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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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