependent on others to protect them from harm, can they be at the same time be autonomous and in control of their own lives? Dodds [25] argues that dependency and autonomy can coexist, as autonomy is fostered and encouraged within dependent relationships throughout infancy, childhood and young adulthood. Autonomy is therefore not something that exists or not, rather it happens on a continuum throughout a person’s life. Adults in children’s and young people’s lives have an important role in supporting and valuing children’s developing agency and autonomy. Morrow and Richards [26] suggest that it is not just age or status that contributes to someone’s vulnerability but also social, cultural and political circumstances that can increase or lessen vulnerability.

For participatory researchers focusing on promoting children’s and young people’s agency, these are important considerations. Vulnerability is not a blanket category based on a predetermined group, but rather participatory researchers are called to think how a child/young person’s background and circumstances may contribute to their vulnerability. Equally, participatory researchers should consider how a child or young person’s individual strengths, capacity and social context may also lessen their vulnerability. The focus at the outset of participatory research on overcoming power issues through children- and young people-led research can help mitigate potential issues that may contribute to children’s and young people’s vulnerability, as well as support their developing autonomy and agency. Alongside this, thinking through the potential harm is important in addressing situations that may increase children's and young people's vulnerability and exposure to harm.

### 3.1.4 Thinking Through Potential Harm in Participatory Research

Alderson and Morrow [27] argue that harm is often invisible as it depends from what view point potential harm is estimated. Children's and young people's experiences of distress, embarrassment, anxiety and loss of self-esteem as a result of information shared and researcher's or co-researcher's response may not always be apparent to the adult researcher [27]. Involving children and young people in the design of the study can help identify areas that may cause harm, whilst being sensitive to the context and participants as the study progresses may help to address any potential harm that arise and allow the researcher to respond in the fluid and dynamic context of participatory research.

One of the considerations in participatory research is that children and young people may share more information than they intended or that the boundaries around what information they shared and when they share this are not clear. The longitudinal nature of participatory research, prolonged engagement and the success of the study depending on good working relationships between the researcher and co-researcher, means there may be a degree of openness to share information that goes beyond the study. At times children and young people may share 'off the record' information as part of a general conversation that was not intended to be part of the research. The balance of establishing a good rapport with children and young people means that at times conversations with participants fall outside the times of 'data collection'. This calls upon researchers to negotiate with the children and young people what might be off the record and what would be on the record and what they would be happy to be included as data.

How researchers and co-researchers respond to information shared is also important, alongside being open and respectful to the different perspectives others bring. As an adult entering the world of a child/young person, it is sometimes difficult to grasp their meaning, and even the act of trying to clarify what they mean can appear as questioning the veracity of what was said. This can also lead to questions around how children's and young people's views are represented and if the findings captured what they intended. Representations of the child/young person may cause harm resulting from what the child/young person sees as a misrepresentation of them as person or experience or a particular representation that stigmatises them in some way [27]. This can be mitigated in participatory approaches by including children and young people in deciding how data will be collected (what methods), taking part in the data analysis, then checking any researcher interpretations and deciding how and in what form the findings might be disseminated. In one participatory study, the researcher took notes in a notebook whilst carrying out observations and interviews with children. The children in the study had access to his notebook and were able to make their own comments to agree or disagree with what had been written—the researcher reported at times there was so much of editing of his notes it was difficult to see what had originally been written [14]. In this instance, children had very strong ownership over who owned the data and how this was being shaped.

In research no question is ever really neutral—and participatory research is no different. Although the questions asked in participatory research may have been directed by children and young people, they still have been framed by the wider research agenda. Within this frame, what may seem as a benign question for one child/young person may be a very significant issue for another. This is particularly heightened in carrying out research on sensitive topics. The concern is that asking about certain sensitive topics may lead to children and young people feeling traumatised by recounting the experience; equally, however, not discussing the topics may lead to ongoing trauma in children's and young people's lives. Therefore, care needs to be taken in including children and young people in the discussions around what questions might be asked, how might they be asked, might there be a better way than others and ultimately how might this contribute to positive outcomes for them. Children and young people also need to be clear that they can choose not to answer any question at any point. The researcher also needs to reflect on their role in the discussion and questions. How will the researcher respond if the question or answer has caused distress? How will they respond if the child or young person discloses information that indicates possible harm to themselves or another? How will the limits of confidentiality be addressed?

Children and young people also need to feel secure that the researcher will hold what they have said with respect and confidence. Equally, there needs to be clear boundaries around when the researcher may act on what the child or young person has disclosed. This brings up questions of autonomy and confidentiality versus ongoing protection of the child or young person [3]. Researchers need to carefully consider the limits of confidentiality and how they will inform the child/young person under what circumstance they may break the confidence of the child/young person. In many countries, there are legal provisions around privacy which state that if a person is at risk to themselves or to others, or in the case of a minor who discloses they are at risk, then there is provision (if not a requirement) that researchers will break the confidence of what was shared act to protect the best interests of a child. This is most likely in the case where a child reveals some form of abuse or harm to them.

Another area that may cause discomfort or distress is the background or demographic data that is collected. In a recent study, the researchers noticed that eight children between the ages of 8 and 16 did not fill in the male/female tick box [28]. Although they could only speculate on the possible reasons for this, with hindsight they realised the normative nature of their approach by only offering categories of 'male' and 'female'. In the ensuing discussion, they considered that even using 'male/female' and 'other' category positioned two categories as the norm and made the other literally 'other'. In subsequent conversations with young people who identified as transgender, they suggested to leave 'gender' open for children and young people to fill out as they wished. Another study with Maori and Pacific youth led to youth expressing their dislike of categories of ethnicity and socio-economic status, as they felt these were often linked to negative stereotypes of health outcomes. Participatory researchers need to consider how important categories such as gender, ethnicity and economic status are. Do these categories adequately capture how children and young people perceive themselves? Including children and young people in designing a participatory research project gives them the opportunity to decide what words or categories they would like used to describe who they are.

Researchers can minimise potential harm firstly by being reflexive and making transparent areas that could contribute to harm and secondly by involving children and young people in the design of the study. Children and young people are in a good position to comment on aspects of design that will meet their needs and expectations as participants. As illustrated in the above example of gender categories, often researchers need another lens to challenge their research approach!

### 3.1.5 Importance of Informed Consent, Tools and Techniques (for Gaining Consent) in Participatory Research

Valuing children's and young people's agency and as experts in their own lives means participatory research actively seeks to engage children and young people in all aspects of the research process, including informed consent. Informed consent is often equated with a process of formally agreeing to take part in research by children, young people and parents and involving statutory or ethics committee requirements. The fluid and ongoing nature of participatory research and heavy involvement of children and young people in directing the research means that consent needs to be ongoing and that opportunities to dissent are equally important—whether or not this is just for one activity or part of the research or to step away from the research altogether.

### 3.1.6 What Is Informed Consent in Participatory Research?

Informed consent is based on the principle that information is given in a way that the person can understand, that the person is competent to understand the benefit and risks of participation, that their decision to participate or not is voluntary and free from any coercion and that consent is an ongoing process throughout the research [3]. For researchers this means thinking how information might be shared in different ways with younger children, children, youth and parents/guardians, thinking around the multiple factors that influence children's and young people's competency and being aware of issues of power throughout the research that may influence children's and young people's ability to say 'yes' or 'no'. Finally, children's and young people's rights to participate and actively assent, consent or dissent or be unsure needs to be respected by parents/guardians, gatekeepers and researchers.

Gaining informed consent can include a ‘statutory or status approach’ based on the age of a child or a ‘maturity or competency approach’ based on a child’s capacity and competency in making a decision. Participatory research favours a maturity or competency approach that values children’s and young people’s agency. Statutory approaches tend to be included in legal approaches to consent. Internationally there are different legal requirements or ethical procedures related to a statutory age-based approach to consent, and this can range from needing parental/legal guardian consent if a child/young person is under the age of 16 or 18. Although countries have their own legal codes and requirements related to age and consent, this is also influenced by international case law such as Gillick vs Gillick and treaties such [10] which focus on the evolving capacity and competency of a child/young person [3]. A critique of the statutory approach is that it tends to support the idea of children/young person lacking competence, rather than building on their potential and developing agency as favoured in participatory approaches [29].

A maturity-based approach to consent acknowledges competency as something that is dynamic and developing, and that children’s and young people’s ability to understand and make decisions is influenced by their life experiences, social and cultural contexts [4]. Factors such as how information has been shared, the environment in which it has been shared (familiar or unfamiliar), the time children have to consider the information and the support of adults can enhance or undermine children’s competency at a given point of time [3]. A maturity-based approach to consent supports children’s agency, their developing competencies and their rights to have a say on things that matter to them as outlined by [10]. However, it is not just the developing competencies of children and young people that participatory researchers acknowledge, but also that children and young people already are ‘beings’ with their own social agency [30]. Research has shown that children as young as 4 years of age are able to understand the purpose of the research and their involvement to make an informed decision around their participation [31].

### 3.1.7 What Is Assent and Dissent in Participatory Approaches?

The term ‘assent’ is used in many contexts yet negates the idea of a maturity approach to consent where the child or young person is able give consent independent of the requirement for parental consent [30]. ‘Assent’ is a term used when a child/young person is considered a legal minor but able to actively make decisions around their participation in research. The same principles of consent apply to that of assent, such as understanding the risks and benefits of participation, and that participation is voluntary. The Declaration of Helsinki states that if a child is considered a legal minor but able to assent to decisions related to participation in research, then their assent alongside the consent of a parent/legal guardian must be obtained. Researchers need to be clear, however, that parental consent indicates their consent to the child’s participation in the research, but not that the child has agreed to participation in the research [32].

In cases where a child/young person gives assent, then there is usually a legal or ethical requirement to seek consent from a parent/legal guardian. Munford and Sanders [33] suggest that consent is a balance of valuing children's autonomy and their right to participate, whilst also acknowledging parent's responsibility to ensure their child's safety and wellbeing. Although children and young people are the co-researchers and participants, researchers also need to work within a dynamic web of relationships which includes parents/legal guardians [34].

Dissent is the process whereby children and young people can refuse participation in the activities of the research once the research is underway. This can include not taking part in certain activities, choosing not answering particular questions or taking time out. Here researchers can help support 'sites of resistance' where children and young people can exercise their agency in saying 'no' and choose their level of participation (as per Hart's ladder) at any given time. Children and young people can also decide if they would like any particular signals or strategies to help support them in saying no or withdraw from the study. Signals could include saying 'pass' if they do not want to answer a question or engage in a particular activity, holding up a yellow card or putting a marble in a jar if they wish to not answer a question or take time out [32]. For the adult researcher, it is also important to negotiate with children and young people when they would like to take a break and watch for subtle signs such as restlessness, which may suggest the child/young person would like to stop [32].

Pivotal to informed consent, assent and dissent is that this is not a one-off event but rather a process that is negotiated throughout the research process [27]. This is particularly important in participatory research than may be more longitudinal in nature. For researchers this means renegotiating verbal consent/assent/dissent at each stage of the study and ensuring that children and young people understand they may withdraw from the study at any time, without having to give a reason. Researchers also need to be aware of nuances, such as body language and behaviour that suggests a child may not wish to participate. Silence should never be interpreted as a sign of assent [30].

In some contexts the focus on individual autonomy may conflict with cultural beliefs of the wider family, community and collective. For example, in New Zealand, Maori children exist in relationship to not only their parents but their grandparents, ancestors, extended family and the land [35]. Consequently a wider group may be involved in the consent process than just the child and parents. Powell et al. [3] describe the particular challenges in majority of countries where children may be living separately from parents; therefore finding a legal guardian to give consent becomes a challenge. Parents' level of literacy and suspicion of signing documents may also impact on gaining written consent, whilst a child's obedience and respect for their parents may overly influence their consent to participate [3].

#### 3.1.7.1 Why Do Children Say Yes or No?

Although the intent of participatory research is to minimise and shift power that could contribute to children's willingness to say yes or reluctance to say no, it is important for the researcher (who is gaining the consent) to think through how the situation and context might influence this. Informed consent is based on the underlying premise of voluntariness. However, often there are situations that arise during the consent process that will influence children's and young people's ability to say 'yes' or 'no'. One of the factors to influence children's and young people's ability to freely consent is being unaware of the process of consent. Children are not aware that they can say 'yes' or 'no' and that even if their parents have said 'yes', they can still say 'no' at any time during the research process [30]. Even if children and young people are aware that they can say 'no', they may be unsure how to do this [36]. For some children and young people, there are concerns around the repercussions of saying 'no'—from the researchers and adults in authority [3]. Although it is hoped this is mitigated through participatory approaches, children and young people are still influenced by a wider sphere of power than just the research project.

Enthusiasm for the project by adults can also be a barrier to children feeling free to decide on their participation. Although researchers and parents may perceive encouragement to participate in the research as supportive, for children and young people, this enthusiasm can make it harder for them to say 'no' [37]. Children often wish to please adults who are perceived as authority figures and will therefore defer to adult decision making and agree with the decision a parent has made [30]. Both parents and children may see the researcher as the knowing expert with qualification; therefore their decision to say 'yes' is influenced by trust in their intentions and professional knowledge [30]. Not only is it important to support child/youth-led research but that this also adequately prepares children and young people to participate fully in decision making and consent processes.

The place where consent is sought can also impact on a child's ability to say 'no'. School or hospitals are places where children and young people often follow the directions of others, and this may influence if they feel free to say 'yes' or 'no' [3]. Time is also another important aspect of consent where children and parents need to have adequate time to consider their possible participations. Feeling rushed or not having time to ask questions can all impact on the voluntariness of consent [32].

### 3.1.8 Seeking Consent

Lambert and Glacken [32] say that alongside the child/young person's ability to understand the information and make a reasoned and voluntary choice, the researchers must also demonstrate their ability to understand the competencies of individual children, in order to explain all issues clearly and resolve misunderstandings, respond to any questions and support children and parents in decision making in a noncoercive manner. Ensuring that the research is child/young person-led is one way of encouraging peer-to-peer sharing of information and may ensure that the information shared is understood in an age-appropriate way.

This may address one of the key aspects to informed consent which is providing information in a way that children and young people can understand. Factors that may impact on children's and young people's understanding of the information presented are their language skills and unfamiliarity with what research is or the specific project is about [36]. Involving children and young people right at the beginning in all aspects of the research process also supports having a clearer understanding of research processes.

The form and content of how information is presented is very important, with many written (even simplified) information leaflets still being inaccessible to many young people [38]. Researchers have suggested different ways of sharing information which include written documents or pamphlets with simplified language, storyboards and story books. One way of ensuring the appropriateness of how the research will be shared with children and young people is for them to decide how and the most appropriate way this can be done. Vindrola-Padros et al. [13] used participatory visual methods to negotiate consent and assent in four stages.

A common way in which research information is shared with children and young people is through information leaflets or pamphlets. An important feature of the pamphlets was that they were age appropriate, using simple language, large print, pictures or clip art and photos of the researchers [15, 32]. Some information leaflets include a crossword puzzle so that children can circle or point out the words they don't understand. Other information leaflets include space for children to write questions and a box to indicate their interest in participation by 'yes', 'unsure' and 'no'.

Storyboards and word searches have been used by other researchers. Bray [39] used an activity storyboard as a way to aid a discussion of topics such as confidentiality or assent with children and young people aged 10–16. The storyboard comprise of 16 topics and 30 pictures (with Velcro on them) which the children then matched up with the topics. Bray [39] found that the use of the board prompted a more open discussion and allowed the opportunity to discuss in more depth some of the concepts or meanings. Kumpunen et al. [40] used story boards with children 4–6 and in this case read the phrases out to the children, omitting certain words for the children to then fill in with a picture. Older children 7–12 were given a world puzzle in research-related words hidden in a grid of letters. When children found a word, they were asked to define that word. If they did not know or were unsure, this provided an opportunity for the researchers to discuss the meanings with them [40].

Mayne et al. [36] describe using an interactive narrative approach to obtaining meaningful consent from children from the ages of 3 to 8. This approach involves the use of a storybook which combines text and images of the research to explain this to children. Factual information can include pictures of the researchers and the research setting. The first part of the story tells the child about the research project, and the second part tells them what their participation might involve, including data collection, what will happen with the data and who might see the results. The final page provides information to the child on how they can agree or not agree to take part in the research. This approach can be used as a hard copy book or with the use of interactive technologies such as touch screen and sound effects. This approach has been found to be appropriate even with very young children as it is in a form they are familiar with and enjoy and allows them to make meaning through both what they can see and hear [36].

### 3.1.9 Gaining Access, Gatekeepers and Parental Responsibility

Children and young people are part of families and social networks, and many of the challenges in participatory research occur in the relational space between the researcher and multiple others including the child, parents/legal guardians, gatekeepers (e.g. schools or healthcare settings), ethical review committees and funders [5]. These social relationships and networks are important in supporting the ongoing physical, social and psychological development of children and young people and their wellbeing. Gaining access to participants and undertaking participatory research is mediated within the web of these relationships.

Many adults in children's lives are responsible for ensuring the best interests of children are upheld, and gatekeeping can be seen as a function of this. A gatekeeper is a person who controls access to something or someone, and in research with children and young people, this can include parents, organisations, ethics committees and individuals such as nurses, doctors or teachers. This can create multiple layers of gatekeepers with whom the researcher must negotiate throughout the research [30]. Campbell [41] describes three layers of gatekeepers which include parents, ethics committees, and organisations or professionals who allow access to particular contexts.

*Parents*. The expectation that adults will advocate for children is particularly relevant to parents and carers' who have a duty to guide a child consistent with the child's evolving capacities (Article 14 & 15, [10]) and support the best interests of the child (Articles 3 & 18, [10]).

*Ethics committees*. Ethics committees also are expected to consider carefully the potential benefit and harm for children as a consequence of participating in research. However, this may lead to a particular emphasis on a protectionist stance towards children and young people taking part in research and limit children's and young people's opportunities and rights to participate. Alderson and Morrow [27] say that traditional approaches to ethics have emphasised the principle of 'do no harm'; however less attention has been given to the harm that may result from overprotecting children, thereby silencing them. Concern with litigation and hypervigilance around research with children have been identified as barriers and decreased representation of children in research [30, 42].

*Organisations*: Organisations that children and young people access for health and education services also have a duty to protect and advocate for children. This may include statutory/legal requirements as well as duties as outlined by [10]. Organisations also represent certain groups with their own goals and interests.

*The other 'adult' in the room*. Although with participatory child-/young person-led research it is less likely that there will be another adult in the room, there are times when children may request or need the presence of a known adult such as a parent or teacher to reassure and support their confidence [43]. For younger children or children who communicate non-verbally, the presence of a known adult can help nuanced communication between the researcher and the child and help the researcher gain a deeper understanding than would otherwise have been possible [43]. Parents or known adults can also support the development of rapport and communication between the researcher and child [43]. However, involvement of ‘other’ adults in the research can also lead to a filtering or interpretation of children’s responses, and their viewpoints and contributions can become a form of proxy for children’s viewpoints [30].

### 3.1.10 Why Are Gatekeepers Cautious About Participatory Research?

There are a variety of reasons that can contribute to caution by gatekeepers around participatory research with children and young people. This includes lack of familiarity with children and young people as a group, or a lack of knowledge about research with children and young people; not understanding the purpose of the research either because other types of research are valued or because of lack of clarity by the researchers; or there may be a genuine concern to protect children and young people from harm.

Clark [44] suggests that some of the barriers for gatekeepers are around issues of methodology, representation, intrusion and disruption. Gatekeepers have been known to make their own value judgments around what constitutes valuable knowledge and research, which may privilege certain types of methodologies over others. Clark [44] suggests that gatekeepers also make value judgements about the social world, where political representation or the reputation of the organisation may come into question. They may be wary of how the organisation and the participants are represented in the findings and if this might have any negative consequences. They may also have concerns around the intrusion of researchers into the private lives of others. Finally, gatekeepers may be concerned about the time and effort they may spend assisting the researchers with the project with no return for them [44].

Factors that support the engagement of gatekeepers include the outcomes of the research supporting their organisation’s aims and interests—often highlighting the role of the organisation and validating their role [44]. Identifying ‘good practice’ as a way to facilitate change was also an enabler to supporting engagement with the research by gatekeepers [44]. Lambert and Glacken [32] suggest that researchers should be open to gatekeepers testing their motives for including children in research and questions of benefit and harm related to participation in research.

### 3.1.11 Participatory Data and Representation: Who Owns the Data?

Whilst children and young people may have given permission for their data and stories to be shared for the research, they have not given up the ownership of their own stories. With participatory approaches, children and young/people should determine who, where and when the data will be used. The ownership of photographic images particularly raises ethical considerations and discussions with children, young people and families around how and where the image may be used, permission to use this in presentations and academic publications, along with a description of the image of what and why it was taken in any dissemination [15].

### 3.1.12 Representation of Participants

Although participatory research with children and young people aims to ensure that their voices are heard on things that matter to them, these voices can still be at risk of being mediated through an adult lens and interpretation. The researcher's interpretation therefore is just on possible interpretation [9]. The risk is that adults may choose to represent children in particular ways that the child themselves may not give primacy to [45] cited in Powell et al. [3] argues that children's perspectives or views should be seen as a standpoint from which analysis proceeds rather a definite representation of children's experience. However, the tension is that research with children and young people is always mediated by child/adult power relationships and lens [3].

The use of visual data can create particular ethical issues in participatory research including what is captured, who is in the picture, how people are represented and the permanence of images. The spaces in which photos are taken and the boundaries around this are not always clear. The law in each country dictates what and where it is permissible to photograph. In general anyone may take a photo in a public place although it is suggested that researchers and participants should ask people for their permission before taking a photo. It is argued though, what is public, semi-public and private is not clear, as some places such as hospitals might be considered to be semi-public spaces, yet where people should be entitled to privacy [46]. Photos in the home may be seen as less invasive, and yet they may cross over into the intimate and private spaces of family life [47].

Confidentiality and anonymity is also a concern with the use of images. Although there may be provision to blur the faces of the children, the counter argument is that anonymity may become another way of silencing participants' voices by rendering them invisible [46]. It is argued that blurring or pixilating photos may dehumanise the children in them [48]. The future use of images is also a concern. Although participants may consent to having their photographs taken, they may be unaware of the implications of the subsequent display or archiving of the image to be used in the future [46]. This also raises the issue around the permanence of images—although a child and family may consent at the time to an image being used, they may not feel the same in the future—particularly if the photograph depicts a vulnerable point in the child's or family's life [46]. How and where the image is displayed may also pose risks in relation to how that image may be used, manipulated or taken out of the original context it was originally set in—this may lead to misinterpretation by others [46].

Along with the risks of being identified is the issue of misrepresentation [46]. The photo itself is a construction, and researchers need to be careful of implied truthfulness of the image [49]. Therefore, the context of taking the photo becomes just as important as the image itself [49]. This brings up issues of trustworthiness where the image can be used by researchers to convey a particular meaning and where veracity of the meaning (as intended by the child) may give way to aesthetic devices [46].

Concerns expressed by ethics committees often centre around the incidental participants in photos, who have not consented to take part in the research, children and young people taking photos of illegal activity and children or young people taking photos of their 'private parts' [15]. Ways to mitigate this include having clear guidelines and discussing with children and young people the boundaries of who, what and where to take photos. The issue around incidental participants can be addressed through children and young people asking their permission to include them in the image and for the researchers to obscure their identity through blurring or pixelating the image.

## 3.2 Key Advice

1. Keep open to questioning how participatory the research really is and to what degree children and young people are/or wish to be involved in all aspects of the research process.
2. Participatory research is dynamic, changeable and challenging—therefore strategies to maintain and uphold ethics throughout the study also need to be responsive.
3. Consent, assent and dissent are important processes that need constant negotiation and renegotiation.
4. Above all, do no harm.

## 3.3 Conclusion

Ethics is very much in the realm of 'it depends' as although the principles such as 'do no harm', minimising risk and informed consent may stay constant related to procedural ethics, how these are able to be enacted depends on a multitude of social, cultural, political, developmental and situational factors. There is no 'one stop shop' or one approach to participatory research; rather the researchers need to be mindful and reflexive and consider ethics as a dynamic process that goes through all aspects of planning and carrying out a participatory study. Being reflexive and flexible allows researchers to respond to the spaces in-between what is planned and what was done (not always the same!). Being aware and open to ethical questions and challenges throughout a participatory study ensures both methodological and ethical integrity of the study and the dignity and integrity of the children and young people.

## 3.4 Useful Resources

- Powell et al. [3] provides an excellent literature review on general ethical issues when undertaking research with children and young people and went on to inform the UNICEF guidelines (ERIC) for undertaking research with children [4]. Gallagher [14] also provides a very good overview on thinking of power issues in participatory methods alongside examples from different studies.

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# Being Participatory

# 4

Kate Harvey

## 4.1 Introduction

This chapter highlights the importance of involving children and young people in policy-making. Through an account of a UK-based think-tank's experiences of working with young people to produce a policy report on clinical research ethics, the chapter draws attention to the valuable, necessary, and important input of children and young people in policy-making contexts, particularly where the policies in question directly affect young people's lives.

### 4.1.1 Background: The Nuffield Council on Bioethics' Report

The Nuffield Council on Bioethics (NCOB) is a UK-based think-tank which focuses on ethical issues arising out of the biological and medical sciences [1]. In May 2015, NCOB published a series of resources on *Children and clinical research: ethical issues*, including a project report and a one-page summary [2].

NCOB also produced resources aimed at an audience of young people, including a set of films on research ethics, a magazine summary version of the project report, and an animation to highlight key aspects of the report's framework and conclusions [2, 3].

The project was guided by a working party with expertise in ethics, nursing, medicine, philosophy, psychology, law, public engagement, and policy [4]. In addition, the project included fact-finding meetings with experts and stakeholders (with a focus, for example, on risks associated with paediatric research and the role of ethical review in paediatric research), a public consultation process, and an external review.

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However, this project had children and young people at its heart, and, as such, it was clear from its inception that the appeal for ‘nothing about us without us’ should be invoked in its strongest terms in a policy-making context—particularly when inquiries focus on matters that affect children’s and young people’s lives.

Rather than summarising the overall findings of our project on *Children and clinical research: ethical issues*, this chapter therefore sets out NCOB’s approach to involving children and young people to support, and indeed enhance, its project and the policies it recommends. Our approach sought young people’s involvement in a wide range of engagement activities, including in workshops, filming, written input, and event participation. These activities are explored and set out in full in the *techniques section* below.

This chapter begins with an account of a deliberative exercise with young people which aimed to produce an animation to make our report’s conclusions and recommendations accessible for their peers [3, 5]. Although our work included a range of engagement activities, this exercise has been chosen as an exemplar as it included perhaps the most diverse and broad involvement of, and engagement with, young people for this project.

## 4.2 Example from a Deliberative Exercise

### 4.2.1 Aim of the Exercise

To produce a short animation (under 5-min), with the guidance and assistance of young people, to reflect the conclusions of NCOB’s report on *Children and clinical research: ethical issues* in an accessible format for young people, with a compelling narrative thread.

### 4.2.2 Participants

Young people between the ages of 10 and 18 recruited from NCOB’s stakeholder group (see further *Technique 1* (*4.4.1*) below), the National Institute for Health Research’s (NIHR) Young Persons’ Advisory Groups (YPAGs), which provide feedback to researchers whose work is relevant to young people [6], and schools and colleges with which NCOB had previous contact (e.g. through delivering workshops and presentations).

### 4.2.3 Process of Participation

Young people were involved in the production of the animation at four stages.

First, during the early stages of report drafting, we sought the advice of a YPAG based at Alder Hey Hospital in Liverpool (UK) [7] to ascertain how the working party might best make its materials accessible to young people. We organised a 3-h workshop in order to ask participants to:

- Discuss the contents, aims, and broad conclusions of the draft report; and
- Give their views on how the report's contents might be made accessible for members of their peer group.

The YPAG members advised that we create an animation with the help of young people and that the animation should be aimed at young people over the age of 10. We adopted the YPAG's advice, and plans were subsequently made to involve young people in the animation development process.

The second core element of young people's participation comprised a 2-h weekend workshop attended by 14 young people between the ages of 10 and 18, along with a production team (a producer/director, an assistant director, and an animator) from the animation company we chose to work with.

Before the workshop, information sheets were distributed to participants to set out the aims of the workshop and how it would proceed (parental permission was also sought). When participants arrived at the workshop venue, they were encouraged to ask questions of the facilitator at that point, or indeed at any point throughout the workshop, and were subsequently asked to read and sign a consent form setting out how their contributions would be used by NCOB.

Facilitators (NCOB staff and producers from the animation company) invited participants to discuss a range of issues based on a series of questions including 'when you hear the term "health research", what images does it bring to mind?' and 'when you think of a typical researcher, what do you imagine them looking like?'.

Throughout discussions, participants were encouraged to describe images which occurred to them during the course of considering these questions. This approach—to encourage engagement through pictures rather than words—was highly effective and provided the animators with evocative content to use when creating the animation. For example, in response to a question which focused on what it might be like to take part in health research, participants suggested that it might be like being controlled in a computer game, an image subsequently used in the final animation.

The third core element of participation resulted from participants' agreement to be contacted after the workshop to provide NCOB with further guidance on the 'voice' and content of draft scripts for the animation, including whether the vocabulary and tone reflected accurately that of a young person or whether explanations included in the animation were in any way patronising. Several participants responded to this call for views, and, again, their contributions were directly embedded into the final animation. An example of one participant's contribution is provided in Box 4.1 below.

Finally, it was important for the animation and Mia, the main character, to have the right 'voice'. Therefore, instead of employing the skills of an actor to provide

**Box 4.1 Example of a Young Person's Influence on the Final Version of the Animation**

One workshop participant commented on a section of the animation which highlighted that young people can always ask questions of researchers in clinical research situations.

To illustrate this point, the animation originally showed bees formed in the shape of question marks flying out of the protagonist's (Mia's) brain through her mouth. The participant felt that, for younger children who might watch the animation, this might be scary or 'too dark'. As a result, the animators changed the images used in the scene to reflect the participant's comments.

voice-over for the animation, a workshop participant embraced the role and accompanied a member of NCOB's staff and the producer of the animation to a studio to record the voice-over.

### 4.2.4 Ethical Issues

Ethical issues which arose during the course of producing the animation included:

- Topic sensitivity: particularly where participants may have had experience of clinical research, either personally or through family connections. Participants were urged to tell facilitators privately if they felt uncomfortable discussing any particular issue.
- Consent: ensuring participants had time to consider the workshop consent forms by giving them sufficient information in advance so that the forms (signed by participants on the day of the workshop) could consolidate what participants already knew about the day.
- Future contact: as part of the consent process, asking participants if they agreed to be contacted after the workshop to provide feedback but highlighting that they could change their mind about this at any time.
- Data protection: ensuring that participants' details were stored on a secure, password-protected server, and not shared with third parties.

### 4.2.5 Findings

Translating policy reports into animated formats is an effective way of ensuring that young people can engage with their contents and that their views are elicited effectively. Moreover, when producing animations, adopting an approach which invites young people to present their thoughts in image form provides a rich visual resource from which animators can draw inspiration [8].

### 4.2.6 What You Would Do Differently in the Next Project

The period between beginning this part of the project and delivering it was very short (just a few weeks). In the future, taking a little more time would be preferable: producing animated content takes longer than might be anticipated by a non-expert.

### 4.2.7 Impact on Participants

Participants' feedback on this animation project was highly positive. The young people indicated that they had enjoyed the experience (e.g. one participant told us 'it was a pleasure to be invited along'), had learnt about clinical research, and felt that their input had contributed directly to the final animation. For NCOB, the project indicated strongly that using visual cues (e.g. 'when you think of a typical researcher, what do you imagine them looking like?') is an effective method of eliciting young people's views.

### 4.2.8 Dissemination Techniques

NCOB distributed news of the animation through its social media and news-sharing channels, in addition to sending targeted emails to stakeholders.

### 4.2.9 Conclusion

Over a 2-year period, the animation was accessed over 7000 times on YouTube. In addition, NCOB uses it frequently to illustrate the findings and approach of this project. We have been made aware of the use of the animation for researchers' training [9] as well as for young people who are asked to consider participating in clinical research [10, 11]. In addition, the animation has been translated into Spanish, Arabic, Swedish, German, and Mandarin [5].

## 4.3 Techniques

This section sets out four techniques we used to engage young people in our project on *Children and clinical research: ethical issues*. These techniques permeated the entire project: from the very beginning of the working party's endeavours through the establishment of a stakeholder group of young people and their parents to the very end of the project and its launch event which was designed with and for young people to participate in meaningfully.

## 4.4 Technique 1: Workshops and Interviews

Workshops and interviews supported five aspects of NCOB's engagement with young people for this project. In some cases, young people who participated at workshops and/or agreed to be interviewed had extensive knowledge of clinical research and its processes through their own experience; others had very little knowledge of clinical research but some knowledge of NCOB's work, whereas other participants contributed to our work as a result of their school agreeing to assist us in our engagement work.

### 4.4.1 Stakeholder Group Workshops

At the start of the project, we established a stakeholder group of 26 individuals (comprised of children, young people, and parents). The group contributed its views throughout the project but also at two specific and important time points.

The first point was at the very beginning of the project when the group was invited to take part in a 1-day workshop in order to help us to 'shape' the project. This meeting took place directly before we began drafting our policy consultation document: timing was key in order to enable stakeholders' input to be considered *before* wider questions began to be asked (perhaps unusually for a policy project). We were thus eager to hear stakeholders' views on the questions *we* wanted to ask, but we also wanted to hear which questions *stakeholders* wanted us to ask. Therefore the workshop focused on participants' consideration of draft consultation questions, particularly for an online questionnaire to gather the views of young people [12].

Participants were asked to come to the workshop prepared with what they saw as the most important ethical challenges for clinical research with young people: in particular, they were asked what they might like to see change (e.g. in terms of policy or practice) and why. Where participants had experience of clinical research, they were asked what worked well or what could have been better, or how research involving young people might be improved or made easier.

Following this workshop, we considered the group's contributions, including practical points (e.g. ensuring that consultation documents were concise and included tick boxes as well as sufficient free text boxes for respondents who wished to submit a longer response). These suggestions were considered after the workshop, and drafts amended accordingly (indeed, some young people actually rewrote the young people's survey for us). The stakeholder group therefore had direct input into and influence on the working party's approach to evidence gathering.

The second point came later in the project, when stakeholders were invited to a 1-day workshop where our preliminary findings were put to participants, and a series of activities to facilitate discussion of our findings were organised in order to make the day enjoyable as well as useful. An example of one of these activities is set out in Box 4.2 below.

**Box 4.2 Stakeholder Group Activity on Priority Setting**

Five tables of stakeholder group members were each given £1,000,000 in fake money which they were asked to spend on clinical research. They were also given five boxes displaying (non-exhaustive) research aims, into which they were asked to divide their money:

- Research into minor illnesses that affect a lot of children, like colds and flu
- Research into very serious illnesses that affect a few children
- Research into serious illnesses that affect lots of children in poor countries, like malaria
- Research into how children feel about being ill and how they like being cared for
- Research into the best ways of training doctors and nurses to look after children

Each group was given 20 mins to discuss how they might divide their funds, and each was asked to explain their reasons for their decision. Where disagreements occurred within groups, facilitators encouraged individual group members to explain their arguments.

This meeting avoided an ‘us and them’ approach: a situation where young people were ‘talked at’ or indeed found themselves in circumstances where they felt ‘put on the spot’ was something which we specifically wanted to avoid. Instead, we favoured an approach where young people, their parents, and NCOB staff and working party members were mixed together, so that each individual participant could contribute on equal terms.

At this workshop, participants were also invited to discuss a range of issues relating to the project’s draft policy recommendations (including challenging the assumption that young people are automatically ‘vulnerable’ in clinical research situations; how young people’s decision-making in clinical research can be facilitated (including consent and assent processes); and how priorities should be set for research endeavours). This workshop was therefore arranged for a time at which the input of participants could have a meaningful impact on our findings and recommendations.

### 4.4.2 ‘Chocolate Research Trial’

The involvement of young people as part of a workshop format continued in a subsequent visit to a state primary school in Wimbledon, London.

Drawing on a research engagement activity devised by the NIHR [13], a group of 60 school children between the ages of 8 and 9 were asked, as an introduction to clinical research concepts, to consider whether they would like to take part in a research trial about chocolate. When asked if they would like to take part, every student raised their hand eagerly. However, the students were then told that they would be asked to compare cabbage-flavoured chocolate with snail-flavoured chocolate. At this point, enthusiasm for participation in this research trial waned considerably, and the students were asked to think about what they might like or need to know *before* agreeing to take part in research and also what researchers needed to do (e.g. provide them with sufficient and clear information about what the research is trying to find out, what participants would be asked to do, and what could be done if participants changed their minds about taking part).

All of these points were discussed while students were randomly split into two groups. Members of Group 1 each received a piece of milk chocolate; and members of Group 2 were each given a piece of dark chocolate (rather than cabbage- or snail-flavoured chocolate). Although this exercise was fun for facilitators and for the children who took part, its conclusions and methods of engagement were very helpful for our next steps. In particular, the engagement exercise highlighted how the use of analogy can be very helpful in 'kick-starting' conversation as, after the chocolate trial had been discussed, the students were then able to apply their newly acquired knowledge to considering how the same messages/need for information might be applied to clinical research scenarios.

The children were then asked to consider the clinical research scenario set out in Box 4.3 below.

**Box 4.3 School Workshop Scenario**

Imagine you have a bad cold. At the moment, there is no cure for a cold (only things that may make you feel a bit better until it goes away). Your doctor asks you to take part in research. This may help to find a treatment for other children in the future.

You will have to swallow a big tablet every day for 3 weeks. It might be a real medicine, or it might be pretend (just like when you were sorted randomly into Group 1 or Group 2, you did not know which type of chocolate you would be given).

You will also be asked to spend one morning at the hospital doing some tests:

- Pedalling on a bike while someone watches, to see how fit you are
- Giving a bit of blood, which a nurse will take using a needle

Things to think about:

1. What makes you want to take part in this research?
2. What puts you off?
3. Are there things about the research you'd like to change, so you feel more likely to say yes?
4. Who should decide? You, your parents, your doctor, or all of you together?

While considering the scenario, participants were encouraged to draw or write their thoughts with coloured pens on large pieces of paper. Participants' thoughts and ideas fed into the report itself, and their drawings were subsequently used for the branding (including the front cover of each written document) of the final report and its associated materials.

### 4.4.3 Interviews with Liverpool YPAG

NCOB's project frequently sought the 'voice' of young people. For the third example in this technique section, this voice was pursued in its most literal sense.

Following an initial visit to the Liverpool YPAG to ask which formats we should consider in order to encourage and enable young people to engage with the project's findings, the group told us that one suggestion we might consider in fulfilling these aims was to create an interactive magazine, in addition to an animation (see *example from a deliberative exercise* at 4.2 above for further information on NCOB's animation).

As a result of this, drafts were prepared for a short magazine version of the report aimed at young people over the age of 14. Group members provided feedback on the written content of the draft magazine, along with other young people from the International Children's Advisory Network (ICAN) [14], the London YPAG [15], and the Scottish Clinical Research Network's Young Persons' Group (ScotCRN YPG) [16].

At a return visit to the Liverpool YPAG, 5-min interviews were undertaken to explore group members' personal experiences and general views on some of the issues addressed in the magazine. These interviews took place after participants were provided with an information sheet setting out the purpose of the interviews and how they would be used in the future, and a consent form which set out the terms of their agreement to be interviewed. In total, 7 interviews were carried out with group members, who were prompted to consider the following questions:

- Do you have any personal experience of taking part in research?
- If so, what was it like?
- What might make you want to take part in research? (Either hypothetically or referring to personal experience.)
- What might put you off?
- What sorts of things do you think might worry children and parents?
- Do you think anything could be done to reduce these worries?
- What would your 'perfect' research experience be like?
- What sorts of things (if anything) would you like to see change in how it works at the moment?
- What would your perfect researcher (who works with young people) be like?
- Who do you think should make decisions about children/young people taking part in research?—you/your parents/all of your together/anyone else?

The audio recordings of the young people's responses to these questions were edited into short audio clips which were then embedded in the electronic version of the magazine [5]. The voices of young people highlighted some of NCOB's own conclusions but also, importantly, contributed to a resource which is more interactive and therefore may be more appealing to other young people.

### 4.4.4 Community Workshop in Kilifi, Kenya

Research with young people crosses borders and takes place in very different situations from those governed by regulatory structures and conventions of the United Kingdom. With this in mind, we invited two researchers from the Kenya Medical Research Institute (KEMRI) to join the working party [17]. These researchers had a wealth of experience and knowledge pertaining to the practical and ethical issues of undertaking school-based research in Kenya as part of an international collaborative health research programme [18].

As part of the working party's evidence-gathering activities, these working party members drew on their links with the community in Kilifi, Kenya and, in particular, KEMRI's Schools Engagement Programme ((SEP), an initiative which links researchers and community liaison staff with a group of secondary schools in the area and aims to support science education and to build understanding of research).

Four schools (including a girls' boarding school and a mixed day school) and 24 students in total took part in 1-h workshops led by KEMRI social science researchers with experience of moderating group discussions and in collaboration with the Kilifi County Education Officer. Participants were selected by form teachers who were asked to identify a diverse group of participants to include a mixture of religious and academic interests while also positively selecting students who were deemed likely to contribute to a group workshop—although participation was on a completely voluntary basis.

Note-takers accompanied each facilitator across the four school workshops and produced a report on participants' views on the acceptability of involving young people in clinical research, decision-making for research involving young people, and other cross-cutting issues [19]. This report was received by the working party at a point at which it was deliberating its conclusions and therefore influenced the final project report.

### 4.4.5 Animation Workshop

Details of the animation workshop are provided extensively above (see *example from a deliberative exercise at 4.2*).

## 4.5 Technique 2: Filming

In addition to engaging with YPAG members (see e*xample from a deliberative exercise* above at 4.2), it was also important for us to take into consideration the views of young people who did *not* have direct experience of clinical research or clinical research ethics. We also wanted to compare these young people's views on research ethics questions with those of adults. In order to fulfil these aims, a film project on Youth Research Ethics Committees (Youth REC) was established, the process of which is set out in seven key steps below.

### 4.5.1 Mock Clinical Research Protocol Development

Before engaging participants in this activity, NCOB devised a mock clinical research protocol. While fictional, every care was taken to ensure that the protocol was drawn from practice and *could* be genuine.

In order to achieve this, we worked with three academic researchers and an asthma consultant/researcher to draft a mock research protocol which focused on a novel way of identifying the most appropriate treatment for childhood asthma, given children's variable responses to two standard medications. The protocol was also designed to prompt responses from participants on particular ethical points such as consent, risk, and privacy. When developing the protocol, we also sought the views of our stakeholder group (see *4.4.1* above) on associated materials, including ethics approval forms, information sheets, and consent forms for young people and their parents/guardians.

### 4.5.2 Filming an Adult 'Mock REC'

The first element of the Youth REC project which involved filming focused on a meeting of six adults with experience of taking part in RECs, including a REC chair, a clinician, an expert in research governance, a student representative, and a 'lay' member. Although the six participants on this 'Adult REC' discussed the protocol at length, their discussions were not subject to any judgement as to their quality; rather they were filmed in order to construct a prompt for young people to respond to after their own deliberations were complete. This enabled us to compare the key points (including concerns or confusion) of the Adult REC, with those of the Youth REC.

### 4.5.3 Highlighting the Research Context

In order for the films to portray more than participants' discussions around a meeting table—which would be unlikely to be either dynamic or compelling for most viewers—our film-maker urged us to allow a story to emerge to complement the RECs' discussions. With the assistance of the asthma consultant who advised on the mock research protocol, we were therefore put in contact with the family of a 7-year-old girl with severe asthma, called Ruby. Along with the film-maker, we arranged to meet Ruby and her family to discuss the film project and to provide information about the aims of the films and how they would be used in the future. After explaining the contextual details, we asked if Ruby and her family might be willing to feature in the films we intended to make. They agreed, and subsequent arrangements were made to film Ruby and her family in the consultant's clinic discussing her condition and medication, and also in her home, in order to highlight how she and her family manage her condition on a daily basis. Ruby's and her family's consent was documented in advance.

### 4.5.4 Editing Film 1

The content of Film 1 of the Youth REC project draws from 4.5.2 and 4.5.3 above and is split into two parts.

Part I sets out and contextualises the protocol. It begins with Ruby and her family meeting with her consultant to discuss her current asthma treatment. Ruby's family context is also highlighted: for example, how her family adapts around Ruby's routine for taking her medication. Following a brief exploration of how asthma can affect the life of children like Ruby and her family, the consultant explains his plans to submit a research protocol to an ethics committee.

Part II focuses on the Adult REC's discussion of the consultant's research protocol and includes their discussions on the broad merits or concerns associated with the protocol and also its accompanying ethics application, consent forms, and information sheets.

### 4.5.5 Facilitating and Filming 'Youth REC' Workshops

Film 1 was produced in time for it to be screened at a series of 'Youth REC' workshops. At these workshops, further filming took place which then led to the production of Film 2 (see below).

The young people who took part in the 'Youth REC' film were from three different age groups (10–11 (junior school), 11–14 (secondary school), and 16–18 (sixth form)), and from a range of socioeconomic backgrounds. During three separate half-day workshops—prior to which consent for filming and participation in the project was sought from the schools, parents, and young people—participants were asked to adopt the role of REC members and to consider the research protocol on asthma treatments which had previously been submitted to the Adult REC. The Youth REC were also supplied with explanatory material, including a background information sheet on what 'research ethics' means and, in addition to the same protocol which the Adult REC considered, a separate information sheet on the mock trial explaining 'what's it all about?'.

The structure of the Youth REC workshops is set out in Box 4.4 below (see further: [20]).

**Box 4.4 Structure of Mock Youth REC Workshops**

(a) Warm-up activity on participants' views on what is meant by 'clinical research' and 'research ethics';
(b) Viewing of Film 1 (Part I), to help participants to understand why clinical research might be important;
(c) Facilitated discussion with participants to encourage debate around key concerns and ethical issues associated with the mock research protocol and its associated materials (information sheets, assent/consent forms, and explanatory letters to parents of potential mock research participants);
(d) Viewing of Film 1 (Part II); and
(e) Facilitated discussion to explore what the Youth REC's thought of the adults' conclusions, drawing out similarities and differences with their own thoughts.

### 4.5.6 Editing Film 2

Film 2 brings together the discussions of the young people who participated in Youth REC workshops on the mock clinical research protocol. In addition to highlighting the young people's opinions on and concerns about the protocol, the film also reintroduces particular parts of the Adult REC's discussions. The film was edited this way in order to show that the young people's concerns mirrored those of the Adult REC in many ways but, in others, contradicted their views. For example, the Adult REC felt that young people in their later teenage years who might be involved in the mock protocol could feel patronised by the protocol's condition that their parents would need to consent on their behalf. However, during discussions with the Youth REC group whose members were in their late teens, it became clear that they would expect their parents to help them to make decisions to take part in clinical research and, moreover, would *welcome* their views and advice.

### 4.5.7 Launch Event and Future Use

The Youth REC project was launched formally at an early evening event at the Brighton and Sussex Medical School in the expectation that organising a launch at a convenient time and location might encourage the film's participants to attend. At the same time, the film resources, including a short trailer, were launched on YouTube and have been viewed over 4000 times in the past 2 years. Since the resources were launched, they have also been presented at other schools, colleges, and universities and form part of NCOB's educational resources [21].

The resulting set of Youth REC films was produced with the input of a diverse range of young people who did not have a prior interest in clinical research and provides a resource which can now be used by other young people and their teachers, as well as by other stakeholders. The films highlight that young people are more than capable of considering the same research protocol as a group of adults, provided that presentation and facilitation of the protocol are approached in appropriate ways (e.g. through summarising key points of the protocol in age-appropriate language).

## 4.6 Technique 3: Written Input

Young people contributed to four written elements of NCOB's project on *Children and clinical research: ethical issues*.

### 4.6.1 Call for Evidence

NCOB promotes calls for evidence for each of its projects (both generally and targeted to particular stakeholders). As with other elements of its work on children and clinical research, it was very important for us to ensure that young people's written input was facilitated in an appropriate way. Therefore, in addition to a survey drafted with an adult audience in mind, a further version was produced for young people with the assistance of members of our stakeholder group, who were asked for their input on the questions we wished to ask, and how we might ask them in the most accessible way. For example, differences in language between the two surveys included, in the young persons' questionnaire: 'if someone said they wanted you to be involved in clinical research, what do you think that would mean?', whereas in the adult survey, we asked: 'what do you understand by the term "clinical research"?'

Forty-six responses were received from young people who accessed the survey independently; and a further 71 young people completed the survey as a result of group discussions in the YPAGs. These responses were subject to an in-depth analysis, the results of which were made available publicly [22]. Following analysis, respondents' contributions were considered by our working party and informed the drafting and 'thinking' processes involved in producing our final report.

### 4.6.2 Magazine Drafting

A visit to the Liverpool YPAG a few months prior to our project's conclusion sought to ask the group's opinion on how we should approach outputs of the project in a way that would appeal to young people. Their opinions were gathered through the use of an ideas tree: YPAG members were asked to write their ideas around what outputs we should consider for our project on a leaf which was then attached to a felt tree. One suggestion that appeared frequently on the tree at the end of the exercise, and was drawn out further through discussions with YPAG members, was that we should draft a written version of the report for young people in the form of a magazine, presented in a visually appealing way with graphics, diagrams, text boxes, and photographs.

In order to create a magazine which appealed to young people, we therefore sought their opinions and assistance throughout the drafting process. Young people's groups in England (in Liverpool and at Great Ormond Street Hospital in London) [7, 15], Scotland (the Young Persons' Group in Aberdeen) [16], and the United States (members of the Connecticut group of the ICAN organisation) [14], in addition to our own stakeholder group, all submitted views on the form and language of draft versions of the magazine.

The idea of a magazine had also been mooted at an earlier meeting with the London YPAG, where group members offered us practical advice, including that we should avoid large paragraphs and instead break down the content of the magazine into as many sub-sections and sub-headings as possible. Similarly, the group felt that the magazine should not be too long (the final version comprised 17 pages). The YPAG's members also suggested that the document should be interactive, with 'live' elements in its online version, such as links to video or audio content.

The London YPAG was, however, also keen to emphasise that the magazine should not be too 'childish', for example, by avoiding cartoon strips and instead using photographs of young people with whom we had met, rather than stock photographs of young people 'posing'. As one young person commented, 'we know clipart when we see it!'

Once initial drafts had been produced, we then sought the opinions of the YPAG groups and our stakeholder group members once again. At this point, the young people's comments made clear that we had more work to do in order to make the magazine appealing for young people. For example, one young person told us 'it seemed too long… I lost interest and felt pretty lost in the length of it'; another stated: 'Not sure whether anyone would really read this paragraph'.

More positively, commenting on the same draft, one young person welcomed our inclusion of quotes and interviews with young people: 'I love the fact that you have added the views of young people and children that are involved in research because it gives adults the idea that we really don't mind it, and we find it really interesting ☺☺☺'.

As a result of the YPAGs' input, the final version of the magazine was significantly shorter than earlier drafts and included much clearer signposting to enable readers to pick out parts of the magazine which were of particular interest to them.

### 4.6.3 External Review

Before NCOB reports are finalised, they are subject to external review from a range of stakeholders. In the case of our project on *Children and clinical research*, we were again eager to take into account the perspective of young people on the arguments made in the written report. We therefore sought to engage a young person to review the report along with other stakeholders.

The external review process applies to the long report we publish only, and, as this report numbered around 200 pages, it felt necessary to invite a young person in their late teens to assist us with our task. This young person had previously taken part in the Youth REC films we produced, and also the animation workshop, so was partially familiar with both how our organisation worked and also with the types of issues with which the report was concerned. The process the young person was asked to follow for external review was exactly the same as that for our other reviewers, although we approached the logistics of receiving her review (i.e. around exam timetables) as flexibly as possible.

### 4.6.4 Blog Posts

In order to provide NCOB's stakeholders with an overview of the Youth REC project in advance of the report's publication, we invited students who took part in the Youth REC film project (see *Technique 2* above at 4.5) to produce a blog which set out some of their views of the process. The concluding paragraph of the blog post, which was drafted jointly by 3 sixth form students, summarises the importance of involving young people in clinical research but can also be applied to policy-making endeavours: 'if adult researchers can understand their limitations, knowing that children and young people have strong opinions that we deserve to have heard, then together we can use our relative expertise and insight for the benefit of children, and maybe even adults too' [23].

## 4.7 Technique 4: Event Participation

Prior to the launch of the project's findings, we again asked the young people and YPAGs with whom we liaised throughout the project for ideas on how we might present our findings at a launch event.

Discussions with members of the Liverpool YPAG elicited a range of suggestions for how we might approach the launch of the report; we also took into account approaches taken for the YPAGs' own 2013 GenerationR conference, where young people very much organised and managed the event [6]. From attending this event, we noted the success of holding discussions as part of a mock TV chat show (e.g. the young people who took part in GenerationR interviewed England's chief medical officer in a breakfast TV-style interview). We therefore decided that as this approach had been so successful for GenerationR, then we might try a similar approach for our own launch and subsequently invited members of our stakeholder group (see *4.4.1* above) to participate in a similar format.

In addition to discussing our project's findings in a TV-style format, we also asked young people who participated in our animation workshop (see *4.2* above) whether they might agree to respond to prepared questions on their involvement by a 'roving reporter'. The responses the young people gave to these questions enlivened the event and provided context to how they had been involved in various aspects of the project. In the light of these activities, and perhaps unlike other policy report launches where professionals commonly take the centre stage, NCOB's launch event focused predominantly on young people's views and input.

Clearly, however, we were keen to ensure that young people who agreed to give up their time to participate in our launch event did not feel pressurised into speaking in public. Therefore, when we asked for volunteers, we made it clear that they could withdraw from speaking at the event at any time of their choosing (indeed, one young person decided to do so). Both the young people who took part in the panel discussion and also those who agreed to be interviewed were all briefed comprehensively beforehand, so that they were aware of the questions/issues we would ask their opinions on, so that they were not put 'on the spot' in front of the assembled audience.

We were also mindful of the fact that a 2-h event might be somewhat boring for young people unless we broke up discussions around our findings with other material. We therefore decided to have screenings of the Youth REC films and our animation, again which several young people in attendance had contributed to and/or appeared in.

Following the launch event, attendees were invited to a reception to celebrate with party food and drinks (soft drinks, sandwiches, and crisps rather than wine and canapés). Policy-makers and other professionals were eager to talk to the young people about how they contributed to the project, with several keen to explore how young people might be involved in their own policy-making endeavours.

## 4.8 Advantages and Challenges

### 4.8.1 Advantages

The involvement of young people in this project enabled us to produce resources which were not just 'about' young people but rather took into account their views and contributions in a meaningful way. Pragmatically, the involvement of young people also made our job easier: rather than second-guessing how young people might, or could, respond to the ethical policies we were drafting, we could simply *ask* them. Moreover, for us, young people's involvement in the project made it a very enjoyable piece of work to be part of.

We propose that, without the input of young people, the outputs of our project on *Clinical research: ethical issues* would *look* very different, and, more crucially, *say* very different things. In the future, by involving young people in policy projects more generally, we suggest that these projects would have an authenticity that they would not be able to boast without their input.

The involvement of young people in our own report has also influenced and will continue to influence how NCOB gathers evidence for its projects in the future. For example, the YPAGs with whom the working party engaged during the course of our work on children and clinical research have since taken part in deliberative events for a subsequent project on ethical issues arising out of the growing use of cosmetic procedures in the United Kingdom [24].

### 4.8.2 Challenges

Challenges of involving young people in our project were primarily logistical, in particular arranging times when we could meet with the young people, given commitments to school, college, and—at particular times of the year—exam pressures. Therefore, we had to adapt the times at which we planned to meet (e.g. in school holidays rather than outside of them and at weekends rather than weekdays). We also benefited from the advice of YPAG coordinators, who undertake the role of managing the organisational details of young people's meetings throughout the year. In addition, as for any other meeting, we had to ensure that each venue for the particular engagement activity had appropriate access.

Before filming in the three schools, the administrators for each school required that the film crew and NCOB staff had all been checked by the UK's Disclosure and Barring Service before being allowed on the premises. Again, this was a purely logistical hurdle but one which needs to be anticipated early on in any policy project which involves visiting schools.

Other challenges around the environment in which we filmed the Youth REC project also arose when we visited a hospital in order to film Ruby's appointment with her asthma consultant. In a busy hospital environment, it was difficult to film without including other people in each shot. Therefore, working with the film's director, each person who walked into shot had to be identified, and an explanation given to them as to the purpose of the film, and where it would be made available. If, on hearing this information and reading it as set out on a filming consent form, the individuals agreed to be filmed, then the director could then use the particular piece of footage in the final cut.

It is important to note, however, that these challenges were far outweighed by the benefits we enjoyed as a result of young people's involvement in the project.

## 4.9 Key Advice

Where policy-makers seek the views of young people, every effort should be made to ensure that they are involved from the start of the project and consistently throughout [25, 26]. The involvement of young people should not be seen as a 'tick-box' or 'one-off' exercise; instead, involvement should be approached as a fundamental part of the project, and planning should anticipate and accommodate the participation of young people throughout the course of the project. In the light of the challenges indicated above regarding the logistics of meeting with young people at a time convenient for them, forward planning is key and should involve relevant group facilitators, teachers, and young people as much as possible to ensure that there are no ‘clashes’ with the young people’s school and exam timetables.

In addition to recognising young people’s contributions, it would not have been possible for us to engage with young people without the support of their parents, teachers, and group facilitators. In engaging young people in policy projects, the role and expertise of these adults should not be overlooked.

### 4.9.1 Five Key Points

1. Before the project begins, consult with young people, parents, and teachers, to ascertain any logistical barriers to young people’s participation.
2. Following these initial consultations, involve young people from the very start of the policy project.
3. Invite young people to participate at each project stage, from setting out terms of reference to the policy’s launch.
4. Young people’s involvement should not be a tick-box exercise; if they make a suggestion, afford it the same consideration as would be offered to adults’ contributions.
5. Young people may be interested in participating in other projects: ensure their preferences are recorded once the project is finished, to support future work with young people.

## 4.10 Conclusion

NCOB’s report on *children and clinical research: ethical issues* concludes that ethical anxieties with respect to the involvement of young people in clinical research can be managed and mitigated with the help of young people themselves [27]. However, this does not only hold true for clinical research: from our own experiences of engaging young people, it is also clearly the case that anxieties around policy-making on issues which focus on young people can be calmed, and outcomes improved, by their meaningful and continuing involvement.

The involvement of young people in our project had a direct impact on the recommendations we made and the approach we took. This involvement was something which we were keen to encourage other stakeholders to realise, particularly those located in the pharmaceutical and life sciences industries. In the light of this, we convened representatives from a number of these industries, along with young people, to explore the benefits of young people’s involvement in the wider research agenda, the challenges to achieving such involvement, and how to approach tackling those challenges [28]. This meeting resulted in a statement of aspiration, a section which warrants repetition to conclude this chapter:

> ‘Children and young people have historically been seen as a “vulnerable” group, so that research and therefore the evidence base underpinning their healthcare has lagged behind that of adults. Active collaboration between researchers and children, young people and parents provides a means of minimising any risk that children taking part in research might be placed in vulnerable situations’ [29].

## 4.11 Useful Resources

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# Being Participatory Through Play

# 5

Judy Rollins

## 5.1 Introduction

Sometimes things are too difficult to talk about, maybe because a child is too young to know the words or maybe things are just too scary to say out loud. Often children don't know or understand how they feel about something until they "mess around" and explore it a bit. Expressive methods, such as play, drawing, painting, creative writing, and performing arts, can provide the language children need to express their thoughts and describe their experiences.

In participatory research, expressive activities are rarely used in isolation but commonly support other data collection methods such as interviews. Also, some studies incorporate several forms of expression to allow children greater choice. For example, children and young people used variety of arts techniques (e.g., painting, collage, mosaic, dance, poetry, music, sculpture) to respond to "What a hospital should be" [1].

To children and observers, it may seem that such methods are merely fun or distractions. However, just as with other research methods, creative means of data collection must be carefully thought out and thoroughly prepared for during the study planning. Research that is fun and engaging for children aims to make it more accessible while maintaining robustness ([2], p. 96): "research that is fun is indeed a serous undertaking, and the use of arts-based approaches can help to introduce 'serious fun' into research."

This chapter begins with a research example that used three drawing techniques. Other participatory techniques—drawing and visual arts, toys and games, puppets, storytelling and creative writing, and the performing arts—are explored. This is

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followed by a discussion of advantages of using expressive techniques and some of the challenges the researcher might face. The chapter concludes with tips for the researcher and helpful resources.

## 5.2 Research Example—"Tell Me About It: Drawing as a Communication Tool for Children with Cancer" [3]

Stress and coping in childhood cancer is a popular research topic. A growing number of researchers are shifting their methods from seeking information about children to seeking information directly from them. However, in many instances, children have been asked to complete lengthy questionnaires that often fail to capture the true nature of their experiences. This international study sought to use a developmentally appropriate means, drawing, to help children communicate their thoughts, feelings, and perceptions regarding stress and coping.

### 5.2.1 Aims of Study

The study had three aims:

1. To explore and compare the nature of stressors of everyday life and disease that children with cancer in the United Kingdom and the United States experience
2. To explore and compare the coping measures they use to manage these stressors
3. To examine the use of drawing to enhance communication

### 5.2.2 Target Population

Participants were 22 children (13 boys, 9 girls) ages 7–18 years, who were receiving treatment for cancer at a UK site in the Midlands region of England and at a US site in the middle Atlantic region of America. The medical directors of the pediatric oncology services at each site identified children who met the eligibility criteria, and the researcher explained the study and invited them to participate.

### 5.2.3 Type of Participation and Model Underpinning the Participatory Approach

Children participated in the research by expressing their views through child-centered forms of communication, which consisted of drawing that accompanied interview.

### 5.2.4 Research Methods/Tools Used and Rationale for Their Use

The study used quantitative and qualitative methods within a grounded theory approach. Triangulation was used to enhance credibility. Data was collected over a 6-month period. Six instruments/methods were—two of which are common to grounded theory research—observation and interview, three drawing instruments, and a background information form.

The researcher conducted a one-time audiotaped unstructured formal interview with children. To obtain specific psychosocial information about each child, focused (or semi-structured) interviews were also conducted with a play therapist (in the United Kingdom) and a child life specialist (in the United States). The researcher also conducted unstructured interviews with nurses and other hospital or clinic personnel.

An unstructured observational approach as a participant observer was used using the following interview guide:

1. I'm going to ask you to do three drawings.
2. If at any time you want to stop, it is okay. You don't need to say why. No one will be mad at you, and nothing bad will happen.
3. First, please draw a person picking an apple from a tree.
4. Please think of and draw the scariest experience, thought, feeling, or dream you have had since you became ill.
5. Please tell me about your drawing.
6. What helped you at that time?
7. Please draw a picture of where you would like to be right now if you could be anywhere you wanted to be. It can be a real place or a make-believe place.
8. Please tell me about your drawing.
9. What advice would you give to children who just found out that they have cancer?
10. Is there anything else you would like to add?

Aspects observed included the physical setting, the participants' activities, frequency and duration, process, and outcomes. Children completed three drawings, which are explained in greater detail later in this paper:

- *Drawing of Person Picking an Apple from a Tree (PPAT)*—Children were asked to draw a picture of a person picking an apple from a tree. Their drawings were scored using Scale 8, Problem-Solving Scale, of the Formal Elements Art Therapy Scale (FEATS) [4]. This scale is found useful in understanding the child's coping ability.
- *Scariest Image Drawing*—This technique, developed by Sourkes [5], was used to provide a starting point for children to discuss their stresses and coping mechanisms. Children were asked to draw the scariest experience, thought, feeling, or dream that they had since becoming ill.

- *Closure Drawing*—Children were asked to draw a picture of wherever they would like to be right then, a real or a make-believe place. The researcher developed this method to help end the session on a brighter note after discussing difficult issues, to help learn more about the child, and to perhaps have the positive physiological benefits that engaging in the arts can bring.

Parents completed a brief background information form. Information included names, gender, and ages of persons living in the child's home, parents' occupations, child's diagnosis, and date of diagnosis.

### 5.2.5 Ethical Issues

Ethical approval was sought and granted from the NHS Trust Ethics Committee at the UK site and the Institutional Review Board at the US site. Child-friendly colorful brochures were created for each site. The brochures outlined the study details. The wording in the UK version was anglicized with the use of the British spelling of words and British terminology and phrases, and the US version used the American spelling of words, terminology, and phrases. The brochures and the formal consent and assent forms were reviewed with children and parents, and questions were sought and answered.

### 5.2.6 Findings

Findings revealed that children, regardless of their ethnicity and other cultural components, responded to the childhood cancer experience in a similar manner. The use of drawing enhanced communication through direct visual expression and/or through verbal expression via the "campfire effect"—the result of an activity or experience that provides a focal point shared by the individuals involved that serves to increase conversation in both quantity and intensity. Much like sitting around a campfire, "sitting around the drawing," allowed the drawing and not the child to serve as an object of focus for both the child and the researcher. This transfer of focus seemed to relax the child by relieving the pressure of being the object of direct verbal communication and led to the sharing of painful thoughts and feelings (see Fig. 5.1).

### 5.2.7 What We Would Do Differently in the Next Project

It might be interesting to add other modalities, such as poetry, to give children greater choice. Although the number of participants was appropriate for the study methods, a larger sample size and greater diversity among participants would have allowed a more sophisticated statistical analysis. Also, as children's drawings are "in the moment," obtaining additional drawings from the same children at a later time could reveal interesting comparisons.

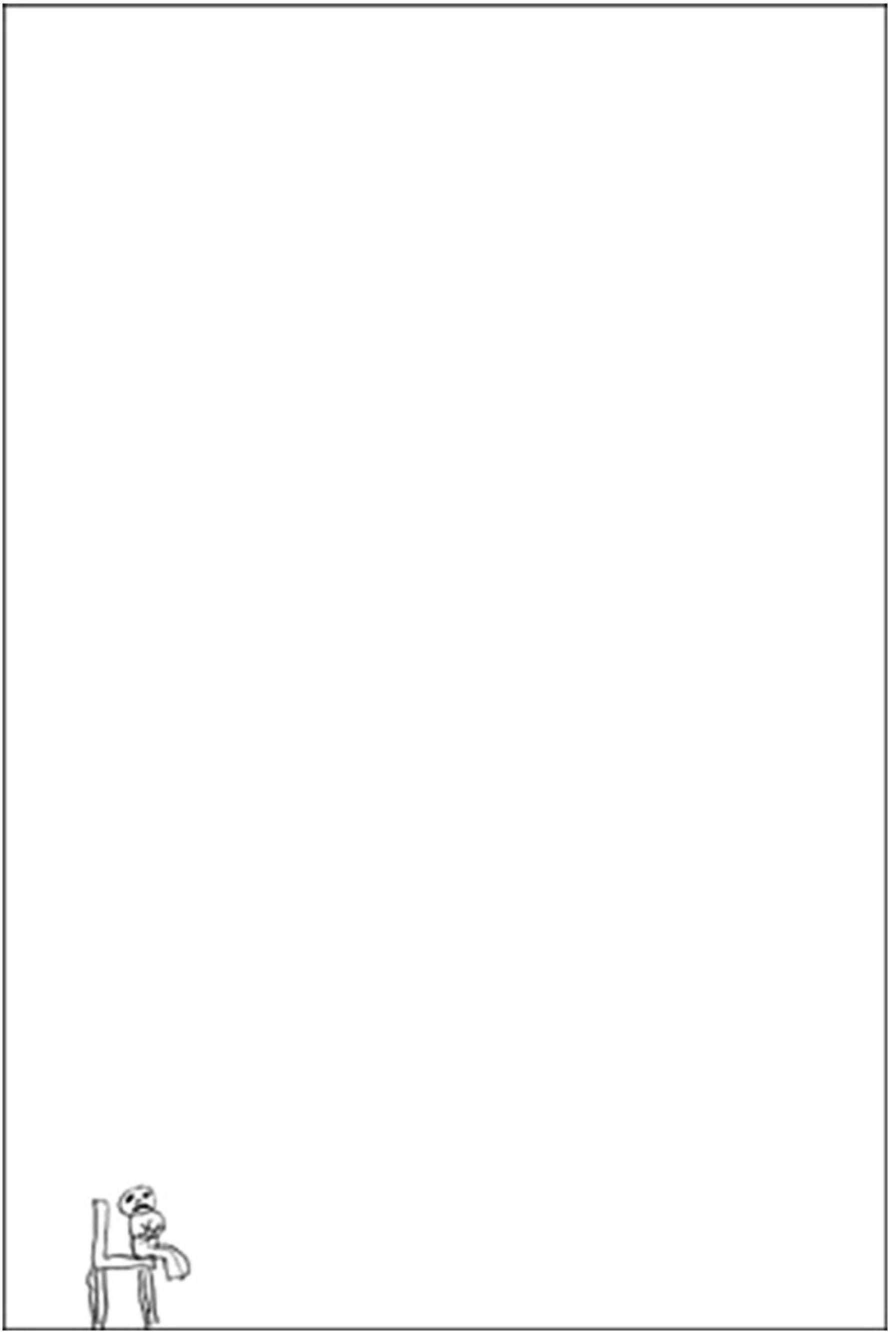

**Fig. 5.1** A 12-year-old girl said this is what she looked like when she was told she had a brain tumor: “I was a scared girl,” adding that she was afraid of dying then and “I am again right now.” She sensed she was dying and, with no treatment options left, in fact was but had not been told

### 5.2.8 Impact on Participants

Participants freely expressed through drawing their appraisal of what was stressful. Some participants said they had never really thought through the experience until drawing and talking about it in the interview. All participants seemed to enjoy the process.

### 5.2.9 Dissemination Techniques

Findings have been presented at several conferences and in a journal article.

### 5.2.10 Conclusion

Drawing was effective in producing significant data with children. Because children may experience significant and immediate benefits from engaging in research that involves drawing, such investigations may be an advantage for those who choose to participate.

## 5.3 Drawing and Other Visual Art Techniques

Drawing and other visual art techniques can draw out information about children's feelings that they may not even be consciously aware of or able to verbally express. When Carney et al. [6] used four methods to elicit children's views of hospitalization, the findings revealed the most concrete information came from a structured questionnaire; however, the visual structured questionnaire (five drawings of hospital events) was most effective in eliciting children's *feelings* about the hospital experience. Weber [7] lists ten reasons for using visual images in research, all of them interlinked:

1. *Images can be used to capture the ineffable, the hard-to-put-into words.* Some things just need to be shown, not merely stated.
2. *Images can make us pay attention to things in new ways.* Art makes us look; it engages us.
3. *Images are likely to be memorable*. Some images are more memorable than academic texts and therefore more likely to influence the ways we think and act.
4. *Images can be used to communicate more holistically, incorporating multiple layers, and evoking stories or questions*. Images enable us to simultaneously keep the whole and the part in view telling a story and helping us synthesize knowledge in a highly efficient way.

5. *Images can enhance empathic understanding and generalizability*. Images literally help us to adopt someone else's gaze, see someone else's point of view, and borrow their experience for a moment.
6. *Through metaphor and symbol, artistic images can carry theory elegantly and eloquently*. The possibilities for using the visual to make effective and economical theoretical statement are often undervalued in research.
7. *Images encourage embodied knowledge*. Visual methods help researchers keep their own bodies and the bodies of those they study in mind.
8. *Images can be more accessible than most forms of academic discourse*. Artistic forms of representation provide a refreshing and necessary challenge to prevailing modes of academic discourse.
9. *Images can facilitate reflexivity in research design*. Using images connects to the self yet provides a certain distance.
10. *Images provoke action for social justice*. No matter how personal or intimate they may seem at first glance, images, by the very nature of the provenance and creation, are also social.

Drawing is the most commonly used visual art modality employed in research with children, either on its own or in concert with other methods, such as interview. Illuminative drawings are simple to administer and allow more flexibility in art materials. Drawings with scoring systems are often used to add a quantitative component to study methods. Painting, collage, and other expressive methods bring additional choices for children to encourage participation.

### 5.3.1 Illuminative Drawings

Children can use any opportunity to draw as a means of communicating, yet certain drawing techniques have shown promise in promoting expression and enhancing communication. Illuminative artwork [8] is one such method. Using this method, the researcher asks the child to render a drawing based on a certain topic or theme. The researcher does not impose his or her analysis of the individual's work but instead encourages the child to use the artwork as a communication tool. Illuminative artwork can be used in much the same way as metaphors are used to express tacit or preconscious feelings about experiences. The researcher follows up by asking the child to explain the drawing and its significance (see Research Example).

The *draw-and-write* technique is a child-friendly and nonthreatening method of collecting data with children. The child is asked to draw a picture relevant to the subject of the research and write about it. The completed picture and any text (speech bubbles, description) are used as a springboard for discussion and questions on the child's experience, thoughts, and beliefs. Asking children to talk about their work puts them in the role of an expert as they guide the researcher through their drawing and what it represented to them.

*Before and after (or pre/post) drawings* provide children opportunities to self-report on their experiences regarding an intervention by drawing and then describing what they drew. The first drawing is done before the intervention; the second occurs afterward. Images are sometimes accompanied by a written text. The *retrospective pre-/postdrawing* is a variation. At the end of the intervention, children are asked to think back and draw themselves as they were before the intervention and then to do a second drawing of themselves as they are now. This method has the obvious advantage for times when it is difficult to collect data on everyone prior to an intervention.

The *closure drawing* is used at the end of interview sessions when children have been discussing difficult issues. Children are asked, "Where would you like to be right now if you could be anywhere else in the world." In addition to ending the interview on a brighter note, engaging in drawing, imagining, and so on has been shown to raise endorphin, immunoglobulin A, and oxygen saturation levels.

Drawing for the child, or *drawing by proxy*, is another way to help children communicate their feelings, especially children who may be too weak or otherwise physically unable to draw. Using this method, the researcher asks children to imagine images or symbols to represent their thoughts and feelings, and the researcher renders the drawing itself. The researcher continuously asks the child for feedback and verification to insure the image is exactly as the child envisions it. As the creative process is a series of decision-making and the child is making the critical decisions along the way, the drawing is truly the child's invention, and the researcher is a tool acting on the child's behalf. Rollins et al. [9] conducted a study with hospitalized children using Drescher's *Moon Balloon* drawing by proxy method (see [10] and Fig. 5.2). Results indicated that drawing by proxy provided an effective method for children to express their thoughts and feelings and that participating in the process improved their present quality of life.

### 5.3.2 Drawings with Scoring Systems

It has long been assumed that the figure drawn is a unique expression of a child's experiences and preferences. Critics of projective measures point out that a high degree of inference is required in gleaning information from projective methods and that data quality depends heavily on the researcher's interpretive skill, thus that of an art therapist. However, with well-developed scoring systems in place, researchers without these skills can feel more confident in their ability to analyze the results—again considering that findings shouldn't be considered valid without the child's accompanying narrative, which is driven by the drawings. Four examples of projective drawing techniques with good scoring systems are described here.

The *Kinetic Family Drawing-Revised (KFD-R)* provides information about how children perceive themselves in their family setting. Kinetic (action) drawings are more informative than those obtained from the traditional akinetic instructions. The addition of movement helps mobilize a child's feelings not only as related to self-concept but also in the area of interpersonal relations. The child is asked, "Please

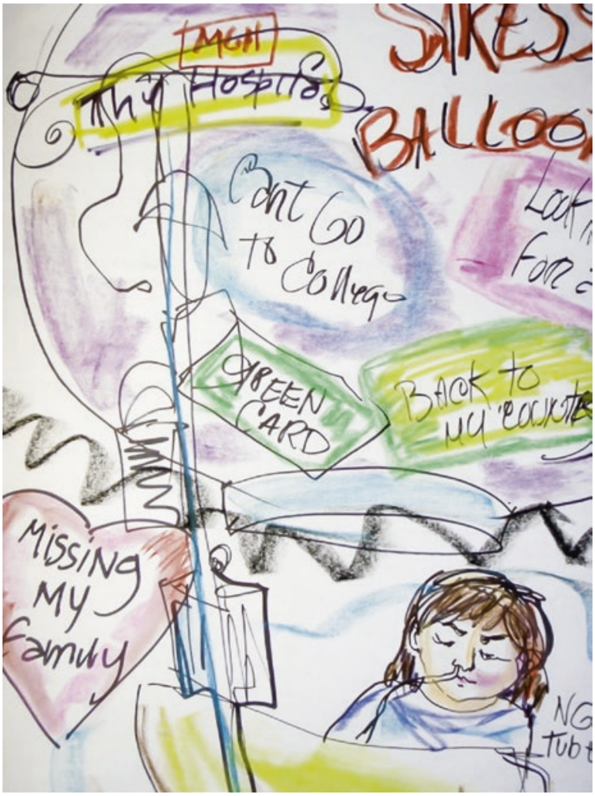

**Fig. 5.2** An 18-year-old girl from El Salvador created images by proxy about things that are causing her stress

draw a picture of everyone in your family doing something, try to draw whole people, not cartoons or stick people. Remember, make everyone doing something."

Spinetta et al. [11] developed a carefully structured and situation-limited administration a scoring procedure (KFD-R) for interpreting the kinetic family drawings of children with cancer and their families. Useful with adults and children 6 years and older, the KFD-R procedure precludes chance and/or the problematic tendency to over-interpret drawings. The KFD-R scales consist of 19 negatively valenced items—such as barriers between family members, figure size, and facial position of mother—each scored 0, 1, or 2. Results are presented in four scores: family communication, self-image, emotional tone, and an overall score of family support. The range of overall score is 0–35, with higher scores indicating poorer adjustment. See the chapter "The Kinetic Family Drawing in Childhood Cancer" [11] in Spinetta and Spinetta's *Living with Childhood Cancer* for the KFD-R scoring system. Researchers have used the KFD-R with adult family members as well as with children. Some studies that have incorporated the KFD-R include research with siblings and parents of bone marrow transplant patients [12], siblings of children with cancer [13], and siblings of children with cancer who attended a summer camp program [14].

Bombi et al. [15] developed the *Pictorial Assessment of Interpersonal Relationships (PAIR)* system to analyze interpersonal relationships of children ages

6–14 years. However, Bombi et al. report PAIR can be used with younger children, and Corsano et al. [16] used the instrument in a study with older adolescents. Bombi et al. [15] have used PAIR to investigate children's friendships, relationships with parents, and relationships with teachers and report good reliability and construct and discriminant validity. The child is asked to draw him- or herself with another person, while they are doing something. Drawings are coded using PAIR's six scales:

1. Cohesion—the degree of interdependence between the partners
2. Distancing—the degree of autonomy of the partners
3. Similarity—the psychological affinity between the partners
4. Value—the comparative value of the partners
5. Emotions—the mood displayed by each partner and the emotional climate of their relationship
6. Conflict—the disruption of the relationship

The researcher assigns a score based on answers to questions such as "Is one figure looking at the other?" (0 = absence; 1 = presence). Scores are reported for each scale individually. Complete details for scoring can be found in *Pictorial Assessment of Interpersonal Relationships (PAIR)* [15]. In the healthcare setting, Corsano et al. [16] looked at children's relationships with doctors and nurses. In addition to coding the drawings, they also conducted a qualitative analysis, which considered the choice of partner as doctor or nurse, the position of the figures, the setting of the drawing, and the details enriching the drawing.

Clatworthy developed the *Child Drawing: Hospital (CD:H)* to measure the emotional status of the hospitalized school-aged child (5–11 years of age) [17]. The child is asked, "Please draw a picture of a person in the hospital. I will take your picture when you are finished." Scoring is divided into three sections [17]:

- Part A (14 items)—Scale ranges from 1 (lowest anxiety) to 10 (highest anxiety). Items include features such as position of person, facial expression, number of colors used, and quality of crayon strokes.
- Part B (8 items)—Adds 5–10 points for the presence of certain items presumed to pathological indices, such as missing body parts or use of shading.
- Part C (Gestalt rating)—The scorer gives an overall response of the child's anxiety as expressed in the drawing on a scale of 1 (coping or low anxiety) to 10 (high anxiety or disturbance).

The three scores are added together to obtain a total score. Scores can range from 15 to 290. Complete details for scoring can be found in *Child Drawing: Hospital Manual* [18]. Burns-Nader et al. [19] used the CD:H in a study that explored the relationships between hospitalized children's anxiety level, mothers' use of coping strategies, and mothers' satisfaction with the hospital experience. Other studies have measured the impact of preoperative preparation on children's anxiety [20].

For the *Person Picking an Apple from a Tree Drawing*, the child is asked, “Please draw a picture of a person picking an apple from a tree.” Little had been written about the technique until Gantt and Tabone’s [4] use of the drawing as an assessment procedure when developing the Formal Elements Art Therapy Scale (FEATS), which consists of 14 scales. The Problem-Solving Scale is useful in understanding a child’s coping ability and resourcefulness. This scale measures whether and how the drawn person gets the apple out of the tree. Problem-solving can be related to affect, and scores on this scale can reflect hopelessness and coping ability. The researcher considers questions such as how effective is the solution for getting the apple out of the tree? Is the method used realistic? Drawings are scored on a continuum of 0–5, with lower scores suggesting less resourcefulness and coping ability. For scoring instructions, see *Formal Elements Art Therapy Scale: The Rating Manual [4]*. Some studies that have used the PPAT include research with children with epilepsy [21], children with cancer ([3]; see Research Example), and children with asthma [22].

### 5.3.3 Other Visual Arts Techniques

As the reason for creating art is self-expression, almost any visual arts activity can serve as a means to generating children’s thoughts and ideas.

*Collage* refers to a method of cutting up “found” natural or made materials and pasting them on another surface. When collage is used in research, objects are given meaning not from something within them but through the way they are perceived in relationship to one another. For the researcher, collage has some advantages over other visual mediums used for research. Collage is easy for a novice to arts-based methods; we likely all had experience cutting and pasting as children. Children often view making a collage as less intimidating than having to draw or create their own images. And regarding the worth of collage as data, “The ambiguity that remains present in collage provides a way of expressing the said and the unsaid, and allows for multiple avenues of interpretation and greater accessibility” ([23], p. 268).

The types of materials used may depend on the research question. Choice is important, so it is helpful to gather a good supply of magazines, catalogues, and a variety of natural and found items, such as feathers, buttons, string, and perhaps medical items like tongue depressors, cotton balls, tape, gloves, or tubing items. Children may also be asked if they have objects they would like to incorporate. Words from magazines and other publications are often used as well as images. *Scrapbooking* uses collage and has become a popular activity with all ages in recent years.

Creating a *personal container* can also incorporate collage. Children are asked to list things that are of personal interest, all the things that make them who they are. Using these ideas, they collage the outside of a container using images from magazines, photos, and natural or found objects. Children may also want to paint or add words or drawings. The container could be a simple cardboard box, or something a bit fancier such as a Chinese carryout box, or even something more permanent, such as a wooden cigar box, which would also allow wood burning. Children can use the inside to reflect things people may not know about them, such as a fear of needles, homesickness, worries about getting behind in schoolwork, or positive things, such as their dreams for the future. The researcher can encourage children to include carefully selected items that represent different facets of self to put into the container.

*Graffiti walls* provide an efficient and inexpensive way to quickly produce a great deal of information from many people. All that's needed is a large sheet of paper taped to a wall and writing/drawing implements nearby. The researcher writes the question on the sheet, with an invitation for individuals to respond with words, drawings, or symbols. The paper is removed when it's determined that data saturation has been reached. Text from the graffiti wall can be fed into a Wordle or other programs to help analyze and present the data. To create ongoing opportunities for graffiti walls, if permitted, walls can be painted with chalkboard paint and chalk used for responses.

*Body mapping* is the process of creating body maps using drawing, collage, painting, or other art-based techniques that children can use to visually represent aspects of their lives, their bodies, and the world they live in. The body maps are data in themselves but can also be supplemented with writing or interviews. Children can create an individual body map or work in gender/age groups. To create a body map, an outline is drawn around a child lying on a large sheet of paper. The next step depends on the research question. O'Kane [24] gives an example that addresses the question of what children like and dislike. A vertical line is drawn down the middle of the body map; one side represents a happy child and the other a sad child. Children then are asked to use the body parts to share and record likes and dislikes, for example, the eyes: What do they see in their homes/schools/communities that makes them happy or sad? What ways do adults see them that make children feel happy or sad? Why? They continue down to the feet and leg and also add other body parts they want to discuss.

## 5.4 Toys and Games

The child's familiar world is the world of play. Thus, incorporating toys, games, and other playful approaches within research methods can help children feel more comfortable and perhaps better able to express their opinions and experiences by using an accustomed means of communication.

### 5.4.1 Toy Props

Researchers have found that the introduction of physical props such as toys into the interview consistently increases the volume of information young children provide [25]. Props can serve both as memory retrieval cues and as communication aids for relaying emotionally difficult or complex information that may be beyond a child's verbal capacity.

The use of props may have an impact on the accuracy of the information a child reports. For example, in interviews with 5-year-old children with toy props, Salmon et al. [25] found that information reported was significantly less accurate than when children were interviewed with real items from an event. However, in other research, the use of props has not affected accuracy. For example, Goodman et al. [26] interviewed children 5 years old and older about a stressful medical procedure using anatomical dolls and toy props and reported no change in accuracy.

Several explanations have been offered for why the use of toy props may affect young children's accuracy in recall [25]. Young children may have trouble understanding the symbolic nature of toy props, i.e., that they represent real items. Other children may see the props as simply an invitation to play. Toys and play may also send the signal that the researcher is interested in fictitious events of children's imagination.

Nigro and Wolpow [25] point out that toy props offer the interviewer more possibilities than do real props. For most researchers, they are readily available, and relative to no props, they significantly increase children's verbal and behavioral communications. However, their results demonstrate that "real items from an experienced event similarly increase communications without compromising accuracy as much as do toys… Our results suggest that children will communicate more incorrect information with such props [toys], but this increase will be offset by an increased volume of correct information" (p. 563).

### 5.4.2 Games

Researchers have developed games specifically to encourage children's participation in research. In fact, games can play an important role even before data collection begins. For example, Bray [27] developed an *activity board* to help children understand consent and the research process, and Kirova [28] created *How do you feel* to orient children to their feelings prior to data collection.

*Pots and Beans* invites children to express their level of agreement or disagreement using tactile resources (e.g., pots and beans, plastic cups and pasta shells, boxes and beads). Each container has a label representing a category, such as an emotion (e.g., anger, joy, fear). The researcher gives children a finite number of beans, shells, or other "counters" to distribute across the containers, putting as few or as many in each container depending upon how closely they associate with the various labels in relation to the verbal question posed.

Regarding ranking choices, although children can usually decide what they like most and what they like least, they typically have more difficulty ranking those choices in the middle. A technique called *diamond ranking* provides a helpful alternative. Prior to the diamond ranking data collection activity, the researcher produces (often with the children's assistance) cards with nine categories or statements. Children then rank the categories according to what they like most (or what is most

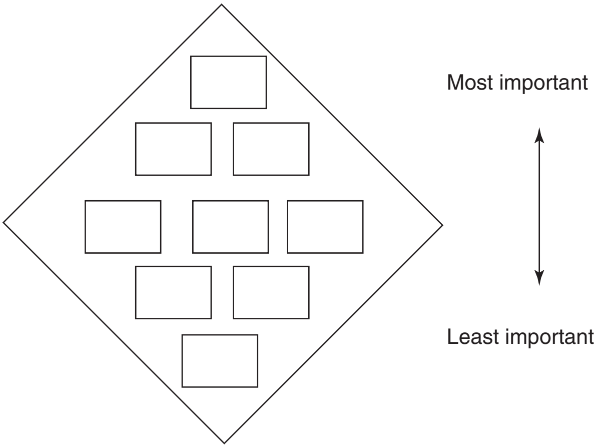

**Fig. 5.3** Diamond ranking diagram. Adapted in part from Schofield, M. (2009). "Eleven year olds' views on school subject and ideal teacher qualities", http://childrensresearch-centre.open.ac.uk [29]

important to them) to what they like least (or what is least important to them) in the shape of a diamond (see Fig. 5.3). The wider area in the middle allows for some categories to be equally ranked.

The *decision-making pocket chart* provides a helpful visual way for children to indicate who currently participates in and influences the decision-making processes in their lives. The tool is often used to contribute to baseline information, which can then be monitored and changes evaluated in areas where children gain more influence in decision-making. The researcher and children create a large grid, listing the "what sorts of decisions" (e.g., where we play, whether we stay in school) on the horizontal axis and "what people," a list of stakeholders (e.g., mother, father, religious leader), including themselves, who make these decisions, on the vertical axis. Children analyze each decision and, using colored stickers, indicate which stakeholders currently have "a lot" (green sticker), "some say" (yellow sticker), or "no say" (red sticker). With information about the children's views on decisions and the people who are important to them, the researcher can facilitate a discussion about decision-making process from the child's point of view.

In the *voting* technique, children are given tokens to cast their votes on a topic without needing to cope with the demands of recording it. Research suggest that confusion can result when children are asked to raise their hands to indicate a choice and that they often tend to raise their hand for every choice available. When children use tokens, the idea is reinforced that only one decision can be reached. This contrasts with polling, which can create undue pressure on children whereas secret ballads might not. However, public voting can encourage peer discussion and consensus.

## 5.5 Puppets

Puppetry is "the act of using an artificial figure representing a human being or an animal, manipulated by hand" ([30], p. 49). However, sometimes inanimate objects are given animate features and made into puppets. Studies demonstrate that puppets can:

- Decrease children's fears of the interview process
- Lower anxiety levels
- Help assess children's knowledge
- Help children to adjust to the environment
- Provide an effective communication and teaching tool ([31], p. 2)

Although many authors emphasize that puppets are more appropriate with younger children, others argue that using a puppet to elicit conversation can be effective with older children as well. Thus, Epstein et al. [30] advocate for researchers to present the use of puppets as a choice for children of all ages.

Three interview techniques incorporating puppets are commonly used, each having a different strategy depending on how the child interacts with the puppet:

1. *Alien Puppet Interview (API)*—The child explains directly to the puppet because the puppet is considered to have no prior knowledge of the topic of interest [32]. Children will often talk to the puppet about things they normally wouldn't mention in the presence of a more experienced "other."
2. *Berkeley Puppet Interview (BPI)*—This interactive process helps elicit children's self-perceptions using two identical puppets [33]. The puppets make opposing statements about themselves before posing the same question to the child [34].
3. *Puppet Interview (PI)*—Children are the puppet masters. They express their own perceptions through the puppet [32].

Gibson et al. [35] used the API technique in their study of children and young people's experiences of cancer care. A play specialist used dolls and other soft toys as puppets to ask the younger children (4- and 5-year-olds) about their experiences; a second researcher acted as an observer and made field notes during the interview.

The BPI method creates a conversational exchange between "a child and two age-mates" ([36], p. 31). The researcher uses two identical puppets that make opposing statements about themselves. For example, one puppet says, "I'm not shy when I meet new people," and the other puppet says, "I'm shy when I meet new people." The researcher then asks the child, "How about you?" Children always hear one puppet endorse a less desirable trait as self-descriptive; they tend to find it easier to acknowledge their own less positive characteristics. In Measelle et al.'s

[37] study on early childhood personality, interviews were videotaped and coded on a 7-point scale depending on the degree to which the free response parallels one of the item halves.

Using the PI technique, Verschueren et al. [38] gave children a large hand puppet (a green crocodile) and asked each child 20 questions in various categories (e.g., social acceptance, behavioral conduct), and the child answered through the puppet. Children's responses were coded as either positive or negative and were evaluated on a 6-point scale.

Researchers who intend to use puppets in data production should receive training to ensure their effectiveness. University theater departments are often willing to train researchers on proper puppet techniques, such as how to develop a character for the puppet, complete with a unique voice, age, and background. The developers of BPI offer workshops for researchers.

### 5.5.1 Considerations When Choosing Puppets

There are several factors to consider when choosing puppets for use in research [31]. Hand puppets are the type of puppet most commonly used in interviews with children. A puppet should be smaller than the child to limit intimidation and to allow the child to handle it easily. Physically rigid puppets should be avoided as the permanent expression (e.g., sneer, smile) can impede emotional display and perhaps bias the child's interaction. Flexible puppets allow increased interaction through gestures and offer more variation for the puppet's character development. Softer puppets generally have more appeal, which may increase the likelihood that a child would want to touch or play with it.

The puppet's gender, race, and physical appearance may influence the child's conduct in the interview. Choosing a gender-neutral puppet, such as an alien or a monster, over a puppet of the opposite gender allows an easier connection between child and puppet. Colors are important; pink and blue denote gender preference in many cultures. Other characteristics that promote gender stereotypes include sex-oriented exaggerated facial features such as long eyelashes, lush lips, boxy jaws, or hairy eyebrows in conjunction with a non-hairy face [31].

Also relevant is the number of puppets presented to the child. Some researchers suggest the need to give children more choices to increase opportunities to engage with the puppet; others argue that one well-chosen puppet is sufficient. Too many puppets may overwhelm the child.

### 5.5.2 Making Puppets

Researchers often make or have children make puppets for use in research. In fact, making puppets may be part of the research protocol. For example, in a study of the use of puppets as a strategy for communicating with children with type 1 diabetes, Sparapani and colleagues [39] used a three-step process: (1) constructing the scenario—a "stage" that simulated the environments in which children with T1DM lived (e.g., school, home, leisure sites), (2) making puppets that represented the child and people encountered daily (e.g., parents, teachers, siblings, friends), and (3) promoting expression of thoughts and feelings using puppets during clinic visits or qualitative interviews. Children received instructions on how to make a puppet and were given puppet-making materials that included pieces to represent body parts; different sizes of soft, colored socks; colored wool strings; cardboard; tissues; crude paper; fake eyes; glue; scissors; and a stapler.

Sposito et al. [40] used puppets in a study on coping strategies hospitalized children with cancer use. In this research, each child made a puppet representing him- or herself prior to the interviews. The researcher also made puppets for use in the interviews and wore a colored apron especially made as the scenario for the puppets.

Often the simplest puppets are most useful in research with children, such as hand puppets made with plain fabric. The researcher can have available fabric, small hats, and other materials children can use to dress them and make them be whatever they would like. Additionally, a puppet can be made very quickly by using inexpensive plastic eyes that loop over the fingers. Disposable gloves of various colors found in medical settings can be slipped on first to add some color.

## 5.6 Storytelling and Creative Writing

Storytelling is the link between reading literature and writing. Researchers have adapted the short story format, fiction, and other literary devices to most vibrantly communicate data from autoethnographic studies as well as date collected through more traditional qualitative methods.

### 5.6.1 Storytelling

Storytelling is a nonthreatening means to facilitate the expression of feelings by bypassing a child's inhibitions, fears, and defensiveness and may reveal feelings of which the child may be unaware. Although some researchers believe that storytelling to elicit feelings can be useful and efficient with children as young as 4 years, others suggest that children are not aware of what makes a story a story until the age of 5 years.

To explore children understanding of illness, Eisner et al. [41] recorded their stories. They suggested that the process of telling a story shifted the equilibrium from the researcher toward the storyteller because stories can be told in the third person, deflecting attention from the personal to depersonalized characters. Further, children with poor literacy skills can usually tell a story even if they cannot write one. Thus, storytelling is perhaps a more socially inclusive or democratic approach to data collection.

The *Barton Hospital Picture Test (BHPT)* is a projective instrument designed to elicit children's perceptions of hospitalization through story and to measure self-reported stress [42]. The instrument, intended for children ages 5–9 years, uses eight black-and-white drawings that represent common types of hospital experiences: (1) admission to the hospital, (2) separation from parents, (3) examination by a doctor, (4) alone in a hospital room, (5) oral medications, (6) injections, (7) operating room, and (8) playroom. The pictures are gender-specific and racially ambiguous. The researcher asks the child to tell a story about each of the eight pictures. Pictures are always presented in the same order. Each picture is presented with a brief identification (e.g., "Here are a boy and his mother going to the hospital. Please tell me a story about this picture."). The researcher encourages children in their storytelling with nondirective prompts. The stories are audiotape-recorded. At the end of the session, children are offered an opportunity to listen to them. Each sense line is coded as "not stress" or one of the four types of stress (i.e., anxiety–fear, anxiety–defense, aggression, dependency). Possible scores range from 0 to 100. Similarly, a standard score is calculated for each of the four types of stress in the story set.

*Digital storytelling* is a popular intervention with children who are ill or hospitalized. When content is connected to a research question, it can be a good source of data. Children collect or create images and artifacts that have personal meaning. With the help of a facilitator trained in the technique, they compose a video, complete with sound of their choice and sometimes voice over, which then becomes a data source to discuss with the child.

### 5.6.2 Creative Writing

Of creative writing forms, children may be particularly responsive to poetry because its nature allows them to express themselves more readily in metaphor. The Internet offers many templates and examples for popular poem formats for use as research tools.

One form of poem increasing used in research is *Where I'm From.* The poem goes beyond just a simple description of the writer's hometown and extends into family traditions and beliefs. In addition to providing some useful data for analysis, the format provides a good introduction to learning more about the child. The researcher may want to write one, too, and share it with the child. Below is a 16-year-old Candlyer's poem that describes where she is from:

I'm from hot dogs, French fries
and Red Bull, and from my Grandma
who taught me a lot of family recipes
like baked chicken or turkey wings,
collard greens, potato salad, and cornbread.
I'm from living in Atlanta
but wanting to live somewhere fast-paced
like New York City where I'd

have to be more outgoing
I'm from being 16 but feeling 18
and ready to leave high school.
I'm from wanting to be a nurse
or performer in musicals or
fashion designer. You would
see me looking different if
I weren't in the hospital—not
wearing a tee-shirt, jeans, and
scarf around my head.
I'm from listening to all kinds
of music and from one of my favorites,
Jessy J, and how her voice
has a rasp jazz undertone. I would
literally sell everything I own, even my dogs,
to have Christina Aguilera's voice.
I'm from feeling a bit disconnected
in school where I can't completely
relate when everyone is hysterical
about something and the things they
do seem immature. I'm from
knowing that if I were a nurse
I would understand what patients
are going through.

The *Six-Word Memoir* can spark the flow of information with just six words. There is a legend that Ernest Hemmingway was once challenged to write a story in only six words. He responded with "For sale: baby shoes, never worn." Children are asked to write six words about an experience. With the word limitation, the format encourages thoughtfulness in word selection and helps individuals to process and discuss their experiences.

## 5.7 Performing Arts

Of all the art forms, music and dance remain the least explored with respect to arts-based methods for collecting research data, and some methods may be too sophisticated and complex for use with by researchers without an arts background. There are, however, some very simple methods that children enjoy that can generate useful data for the researcher to analyze.

Children can write songs to address a research question. Changing the words to an existing song (creating a parody) makes the process easy. Not only the words can be the subject of analysis but also observations of the performance.

Dance can be adapted as a research method for data collection or representation. Dance is particularly well suited to projects focused on discovery and exploration or in multimethod research to add dimensionality to data gathered in more conventional ways. For example, a dancer can help children create movements to reflect their thoughts, feelings, and experiences. Dance is also an exciting method for presenting research data, thus the term, "dancing the data."

Drama or theater arts is a natural fit for participatory action research. According to story creation theory, writing a story or play provides an opportunity to create a shared humanity. Lind et al. [43] describe the methods they used to help adolescent girls in a group home create and present a play based on the girls' experiences. The theater performance of the findings had a profound audience impact, challenging harmful societal assumptions.

## 5.8 Advantages and Challenges

Play, art, games, and other expressive approaches have benefits for both children and the researcher. Methods can be adapted to meet children's developmental requirements and capabilities and give children a greater sense of control over and involvement in the research process [2]. The researcher gains greater flexibility in pacing, language, simplicity of explanations, and an ability to follow children's stories through their creative actions and products. Further, the data collection process is engaging and fun, an essential component in holding children's attention. On the other hand, play- and arts-based methods may intimidate participants if they lack confidence in their creative abilities. This commonly occurs at around the age of 12 when some children become frustrated if they cannot draw realistically and decide to leave the world of drawing and art behind them. Older adolescents may find such methods patronizing. "Draw and Write" or other supplementary techniques have been found effective in such instances.

As with all qualitative research, participants risk being identified (by themselves and others), and they risk being misrepresented and witnessing their lives and struggles analyzed and objectified. "Each of these risks takes on particular texture when research is represented artistically" ([44], p. 464). Participants should be asked to approve of and consent to what is shared with others, whether through publications, conferences, or exhibitions for the general public. Additionally, researchers should acknowledge and respect children's drawings and other artistic creations used for research. Driessnak [45] explains that how researchers respond to these items not only gives them value but also provides us with a framework for respecting the children who shared them:

> Once children share their drawings, we are presented with a great responsibility. If their drawings are not perceived in this way, they might become susceptible to inappropriate interpretation and exposure. For this reason, I believe that children's drawings need to be accompanied by the children's personal narratives so that they can be placed fully in the contexts of children's lived experiences. (p. 156)

Another challenge researchers who use expressive measures face is the general level of skepticism of the validity regarding experiential knowledge produced by social research in general. The idea that knowledge of any value could be obtained by methods that have children playing or engaging art activities might make such research seem even more frivolous. On the other hand, the notion that nothing harmful could arise with children being asked to participate in typical childhood activities might sooth the minds of ethics committee members concerning the vulnerability of children and young people and their need for protection.

Researchers need to apply the same degree professionalism of thought and preparation to studies using these methods as they would to more traditional ones. They need to make efforts to see that results are shared in peer-reviewed publications and at professional meetings to confirm validation by the scientific community.

Multidisciplinary research teams are more common today than in the past and should be promoted. Such teams often make studies stronger, are tremendous learning opportunities for everyone, and can expose those outside the researcher's profession to expressive methods and their worth. Finally, artists can make valuable contributions as members of the research team at every stage of the research process, especially by adding authenticity of the art form to the arts-based research tool. In this author's experience, artists take all aspects of research seriously and often prove to be among the most conscientious team members.

## 5.9 Key Advice

1. Resist the urge to over-interpret children's drawings and other creations; listen to what the child says.
2. Remember that the drawings, stories, and other expressions are the products of the child's creation. Ask for permission to use them in dissemination activities.
3. Be sure to have appropriate preparation for whatever methods used.
4. Consider partnering with artists. For example, a poet who works in schools can help facilitate poetry with children for research.
5. Become familiar with websites, books, journals, and organizations that incorporate arts in health and/or education.

## 5.10 Conclusion

As the language of childhood, play and other expressive techniques are appropriate and valuable tools for researcher committed to facilitating children's participation in research. Such methods are rarely used alone but are used in support of other more traditional research methods such as interviews.

Drawing is the most common visual arts methods researchers use with children. Illuminative drawing techniques are specifically designed to enhance verbal communication. Projective drawing techniques with scoring system allow researchers to also add a quantitative component. Researchers without art therapy training should avoid interpretation of any art children create. It is what children say about their art work that is important.

Using other expressive methods, such as play, games, puppets, storytelling, creative writing, and performance arts, can increase data in both quantity and depth. Knowing which methods to choose depends on the research question, the target population, and the researcher's skills and resources. The products and processes that result are the child's creations, and children must be treated with great care and respect.

According to Boydell et al. [45], the use of expressive techniques is shifting our understanding of what counts as evidence. They suggest that the inclusion of arts-based approaches offers more than simply adjuncts to typical data collection and dissemination approaches; rather, it presents different ways of knowing: "We believe that this may be a significant moment in the field in which to question whether or not we are witness to a paradigmatic shift in the ways we approach inquiry."

## 5.11 Useful Resources

- Coad J, Plumridge G, Metcalfe A. Involving children and young people in the development of art-based research tools. Nurse Res. 2009;16(4):56–64.
- Coad and colleagues describe how they worked with children and young people to develop art-based techniques and activities for use in a study. It highlights key methodological issues about children and young people's participation in research, the concept of what constitutes an arts-based activity, and how this was applied to developing arts-based data collection tools.
- Knowles JG, Cole A, editors. Handbook of the arts in qualitative research: perspectives methodologies, examples, and issues. Thousand Oaks, CA: Sage; 2008.
- Knowles and Cole bring together the top scholars to provide a comprehensive overview of the past, present, and future of arts-based research. The book offers theoretical arguments and illustrative examples that delineate the role of the arts in qualitative social science research.
- Leavy, P. Method meets art: arts-based research practice. New York: Guilford Press; 2009.
- Patricia Leavy presents the first comprehensive introduction to arts-based research practices. Each of the six major arts-based genres is covered in chapters that introduce key concepts and tools and presents an exemplary research article by a leading arts-based research practitioner.

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# Being Participatory Through Interviews

## 6

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## 6.1 Introduction

This chapter takes as its starting point the following 'top tip' from The NSPCC website:

> 'Children are experts when it comes to their own lives, but you can help them express themselves' [1].

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We, as researchers, need to be aware of the many different ways available to us to help children and young people to express themselves. One such approach is the research interview, a place where researchers hold conversations with children and young people: these have in the past been avoided. The long-held belief that children and young people did not have the social competence to recall credible accounts of their experiences has been replaced with a more contemporary view that prioritises children's rights in a broad framework of child-centred research [2, 3]. As a result, there are now vast amounts of literature detailing different ways to carry out interviews; see, for example, O'Reilly and Dogra [4] and emerging literature on undertaking interviews in the home [5], as well as interviewing children and young people about sensitive topics [6]. Solutions to what were once described as the challenges of using interviews, such as language, literacy, age and cognitive development, have been identified, and interviews are now described as a highly versatile research 'tool'. The researcher of today is presented with many different ways to use interviews, thereby realising the benefits the method has for collecting data directly from children and young people [7]. We can now be confident that interviews can:

- Generate insights into participants' lives which would otherwise remain hidden to healthcare professionals and researchers
- Give access to individuals' understanding of the contexts they are in, to their opinions, aspirations, attitudes and feelings
- Generate complex insights into others' perceptions of social phenomenon and why they make certain choices and act in the way they do [8]

One main reason for this increased confidence in the role of interviews, within the 'toolkit' of methods used by researchers working with children and young people, is the ability to make these 'conversations' nonthreatening, more participatory and individualised to the interviewee ([4], pp. 95–108). By being participatory, we mean a research style, an orientation to inquiry, that enables us to work with our research participants in the 'knowledge-production process' ([9], p. 2). Participatory research is designed and executed in collaboration with the target population—it is research with the population, not just on it: this shift in methodological thinking in research methods has been charted elsewhere (see, e.g. [2, 3, 10–12]). What we offer here are more of the practical issues associated with using the research interview in a participatory way with different child populations, techniques and strategies we have learnt through 'use in the field'. Our focus is on practice, with each example illustrating the basic principles of openness, good communication and the appropriateness of the method to the study population.

Our intention is not to reproduce the many different theoretical perspectives on the use of interviews with children and young people; the reader can refer to the growing body of texts that do that (see, e.g. [4, 8, 13, 14]). We first present a research study, to present an exemplar for how participatory group interviews have been used with a child cancer population. We then give examples of techniques, again from our own research studies, in which interviews have been used in a variety of ways: reflecting on how interviews were actually used and how the method was adapted for the population. We hope by taking this very practical approach we offer what is often missing in research articles: the real data about the method and how it was applied in that particular study. We present in this chapter group interviews, focus groups, peer-to-peer interviews, interviews with children and young people who have a learning disability as well as a more traditional approach to interviewing adolescents: providing examples where flexible techniques have helped to enable active engagement with diverse research cohorts. Underpinning the following sections are Shier's [15] five levels of participation: (1) children and young people are listened to; (2) children and young people are supported in expressing their views; (3) children and young people's views are taken into account; (4) children and young people are involved in decision-making processes; and (5) children and young people share power and responsibility for decision-making.

## 6.2 Example from a Research Study

### 6.2.1 Children and Young People's Experiences of Cancer Care: A Qualitative Research Study Using Participatory Methods [16]

In this study, a range of approaches to data collection were used, including play and puppets with children aged 4–5 years, draw and write with those aged 6–12 years and an activities day with young people aged 13–15: it is the activities day referred to here, more specifically the focus group, that was part of the overall day (see Table 6.1). Using these different approaches to interview, we sought:

1. To explore the perception of children and young people with cancer regarding their care and support needs
2. To map the needs of children and young people with cancer from their perspective
3. To gain an understanding of their views of current cancer care services, including positive experiences and issues that have been less positive
4. To offer developmental work on fostering avenues of communication with children and young people with cancer

**Table 6.1** Plan of the activities day

| Listening to children and young people with cancer project | |
|---|---|
| 12:00 p.m. | Introductions |
| 12:20 p.m. | Split into pairs to interview each other about your experiences of hospital |
| 1:00 p.m. | 'What is important for you?' |
| | We will talk about the interviews and write down on post-it notes the points that came up. These post-its will be stuck onto the wall to show what you think are the most and least important aspects of what we have talked about |
| 1:30 p.m. | Lunch |
| 2.15 p.m. | Focus group |
| | We will talk together as a group about the things that came up in the morning sessions |
| 3.15 p.m. | Drinks |
| 3.30 p.m. | 'Choice of hospital' exercise and your thoughts about the day |
| 4 p.m. | End |

#### 6.2.1.1 Target Population/Who Participated/Recruitment

Participants were recruited from three hospitals, two for the study with adolescents. At each of these hospitals, the researcher identified suitable participants with assistance from clinical staff. The researcher or clinical staff approached potential participants when they attended as an inpatient or outpatient. Posters were also displayed in each of the hospitals. Young people who expressed an interest in taking part were given time to consider their decision. Confirmation of participation was ascertained via telephone contact if the young person was at home or at a face-to-face visit if in hospital, and background information was recorded. If the young person declined to take part, they were asked if this information could be recorded to monitor whether a representative sample of young people was included in the study.

Two activities days were originally planned; one for young people aged 13–15 years and one for those 16–19 years. The study was conceived this way to take into consideration the potential for a wide variation in emotional and social maturity of individuals. However, it was difficult to find a date when the older group could attend: individual interviews were carried out instead and with anyone from the younger age group who were unable to attend the activities day or felt more comfortable talking on a one-to-one basis. The participants selected the interview venue; five were interviewed at home and two when they were in hospital. It was left up to the young people to decide whether they wanted a parent to be present during the interview. Four young people gave their views at the activities day.

#### 6.2.1.2 Research Methods/Tools Used and Rationale for Their Use

The ‘activities day’ was facilitated by two researchers and comprised a focus group alongside other methods including peer interviews and written tasks. It took place at a weekend in a private room of a pizza restaurant. The day lasted 4 hours with the focus group taking place after lunch, allowing participants to get to know each other beforehand, which facilitated open discussion. Having a variety of group and individual activities, selected to suit young people’s tastes and skills, worked well. At the end of the day, a ‘secret box’ was provided where participants could write down and post anything else they had wanted to say but felt unable to share in the group [17]. We sought to encourage both individual and shared perspectives through our approach to data collection.

It has been suggested that focus groups can work well with children aged 6 and above as by this age children usually have the social and language skills to engage in group discussion [18]. Participants are usually invited to attend a focus group because of common experiences related to the topic of interest (in this case young people who had cancer), and they are encouraged to share their ideas, attitudes and perceptions in a relaxed atmosphere. Focus groups allow participants to ‘feed off’ each other as they respond to each other’s comments and support or disagree with each other; thus they can provide richer data than an individual interview: used not to reach consensus but to better understand different needs and opinions. Groups with children and young people can be fun to undertake, and the presence of peers can produce a more natural environment and reduce some of the ‘power’ issues involved where there is an adult researcher interviewing a child on a one-to-one basis. We thought that all of these characteristics would enable young people to recount their story better and that we could maximise this ‘group feel’ to help them share what was important. Although there are similarities, a focus group involving children or young people demands a slightly different approach than a focus group with adults [19]. This includes modifying the number of participants, format and length of the groups: all of these issues are discussed later under the heading ‘techniques’. For all of these broad reasons, using a focus group was an obvious choice.

At the outset we wanted it to be more than what might be traditionally thought of as a focus group. We wanted to use activities that would allow space and time for young people to think on their own, and we also wanted to draw upon their experience from the outset, hence the inclusion of the peer-peer interviews. We provided a ‘starter’ list of questions and encouraged young people to ask other questions they thought important. Each participant selected one key headline to share with the group. These were then shared and discussed as a group, allowing participants to provide more detail if they wished about the story behind the headline. The focus group questions emerged out of these two exercises: the interview schedule was generated from participants’ contributions. Although this approach to developing the focus group questions required the researchers to be very organised, and confident in the approach taken, the benefit of ‘going deeper’ and engaging in dynamic conversations shaped by young people’s accounts was our reward.

#### 6.2.1.3 Ethical Issues

Signed parental consent was obtained for participants under 16 years old prior to data collection. Participants over 16 signed their own consent forms and participants under 16 signed an assent form. Before each interview/focus group began, the researcher outlined the study again, what it involved, reaffirmed that it was their choice to take part or not and explained that they could stop taking part at any time. The protocol was subject to ethical scrutiny at the NHS Trusts where data were collected and approved by relevant Local Research Ethics Committees. To ensure confidentiality, the young people’s names were replaced by pseudonyms. All the young people were given a voucher for participating; they were not informed of this until after they had participated in order to avoid coercion.

#### 6.2.1.4 Findings

Data analysis was based on an inductive thematic analysis approach, initially analysed within the defined age groups associated with each data collection method and then brought together into key themes through a process of iterative integration [20]: these findings are reported in Gibson et al. [16]. Five themes, with subthemes, were identified from this data set:

1. ‘Life in hospital’, food, environment, activities, privacy and keeping different ages separate
2. ‘Making the hard times better’, parents, friends, nurses and keeping things as normal as possible

3. ‘Reading the signs, watch, think and then act’; relationships with nurses, doctors and other staff; being left alone; being able to ask questions; and being listened to
4. ‘It’s my body—talk to me, not my parents’, information, offer choice and ask, don’t presume and be prepared
5. ‘Treatment—getting on with it’, know own body, how treatment makes me feel, getting on with it, waiting and specialist vs. nonspecialist care

#### 6.2.1.5 What You Would Do Differently in the Next Project

Checking out the venue thoroughly is really important. There were two issues with the venue for the activities day that were not apparent on first booking: the first was that although it was a private room, other people in the restaurant had to walk through our room in order to access the toilets with changing facilities. Secondly, the room was open plan, which meant noise from the kitchen downstairs travelled making it difficult to record discussions.

#### 6.2.1.6 Impact on Participants

The participants commented afterwards that they had enjoyed talking with other young people with similar experiences to themselves. Two participants kept in touch with the others following the activities day. Some of those aged 16–19 commented that meeting other young people with cancer was something they looked forward to and had influenced their decision to take part in the project, so they were disappointed when we were unable to schedule a group for them. Perhaps paired or peer interviews might be a solution where a larger group is not possible. The researcher contacted the young people/family by telephone in the week following the activities day, to check that the day had not raised anything distressing for them. Overall, the participants’ feedback indicated that taking part had been a positive experience for them. One parent commented that she thought her son had been quieter than usual during the evening following the group, she thought that it had made him reflect more on his cancer and situation, but she did not feel this was a cause for concern.

#### 6.2.1.7 Dissemination Techniques

A summary leaflet (two sides of A4) was written to feedback the findings of the study to participants. This was posted to the children and young people at home. Three versions of this leaflet were written to reflect the findings from the different age groups of children and young people participating in the study and to tailor the information to reflect their understanding/reading ability. Young people were also sent a copy of the full report from the project. We received feedback from young people on our summary leaflet prior to finalising.

#### 6.2.1.8 Conclusion

Planning a focus group with young people is intensive in terms of the organisation beforehand, but as the above findings demonstrate, focus groups can provide rich data. The participants appeared comfortable to discuss their experiences and views with each other; this was aided by them having the shared experience of cancer and having time to get to know one another first prior to the focus group. Using a variety of different techniques in addition to the focus group enabled the participants to express their views in different ways and privately if they wished. The participants, as well as the researchers, reflected that overall the activities day was an enjoyable experience.

## 6.3 Technique Section

Here we reflect on the use of the interview with different populations, in different ways, to show its versatility: a technique that can be part of a 'toolkit' of methods. We offer our top ten tips for the use of interviews with these different populations. We start with focus groups, reflecting on the study we presented in detail earlier in this chapter, making explicit techniques that will help in the running of successful groups.

### 6.3.1 Focus Groups with Children and Young People

In a study seeking children and young people's views and experiences of cancer care, one of the data collection methods we used was a focus group [16]. Our intention at the outset was to use an approach that would facilitate both group and individual contributions.

Composition of the group is crucial. To increase involvement, level of engagement and quality of responses, limit the numbers to four–six participants when working with younger children and up to eight if working with older children [18]. Even when participant numbers are small, rich data can still be yielded. Over-recruiting by a few participants is often a good idea in case of cancellations. Holding groups with children of similar age (2–3-year difference) helps to prevent children's responses from being overly influenced by older peers and enables the facilitator to pitch the discussion at a level that is accessible and interesting for all participants. Another important consideration is the gender mix in the group, and depending on the topic of discussion, it may be appropriate to have single-sex focus groups.

Preparation is key. Focus groups are often perceived as saving time when compared with individual interviews; however they require considerable preparation. The venue and timing must be carefully planned. Holding the group at an 'interesting' location may encourage attendance. The venue should be easy for participants to get to and not start too early in the day; this may particularly put young people off attending. Recognising the other commitments that children and young people have is important, so timing the group out of school hours, perhaps at a weekend, may increase attendance. An 'ideal' time for all participants to attend is always a challenge, as indicated in this study where we were unable to schedule a group that fitted around young people's weekend jobs, college work and sporting activities. Offering to reimburse travel expenses for participants and an accompanying adult (or friend in the case of young people) is important. The duration of stand-alone focus groups with younger children (e.g. those under 6 years) should not be more than 45 min to 1 hour, while this may be extended to 90 min for young people [21].

Setting the tone, getting the environment right helps everyone. Children and young people are more likely to be engaged in focus groups that foster a relaxed environment where they feel comfortable enough to express their thoughts and feelings. It is important to put participants at ease as soon as they arrive through informal introductions to other participants and the venue. Participants should also be allowed to leave the focus group before it ends if they so wish, and given that young children may be involved, it is important that parents are aware of this and can be contacted if necessary. Once everyone has introduced themselves, ice-breakers are a good way to put children and young people at ease and build trust with each other as well as with the facilitators. Ice-breakers serve a number of functions: they help participants to feel relaxed and comfortable before starting data collection; they give everyone a chance to practise saying something in the group; they help the participants and facilitators to get to know each other; and they also help to establish an environment in which sharing and listening are valued. For example, participants could pair up with a partner to learn something about each other and take turns introducing their partner to the rest of the group, or a game can be introduced that gets children and young people to talk to each other. Ice-breakers need to be chosen carefully, based on the likely skills, interests and capabilities of the participants, taking account of disabilities or difficulties some children may encounter. Participation of the facilitators in the ice-breaker is a good way to break down the more traditional adult-child relationship often associated with a classroom setting and helps the participants to view the facilitators in a more informal way, hopefully encouraging honest and open responses later. Following the ice-breaker, it can be beneficial to establish ground rules. Ground rules help children understand their role in the group, what is expected from them and what they can expect from the facilitator. Key ‘rules’ include the importance of enabling individuals to make their points without being interrupted and listening and respecting other people’s views. Asking the participants to establish the rules themselves is a good strategy as it helps them to take ownership and shows their opinion is important, as it will be in the discussion that follows. This is also a good time to talk about confidentiality and explain how what they say will be used/shared. It is important to allow participants to ask questions addressing any concerns they might have at the outset. Establishing this two-way communication is essential if participants are to feel part of the process.

The skills of the focus group facilitator are essential. This will influence the quality of the discussion. The facilitator should be experienced in talking and working with children and young people around the same age as those attending the group: an understanding of the distinction between age and competence will help here so that we do not underestimate children’s capacities to participate [22]. A focus group is not to be understood as an extended form of an interview. It is therefore not the facilitator’s role to ask questions directly to all participants but rather to take care to engage all participants equally and to avoid leaders in a group dominating the conversation. In a group with adults, once the discussion has started, the facilitator would usually hold back as far as possible, to allow the participants to talk freely.

However, groups with young children especially may need more input from the facilitator to keep the conversation moving. A co-facilitator is also necessary to handle any unexpected issues that may arise (such as someone wanting to leave early), take notes and monitor participants' stress/comfort levels. It is essential that participants understand the role of the co-facilitator including why they are observing the group and writing things down.

Types of questions to be asked need to be considered at the outset. The focus group guide should primarily consist of open-ended questions, with direct questions only used as a means to clarify or elicit more detail on a response. Close attention should be paid to the wording of questions to ensure they are developmentally appropriate and that children and young people will understand what they are being asked. Starting with 'easier' questions, such as 'tell us a little bit about your illness', can provide a good lead into the discussion, leaving more difficult or personal questions until later when participants feel more at ease, for example, 'what is the most challenging issue you face with cancer today?' Depending on the age of the participants, a dry 'question-and-answer' format may not work for the entire session; more interactive and creative activities might be necessary to maintain children's concentration and interest. Other ways to ensure individual thoughts are gathered are to add in another method to the focus group, such as free text writing, where children and young people can record their own thoughts [23]: combining these two approaches presents an opportunity to elicit shared understanding and meaning and can offer children ways to express their views in a range of different ways [8]. For example, we asked young people the following question: 'If you moved to a new town you did not know and there were two hospitals you could receive your care from, what would make you decide which one to go to? Their responses were posted in a post box and looked at after the session, offering an opportunity for a private contribution. With prior permission of participants (and parents), focus group discussions can be recorded by voice or video. The advantage of recording by video is that it allows the researcher to assign the voices of individuals to particular statements. However, a video camera can be intrusive. An alternative is for a co-facilitator to take detailed notes (in addition to a voice recorder) as to who said what, if indeed this level of information is required.

#### 6.3.1.1 Top Ten Tips for Undertaking Focus Groups with Children and Young People

1. *Do* think carefully about when and where to hold the group to make attending as easy as possible with the least disruption to the everyday lives of participants and their families.
2. *Do* prepare for cancellations and non-attendance. Contact families a few days before the group to check whether they can still attend. Over-recruit to the group in case of drop-outs.
3. *Do* consider the composition and dynamics of the group, and have children of a similar age within a group.
4. *Do* consider what the parents will do while their children take part, and provide a room where parents can wait and have refreshments.

5. *Do* start with an ice-breaker to help everyone get to know each other and feel more relaxed.
6. *Do* establish ground rules for the group so that everyone knows what is expected of them.
7. *Do* have a main facilitator who leads the group and a co-facilitator who can provide any additional help that is needed, including taking notes.
8. *Do* consider using interactive and creative activities within the group session rather than just a question-and-answer format, particularly for younger children.
9. *Do* monitor how everyone is participating—encourage everyone to have a say; there will often be a participant who finds it hard to speak up in a group.
10. *Do* offer an additional way for participants to raise points they may not wish to say in front of the group (e.g. a written task).

### 6.3.2 Peer-to-Peer Interviews with Young People

The 'Essence of Teenage and Young Adult (TYA) Cancer Care' was a feasibility study carried out to determine how best to answer the question 'Does specialist care for young people add value?' The 'Essence of Care' study was novel in that we worked alongside five young people with a previous cancer diagnosis as co-researchers, who assisted with study design, data collection, analysis and dissemination [24, 25]. Engaging young people and incorporating their unique expertise into the research process were important, and researchers have largely welcomed this approach with the potential to combat paternalistic attitudes that can influence more traditional research [26]. Although specialist care is advocated for young people with cancer in the National Institute for Clinical Excellence Improving Outcomes Guidance for Children and Young People with Cancer [27], four key points remain unanswered:

1. What is specialist care for young people with cancer?
2. What are the core parts of this service?
3. What outcomes are affected?
4. How much does specialist care cost the National Health Service, young people and their families?

One of the aims of this feasibility work was to determine the impact of cancer on the lives of young people, aged 13–24, of how having a cancer diagnosis impacted on their everyday lives and ability to return to 'as normal a life as possible'. We wanted to develop a patient survey for young people with patient experience as an outcome measure, which captured their unique life-stage commitments. Following a meta-analysis of the lived patient experience [28], we carried out in-depth interviews with young people working with our young people co-researchers to undertake peer-to-peer interviewers [24]. We aimed to add to the limited evidence base by offering greater insight into young people's experiences of cancer, as well as testing out this approach to data collection.

#### 6.3.2.1 Why This Approach Above Any Other?

We wanted to capture what really mattered to young people, to gather a narrative that was a true representation of their cancer experience. Previous patient experience surveys have come under some criticism for their lack of theoretical basis and patient involvement [29], and we aimed to address this by developing a conceptual and theoretical framework on which to base the survey, ensuring young people were involved from the beginning.

We chose to use peer-to-peer interviews where five young people who worked with us as co-researchers interviewed other young people during a 1-day workshop. We recognised early on in our study that young people would be more likely to share more intimate details about their experiences if they were talking with someone who had been through a similar experience and were a similar age. The interviews were approximately 30 minutes long and were digitally recorded. The interview guide had been developed by the research team and our young co-researchers. Our co-researchers were encouraged to explore issues beyond the interview guide, drawing upon their own experience where they thought it might help. The transcripts revealed a wealth of information much of which we felt would not have been disclosed if the interviews had been professional-young person conversations, for example, information about reactivation of sexually transmitted diseases during treatment, the importance of healthcare professionals beyond their treatment team such as the cleaners and a lack of general health information such as the impact of alcohol and recreational drug use during treatment. Young people spoke about the benefits of having young people as co-researchers and vice versa:

> ‘I have also enjoyed interviewing other TYAs the unique connection between two TYAs who can share a cancer experience can never be underestimated.’—Core Consumer Group Member [30]

Young people valued having a ‘safe haven’, an environment which allowed in-depth transparent and honest discussion around their experiences adding value to the study and the development of the survey.

#### 6.3.2.2 What Particular Issues Are Relevant to the Population You Were Working with?

Involving young people as co-researchers is resource intensive; however, for this particular study, the benefits were clear and similar to other researchers, confirmed the benefits of these experiences outweigh any costs [26]. Support systems for young people working as co-researchers need to be established and implemented prior to the study and include a degree of flexibility as the study progresses. These include practical things like booking travel, accommodation and processing expenses, as well as who will be responsible for the training of the young people.

It is important to have an experienced healthcare professional on site during data collection to manage any potential upset which may manifest for either the peer interviewer or interviewee in revisiting what could be potentially difficult and sensitive topics. It is also important to check up with each of the co-researchers and interviewees following the interview to ensure that upset has not manifested, although, in our experience to date, this has not happened.

For this particular study, we wanted to capture young people's experiences of care. Because young people have a tendency to focus on their diagnostic trajectory, we specifically asked them to focus on the point from diagnosis, which helped manage the time of the interviews, recognising that both the peer interviewer and interview may by susceptible to fatigue.

#### 6.3.2.3 Ten Top Tips When Using Peer-to-Peer Interviews

1. *Do* carry out the interview away from healthcare premises.
2. *Do* allow for flexibility in timing of interview (evening and weekends).
3. *Do* make arrangements in advance of how you will contact participants: if contacting the young person from an 'unknown' number, let them know prior to calling what time you will be calling (many do not answer unknown calls).
4. *Do* think in advance about the degree of participation, creating opportunities for young people to have a genuine influence on the research process; this requires shared confidence between researchers and co-researchers and for researchers to see co-researchers as equal partners.
5. *Do* ensure the young people know what interview they are taking part in and why and that they will be interviewed by a peer.
6. *Do* provide training and support for the young people doing the interviews, provide mentors, provide feedback and facilitate their engagement throughout the study from data collection, analysis, to write up.
7. *Do* let the young people know you will contact them within 24–48 hours of the interview to ensure the interview has not caused any distress for either party in the research conversation. Have a process in place/sign posting if distress has been caused.
8. *Do* provide payment or financial voucher to the interviewers.
9. *Do* stress the importance of confidentiality to all partners in the process.
10. *Do* ask if they would like to receive a copy of the study results. Ensure this is available in an understandable format.

### 6.3.3 Interviewing Children with Learning Disabilities

Arts-based interviews were used with children and young people with learning disabilities as part of an ethnographic study aimed at understanding the hospital-related needs and experiences of this group of patients, as well as those of their parents [31]. This study was titled Individualising hospital care for children and young people with learning disabilities: it's the little things that make the difference.

Interviews were used to elicit participants' feelings about being in hospital and views of what was important to them during this time. Interviews were carried out in the hospital setting during the child's inpatient admission or immediately before/after an outpatient appointment. Four different arts-based activities were used during interviews. The card sorting activity involved children decorating two

**Fig. 6.1** Activity 1: Likes and dislikes activity

boxes, one to represent their likes and the other their dislikes, and placing hospital-based symbol cards into one or both of the boxes (Fig. 6.1). Those who were able to express their views were asked why they had placed the card in the relevant box, which generated further discussion. The symbol activity was a simplified version of the card sorting activity, with children matching hospital-based symbol cards with an emotion card and indicating, if able, why they had made that choice (Fig. 6.2). A third activity involved children decorating a cut-out ‘gingerbread’ figure to make an imaginary person (Fig. 6.3). They were invited to name the person, and this was used as an avenue for discussion. During a fourth activity, the researcher asked children to draw onto a life-size cut-out paper person anything that reminded them of tests/treatments they had experienced during their admission (Fig. 6.4).

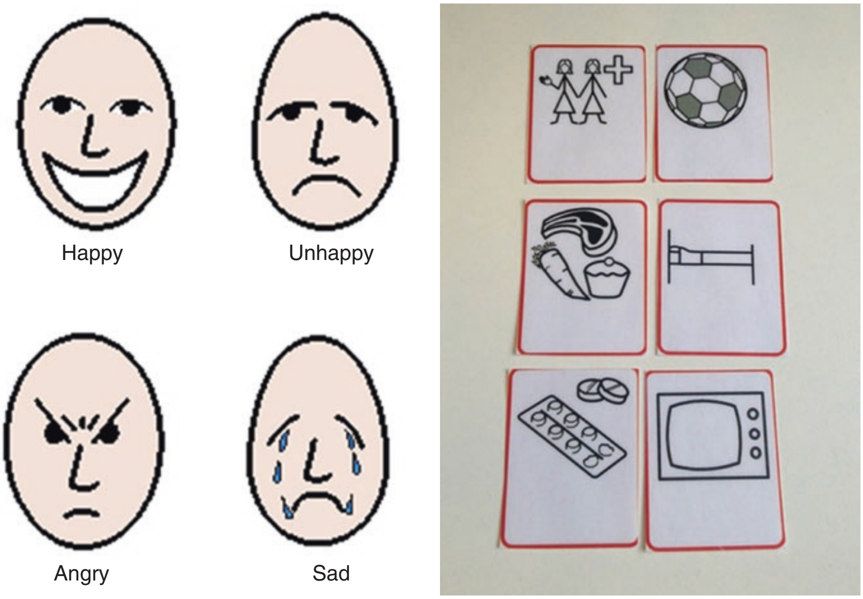

**Fig. 6.2** Activity 2: Emotions activity

**Fig. 6.3** Activity 3: Person craft

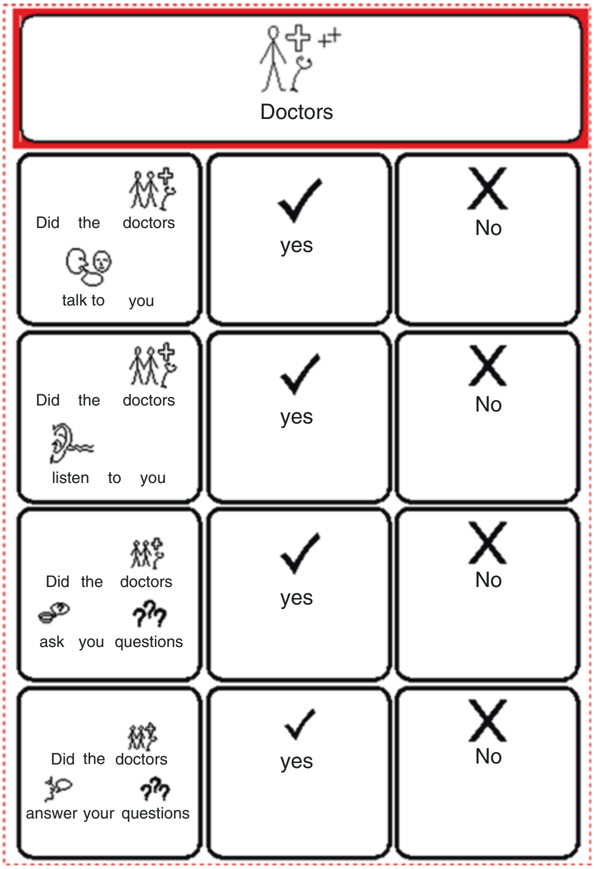

**Fig. 6.4** Activity 4: Example of specific questions to gather experiences

#### 6.3.3.1 Why This Approach Above Any Other?

Semi-structured individual interviews were felt to offer the best opportunity to capture how children with learning disabilities feel about being in hospital, what their experience is like and what needs they have during that time. As very little is currently known about this subject, we wanted a data collection method that allowed participants the freedom to raise issues of importance to them and that facilitated exploration of these issues. It was important with this population of participants, however, to have structure to the interviews rather than being completely open-ended in our approach. Interviews were arts-based, providing children with learning disabilities a creative way of expressing their views and experiences rather than relying solely on them communicating verbally. Due to the individualised needs of children and young people with learning disabilities, individual interviews were favoured over focus group interviews.

#### 6.3.3.2 What Particular Issues Are Relevant to the Population You Were Working with?

Children with learning disabilities have a reduced intellectual ability which impacts on one or more areas of their learning, such as thinking, attention or memory [32]. Their reduced ability to understand new or complex information [33] needs to be taken into account when providing information about the study prior to gaining assent. In terms of providing information about the study, the use of symbols/photographs and/or pictures may be useful. We used Communicate in Print Software to produce three versions of the patient information sheet—(1) full symbol version with a symbol for every word, (2) partial symbol version with a symbol for keywords only and (3) words and symbol version with a symbol for each statement. The need for this emerged after consultation with a parent of three young people with learning disabilities whose daughter would not read the partial symbol version because it 'had symbols missing' and was not what she was used to, whereas the full symbol version may be too 'busy' for some children. We also provided each participant with a talking photograph album comprising pages of symbols/photographs each one with an accompanying audio message explaining the purpose of the interview, how it would be carried out, by whom, where and so on. Combining audio with visual information may be particularly useful for children with accompanying visual impairment and those with limited reading ability. It also means children have repeated access to simple, consistent information about the interview process, which can be particularly useful for those who also have impaired memory.

Interview questions need to be kept short and simple using language and concepts that the individual child is familiar with. We used a 'scaffolding approach' to our arts-based interviews, which involved targeting children's strengths, abilities and interests, breaking down creative activities into short sections, demonstrating and talking through each activity and using visual cues and prompts [34]. The card sorting activity, for example, was built around children's likes and dislikes and was broken down into participants first thinking about what they like and dislike, decorating each of two boxes to represent their likes and dislikes, selecting symbols that related to their experience of being in hospital, choosing which box to put the symbol into and finally explaining why they had made that choice. At each stage, the researcher became increasingly responsive to the child and able to tailor the next stage of the activity or subsequent activities according to their individual needs. For example, one participant with associated physical impairment found decorating his likes/dislikes boxes challenging and tiring and hence added in a break before moving onto the card sorting.

Children with learning disabilities may have a reduced attention span, which will impact on the timing and length of the interview session. Some children who participated in our study were only able to concentrate long enough for the rapport-building activities, with interviews being scheduled for another time, often spread over two or three short sessions. One child's attention span was limited to just a few minutes, which precluded her from being interviewed. In this instance, interviews were replaced with observation and interaction.

Communication needs are an important consideration when conducting interviews with children with learning disabilities. They may have limited or no verbal communication skills and use alternative methods of communication such as Makaton or a picture exchange communication system. Where possible, it is important to use the child's usual method of communication rather than trying to introduce something new. One child who took part in our study also had processing issues, which meant he took up to 15 seconds to formulate and verbalise a response to questions. Having full knowledge of his communication needs prior to interview was vital in ensuring he was given sufficient time to answer the interview questions. The use of symbols, pictures and photographs alongside interview questions were used.

Children with learning disabilities are more likely than other children to have challenging behaviour. It is important when interviewing them to be aware of things that can trigger such behaviours and how best to respond to them should they arise. This is important for minimising the child's distress and also maintaining safety of both child and researcher. Children with learning disabilities can quickly become emotionally attached to the researcher, which can make ending the interviewing particularly challenging. In our study, one child asked for the researcher in the recovery room after her surgery and later became very upset and tearful when the researcher said she had to go home. The use of social stories can help prepare children with learning disabilities for how and when their participation in research will end.

The most important thing when conducting interviews with children with learning disabilities is not to make assumptions but to collate as much information as possible so that the interview can be tailored to each child's individual needs. These are not procedures that can be rushed. If we are to avoid the risk of tokenism, then we need to keep asking ourselves what trust we can place in our methods and check that we have not overly predetermined the views that we have encouraged to be heard [35].

As Nind [36] states, the premise for all studies should be that:

- The difficulties experienced by people with learning difficulties, communication difficulties, autistic spectrum disorders, etc. will be subtly different, but none of these groups are homogeneous, and the impairment does not define the individual and their experience.
- The challenges faced by qualitative researchers doing research with this group, like the challenges faced by the disabled individuals themselves, are as much a product of the interactions between them and the wider context as of any inherent impairment.
- People with learning/communication difficulties have something to say that is worth hearing and experiences that are worth understanding, making it important to commit serious attention to the methodological challenges involved in undertaking research with them.

#### 6.3.3.3 Ten Top Tips for Interviewing Children and Young People with a Learning Disability

1. *Do* prepare well; preparation is key—know your participants, plan everything carefully and work in partnership with parents.
2. *Do* take your time—test out your methods first, build rapport and be patient.
3. *Do* break down the interview process into short sections.

4. *Do* keep tasks simple and concrete.
5. *Do* use simple language and fewer words—less is more!
6. *Do* be flexible—come armed with a toolkit of resources, and be ready to adapt them.
7. *Do* think in advance about the space and environment; they are important.
8. *Do* empower children and young people; do not patronise them.
9. *Do* consider combining interviews with other data sources.
10. *Do* keep expectations realistic—prioritise what you need to come away with.

### 6.3.4 Interviewing Adolescents

A longitudinal qualitative descriptive approach was applied in this study using in-depth interviews as the primary source of data. This study followed adolescents with cancer over their first year following diagnosis and was entitled 'I'm a survivor, go study that world and you'll see my name'. The actual research question was 'What are the thoughts, needs and perceptions of adolescents diagnosed with cancer related to their cancer experiences over time?'

The longitudinal nature of the study was a challenge, particularly keeping track of adolescents. Maybe in future studies, social media, and/or texting or email, would be useful to keep in touch with participants [37]. Preparation was key to getting good data, including having a good interview guide and well-thought-through plan for the interview. This is particularly true when working with adolescents who may have difficulty conceptualising abstract thoughts and opinions and communicating them to others [38]. It is crucial that adolescents are able to understand the meaning of the interview questions and the degree of detail the interviewee is seeking in the response [39].

We share here specific tips related to the successes and pitfalls of interviewing adolescents from our experience of this study, combined with about 10 years of experience in this field (see also [40, 41]). While adolescents and young adults with cancer 'can be great fun to work with', they can also present some practical challenges to the researcher because they are in a demanding time of life, both developmentally and situationally [42].

#### 6.3.4.1 Why This Approach Above Any Other?

Open-ended questions are key to gathering good data from an adolescent population. Some adolescents will try to answer even the most open-ended question with as few words as possible so it is important to develop questions that encourage them to feel comfortable and to talk. Whereas some only need to be given space, ask questions that are important to them, for them to be able to contribute fully. The following are some recommendations for a good interview guide:

1. Check each question to ensure it is open-ended (cannot be answered with a 'yes' or 'no').

2. Start the interview with a general question that is topic specific but can be viewed as an ice-breaker. For instance, with my population, I asked them to tell me about hearing that they had cancer. It invites a story from them and lets them know that you are there to listen.
3. Have less questions but more probes, and use participant's own words as part of the probe 'you mentioned XX, tell me more about that'.
4. If your participant seems uncomfortable or is trying to answer your open-ended questions with 'yes' or 'no', ask another question that is more storytelling focused like 'tell me about what it was like to XX'. This may encourage them to start talking more, and as you listen carefully, their comfort level will increase.
5. Always have a conversational tone. Read your interview guide out loud to yourself and/or practise with an adolescent prior to actually using it with study participants. If you use language that is not adolescent-friendly, you will alienate your participants. While you might be interested in 'self-efficacy' or some other similar concept, now is not the time to use that term! Speak like you are having a conversation with them, not a formal interview. This will help build rapport.

#### 6.3.4.2 What Particular Issues Are Relevant to the Population You Were Working with?

In addition to a good interview guide, it is vital to have a good plan for the interview itself. Particularly with adolescents and young adults, there is a need to consider their schedule. When is a good time for them to talk? Scheduling interviews to coincide with other appointments and meeting them at a neutral location near their home are all good ways to respect their time and acknowledge that they have a life outside of the illness for which researchers are seeking information. When you are considering the timing of data collection, it might be best to consider the average sleep and wake times of adolescents in order to get the best data from them. The average adolescent is not up at 8 a.m. ready to talk! In the case of adolescents with cancer, it is also important to plan interviews around procedures if they are receiving active treatment. Adolescents who have received sedation do not generally make good interviewees.

Set up a comfortable place to have the interview. Choosing a location that is comfortable is also helpful. Sometimes having a drink or snack available is appropriate. Always sit at a level with participants and not above them, which will help establish a rapport where they will feel comfortable to talk rather than feeling like they are being interrogated. For this study, we planned data collection around appointments that participants had already scheduled with their medical team. Interviews were conducted at the oncology clinic because it was convenient and comfortable for them and did not require an extra trip which was very important for this population of participants who had already missed a lot of other activities for cancer treatment. Rapport was built with the first interview, with participants seeming to look forward to subsequent interviews when they could talk about what had happened in the intervening months. Having decided perhaps that the interviewer was someone who would listen to them, they appeared eager to share information, both positive and negative about their lives since the last interview.

The challenges in this study centred around attrition. One participant decided he did not want to talk about his experiences beyond the first interview as he was simply 'done talking', while another participant passed away during the study. Other participants were lost to follow up because without multiple ways to contact them, it was hard to reach them if they did not answer their phone. As well as thinking through how to interview adolescents, it is important to think about alternative methods of contacting them during their busy lives, since keeping them in the study is key to having the opportunity to interview them!

#### 6.3.4.3 Ten Top Tips for Interviewing Adolescents

1. *Do* set up a comfortable environment for the interview.
2. *Do* plan the interview for a time that is convenient for the adolescent.
3. *Do* plan your interview guide so that the questions are meaningful and open-ended.
4. *Do* establish rapport before starting the interview.
5. *Do* start with a question that invites the adolescent to talk.
6. *Do* approach your questions with a conversational tone.
7. *Do* probe for more information so that you get rich description of what each adolescent's experience is.
8. *Do* deviate from the interview guide (with open-ended questions) if your participant starts telling you important information that you had not thought to ask about.
9. *Do* be flexible—nothing in research ever goes 100% as planned! (Appointments run late, participants do not show up, people get sick, etc.)
10. *Do* show appreciation for your participants. They are the only ones who know the answers to the questions you are asking!

## 6.4 Advantages and Challenges of Using Interviews as a Research Method

### 6.4.1 Advantages

- The research interview is flexible, the basic tenets of which can be revised to suit a range of populations with differing levels of skills and abilities.
- Interviews offer opportunity to 'get beneath the surface'.
- Although the ways of using new technologies to undertake interviews are increasing, being face-to-face with a child or young person provides the best opportunity to reduce the power dynamic that probably exists, the researcher can read non-verbal cues, and there is more opportunity to probe and explore responses.
- Interviews, used correctly, might also appear less like a test, less reliant on literacy and handwriting/computer skills that other techniques may require.

### 6.4.2 Challenges

- It is not always possible to predict all challenges; researchers must always be prepared, able to think of their feet and draw upon solid theoretical and practical knowledge of working with children and young people.
- Recruitment usually takes longer than expected—plenty of time should be factored into study timelines and for rearranging appointments for data collection if it is no longer convenient for the participant.
- Environment is important, and it is not always easy to find the right space at the right time. Consideration of space, access for those in wheelchairs, not too medicalised and not too 'child-like', with privacy and not too noisy are all difficult specifications to match, so preparation in advance is key.
- Interviews require a particular type of investment from children and young people in terms of what they give of themselves—how and when to end research relationships require consideration at the outset.

## 6.5 Key Advice

1. Consider the many different interview techniques available; consider the benefits and limitations of each, in the context of the population you are working with, and the research question being addressed; and then make your final choice (see, e.g. [43]).
2. Preparation is always key to all interview techniques, good, thoughtful planning, where time has been allowed to consider the essential steps to assure success: be prepared also to be flexible; thinking on your feet will still be required for the unexpected.
3. Confidence is essential; this comes with knowledge, as well as a described skill set: training, education, practice and feedback from our peers and our research participants are the core features of assuring personal belief in being able to have a research conversation with children and young people.
4. Patient and public involvement at all stages of research is essential. In this context, consulting children and young people about interview techniques, what might work and what would be more appealing could assist with recruitment, quality of data and dissemination.

## 6.6 Conclusion

This chapter has provided a platform for researchers to share their knowledge and skills about the use of the research interview. Those being interviewed are at the centre of these descriptions. Researchers illustrate how they ensure they get the most out of these research conversations, through diligent planning, considering a range of eventualities, understanding the methodological issues and applying expertise to the research questions and study design. The focus has been on the practical considerations, but implicit is expertise, developed through practice, adapted and refined over time, with researchers being creative where needed. Reinforced here is the need for researchers to have a 'method toolbox', used with skill to ensure a relationship is built from the outset, one which the research conversation will benefit from. Being flexible, thoughtful and knowledgeable about the populations we work with is clearly essential. But we also need to be brave, to embrace the notion of 'serious fun' and to make the interview process as enjoyable as we can. Throughout this chapter, the emphasis has been on 'giving children and young people a voice'; having made that happen, we, the researchers, need to explain to our participants how and why, having heard their views, we are making (or not making) a particular response [36].

## 6.7 Useful Resources

1. http://www.azcourts.gov/casa/Training/Training-Courses/Interviewing-Children. (On online training course when interviewing children.)
2. http://www.mefirst.org.uk/resource/interviewing-and-communicating-with-adolescents-headss-technique/. (The focus here is on adolescents, but there is also a section about children.)
3. http://blogs.lse.ac.uk/gko/tools/guides/participatory-research/. (An international project with some useful tips.)
4. http://www.youngcarer.com/resources/ptp/participation-pack. (Lots of very helpful resources are here about children and young people's participation.)

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# Being Participatory Through Photo-Based Images

# 7

Karen Ford and Steven Campbell

## 7.1 Introduction

Arts-based participatory methods provide an opportunity for children and young people's involvement in research in meaningful ways, facilitating their engagement, communication, control and interpretation of their own experiences [1]. In this chapter children and young people's participation in research, through arts-based methods using photographic images, is explored. These methods include photo voice and photo elicitation. Such participatory research methods enhance access to children's own views and understandings, as a way of giving voice to children and young people. These methods have resonance with children's lives and their day-to-day activities. For many children, these participatory research methods can be fun and can accommodate individual children's skills, abilities and interests—children and young people often feel more comfortable and confident using drawings, photographs and videos than relying solely on words. Furthermore, image-based techniques and activities can provide child-centred structures for children and young people who are not literate or who have language difficulties.

Researchers are usually adults and adults usually have dominion over words. This level of control can therefore be disempowering for children and young people. Images, on the other hand, are central to children and young people's worlds even

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from a very young age and therefore can be empowering [2]. Visual media can provide a unique (but also familiar) way for children to express and represent aspects of their lives [3] and are central to children's early development and learning [4]. Children and young people can find it difficult to express their feelings in words, and image-based methods can provide means for them to express their fears, feelings, sensitive issues and can (importantly) be fun [4]. They provide clear, tangible prompts [3] and bridges that enable children and young people to express themselves in ways that are not reliant upon words alone [5].

Pictures change the dynamic of the interview conversation [6] and give rise to information and understandings that traditional oral interviews do not. Because language processing uses different areas of the brain than processing of visual information, the use of visual/image-based methods provides different ways of expressing ideas and experiences creatively and so provide a different way of knowing as well as of telling [6]. These approaches also support a deeper level of understanding and meaning making. The use of images in interviews creates a participatory space for the child or young person and researcher to come together, to engage in dialogue and to create meanings together. Many children and young people may find pictures easier to talk about; they may be more comfortable and more interested in the interactive, participatory interview activity than they are with dialogue alone. The photographs serve to facilitate a more relaxed atmosphere because continued direct eye contact is not needed as the child/young person and adult look at the photograph together—this refocuses attention and lessens the directness of the researcher's gaze [7], reducing the likelihood of the child or young person feeling shy or overwhelmed by the researcher's presence. Although the potential benefits for children and young people are evident, the use of photo-based approaches requires particular consideration.

When photos taken by participants form part of the data, consideration needs to be given to how they will be used. For example, will there be any interpretation of images by the researcher, or will they be purely used for elicitation in interview? Specific ethical considerations in arts-based research have largely been neglected [6]. Photo-based methods present important ethical considerations as participants are more visible, including, but not limited to, their physical appearance and representation. Details of their lives are revealed making them much more identifiable than they might be in conventional research [8].

In this chapter we discuss the theoretical underpinnings of participatory photo-based research. We include reflexive discussion about how photo-based images are used and specific ethical considerations and challenges photo-based methods pose in research with children and young people. By drawing upon published works, we discuss practicalities and techniques and advantages and challenges the methods may present. We focus on three specific methods using photographic images in research with children and young people: firstly, auto-driven photo elicitation where the photographs are taken by the children and young people; secondly, photo voice where the photographs are taken by the researcher; and finally, visual storytelling that combines aspects of both photo voice and photo elicitation.

## 7.2 An Example from an International Photo Elicitation Study: Young Children's Experiences of Growing Up with a Chronic Condition in England, Australia and New Zealand

*Aim:* The aim of this study was to explore what it is like for children to live with their chronic health condition and symptoms, what differences it makes to their lives and how they manage their symptoms, medication/intervention and decision-making.

*Target population/who participated/recruitment:* This study was conducted across three countries—England, Australia and New Zealand. A purposive sample of 45 children aged 6–12 years (15 from each country) who had been diagnosed with a chronic health condition for at least 6 months (requiring daily/frequent management by medication and/or interventions) were eligible to participate. Children were intentionally sought from across a diverse range of diagnostic groups, and participants included children with Crohn's disease, asthma, leukaemia, cardiac conditions, renal failure and haemophilia [9].

### 7.2.1 Type of Participation and Model Underpinning the Participatory Approach

The study used a qualitative methodological approach with the child at the centre and was an arts-based, participatory study. It was emancipatory in terms of empowering each child's own agency, by allowing them to set the agenda through taking photographs of meaningful phenomena that would then be discussed at interview. Therefore, photo elicitation (photographs and interviews) was used to develop understanding of children's experiences that were meaningful to them.

### 7.2.2 Research Methods/Tools Used and Rationale for Their Use

The research method used aimed to promote the child's own views and uses more than words as a source of data. Auto-driven photo elicitation interviews involve each participant taking photographs to facilitate or set the agenda for an interview [10]. This method was chosen to create a situation in which children could use visual prompts to express themselves and not be confined just to words as a form of expression [1]. The method shifts the balance of control of data creation in favour of the child, who leads the process and sets the agenda through the photographs taken. Children were supplied with a digital camera and an information sheet that focused on the taking of the photographs, including photographic etiquette and some general, but not leading, suggestions about the subject matter they might wish to photograph. These instructions are presented in Fig. 7.1. The aim was for the agenda to be with the children, rather than an agenda from the researchers' viewpoint.

## International Children's Illness & Symptoms Study

### Information about taking the photos

Thank you for agreeing to take some photos so we can understand about how having a chronic illness makes you feel and how it affects your life.

Please take photos of you think is important, we want to know what YOU think!

### Some things you could take photographs of

- Things you have to do because you have a chronic illness
- Things that seem different because of your illness
- People who help and things that help you
- Anything or anyone else you think we need to know about

### Things to remember

- We are looking forward to seeing your photos but please make sure that anyone you take a photograph of (who isn't part of our project and who hasn't given us written consent) knows you are taking their photo. If you are not sure about whether you should take a photo, check with your mum or dad.
- Only take photos of things you want to share with us.
- You can delete any photos you don't like or don't want to share with us before you give back the camera.

**Fig. 7.1** Instructions for children about taking photographs

There were some informal aspects to the recruitment process. The time period for the children keeping and using the cameras was negotiated, meaning that most had the camera for about 3 weeks. The negotiations were aimed at fitting the photography around the children's day-to-day events and obligations. This allowed for a range of photographs to be taken before the interview part of the process. The children also needed to have control over the photographs taken, and the support of each parent/carer was sought in this important aspect of the research process. The photographs were subsequently shared with the researcher (as well as being retained for study purposes) [9].

The photographs selected by each child set the agenda for the audio-recorded interview between the researcher and the child. At times the interviewer sought further information to gain deeper insight into the experiences the child had highlighted and wished to share. This also created the opportunity for children to talk about what they would have liked to have photographed, but were not able to do so. The first preference for interview location was the child's home, but three occurred, out of necessity or choice, whilst the child was in hospital or at a clinic visit. The children made the decision about whether their parents would be present at the interview or not. Interviews were carried out by all members of the research team.

### 7.2.3 Ethical Issues

As would be anticipated, there were ethical concerns that the children might take photographs of people or situations without the permission of those involved or at times that were either not appropriate or not supported by the parents. There were also the mirror concerns about not impacting on the child's ability to choose what they wanted to photograph. Therefore, it was necessary to develop a clear guide for the children about taking photographs and their use. The guidance that was developed ensured that the children had a good grasp of what they were participating in and their commitments. As a result, the team was confident that the children's assent was genuine and that they felt able to give a clear indication about their discomfort at any time, allowing them to pause/stop/withdraw. Informed consent was obtained from the parents/carers and assent from the children ensuring that the use of their words in quotations and their photographs or other images, in academic presentations or papers, was understood and agreed to by the children and their parents.

### 7.2.4 Findings

Data were in the form of photographs and interview transcripts. Data analysis was underpinned by interpretive description [11], and interview transcripts were analysed thematically [12]. The main theme identified was *It's not who I am*. This was a reflection of the children's resourcefulness, resolution and capacity to promote that they were not defined by their chronic condition whilst being very aware that it impacts in varying degrees upon their lives and the pattern of their lifestyle. The findings had a stream of data that was about *awareness of time* and that their condition impacts upon the fast(er) nature of time and its quality, for this group of children. The data showed how their chronic condition affects their being in different places and spaces, whether physical or emotional.

Three subordinate themes link to the children regarding themselves as *not being different* and the corollary that they are holding on to regarding themselves *being normal*. This was supported by not being problem-orientated, but rather their solution-focused approach to challenges of day-to-day living, by finding ways of living life *normally*. Of note was the subconscious use of the word 'but', or the qualification of statements with the word, or in another way: *It's not who I am, but it is part of me*; *getting on with my life* despite the chronic condition. They recognised the centrality of *family* and the need for *friendship, support and comfort* because of the challenges of the condition. This recognition went to *things that get in the way of getting on,* those things caused by the condition, and needing the support and comfort of their loved ones to deal with or get over the challenges [9].

#### 7.2.4.1 What We Would Do Differently?

The children did not use the term 'chronic illness', so we would be very careful about such language in the future. In the future we will be more confident about using the method, and we see its potential for exploring more sensitive subjects, such as relationships, having established *our* expertise in the method.

#### 7.2.4.2 Impact on Participants

The impact on participation was generally empowering for the children, but in saying this, some withdrew from the study because it was not as much fun as they thought it was going to be. Some chose not to participate because they just wanted to 'be normal'. Participation in the research had benefit for some children, for example, one mother told of her son's increased interest in his condition and treatment and that he had asked her to help him explain his condition to his school class.

#### 7.2.4.3 Dissemination Techniques

The results (including images from the study) have been well received by clinicians, in publication/reporting and conference presentations and importantly by the children who have been happy to see their work represented. Using other arts-based media, the findings have also been disseminated directly to the public in a performance of interpretive dance with an accompanying music composition [13].

## 7.3 Techniques

Different techniques can be used in photo-based research, and, at times, the different terms used to describe research using photographs can be confusing. For instance, photo voice and photo elicitation are sometimes used interchangeably, and whilst these two photo-based methods share similarities, there are also important differences. Some of these differences are around methodology, and some have to do with the actual methods.

Photo elicitation refers to the use of one or more photographs as a stimulus in the research interview context [14]. In photo elicitation, the interview is stimulated and guided by images. They can be chosen from archives, magazines, etc., or they can be created by the participant. When the photographs are taken by the participant, the method is referred to as native, reflexive or auto-driven photo elicitation [15].

Methodologically, photo voice is quite strongly linked to community-based participatory, change-oriented research. Wang and Burris define photo voice as:

> a process by which people can identify, represent, and enhance their community through a specific photographic technique… to furnish evidence and promote an effective participatory means of sharing expertise and knowledge. ([16], p. 361)

Both approaches are empowering and participatory and, in the context of this chapter, child-centred. Traditionally, photo elicitation and photo voice have referred to the use of photographs, although, the types of images incorporated under photo elicitation/photo voice can be broadened to include film, video, drawings or objects [2]. Whilst acknowledging this broader view of image-based media, in this chapter the discussion specifically focuses on the use of photographs.

## 7.4 Auto-Driven Photo Elicitation with Children

In auto-driven photo elicitation research with children and young people, the photographs act as a medium to enable children to record their lives through their own eyes [4]. This method promotes children and young people's inclusion and self-directed participation in developmentally appropriate ways that acknowledge their unique abilities and perspectives and as active meaning makers in their own lives. Auto-driven photo elicitation presents a way for children and young people to have control over key aspects of data generation. The children and young people take the photographs and choose which photographs to discuss. When they are able to participate actively in the research process, by creating images for themselves and about themselves, some of the power differential between children/young people and adults is shifted, enabling their personal control, participation and empowerment.

In the auto-driven photo elicitation study used as the exemplar for this chapter, children aged 6–12 years living with a chronic condition were provided with a digital camera to use and were asked to record aspects of their lives and chronic health condition. The children took the photos, and these then formed the basis for a semi-structured, individual interview to explore the children's own perspectives and experiences (Fig. 7.2). In the interviews, the children chose which photographs they wanted to talk about, and the children and interviewer came together for joint meaning making. Photo elicitation enables and encourages the ongoing participation of children and young people in research beyond the generation of data.

### 7.4.1 Using Cameras

The children in our chronic condition study used digital cameras, but others have used disposable cameras. The type of camera chosen might be influenced by practical considerations such as available resources and costs of cameras and of processing. When disposable cameras are used, there can be a delay in having the images available because the film is sent away for processing. The note of anticipation and mystery may add to the 'fun' of using the disposable camera [1], or the time taken for processing and printing may be seen as delaying and demotivating [4]. Children in our study experienced the immediacy of being able to review images, delete, upload and download images immediately. The research team felt the children enjoyed the level of active participation and control they had in the act of

**Fig. 7.2** Children and young people can use photographs to project their own self-concept

picture-making itself; being able to 'manage' the technical aspects of the photographs, such as loading images onto a computer or tablet; and choosing and progressing through the images in the interview. Kullman [17] refers to different kinds of 'performances' by children that is part of using digital cameras and that includes producing and interpreting the images, sharing images and even using the equipment as play objects. Kullman identifies that photo-based methods enable children to 'diversify their participation through varied doings' ([17], p. 2).

Even those children who have not used a camera can quickly gain the skills required using an instinctive trial and error approach, and many (although not all children) enjoy the opportunity to take photographs (largely) free of adult constraints [4]. When using a disposable camera, the maximum number of photos is predetermined by the size of the film. This is not the case with a digital camera, and so when using digital devices, it is a good idea to have a conversation about the numbers of photographs the child or young person might take. A suggested number gives them an understanding of what is being asked of them in terms of their participation. There is also the pragmatic consideration of the amount of data the research team can effectively work with (in our experience, even young children can provide a very realistic and workable number).

### 7.4.2 What to Photograph

Children and young people require guidance and clear instructions about the nature of the study and the nature of the photographs they are being asked to take. Some children and adolescents can find it a little difficult initially to know how they might represent quite abstract ideas in visual terms [18]. Guidance or coaching can help them understand the intent of the study and the kinds of issues the study is seeking to explore. A written printout with this guidance can be helpful. Again, our experience is they generally readily achieve this and their readiness to test out different ways of conveying their everyday experiences using photos is also described by others [17].

Clear information and guidance about whom and what might be included in photographs are also important. In some studies, children and young people are specifically directed not to take photographs of themselves or other people [19, 20] because of issues of privacy. Researchers need to consider whether such decisions fit with their research aim or whether they present restrictions that will impose significant limitations on the intent of the research and the findings. The research team needs to give careful consideration to how images will be used. The sole use of the images for the purposes of elicitation at interview presents quite different issues to the use of images in presentations and publication. When used only for interview, photographic images do not enter the public space—when they are part of the dissemination and reporting, these images cannot be recalled.

Photographs are constructions rather than replicas of reality, and the context of taking a photo can be as important as the image itself [5]. The data can be ‘shaped’ by gatekeepers, such as parents, teachers or researchers, and there may be issues around gatekeepers who prompt or direct children and young people to take certain photographs the gatekeeper deems important (but perhaps not important to the child/young person). In our experience, children exerted control over ‘unwanted’ images by deleting these or passing over them at interview, perhaps with a comment that ‘mum (or dad) took that one’ [5]. By giving children and young people cameras, control is passed to them [2] and they are auto driving. Children and young people may ‘direct’ or drive others to take a photograph, for example, children directed their parent to take photographs of the child receiving or self-administering treatment or playing sport [5].

The research data are also shaped by where the camera is taken, for example, on a trip away, a holiday or a special event, such as a birthday (Fig. 7.3). There may be images the child or young person would like to take, but the opportunity does not present itself. In the example study, one child wanted a photograph of himself

**Fig. 7.3** Through photographs children and young people can portray people, places and events important to them

surfing, but because it was winter, the water was too cold [5]. This issue can be addressed by including a question at interview whether there were photographs the child would have liked to have included, opening up the opportunity for discussion about matters important to them and not captured in an image.

### 7.4.3 How Photographs Are Used in the Interview

The photographs used in photo elicitation are not ‘standalone’ as the intent is that the photographs are used as a prompt to generate dialogue that is grounded in the meanings and lifeworld of the child and young person [1]. The images created by the child or young person have relevance to them and act as a trigger or aide-memoire, assisting recall and stimulating conversation. As well as facilitating conversation, the photographs facilitate reflection during the interviews enhancing the children and young people’s own self-awareness [21].

Using photographs to shape the interview can mean the child or young person is more at ease to talk about their experiences and meanings [5]. When they are able to choose the photographs they want to discuss, the interview is ‘child-led’ (or ‘participant led’). The child’s and young person’s authority is increased by their ownership and knowledge of the images and in being able to drive the conversation they create. This acknowledges the child or young person as the authority in their own life [14, 22]. In the chronic condition study, children felt free to pass over photographs they did not wish to discuss, and this choice was respected by the interviewer (even though as researchers, we might really have liked to hear the story behind the picture we had a fleeting glance of). We also found the use of photographs helped to elicit longer interviews that were more comprehensive than a traditional oral interview might achieve [5].

When listening to the children's and young people's own interpretations of the images they have created, authority shifts from the researcher to the child or young person who is in fact 'participant–researcher' as they have created the data. This ownership and control enhances their active participatory role in the research. There needs also to be shared comprehension between the adult researcher and the child's or young person's meaning in the photograph. This is a task of translation or interpretation where the emphasis is on being faithful to the child's or young person's intended meaning. This also refers back to the researcher's underlying philosophical and methodological stance, that is, how the researcher views childhood and children's and young people's role in society and in research.

The process of analysis begins in the interview during the discussion about the photographs. What might seem clear to the researcher can have quite different and nuanced meaning for the participant. Hatten et al. [23] provide the example of a photo of a boy standing on a path (from the researcher's perspective) that (from the child's perspective) is a photo of the child's best friend who has moved away and the photograph depicts the loneliness the child feels. For some children and young people, participation in photo-based research provides an opportunity to talk about a topic they have not spoken about so deeply before [24].

### 7.4.4 Ethical Considerations

Using visual methods in research with children and young people may pose problems, obstacles and delays with ethical approval, because review boards can have limited knowledge and experience with these less conventional research methods [6]. Researchers need to have a clear justification for the use of photo elicitation in the study, including the establishment of unequivocal study protocols, particularly around children's and young people's safety. Specific ethical considerations to be addressed when using images in research include determining the subject in the photographs, obtaining consent to be photographed and maintaining anonymity of people and organisations [19]. These ethical considerations can be even more difficult because they are not directly under the control of the researcher, but 'responsibility' lies with the child or young person.

As well as the duty of care to participants, researchers have a duty of care to protect non-participants who might appear in photographs, for example, siblings, friends and adults who have not assented or consented. There is the potential for invasion of privacy when photographs of others are taken without their knowledge. Where practical and appropriate, verbal permission should be obtained from identifiable people who appear in photographs. This can be challenging for the participant child and young person to manage and can be even more difficult when the other is another child/young person. In addition, to keep them safe, participant children and young people should not approach strangers for consent to be included in a photograph, such as in the background of a photo taken in a public space (e.g. a park).

Editing photos may be a part of the research process. However, it is not about whether a photograph is good or bad, or right or wrong, and should editing be required, the child or young person as creator of the image should be involved. Importantly, any editing should not change any meanings the child or young person wants to convey. In the chronic condition study, an image of a child, who was incidentally included, was cropped from a photograph. This did not alter the focus of the photograph of the participant child taking part in a dance competition.

Ethical considerations are different when photographs are used for elicitation purposes in interview only and when they are used for dissemination of the research through websites, conference presentations and papers, including this chapter. Publication in these fora makes anonymisation of people and places difficult [5]. Attempts to preserve anonymity, for example, by pixelating faces, can serve to undermine authenticity, and children and young people might not appreciate this anonymisation and othering. In some studies, images of people who have not provided written research consent are excluded from the data (e.g. [20]). In the chronic condition study, where identifiable people had not provided assent for the ongoing use of the image in research reporting, the image was retained as part of the dataset but was not used in presentations or publications [5]. Children were given the choice to be represented in the reporting of the study. The future use and access to images should be acknowledged as once in the public domain, the images are permanent.

## 7.5 Other Techniques

### 7.5.1 Photo Elicitation Using Photos Taken by the Researcher

The example in this chapter so far has focused upon the children and young people having more control and taking the photographs themselves. However, another approach is where the researchers take (or choose) the photographs and therefore set the agenda. Epstein et al. [15] characterised such studies in a number of ways. There were some studies where the investigators were professional photographers, and this skill led them to take the photographs themselves [14, 25]. This group of studies does not of themselves justify the approach in methodological terms, purely pragmatism and opportunism. In contrast, other studies were driven by an interest in specific issues, so the researchers choose the photographs to exemplify the topic for investigation [26]. Foster was interested in what children made of historical photographs and children's capacity to make judgements about the nature of the photograph, such as when it was taken. There were also studies that focused upon younger children (3–12 years), and the researchers took the photos because of their perception of a lack of capacity for the children to take the 'right' photographs or a general lack of capacity to take photographs. Such approaches exemplify researching on the children, rather than researching with them, and being participatory and empowering of the children [27]. Salmon's work is seminal in that her findings show how props, such as photographs, facilitate children's reports of past events. The final category that Epstein et al. [15] identified was studies exploring place, such as school, or care at school, and the photographs assisted in creating a conversation but also to map where the activity took place, such as where in the school.

Studies about place reported by Cook and Hess [28] include a project with pupils attending a special school that was to close, another with children aged 4–5 years about their reception (early years) schools and a third with pre-school children attending art museums.

In their study, Epstein et al. [15] aimed to explore children with cancer's perspectives of a specialised summer camp. Thirty-five children and young people aged 6–12 years participated in photo elicitation interviews, where the photographs used were taken by the researchers. The rationale used by the researchers for the appropriateness of this method was primarily because they did not want to burden this group of children. These children regularly participated in research, and the taking of photographs by them could be seen as extra work whilst at camp. Researchers were also concerned about consent/assent and that the participating children might take photographs of other children at camp who were not in the study [15]. The research team recognised that their taking the photographs could mean that the focus might be on what the researchers were interested in, rather than what was meaningful for the children and reflexively worked to address this. Harper [14] referred to 'break(ing) the frame' (p. 20) of the participant's normal views. Breaking the frame is about challenging the way people perceive issues by visually presenting them in a different manner, presenting a photograph that challenges the taken for granted way of seeing. In the study by Epstein et al. [15], the intent was to focus on what was meaningful for the children (rather than the researchers) and to evoke reflection, thus 'breaking the frame'. The researchers wanted to promote understanding of the children's own perspectives and views of their world [15].

Epstein et al.'s [15] approach was to concentrate on places most frequented by the children, focusing particularly upon:

(a) The form and content of the photos
(b) Pretesting the photos
(c) Considering the location of the PEI [photo elicitation interview] ([15], p. 4)

The researchers used a set of coloured photographs of the camp including built physical structures (e.g. the rock wall and cabins), natural environments (e.g. the lake view) and social environments (e.g. a phone) in the camp, and these were assembled into a photo interview kit. These photographs were directly related to the research questions and so formed the basis for the children's reporting on their perspectives of camp. Harper's [14] emphasis upon breaking the frame included the photographs being presented from an 'unusual angle'. The reason for this was about opening up the children to new ways of looking at their own lives. The notion of an unusual angle is interesting in that for some this might literally mean the photograph being taken from an unusual angle, whereas for others it might be more metaphorical, about the image portraying the phenomenon in an unusual manner. Epstein et al. [15] emphasised the importance in breaking the frame of the environment for the interviews. In their study, some interviews were undertaken in the subject's home and others whilst in hospital. Those at home were longer interviews, whereas those in the hospital were shorter and interrupted and did not cover all of the planned photographs. This is good evidence for conducting interviews in the home if possible, but length of interview does not necessarily mean that the frame was broken [15].

Epstein et al. [15] found the use of photographs provided an ice breaker and helped create a comfortable space for discussion and opportunities for the children's open responses. The researchers claimed that the use of photographs affected their relationship with the children 'in a positive way' and that children were able to take the lead in the interview.

### 7.5.2 Visual Storytelling

A qualitative study by Drew et al. [18] involved a youth-centred study of self-management in young people with chronic conditions using visual storytelling. Visual storytelling described by Drew et al. [18] draws upon the established methods of photo voice and photo elicitation. The origins of photo voice came from group work in health promotion [16]. In photo voice, the participants came together out of a shared interest or characteristic for a project that uses photographs (taken by the participants themselves) [16]. The philosophical approach is community development, and Drew et al. [18] emphasised its capacity to bring issues to the fore, empower people and promote understanding of shared issues. Issues of greatest meaning are key, with participants being encouraged to capture the 'realities' [18] of their lives. When the photographs have been collected, there is a group process of discussion where titles and descriptions are developed. The ultimate goal of this process is to create an exhibition to expose these realities to key stakeholders, such as for policy makers, health managers or politicians, for instance. This approach promotes the communication of ideas on the topic, as well as creating an environment for change [16]. The exhibition is about the photographs and how they are titled (described) rather than any narrative from the participants on their views on the images.

Drew et al. [18] found a point of difference from photo voice, as they were interested in uncovering the meaning of the images in terms of adolescents' experiences in their study. They adapted the photo voice approach to create their visual storytelling. The group discussions of the images led to one-to-one interviews. Photographs remained central to the interview process, and so Drew et al. [18] incorporated the fundamentals of photo elicitation [3, 14, 25]. Photographs for the interviews come either from the researcher or from the participant. Clark-Ibanez [3] promoted the idea that the images can elicit insights that words on their own cannot. This approach also acts as a bridge between the two worlds of the researcher and the researched [5].

Photo elicitation differs from photo voice, in emphasising the images as a means of collecting insightful interview data, often at the expense of the photographs themselves. Drew et al.'s approach to the visual storytelling in a study about adolescents with chronic conditions was based upon six guiding principles, fitting the context of their research, which were:

(a) Focus on young people as social actors
(b) Seek research information directly from young people
(c) Promote depth of communication by extending the established technique of in-depth interviewing
(d) Appeal to young people with an activity they would like to take part in
(e) Be enabling and empowering to young people
(f) Promote young people's voices being heard throughout the research process ([18]; p. 1679)

Drew et al. [18] argued that an approach that was about images could accommodate these six principles. In combining aspects of photo voice and photo elicitation, they claim to have avoided visual or verbal information having precedence in the research, by regarding each as valuable.

Drew et al. [18] sought pairs for their research, in the form of a parent and young person. The participant young person was given a disposable (35 mm) camera with the potential to take 36 photographs. They were given coaching on how to use the camera, and the researchers noted that they had to spend some considerable time reinforcing this guidance during the time the young person was actually using the camera. (Some young people struggled to take any photographs.) On return of the camera, the research team then separately and simultaneously interviewed the young person and the parent. (It was noted, but not commented upon, that the parents did not have access to the photographs, whereas the young people did.) Drew et al. [18] were not concerned that in some cases the parents or another child had promoted aspects of the photo taking. During the interviews, the adolescents were encouraged to explain the images, to explain their choice of images, and how they had created them, as well as their intended meaning for each photograph, or set of photographs.

In order to evaluate the process of visual storytelling, Drew et al. [18] designed their study so that data from the young people and their parents were analysed through a process of open coding and then reconstruction in the form of memoing and axial coding [18]. Through this approach, they were able to show the feasibility of their visual storytelling method in terms of increasing understanding of the lived experiences of young people living with chronic conditions and also for engaging young people in research more generally. They showed how the method could be used and its potential to develop deeper understanding of adolescents' experience of chronic conditions. They also made the case for visual storytelling as a means of engagement of young people in other settings [18].

## 7.6 Advantages and Challenges of Photo-Based Approaches

Conventional data collection methods such as focus group or interview may limit the depth of inquiry because of a reliance on children's verbal skills and adult points of reference. In addition, such methods may not be inherently participatory. Image-based research methods can provide different and creative ways for children and young people to capture aspects of their lives and generate rich data in child-centred ways that do not rely upon words alone. Images provide a medium of communication over and above words but also serve to assist children and young people in articulating their experiences (Fig 7.4). These methods are accessible to children and young people, can enable their participation in research in meaningful ways and can help address the power imbalances that exist between adults and children or young people in research.

Image-based methods can provide artefacts that assist with recall, that stimulate reflection and that empower children and young people in research. The methods are often readily mastered by children and are generally seen to be fun. Indeed Meo [29] claimed further that the major advantages of photo elicitation over traditional oral interviews are:

**Fig. 7.4** Knowledge from photo elicitation is grounded in the child's experience and the meanings they give to the images

- Eliciting longer interviews that are more fun
- Enhancing participation and control for participants
- Gaining richer data that enables a closer look at the things the children consider important
- Facilitating the emergence of unexpected topics and
- Enhanced understanding of some data that would otherwise be more difficult to interpret ([29]; p. 155)

Further, the use of photos helps to maximise the inclusion of children's interpretations and also minimise the potentially distorting influence of adult opinions [17].

Some of the perceived difficulties associated with photo elicitation are that studies can be more time-consuming, expensive and demanding [6, 29] for both participants and researchers. The potential influence of parents or caregivers who might suggest photos children *should* take can reduce children's control and is a limitation identified by Phelan and Kinsella [30]. In addition, when photographs are taken by the researcher rather than the child or young person, the voice of the child/young person within the work may be reduced. As a limitation, these authors identified that photographs represent only one moment in time and what is excluded and why it was excluded is important and should also be questioned. The time commitment by children, young people and parents, the busyness of family life and even the time of year can all impact on the opportunities for taking photos.

The safety of children and young people and their representations in image-based studies present specific challenges. In response to these, some studies have directed that participants do not photograph themselves or other people [20] and many disallow images capturing any person's face [6]. Such a stance potentially perpetuates the marginalisation of children and young people in research and limits their ability to represent themselves in and on their own terms.

We suggest also that just as in other forms of research, children and young people may wish to please the (adult) researcher by providing photos they think the adult wants from them. Therefore balance may be achieved by providing careful but not overly constrained/directive guidance.

Image-based methods have much to offer when researching with children and young people. However, one method will not suit all children or all young people, and (just as in any research with children and young people as participants) there is a need to be flexible in the ways of working with each child or young person because, as Hill [31] noted, a 'one size fits all' approach is not likely to work.

## 7.7 Key Advice

1. Be flexible and responsive to enable the child's or young person's participation in any way they can.
2. Provide clear (but not complex or directive) instructions about what (and who) they might take photographs of and what to do if they are worried.

3. Have clear processes for gaining permissions for images that can be used in dissemination and the limits for their use. Have in place processes to clearly track and determine what images you can and do use.
4. Researchers need to be highly reflexive throughout the study so as to navigate potential risks and disclosures.
5. Make it fun!

## 7.8 Conclusion

Participatory research with children and young people, engaging them in research, recognises and pays attention to their many different ways of viewing their lives and the world in general. Child-centred research methods recognise the value of children's and young people's experience and agency. Using images in research with children and young people is a participatory approach for working with them in ways that recognise and value their agency, experience, abilities and perspectives. The approaches take the emphasis away from traditional adult power-based research methods that emphasise the spoken or written word and provide flexibility and creativity, essential elements when researching with children and young people. These research methods provide opportunities for enhancing the engagement of both participants and audiences. They present methods for enriching communication and facilitating conversation in interviews and increasing accessibility. When photos are taken by, or chosen by, adults (whether that is the researcher or others such as parents), the methods may be less child-centred and participatory. However, the research intent, design and methods, including the directions and control given to participants, will all impact upon the participatory nature of the research. When children have control of the camera, control is passed to them, and they can be perceived as fellow researchers [2].

Image-based research can empower children and young people, giving them choice and control over the substance of photographic images and also which images they choose to talk about in interview. Children's and young people's use of photos can contribute to making the invisible visible and provides a powerful and effective vehicle to gain insights, into how they see, experience and make meaning of their lives. For many children and young people, this approach is fun and engaging. Importantly, when they are given the opportunity to drive the creation of images and the interview itself, there is a shift from research *on* and *about* to research *with* and *by* children and young people.

## 7.9 Useful Resources

- The Health Promotion Research Centre at Dartmouth presents photo voice and photo elicitation studies with people of all ages on this website: http://www.hprcd.org/photovoice/.Accessed 26 Apr 2017

- *PhotoVoice* is a UK-based organisation. The website has information about participatory photography projects: https://photovoice.org/. Accessed 26 Apr 2017
- The website for *PhotoVoice Australia* has information about a number of photo voice projects including ones with children and youth: http://photovoiceaustralia.com.au/. Accessed 26 Apr 2017
- Circle is a collaboration between academic nurse researchers in the UK, Australia and New Zealand. Their research with children and young people is participatory and arts-based. The web site provides examples of projects, methods and publications: http://circle-research.weebly.com/. Accessed 11 May 2017

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# Being Participatory Through the Use of App-Based Research Tools

# 8

Sophie Hadfield-Hill and Cristiana Zara

## 8.1 Participatory Research Using Mobile Technological Tools

The focus of this chapter is the ethical and appropriate use of technological tools in supporting social scientific, participatory research with children and young people [1]. We live in an age where digital technologies are pervasive and where smartphones, tablets and mobility trackers are interwoven in the comings and goings of everyday life both across the minority and, increasingly, majority world [2–4]. Over a decade ago, Sheller and Urry [5], in their work on mobile cities, argued that socio-technologies have the capacity to reform our understandings and experiences of urban space. Indeed, this work on how mobile communications can shape physical mobility and everyday experiences of the city has been influential in considering the mobile tools themselves as important actors in the nexus of social science research. Thus, the role of technologies in social science research is an expanding and important subfield of social research methodologies [6, 7]. Hesse-Bieber's [8] edited collection of emerging technologies in social research addresses a diverse range of technologically enabled tools from personalised health monitoring systems [9], digital ethnography [10], online focus groups [11], data mining [12], digital storytelling [13] and mobile phones [14] to name a few examples.

Increasingly, the digital world permeates our research with children and young people [15, 16]. We are surrounded by daily media discourse which simultaneously posits technological innovation as both an enabler and a threat to everyday life. On the one hand, we see reports published from the House of Lords Communications Committee in the UK, for example, which argued that young people should leave school with a 'well-rounded understanding of the digital world', emphasising the importance of technological skills [17]. On the other, we

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see that smartphone use whilst driving is a significant cause of injury for young people and is often blamed for young people's perceived lack of engagement with nature [18] and a primary cause of obesity [19]. In 2016, we saw the development of Pokemon Go, a free app-based game, where users searched for gaming characters in their proximate physical environment. Users sought out PokeStops, augmented reality overlaid onto everyday, real-world physical features, such as bus stops, cafes and museums. The media frenzy which surrounded the Pokemon Go soon heralded it as a tool to encourage walking, exercise and thus having a direct impact on obesity and as a tool to further connect people with the outdoors [20]. With over six million downloads, this was a moment which prompted widespread discussion about young people's mobility, use of technologies and the gamification of everyday life, although like other social and cultural trends of the past, user figures are now on the decline [21]. The opportunities for researching young people's social and cultural interactions with digital technologies, and everyday implications, are diverse. Literatures are often grounded in broader discussion of youth culture [22, 23], safety [24], techno-childhoods [25], mobility [26, 27] and spatial literacy [28] and often theorised with the lens of actor-network theory [29]. Indeed, in the context of using apps and other technological tools in researching childhood, actor-network theory (ANT) encourages us to consider the objects of research, i.e. the GPS devices, the batteries, the mobile phones and the chargers as key components of the social network thus 'explor[ing] processes by and through which humans and non-human entities involved in social life relate to each other' [30, p. 201].

What then of the opportunities for using technological tools in our research with children and young people? In this regard, comprehensive literature on the usability and appropriateness of digital methodologies with children and young people are limited. However, a recent editorial by Ergler et al. [31] began to unpack the methodological intricacies of using mobile technological tools in research with young people. Other specific examples to note include the use of wearable ICT devices in research [32], studies which have used the tracking capacity of GPS-enabled technologies [33–35], the use of digital technologies for understanding neighbourhood spatialities [36, 37] and the implementation of social media in prompting online discussion [38].

Researchers in health studies have also embraced the use of GPS and accelerometer technologies in their research with adults [39] and increasingly young people. These studies are often characterised as large scale (usually in excess of several hundred young participants) and quantitative and have a principal focus on young people's outdoor mobility and health-related consequences [40–42]. Sadler et al. [43], for example, used GPS technology and diaries to investigate young people's exposure to 'junk food' through their mobility patterns, analysing 7499 journeys from 654 young people. In this regard, Chaiz et al. [40] argue that the use of GPS within health-related studies should be integrated with daily mobility surveys, to triangulate and verify the data. Indeed, they suggest using online mapping tools to 'prompt recall of the places visited … and reconstruct missing portions of trajectories' [40, p. 50]. As social scientists, we advocate that it is principally through talking to young participants and co-analysing the data, together, that we can get closer to the lived experience of mobilities and spatial literacies of young people [31]. From a review of principally health-related research in using GPS technology with young people, participatory tools are an underutilised methodology in this field. In a similar vein, Christensen et al. [33, p. 16] argue that ‘in combination, the ethnography and the new technologies worked successfully to produce a multi-layered dataset, which makes it possible to carry out analysis that can broaden and deepen our understanding of children’s everyday mobility’.

With the increased implementation of digital methodologies in research with children and young people, it is vital that we seriously consider the intricacies of such approaches, their advantages and pitfalls, ethical issues and practical implementation. Indeed, Ergler [31] suggests that ‘there is a risk that researchers will be enticed by the allure of new modes of data collection’ which would undoubtedly lead to ethical and implementation oversights. We need to think carefully about how digital technologies are conceived, designed, applied and analysed – ethically and appropriately in all our research interactions with children and young people. Indeed, it is also the emotional and affectual aspects of using digital technologies which should be given due consideration, as discussed by Hadfield-Hill and Horton [34] on young people’s emotional engagements with digital technologies in social science research. This chapter then focuses on the appropriate use of app-based tools in research with young people. Using the case of the *Map My Community* mobile application, we review the method, practicalities, opportunities and challenges associated with *participatory* app-based research. Here we emphasise and advocate for a participatory approach to using such digital technologies, working *with* young participants in the design, implementation and analysis of digital data.

## 8.2 App-Based Participatory Research in Practice

### 8.2.1 Aim of Study

The *Map My Community* mobile application was conceived, designed and implemented as part of a large research project funded by the Economic and Social Research Council (ESRC). The project, *New Urbanisms in India: Urban living, sustainability and everyday life* (ES/K00932X/2), was an in-depth investigation into everyday experiences of urban transformation in India, to understand the impacts of urban development on the lives of diverse groups of young people. The principal aim of the mobile app tool *Map My Community* was to capture data on the mobilities, patterns and everyday experiences of young people. The use of the app builds on previous ESRC-funded research (*New Urbanisms, New Citizens*: RES-062-23-1549) which used mobile phones and GPS devices to collate data on young people’s mobility in spaces of urban development in the UK (see [28, 34, 44]).

### 8.2.2 Target Population/Who Participated/Recruitment

In the context of widespread urban change in India, this project was a unique opportunity to gather empirical evidence of the experiences, issues and needs of children, young people and their families, living in and moving through new urban spaces. Lavasa, a development under construction in the Indian state of Maharashtra, was the focus of the research, a private sector-led initiative, where five towns for a projected population of 300,000 people were being constructed (fieldwork took place in 2015). Forty core families from diverse social backgrounds participated. Across the methodologies, the team conducted 170 interviews and involved 350 children, young people (aged 5–23) and adults in the research. Participants were recruited through a range of education and social spaces. For an 11-month period, the researchers lived and worked in the case study site, living alongside the participants, being seen and known as the researchers. *Map My Community* was introduced to participants once a relationship of trust had been formed, to begin the co-designed process of app design and implementation.

### 8.2.3 Participatory Research

As Children's Geographers, our approach enables children and young people to be key informants in retelling their experiences of urban change—through their voice, mobilities and everyday interactions (see [45, 46] for an overview of Children's Geographies literatures). Grounded in ethnography and aware of the benefits of participatory research (both for the participants and the research) [1], we were committed to ensuring that young people had a significant stake in the design (layout, form and function), implementation and the analysis of their data. The different stages of the process are outlined in Table 8.1 below.

### 8.2.4 Research Methods/Tools Used and Rationale for Their Use

A mixed methodological, qualitative approach informed the basis of the data collection for the wider *New Urbanisms in India* project. Of the 40 research families, 30 participants took part in *Map My Community*. There were three research-led features in the app which were informed from previous research with GPS-enabled devices and mobile phones to glean data on young people's mobility in new urban spaces [28, 34, 44]. An overview of the app activities can be seen in Table 8.2 below.

### 8.2.5 Ethical Issues

There are a series of ethical issues to be considered, particularly with regard to digital literacy, non-English-speaking participants, loaning of mobile phones, capacity for participant withdrawal, working with location-based data, anonymity and cultural appropriateness. These ethical concerns are addressed directly in the Techniques

**Table 8.1** The process of app development, involving researchers and young participants

| Stage | Activity | Involvement |
|---|---|---|
| 1 | App questions and consent statements drafted by researchers in line with funder and institutional requirements (aims and objectives of the project) | Researcher led |
| | Draft app questions and consent statements tested with 100 young people in the UK (aged 14–16) to ensure understanding | Researchers and young people |
| | Workshop with eight young people in the UK, inputting into the design, layout, process and form | Researchers and young people |
| | Feedback from young people was used by researchers and the app developers to complete Stage 1 of the app design | Researcher led |
| 2 | Participants from the research site spent time with the researchers adapting the content of the app to further suit their specific cultural context | Researchers and young people |
| | Workshops addressed: (i) the design and layout of the app and cultural appropriateness of the logos; (ii) the language of the app content ensuring age relevance and cultural specificity; (iii) translation into the local language, Marathi; (iv) the design and implementation of an app related consent form for young people and their guardians | Researchers and young people |
| 3 | Realisation of the method—young participants actively facilitated the process, including peer-to-peer learning, intergenerational guidance and digital literacy | Researchers and young people |
| 4 | Analysis of the data in the form of a follow-up interview. The researcher and the participant co-analysed the data | Researchers and young people |

**Table 8.2** Summary of ‘Map My Community’ activities

| Activity | Aim | Description |
|---|---|---|
| *Map my week* | To gather data on participants’ everyday life, mobility and use space | Outdoor movements were tracked for up to a 1-week period, using the GPS enabled on the smartphone device. During this period, at regular intervals, participants were prompted by the app to participate in a short survey, asking where they were, who they were with and how they were travelling. This process spatially verified the data and ascertained the social and spatial mobilities of young people and their families |
| *Capture that* | To enable participants to share their emotional responses to specific features of the built environment | Participants took photographs of their surroundings and commented on features which they liked or thought needed improving |
| *Explore that space* | To explore participants experiences of and feelings towards specific features of the built environment | Informed by dialogue with key stakeholders (i.e. architects and urban designers) at the app design stage, a series of predefined areas were input into the app architecture. On a regular basis, the app polled for the participant’s position, if within one of the preselected boundaries, they were requested to complete a survey about their experiences of that space |
| Follow-up interview | To co-analyse the data | Tracking data was inputted into Google Earth which enabled participants to follow their routes and view the data at different spatial scales. It was this layering of data which offered the most valuable insights into participants’ experiences of shifting urban landscapes |

section of the chapter. It was vital that both adult and young person consent was gained for participation, to ensure that all were aware of the implications of mobile app-based research. Importantly, participants took part in a training session prior to participation. This project received full ethical approval from the University of Birmingham Research Ethics Committee.

### 8.2.6 Findings

The app-based tool was an effective conduit for data collection, complementing the other project methodologies. The GPS-tagged tracks were used as a prompt for discussion about everyday mobility, based on actual mobility patterns; the survey data gave specific insights into location-based experiences (see Fig. 8.1); and the photographs, which in some cases yielded up to 80 photographs per participant, gave detailed insight into everyday life (from playing to cooking and farming). Based on the app data and analysis of the complete range of research material gathered, 12 core themes emerged which represents significant new knowledge about the everyday lives of children, young people and their families living in a site of urban transformation (see [47] for the final project report and key findings).

**Fig. 8.1** Example of GPS tracks produced through the app and uploaded onto Google Earth

### 8.2.7 What You Would Do Differently in the Next Project?

The *Map My Community* app is now being used in a participatory project in Delhi, India. Working in collaboration with Humara Bachpan, an NGO who works on participatory urban planning advocating for change in children's local environments, the app has been co-adapted with young people to support their work (see Fig. 8.2 for an example of this data). There are three important points to consider in the process of app development: (i) factor in plenty of time for testing the technology, fixing the tweaks which are needed and ensuring that young participants are aware of the potential technicalities which can occur from the outset (i.e. with battery life of devices or loss of mobile signal); (ii) ensure expectations are managed (of the stakeholders, the young people and the broader community); and (iii) recognise that it is the co-development of app-based tools with participants which will lead to the most meaningful outcomes.

### 8.2.8 Impact on Participants

Young participants reported that they had developed their team working, research, technological skills and increased digital literacy as part of the co-design process. Overwhelmingly, participants enjoyed using the tool, although there were

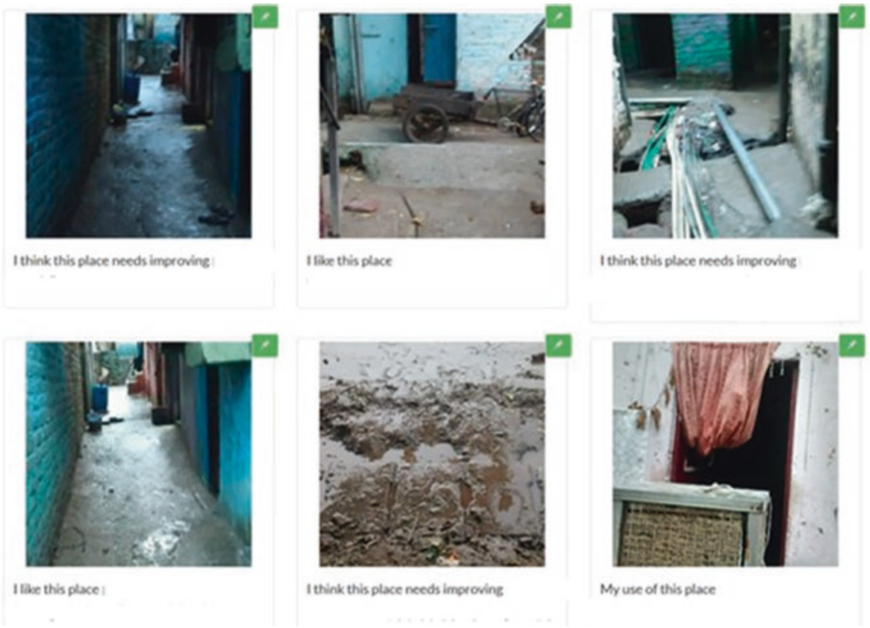


**Fig. 8.2** Example of the data being produced by young participants living in informal settlements in Delhi

frustrations reported with battery life and signal range in the case study area. Impacts also emerged from changes to infrastructures which were recommended via the data collection; these changes to local environments will mean that these environments are more suitable for the needs of children and their families. It was the involvement of stakeholders early on in the app design and project development which ensured the applicability of the research findings to the context and the potential for impact.

### 8.2.9 Dissemination Techniques

The app-based data and results of the study were disseminated via a series of participatory model building workshops. Young people worked together to build a model of the next town being developed, using recycled materials, informed by the findings of the research. The data were used to present key findings back to the young people which they used to inform the building of the model. The output was displayed locally, showcasing young people's experiences and future visions of urban change (see [47], for further information).

### 8.2.10 Conclusion

This app-based research tool lends itself to participatory processes, involving young people in the design, interpretation and dissemination of the results. The app data gave insight into everyday mobilities and routines, giving access to marginal time-spaces which are normally difficult to access (e.g. favourite places, routines and habits). However, data also enabled research into sensitive issues, particularly the gendered nature of space, social and cultural norms and expectations.

## 8.3 Techniques Section

This section is structured around the techniques of implementing app-based research with children and young people. There are five sections to address here, (a) *appropriateness for the research;* (b) *appropriateness for research with children and young people—socially and culturally;* (c) *participatory app research;* (d) *the process of app development; and* (e) *practicalities of collecting the data.*

### 8.3.1 Appropriateness for the Research

The first consideration needs to be, is the use of app-based research tools appropriate for the research? Like with any methodology, the advantages and disadvantages of the method need to be weighed up before embarking on data collection. Will the data collected from the app help to answer the aims and objectives of the research?

What type of data needs to be collated? Can this data be collected with an app (either one which is already designed and on the market, or one which you are designing yourself)? This is an important point. Available in the market are a series of apps, designed for research purposes; Apple, for example, has recently launched ResearchKit, using open-source software to enable medical researchers to use the Apple community in large-scale research studies [48]. Social science research app frameworks are also available for researchers to use to collect data (see, e.g. *EpiCollect*—http://www.epicollect.net/). This can be a more cost-effective way of implementing a research app tool; however, it is important to be aware of the current inflexibility of many of these instruments. As we have found in our research, having the ability, in participatory app-based research, to be flexible is hugely important: flexibility in terms of the questions and measurements being collected, flexibility to ensure cultural and age appropriateness and flexibility to ensure the best possible data is being collected to answer the research questions.

There are other important factors to consider in deciding whether an app is an appropriate tool, and this relates to cost [49]. Unlike other social science methods where the costs are relatively low in terms of the design and implementation of the method (i.e. interviews and focus groups), using any form of technology is going to add to the cost of the project. With app-based research, there are costs associated with development, the design, the testing, the ongoing maintenance, the cost of the devices (if users do not have their own) and the costs associated with time; this is a time-intensive methodology on the part of the researcher which should not be underestimated. Similarly, the sustainability of the app needs consideration. At the outset of the research, there will be a timeframe for the completion of the data collection and writing up. For example, an undergraduate dissertation student will have a couple of months to collect data, or a longer-term research study may have several years—in any case, this timeframe needs to be realistic in deciding which methodologies would be the most appropriate. A further consideration should be: What happens to the research tool, the app, after the end of the project? Can it be used by other researchers? How can the investment in the app be extended and best utilised?

Finally, in this chapter we advocate for a mixed methodological approach [50] when using app-based research tools—how might the use of an app complement and extend the other methodologies being used in the project? An important point in this regard is relationships; building trustful relationships with participants is vital for the success of using participatory app-based tools. In social science research, we seek to get close to the lives of children, young people and adults to understand their lives in-depth. Using app-based participatory methodologies is one way of doing this, but only if it is appropriate for the research.

### 8.3.2 Appropriateness for Research with Children and Young People: Socially and Culturally

Second, the app-based project should be appropriate for research with children and young people. Indeed, this is similar to any research with potentially vulnerable participants, ensuring methodologies are suitable for young people's participation. To an extent, this is determined by the specific research questions; if the project has an aim and research questions which are suitable for the collection of data from young people and it is already determined that the use of an app would be an appropriate tool for data collection, then researchers should consider how best to design the app with and for young participants. Ensuring the appropriateness of the tool will emerge from discussions with young people themselves in the design and implementation stages.

A primary consideration regarding appropriateness is the type of data to be collected and the ethical implications (see [51], for a discussion of ethical implications of using tracking data in public health research and [31], on 'rethinking the ethics of research for a digital age'). For example, if location-based data on mobilities is required, then the implications for childhood need to be considered [33]. The data will be pinpointing, with high accuracy, the routines, spaces and times of children's outdoor activity. To ensure the ethical and safe use of these data, this will need to be aggregated to ensure that the spaces and times of specific childhoods are not disclosed in public forums. If the app will be collecting image data, how will individual identities be protected in the visualising and future use of the data? These issues relate to having appropriate, informative consent procedures for using the app. Indeed, Ergler et al. [31] comment that 'we should more actively engage in debates about what confidentiality, privacy and anonymity mean in digitised research environments'. As with all research with young people, ensuring parents, guardians and young people themselves are fully informed about the purpose of the research, what data collection involves, how the data will be stored and managed and what the researcher will do with the data is very important in the informed consent process. Additionally, consent procedures should involve the means for young people to withdraw from the study, either automatically through the app or by speaking to the researcher. A further aspect which needs attention is the safe handling of data. As social science researchers, this most often means how we store it on our computers and backup copies on password-protected, encrypted devices [52]. However, app-based tools open up further ethical complexities associated with the transmission of data. In building the app, researchers should ensure that the data collected from young participants is secured safely on transmission. Data needs to be encrypted when transmitted from the phone to the end point, where the data will be stored. Failure to ensure the safe passage could mean compromising the data, opening up the transmission to hackers.

Given the newness of these tools in social science research, it is important not only to have appropriate consent procedures but that adults and young people understand the information given to them. Living in an era when controversies over technological data are rife, in terms of how third parties use and sell personal data [53], the consent process for mobile technological research needs to ensure users fully understand the research process. Particularly for multi-method research, it is recommended that researchers design a specific consent form, purely for the app-based research. It would be unethical to ask for consent for a suite of methodologies, i.e. interviews, focus groups and app-based research, when the use of technological tools prompts specific ethical ways of working.

There are further ethical and practical issues which need to be considered in the implementation of app-based technologies. First, in terms of digital literacy [28], we should not assume that all young people have access to, use and are familiar with smart technologies; indeed, to some extent, this will be guided by the social and cultural context of the research. In our research in India, for example, young people were generally aware of the capacity of smart technologies, often having seen a device used by an extended family member, but traditional mobile technologies (no smart capacities) were primarily used in this setting. This strengthens our case for participatory app-based research, involving young people in the app design and implementation. Young people should be involved in designing consent forms and being part of the app-training sessions—this ensures the appropriateness of the method for the local context. A further issue relates to how young people could be using the phones in the research. Some researchers may ask young people to carry the device in their pocket or their bag when they are outdoors, to map their mobility. Or perhaps, young participants may be asked to use the mobile device to take photographs or answer short surveys when they are in their local environment. In some research, it may be that the young people have their own devices which they would like to use for the project (whilst being aware of data limits) or perhaps the research project will loan them a phone. In either case, the researcher needs to be clear about the safety implications of using mobile devices in the public [54]. In all of our research, we have made it explicitly clear that if someone tries to steal the phone, the participant should hand it over immediately; the young person's safety is the priority. There are other safeguarding issues which need due consideration particularly with the loaning of devices to young participants. Researchers need to be aware of what other activities (i.e. phone and internet activities) mobile phones can be used for [45]. We need to consider the ethical responsibilities that we have as adults in terms of potentially exposing young people to harmful material. In our research, we have used app blockers to prevent use of the Internet, primarily to ensure the mobile data is used for the sole purpose of the research and also to prevent misuse, by either the young participant or whoever else may come into contact with the device [55, 56]. All of these issues are mitigated to some extent by the research approach being participatory, involving the young participants in the research process, building up a relationship of trust, for the safe use of mobile technologies in research. Participatory app-based research ensures that the technologies are implemented in a culturally sensitive way. Working with young people, co-designing the research tool—from the initial functionalities of the app to its design, including associated consent procedures and issues related to language, visual representations and framing—will ensure the ethical and culturally appropriate use of the tool.

### 8.3.3 Participatory App Research

App-based social science research with children and young people is most effective when the process is participatory, involving young participants in the design, implementation, analysis and dissemination of the data. Here we draw parallels with participatory research methodologies in working with children and young people; see, for example, Bitou and Waller's [57] and Groundwater-Smith et al. [1]. How participatory app development works in practice will depend on the social and cultural context in which the research is taking place, the other research methodologies and the amount of time for the research. In this section, we suggest some times and spaces when researchers and young people can work together, co-designing and co-delivering the research (see Table 8.1 earlier in the chapter). Here we follow Cahill [58] in arguing that the approach should take 'seriously young people's agency and capacity' [58, p. 299] and be about more than data collection—'a collective praxis approach' [58, p. 297]. First, at the *conceptualisation* stage of the project, it may be that young people can be engaged in the initial stages of the research, in formulating the research questions and the methodologies. Involving young participants in this early phase is ideal, but we are all aware of the constraints of research proposals and funding agencies in defining our research agendas and methodologies prior to entering the field. Bitou and Waller [57] rightly highlight that 'research is not usually the child's priority … in participatory research the assumption is that children can be co-researcher in a set of research questions defined by the adult researcher'. However, there are times and spaces whereby research may be a priority for young people (as in the case with the Map My Community project in Delhi), and as adult researchers, we can facilitate the process, together with the young participants. Second, the *design of the app activities* involves young participants in the explicit design of the core app features; this enables participants to have a stake in the type and form of the data collected, and it ensures that they understand how the app works and that it is usable for other young participants (see Fig. 8.3). It is vital that the language used in the app is accessible, being aware of social and cultural linguistic nuances. It may also be that the app content will need translating.

In our research, we participated in language classes at local schools—during these sessions, young people worked on the translation of the app, i.e. Marathi to English/English to Marathi. In terms of the design of the app activities, there is also the option to involve other stakeholders in this process. For example, in the development of *Map My Community*, the research feature *Explore that space* involved working with architects and urban designers of the case study area to identify specific zones to input into the app. Working with stakeholders from the outset, asking them which areas they would like to know more about (in terms of how participants use public space), meant that the data was relevant to the needs of the stakeholders and the project had greater opportunity for impact and influence. The third opportunity for participatory work with young people is *testing the technology* to find out, technically, which aspects of the app work and which need improving (Fig. 8.4).

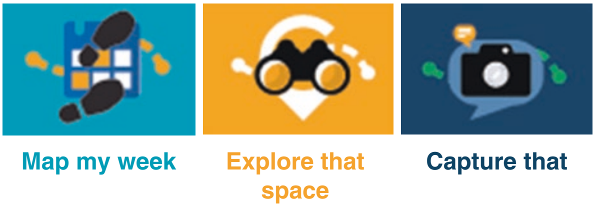


**Fig. 8.3** Map My Community logos used in the app

It is important in all these stages of participatory app development that expectations of young people are managed [1], particularly in terms of the capability of the technology and associated costs (what it can and cannot do); working with an external app development company in the production process means that there may be limitations to the initial project brief and app functionalities. The fourth opportunity for participatory working is through the co-designing of the consent statements. The consent process is vital for the ethical applicability of the research; by involving young people in the design of the statements and the consent form itself, this ensures that (i) a pool of young participants are well-versed in the ethical complexities and thus can act as advocates for the research and ethical processes, and (ii) by co-designing the app consent statements with young people, we can ensure that their language is accessible for diverse groups of young participants (also see [59]). Fig 8.5 below shows a series of consent diagrams drawn by young participants to help explain to other young participants what will happen to their data during the research. All app-based research needs to ensure that high ethical standards are met, given the precision of new smartphone technologies; as recognised by de Souza [60] 'due to a combination of GPS, triangulation of waves and wifi [there are three key issues] privacy, sociality and spatiality' [60]. Locational privacy is a central concern in the western media context where 'obscure and often hard-to-find privacy policies make it hard for customers to control their locational privacy … users often feel vulnerable when they are not in control of with whom their location is being shared' [60]. Ensuring that we, as researchers, are maintaining high ethical integrity in all our research interactions is highly important, particularly as app-based research in the social sciences becomes more commonplace.

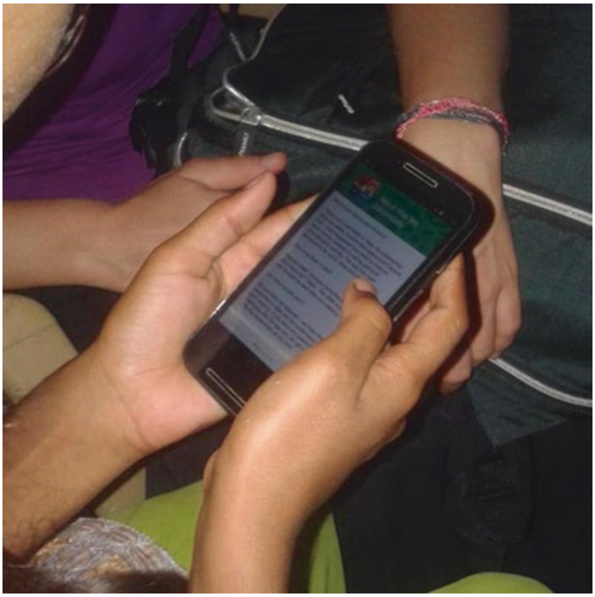


**Fig. 8.4** Testing the mobile app activities and content with young participants

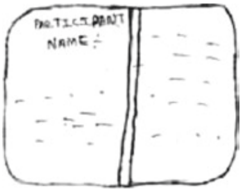
| | |
|---|---|
|  | a. Drawing to represent:I understand that I do not have to take part in this research and I can stop taking part at any time. |
|  | b. Drawing to represent:I have received information about storing the collected information safely |
|  | c. Drawing to represent:I understand that my name will not be used in any reports, publications (like books or magazines), but the researcher will speak and write about the research findings both here in India and in other countries |

**Fig. 8.5** Consent drawings and corresponding statements

The fifth participatory opportunity is the post-app, *co-analysis interview*. This is an important part of the process for the co-analysis and verification of the app data (see also [33]). In our own research, young participants took part in the app activity for up to a 1-week period; then, in arrangement with the young person, a follow-up interview was organised for several days after the end of the data collection period. This is framed as a co-analysis, interview session, where the young person and the researcher review the data together (presented on a laptop), talking through the collected information to glean further insight into the spatial and temporal intricacies of the data (see Fig. 8.6). The final opportunity for participatory working with young people would be in the *dissemination of the app-based data*; in our research, these sessions were run as workshops bringing together young people, the researchers and the data to work together to find the best way of presenting the data to key stakeholders and the wider community. In our work in Delhi supported by Humara Bachpan, young people themselves ran community-based workshops with the community to showcase the app findings and initiate conversations with stakeholders about changes which were needed on the ground. By involving young people in all aspects of the app-research process, from the conception to design, data collection, analysis and implementation, this can have significant benefits both for the research and the wider impact of doing participatory research with young people.

### 8.3.4 The Process of App Development

In all of our app-based research to date, we have worked with an app development company who has realised the vision of us as researchers and our co-developers, the

**Fig. 8.6** Participant reviewing app data in a follow-up interview

young participants. Here we do not pretend to be experts in the technical development of mobile applications; rather, over the years of using these technologies, we can offer a series of reflections and points of recommendations for the development of an app for use in social science research. One of the key points in developing the app-research tool is to be clear from the outset what you as the research team (both researchers and young people) want to get out of the data collection process. Some key questions you may like to consider:

- How will the app-based data help you to answer your research questions?
- Which features of the phone (i.e. the camera; the GPS) will be needed to be integrated into the app architecture?
- How many app activities will be appropriate for your project?
- How will the consent procedure and registration for the app be formulated?
- How do you want the data to be presented? In what format?

Prior to the stage of the actual app development (technically), researchers, together with young people, will need to ensure they are clear about all of these aspects. From experience, once the process of the app development has begun, there is the potential for minor modifications to the flow and the presentation of the app, but structural modification will entail more work and ultimately more cost.

There are a series of points which need consideration when designing the app which will need to be discussed with the app developers. Once the app activities have been formulated, in line with the specific research questions, these will need to be translated into a working app logic for the developers to build the app infrastructure. The working details and framework of the app need due consideration, thinking through how the app will work in practice. Associated with working out the app journey of the participants, it is also important to spend time on the information screen which users will read on downloading the app. This information will need to be concise and informative to ensure users read and engage with this material (see the project website, http://www.new-urbanism-india.com/map-my-community.php, for an example of the information statements). After the information screen will come the consent agreement. All research apps should have the consent procedure built in to the app, although we also suggest that traditional face-to-face informed consent processes are also built into the process (for reasons identified earlier in the chapter). Similar to the app information, the consent statements should be concise and easy to understand. The following consent statements have been adapted from the 'Map My Community' project:

- I have read and understand that [*Insert app name*] is a research app.
- I can contact the researchers to ask any questions I have (via the Settings menu).
- There are 3 activities: [*Insert names of activities*]. Once registered I need to click on each icon to consent to taking part and activate each activity. I can stop and withdraw my data within 2 months of registering.
- I give permission for my data to be used by the researchers in reports, publications and other project materials (my name will not be used).
- The researchers will speak and write about the project findings to the public and academic community.
- Personal GPS tracks will not be given to the [*Insert name of archive*]; this means that other researchers will not be able to use your data. Your photos and survey comments will be shared with other researchers, but your name will not be identified.
- I agree to take part in the [*Insert name of app*] research activity.
- If I am under the age of 18, a written consent statement is needed from a parent or guardian before I can participate.

With regard to the types of data which are going to be collected in the app, parameters for data collection will need to be decided. For example, if location-based data is to be collected, what will be the limits for GPS tracking? How often will you want to poll for a participant's position, e.g. every 2 s, every 5 s? Your decision will impact on battery life of the phone and the amount of data which will need to be stored, so testing this will be paramount. The process for storing data, safely and securely, on encrypted servers also needs consideration. At the outset of the project, it is also important to know: What the data should look like? What will you want to be able to do with it? How are you going to analyse it? The answers to all of these questions will shape how the app is developed. The testing of the app also relies on a close working relationship between the young people, the researchers and the app developers. Young people will be testing for usability and accessibility in terms of the understanding of language, flow of the app infrastructure and the data required in each activity. The researchers will be testing for accuracy, for example, is the data geospatially accurate and to what degree, and is the phone performing to its best ability given the external conditions (i.e. signal strength/transmission of data)? Is the data showing correctly in the back-end website? The developers will work with this information to modify the content to ensure robust data collection on the ground.

### 8.3.5 Practicalities of Collecting the Data

In this final section, we address some of the further practicalities of collecting the app-based data with children and young people as participants. Given the participatory approach which we advocate, the parents and guardians of the core participatory group will have been involved from the outset, giving permission for workshop attendance and meetings with the researchers to discuss app development [58]. However, once the app has been developed and a wider group of young participants become involved in the project, it is important to ensure that parents and guardians are clear of the app-research process and all it entails. In our research, we visited the homes of all young people taking part in this aspect of the project in order to go through in detail the consent procedure and the core features of the app. A training session with the young person took place, explaining in detail all of the app features, how it worked and what to do if there was a problem. As already explained, some young people may not have access to the technology to enable them to participate. If this is the case, then the research project will have to loan a phone, charger and perhaps an external battery pack (for those homes which do not have a regular supply of electricity to charge the phone). This loan is for a defined period, determined by how long the young person would like to take part for; in our research, this has been any time up to a week. If a young person already has access to a smartphone to be able to take part in the project, the researcher may need to offer to pay the cost of the data package for the defined period. During the data collection, the researcher can check to see if the data is being transmitted and contact the young participant if there are any problems. At the end of the predefined period, the researcher collects the equipment, downloads the data and arranges for the follow-up co-analysis interview.

In this section on *Technicalities of participatory app research*, we have identified key areas which need due consideration when embarking on this type of methodology. First, we have argued that researchers must consider whether their research is suitable for app-based methodologies and also appropriate for researching childhood. Second, we have asked researchers to consider the ethical and practical nuances of using this methodology with children and young people. Third, in advocating for a participatory app-based method, we identified spaces and times in the app development process for this to occur *with* young participants.

## 8.4 Advantages and Challenges

In this final section, we consider the advantages and challenges associated with participatory app research with children and young people. These are based on our own experiences of conducting this type of research. We recognise that as the technologies develop and app-based methodologies become more commonplace in social science research, indeed in different social and cultural contexts, the advantages of this method will expand, but so too will the challenges.

### 8.4.1 Advantages

There are a whole host of advantages which participatory app-based technologies offer in researching with children and young people. We start with the participatory potential of the method, through the involvement of young people in the conception, the design, the advocating of data collection, the analysis and dissemination; this ultimately leads to greater uptake by young people and willingness to participate. It is the co-working on the project which gives young people a stake in the research process [59]. In our own research, we can make a direct comparison between a participatory app-based methodology and an app-based research where participants were recruited with limited knowledge of the process. In the *New Urbanisms in India* project (see [47]), initially we set out to include tourists in the research sample, visitors to the new urban space, to garner their experiences and views through the research app. This was the least successful aspect of the research, primarily due to time constraints (when people are tourists), which meant that there were less opportunities to involve this group in the research process, resulting in an impact on uptake of the research method amongst this group of participants.

A further advantage of the participatory way of working with the technology is the resulting community involvement in the research process. We have found in both of our projects in India that participatory app-based methodologies prompted wider engagement from the community, with parents, siblings and friends expressing interest and wanting to be involved in the data collection and outcomes of the research. Thus, the intergenerational potential of using this methodology is significant. Above all, we have found these tools to be key ways in which young people can actively collect data about their local communities, both for the research and for broader societal goals.

This methodology offers a series of advantages for social science research. In our research, we have found that the data collected from app-based tools has been vastly different to the data we have previously collected from more traditional social science methodologies with children and young people. The data collected from *Map My Community* gave us access to marginal and often hidden spaces of everyday life which we, as researchers, rarely get access to; however, importantly, it is the combining of the technological data with the co-analysis process which leads to the most insightful data (see also [61]). These tools enable researchers to capture data as it happens, for example, mapping mobilities. As researchers, we are not purely relying on a narrative of the data, after it has happened, but using locational based data tracking, we can see young people's lives on the move which enables for a more accurate representation of young people's mobilities and experiences of space.

### 8.4.2 Challenges

There are a series of challenges associated with participatory app-based research. First, we recognise that some of these are not distinct from the broader set of challenges which are associated with participatory research with young people [62]. On the one hand, we are advocates of participatory research with young people as it 'helps challenge social exclusion, democratize the research process and build the capacity of young people to analyse and transform their own lives and communities' [58, p. 298]. On the other hand, however, we are aware that some participatory methods can be nothing more than tokenistic, particularly given the requirement by funding agencies to already know what our research questions and methodologies are, in exact detail, before enlisting the support of 'co-researchers' [62], which ultimately runs the risk of reproducing unequal power relations [58]. To overcome these challenges, in app-based, participatory research, we have found that involving young people in the design, implementation, analysis and dissemination of the data enabled their voices, actions and thoughts to be taken seriously in the research process. We have found the sharing of knowledge between young people and researchers throughout the process to be a point of mutual understanding and learning. In participatory research, often barriers, such as skills or competence, are considered to be challenges. However, in app-based research, we have found it to be a co-learning process of app design and development. Furthermore, there were times and spaces when the young people themselves positioned themselves as experts, for example, in the translation of the app content from English to Marathi and further along the research process where the young people knew more about the features of the app than the researchers; they were the ones training other young people and family members in use and functionality.

Notwithstanding the challenges of doing participatory research with young people, there were a series of technical challenges. Aside from the hardware (the phone) and the software (the app) needed to conduct the research, a further important consideration is the data coverage of the mobile network in the area of the research. Prior to deciding on a provider, it is advisable to check the network coverage. Researchers should also consider the availability of electricity for charging electronic devices; in contexts where families only get several hours of electricity per day, alternative charging points are needed (i.e. loaning portable devices). Other challenges include an awareness of the glitches and faults which can occur with technological data collection tools; the time taken for accuracy and functionality testing should not be underestimated [63]. Indeed, in considering all of these challenges, it is important to remember the position of the young person in the research, how have they experienced using the technology and what can we learn from their involvement in the project? Recent literature has begun to explore these questions, considering participant experiences of using GPS devices [63] and children's emotional commitment to such technological research [34].

## 8.5 Key Advice

1. Designing and implementing app-based tools takes time, particularly during the testing phase (to ensure data accuracy).
2. Sustained working *with* children and young people to design and implement the app-based methodologies yields positive outcomes for the research and the broader community.
3. Working with children and young people creates opportunities for learning together about technological tools.
4. Clear and concise ethical statements are needed on downloading the app; participants need to be well-informed of the use, safety, anonymity and security of the data and be given opportunities to withdraw.
5. Using app-based research tools are most effective in combination with other methodologies (i.e. a follow-up interview with co-analysis of data).
6. The research tools have to be appropriate to the research questions and context. If you choose app-based methods in your research with children and young people, embrace the opportunities (and challenges) that this affords.

## 8.6 Conclusion

This chapter has considered the practical and ethical complexities of carrying out participatory, app-based research with children and young people. As technological tools become further integrated into social science research with young people, the academic community needs to think carefully about how digital technologies are conceived, designed, applied and analysed—ethically and appropriately. Using the app-based research *Map My community* as a case study, we have highlighted both the advantages and the challenges associated with this type of methodology. We advocate for meaningful, ethical, participatory interactions with young participants, where young people are co-designers, co-analysers and co-disseminators in the use of app-based data—this gives opportunities for in-depth, multi-method research into young lives and provides opportunity for wider societal impact.

## 8.7 Useful Resources

*Map My Community mobile application*
http://www.new-urbanism-india.com/map-my-community.php

An overview of the *Map My Community* research app used in the New Urbanisms in India (ESRC-funded) research project. Information about the participant guidance and the consent statements.

*EpiCollect*

http://www.epicollect.net/

This is a resource to assist researchers with the development of a mobile app (suitable for both Android and iPhone). Basic questionnaires can be created with geotagged entries. This is an open-source project, funded by the Wellcome Trust.

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# 9

# Participatory Research: Does It Genuinely Extend the Sphere of Children's and Young People's Participation?

Bernie Carter and Imelda Coyne

## 9.1 Introduction

> …..adults and children are alike—as humans we are all social subjects who continuously develop and change in relation to the material and social context and the experiences we obtain from these. [1]

Throughout this book, good evidence of innovative and engaging participatory research practice with children and young people has been presented. The history and traditions of participatory research practice have been explored, examples of good practice have been shared, and different methodologies and methods have been presented. The enthusiasm, skill, knowledge and passion of experienced participatory researchers reveal ways in which other researchers, especially those taking their first steps in participatory research with children and young people, can adopt this approach and these techniques in their own research studies.

Although there is inevitably 'more to do', it would be easy to be complacent about participatory research with children and young people. At first glance our table of contents perhaps suggests that we have participatory research 'wrapped up'. If we were using a mental checklist of progress with participatory research with children and young people, a naïve consideration might suggest that we have participatory research nailed down. In effect, a complacent researcher approaching

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participatory research might well think the following: historical and contextual triggers for shift to participatory research, sorted; ontological, epistemological and methodological issues, sorted; ethical considerations and guidance for good practice, sorted; methods, sorted; and so on. We are certainly more ‘sorted’ than we were even 10 years ago; undoubtedly, participatory research is becoming a more established part of the research landscape mirroring or even exceeding the pace of change of wider participatory practices within society. However, this, in itself, raises some issues. Many people are claiming to do participatory research; some are actually doing participatory research, but there are a lot of people making dubious participatory research claims whose research reflects ‘not very participatory’ research practices.

In this chapter, we raise questions about the current positioning of participatory research and critique whether or not participatory research is firmly established. We also raise some questions about the extent to which the claims that even committed researchers and academics make about participatory research are authentic and where and why we might be failing to be genuinely participatory. In brief, we explore whether participatory research is just ‘froth and bubbles’ or a genuine extension of the sphere of children and young people’s participation. And as part of this critique, we consider whether any of us can truly act in a participatory manner when we each have a ‘welfare monkey’ sitting on our shoulders (more about the welfare monkey later on, but in brief this reflects the welfarist protectionist voice that is hard to ignore and which often limits our actions).

Before we go much further in the chapter, it is important to turn to the voices of children and young people and consider what they have to say about participatory research. Drawing on field notes from our research, we share a couple of stories.

### 9.1.1 Story 1: Boundaries and Roles

In the step-up phases of a participatory research project, I (Bernie) was explaining more about participatory research to the children, aged between 6 and 11 years, who were interested in co-producing the study with me. During the early part of a discussion that was broadly about power relations, one of the children raised the following question, ‘…so this study is about us and we are important and can have our say and you’re gonna listen and take notice of us, so what happens if we say something wrong or do something stupid?’. It was a good point and one not just of relevance to children and young people’s engagement in participatory research. My response was ‘that’s a really super question, but let’s think about it a bit more, so what are you going to do if I say something wrong or do something stupid?’. This seemingly simple exchange became the foundations of participatory practice within this study. It illustrates not only the children’s insights into the implications for themselves and other children as a result of their engagement in research but also their implicit understanding of their own usual, somewhat marginal and powerless positioning within society. It also revealed their expectation that an adult (the researcher in this situation) would have a role in control and boundary management as well as have the knowledge to know if something was stupid or not. The exchange that followed started to break down some of these background assumptions. It also made clear to the children that despite my ardent espousal of participatory research I would, indeed, exert my adult/professional authority if I judged the situation merited it. On the whole, I think the children were more comfortable with this ‘disclosure’ than I was; they accepted this as both inevitable and reassuring providing, as one of the other children warned, ‘you don’t forget your promise not to interfere too much’.

### 9.1.2 Story 2: A Bit of Magic Dust

In one participatory research study, I (Bernie) was becoming a bit concerned as one young person seemed to be on the margins of the group; she was quieter and seemed more reticent about engaging in the activities than the other members. Even using different approaches did not seem to be making much of a difference. Talking to her during the project about how she was finding her involvement elicited equally reticent responses: ‘it was fine’; she was ‘OK’, so we continued. Gradually, she seemed to become more comfortable and assured, and although her contributions might have been measured as slight in terms of frequency, length, etc., the other group members always listened and took her seriously. The relative infrequency of her contributions was not related to the quality and value of her participation. Towards the end of the study, this quiet girl came up to me and said she had something to tell me. She went on to explain being part of the study had been ‘pretty difficult’ at times as sharing ideas and talking with new people were not easy but that being part of the group had been important and made her realise that she had ‘good ideas’ and should ‘trust herself a bit more’. She felt that this had happened for lots of reasons, such as the ‘warmth’ of the group and the fact she felt that people (young people and the researchers) ‘really respected’ her. She talked of how this had made a ‘huge difference to how I think about myself’ and that she had used the example of her engagement in the research within a successful job application. This example is not a justification for claiming that participatory research will ‘save the world’, but it is a clear, albeit small, example of the transformative effects that participatory research can have on groups and individuals. As Peter Pan might once said had he been a participatory researcher rather than a boy who did not want to grow up, ‘All you need is trust …..and a little bit of magic [participation] dust’. The change that occurred for this particular participant resonates with the transformative potential talked about by other authors (e.g. [2, 3]).

## 9.2 Froth and the ‘Welfare Monkey’

In the previous writing about children’s participation in research [2], I drew on a quote from Arnstein’s [4] work on citizen participation that still seems to me to sum up some of the core issues surrounding participation

> [Citizen] participation is a little like eating spinach: no-one is against it in principle because it is good for you. [4]

I might be unusual in actually liking spinach (there might or might not be a correlation to be drawn between spinach eating researchers and their tendency to undertake participatory research), but the quotation makes a good and applicable point to participatory research with children and young people; in theory participation is good, the rhetoric is strong, but the application and implementation are not always as convincing. Moving away from the spinach analogy, a form of 'greens' not universally loved by children, we're adopting a different analogy/image as the basis for exploring participatory research. Imagine a contemporary and trendy coffee shop with participatory researchers acting as baristas serving up coffee (participation) in a wide variety of different, value added (or not) versions of the core beverage. The purest, most intense form of participation perhaps equates with a double espresso made from the finest beans available served in the perfect cup and with plenty of time to enjoy the entire experience. However, other options include adding to (e.g. an Americano) or changing the coffee into something that an espresso purist would see as sacrilege and who would not recognise a skinny, frothy, caramel macchiato in a cardboard cup as anything to do with their experience and expectation of coffee. What we explore in this chapter is why some participation within participatory research is skinnier, frothier and less pure than the double espresso version of participation. This is not to suggest that there is a regulatory ideal of what participatory research should be. Part of the problem or maybe part of the freedom of participatory research is that it can be many things to many people and that it can be adapted and responsive to many diverse situations, contexts and circumstances.

By froth, we mean that the use of participatory research can be more rhetoric than reality with researchers picking and choosing, adding in elements without understanding the ontological and epistemological roots and rejecting those components of participatory research that are simply either too hard to implement or because they themselves are constrained in what they are allowed to do. Essentialist attitudes in defining the child can limit researchers' vision and understanding of children's evolving capacities by focusing on historical perceptions of passiveness and dependence rather than considering that both children *and* adults are 'simultaneously interdependent and vulnerable as competent active agents' [1, p. 186] and have strengths, competencies and the need to influence their own lives [5]. Froth might look good, but it is ephemeral and not terribly satisfying, and children and young people can quickly see through the pretence of these particular attempts at alleged participation.

The notion of the 'welfare monkey' arises from the welfare of the child principle which dominates so much contemporary thinking within the minority (western) world and which Neale [6] argues is 'essentially an adult construction that assumes children to be inadequately socialized dependants in need of care, protection and control'. This perspective immediately positions children as subordinate to adults, with any right to participate being both conditional and subordinate to their welfare needs. There is tension across much public policy in terms of the rhetoric and drive to encourage children and young people's participation and a sense of the incompatibility of participation with the equally strong drive to ensure their protection. Whilst not specially talking about participatory research, Tisdall [7] notes that how we perceive children and young people directly influences our informal and formal practices. However, the influence of the welfare principle goes beyond just our perceptions. As researchers, we are influenced by the organisations we work for and the rules we are governed by, and these are often risk-aversive, conservative and limiting. Gatekeeping is a prime example where reasonable protection can tip into paternalism and overprotection [8], denying children access to opportunities well within their compass [9]. Stoecklin [10] acknowledges the double-blind relationship that professionals (in his paper, teachers) are bound within and how this relationship limits their participatory actions and ways of being. Stoecklin [10] argues that teachers are expected to exert authority as well as to listen to children. For those of us undertaking participatory research, there is still often a tension between the principles and values we advocate and the requirement for us to work within a welfarist approach; the welfare approach literally becomes the 'monkey on our shoulders', chattering in our ears to 'protect the children', 'take great care' and 'work cautiously, whilst our participatory nature is calling us to 'be open' and 'work in a more unpredictable and possibly more risky manner' and 'acknowledge the different capabilities and capacities' of the children and young people. For those of us whose professional background is within healthcare, we ourselves will have been, to a greater or lesser degree, encultured into a hierarchical, often paternalistic culture that limits personal autonomy despite the current shift to more fluid, empowered thinking and practice.

## 9.3 Bubbles and the Extension of Spheres of Participation

Two major spheres of participation exist: the private sphere and the public sphere. Authors writing about participation propose that children and young people's participation is mostly limited to the private sphere [10–13]. Children and young people's strongest opportunities for engagement, negotiation, expressing their views, decision-making and influence occur within their home, conditional on their parents/carers having democratic parenting practices [11]. Some authors such as Larkins [13] propose that the private sphere extends beyond the home and into the children and young people's neighbourhoods, school and leisure activities. However, the private sphere is never completely private, and it can be constrained or otherwise by sociocultural influences, political context, intergenerational power relations and other factors that limit agency [1]. The home is an important place to nurture children and young people's evolving capacity to participate [12], and this is important as it can prepare children and young people for participation in the public sphere. However, children and young people's ability to genuinely influence the public sphere—the places where 'decisions are made about individuals, communities and markets'—is limited [12, p. 446]. Children and young people often have a low impact within the political area [14], and children can be marginalised and excluded from opportunities for authentic participation. Engaging right from the start with community partners means that there is effective buy-in and a vested interest in the study [15] by the 'public sphere' increasing the potential for successful and meaningful engagement and action. Studies that engage with their target audience can produce insightful understandings of how members of this audience can respond to the messages that children and young people want to represent. Mitchell's [16] study, for example, illuminates the tensions and different positionings of a group of policymakers to a photograph that the young people felt held an important message but which presented a negative image of the setting.

So, what does participatory research offer children and young people? We propose that participatory research can act as a bridge between the private and the public spheres. Participatory research generates the potential for children and young people and researchers to create the conditions for building a robust network of relationships and opportunities. These opportunities include sharing ideas and co-producing knowledge as well as empowerment and transformation. These changes should not just occur within the boundaries of the research study itself, but they should reach out and create more systemic change in both the children and young people's neighbourhoods and communities as well as wider society. Participatory research should facilitate the mutual and reciprocal exchange of ideas between children and young people and the people in power within the public sphere; opportunities for activism should arise from participatory research (see Fig. 9.1). Wyness [17] notes that there are five dominant narratives of children's agency/participation in the literature: formalised, event-based, outcomes-oriented, discursive and individualistic. The risk for participatory researchers is that the research study acts as a bounded event-based act. If research is primarily event-based, few voices leak out and those that do stand the risk of being ignored or dismissed, and the research has little sustained impact beyond the time-boundedness of the event: a potential situation of more froth than substance.

Stoecklin [10] proposes that considering children and young people as actors within a networked system creates opportunities for a new way of looking at participation. This perspective offers insights for participatory researchers who can view participation not simply as the immediate external and visible actions (e.g. how often a child or young person contributes an idea to the study) but also as the inner, internal and longer-term changes that happen to the children and young people as a result of their participation. Seeing children and ourselves as actors within a

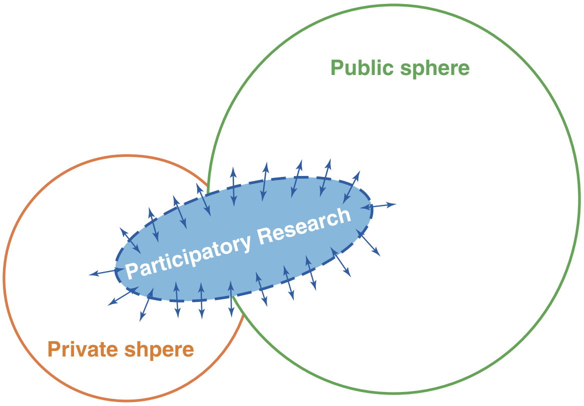

**Fig. 9.1** Participatory research as a bridge supporting mutual and reciprocal exchange

networked participatory system of research means that we need to consider the implications of everything we do; within a networked system, everything affects everything else. What each actor (researcher and children and young people) does both shapes the system and shapes the actors. The conditions we create for our participatory research in turn create social opportunities for children's and young people's capacities as social actors to be transformed, not just within the bubble of the participatory research study but much more widely than that.

Creating the conditions to support the children and young people's personal reflexivity is considered key to the evolution of their capacity and capability for participation. Participatory research should take heed of this and consider ways in which children and young people's reflexivity can be promoted and supported within their research. Hanson [18] notes that the practices we instigate can either support or limit children and young people's participation. Key to this is ensuring that our participatory research studies are genuine co-productions that endeavour to be transformative and empowering, both individually and collectively, and with an underpinning determination to influence and change society. Transformation can occur through the empowerment of children and young people by developing their skills [19] and sense of self or recognition of the respect afforded by others [20]. The outcomes of participatory research have the potential to challenge the ideas, attitudes and feelings of all those involved in its co-production; authentic participatory research should involve the questioning of past practice, should reveal present practices and, most importantly, should cause what Gatens [21, p. 53] calls 'a shift or tremor in the web'. In other words, outcomes should cause shifts in thinking and create change in society; this change may not be massive, but the gradual accumulation of small changes can have a major effect on the webs of relations within society. Cockburn [12] talks of co-production of 'governance through partnerships and community involvement' but talks of the need for public sphere to change in order to accommodate the different voices of children and young people; participatory research can help do this.

## 9.4 Conclusion

In conclusion, participatory research has achieved much. This we can see from the examples presented in this book. However, in order for it to really achieve its potential, participatory research needs to become more engaged in a sustained way with enabling and supporting change.

Participatory research needs to be more than an event bounded by the start and end of the study; it needs to be part of a wider shift in society that is about co-producing change with children and young people. Neale and Flowerdew [5] talk of the importance 'now being accorded to children's own histories, biographies and projected futures in understanding how their lives unfold over time'. We can only really understand their lives if we engage with children and young people and gain a sense of their lives and their future orientations and respect their perspectives, opinions, values and ideas.

If we genuinely want our participatory research to be more than froth and bubbles, we need to consider the essential and fundamental ways we can support children and young people's reflexivity, and to co-design and co-produce studies that will be transformative and empowering for the individuals and which will reach out beyond the participatory bubble of the study into wider society.

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