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Children's participation in health research: from objects to agents?

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Abstract

Background In the UK, there is a growing recognition of the need to include children's accounts in research on paediatric health care. This paper seeks to examine ways in which children have been included in health-related studies to identify strengths and weaknesses.

Methods Key empirical based studies were identified via comprehensive searches of academic literature databases to exemplify research practices related to three ways of engaging with children in health-related research. These three approaches are summarized as research *on* children, *with* children and *by* children.

Results Research *on* children engages with adult 'authorities', such as parents and medical professionals. This approach allows some access to children including those understood as hard-to-reach: for example, pre-speech infants, or children with complex developmental disabilities. Research *with* children includes children as respondents to engage directly with their own understandings. This may be achieved alongside adult representatives, or by focusing only on the children themselves. Research *by* children encourages children to participate in the research process itself. This may occur across any, or indeed, every stage from design to dissemination to enable children to set the agenda themselves. Each of the three approaches has strengths and weaknesses, and involves some form of adult-mediation.

Conclusion Inclusion of children's perspectives can be achieved, at varying levels, in each approach (on, with and by) examined here. Although claims to authority around including children's perspectives may appear to hold more credence when children have directly participated in the research, there may be times when this is neither possible nor appropriate. Researchers are challenged to be open and reflexive about ways in which children are engaged with, incorporated in and represented across the many stages of research. Whichever approach is taken, ethical issues and notions of equity remain problematic. This point holds particular resonance for ways in which ethics around children may be considered in National Health Service ethics governance processes.

Keywords
childhood, children's views, ethics, health, participation

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Part of the policy context of this includes *Every Child Matters* Nesman, T.M. (2007) A participatory study of school dropout and behavioral health of Latino adolescents. *Journal of Behavioral Health Services & Research*, **34**, 414–430. and *Aiming High for Disabled Children* Department for Education and Skills (2004) *Every Child Matters: Change for Children*. Stationery Office, London.

'Talking Mats' have been developed from speech and language therapy aides. They are laminated cards, with a question or point written on, plus a number of response cards that are then offered to the child to pick out. Department for Education and Skills (2007) *Aiming High for Disabled Children: Better Support for Families*. HM Treasury with the Department for Education and Skills, London.

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Introduction

In both healthcare studies and policy making, research that evaluates the care experiences of disabled or chronically ill children is being given greater priority (Wise 2002). At the same time in the context of policies and legislation in the UK that focus on the rights of children, the demand is that such research is carried out in a way that children themselves, as opposed to their parents or service providers, are listened to and heard (Roberts 2000). In recognizing the value of exploring children's experiences from their own perspective, we are left with the challenge to find appropriate ways to do so. This challenge is what this paper seeks to explore; it asks what kinds of approach can include children, how and for what purpose? It does so by drawing from the long history of research about children in areas, such as sociology, and increasingly within healthcare studies, in order to highlight both good practical ways of working, while also identifying the principles that lie behind such techniques. The focus is on literature and empirical evidence from health-related research in which children have been engaged with in some way. Our argument is framed around a continuum, from research done *on* children, to that which is carried out *with* children, and finally that which is *by* children. To explore the continuum, we highlight particular research studies that we believe are useful 'exemplars' of what is possible and what the costs and benefits are within each approach.

Before we work through this continuum, we will first briefly summarize two key ways of conceptualizing children's lives and identities from within the sociology of childhood (Mayall 1998; Corsaro 2005). These understandings inform our approach and are useful for researchers working in health to consider. First, it is important for researchers to think through what they mean by the category of 'child' or 'children'. It is easy to associate this category with clearly defined boundaries of age, after all the key legal boundaries between adulthood and childhood invoke age as the definitive marker of when something, such as marriage or voting, becomes permissible or someone becomes responsible, such as for a criminal act. In the research context, it is perfectly reasonable to think that the same approach for working with 5-year-olds may not be appropriate for 14-year-olds, and visa versa. The assumption often is made that it is easier, more productive and less ethically complex to work with older children rather than younger ones (Clark *et al.* 2005). The downside of such assumptions is that we do not hear the perspectives of younger children, who will not necessarily have the same concerns or needs as older children. Recognition of this dilemma has led researchers to develop approaches which they propose can be used with the youngest of children (Docherty & Sandelowski 1999; Harden *et al.* 2000).

A broader point here, however, is the need to trouble the use of age as a fixed and clear cut category within which to distinguish which approach works for which children. What we know from the sociology of childhood literature is that childhood is complex and socially contingent (James & Prout 1997; James *et al.* 1998). The stages of development, the levels of maturity and the breadth of ability expected of children of different ages, vary over time and place (Qvortrup 2007). The expectations society has of what a child of a certain age should be like, and what stage their development towards adulthood has taken them to can be thought of as normative constructions against which children are measured and judged. Indeed assumptions that are made about a child's development based on their age can contribute to their social and political vulnerability by justifying their exclusion from decision making about their lives (Qvortrup 1994; Mayall 2002). What this means for research with children is that age becomes only a loose approximation of what a child's aptitudes are and at times even a barrier to engaging with the child as an individual who cannot simply be read against an age-defined template.

The second understanding to draw from the sociology of childhood is that 'child' is not the only social category of significance here. Other aspects of a child's social background – their race and ethnicity, social class, religion, emerging sexuality for example – will also intersect as aspects of who they are, their social position, and what researchers need to consider in designing research approaches appropriate to the children they are studying. It is important to do so, if research is to move beyond a tendency to present a relatively narrow range of child-types (Clark *et al.* 2005). Alternative children's voices, such as those from non-white and/or ethnic minority communities, are often missing. The reasons given for this omission often focus on assumptions that certain children are just too difficult to reach, and/or difficult to engage with in any depth (Dwivedi 2002). An increasing wealth of research does now exist which indicates ways to both reach such groups and also develop culturally and socially responsive approaches that can engage with socially marginalized children.

One example where we can see this is within work with disabled and chronically ill children (Connors & Stalker 2003). Limitations associated with comprehension and communication, which can emerge from the affects of the illness and/or impairment, are crucial to areas, such as assessing competence, negotiating consent and engaging with individuals throughout the lifespan of the research (Alderson 1998). However, the danger is that the apparent complexity of working with a diverse

range of ill or disabled children, can also lead to marginalizing their views by limiting the research done which includes them. Assumptions remain that ill or disabled children will not be able to communicate something of value to the research or comprehend what is involved (Hughes 1989). There is significant work available suggesting ways to challenge such reserve, particularly in disability studies, which explore techniques that can overcome these problems (e.g. Beresford 1997; Connors & Stalker 2003; Lewis & Porter 2004). For example, finding appropriate alternative ways to communicate is crucial, and Lewis and Porter (2004) recommend a range of innovative methods, such as use of pictures, cue cards and Talking Mats, while Connors and Stalker (2003) encouraged children to express themselves more freely through drawings, tape recordings and writing before moving on to more formal interview techniques around the chosen research topic. It is important to also stress that illness and disability are not only factors in evaluating a child's competency to participate in research and which methods are most appropriate. They are also social categories, which have embedded within them various cultural and social meanings, which can influence how researchers engage with disabled or ill children (e.g. assuming their lives are tragic), which must either be worked past or worked with.

Childhood is a social phenomenon shaped and mediated by social and cultural factors, which are politically and materially significant when we also consider issues, such as economic position and marginalization. Researchers need to consider such issues in order to adapt the approaches described below to the particular contexts that inform the lives of the children they will be working with, produce a socially responsive evaluation of what will work with the children, and finally to ensure they avoid repeating the patterns of exclusion and marginalization the children may be experiencing in other aspects of their lives.

Methods

Key methodological and empirical based studies were identified via comprehensive searches of academic literature databases (in particular Web of Knowledge). Searching was designed to capture both work discussing research with children and also exemplary studies in applying such approaches to research activity. We were particularly focused on capturing work which included considerations of both power dynamics and ethical issues within their research approach and design. Through our searches and analysis, we identified three ways of engaging with children in health-related research: research *on* children, *with* children and *by* children.

Research on children

Research on children asks adults around children, such as parents, teachers, nurses and doctors, to discuss and define children's views, interests and priorities. This approach can be found across the spectrum of quantitative and qualitative research methodologies, and disciplines including sociology and healthcare studies. It has a long history from, for example, early revelations of children's experiences of poverty and destitution alongside their adult counterparts at the start of the industrialized age by Charles Booth (Donzelot 1997; Bales 1999). Often it is through children's main caregivers, in particular parents, from whom we gain a sense of what children are about (Baldwin & Carlisle 1994; cited in Connors & Stalker 2003). Perhaps it is no surprise that adults responsible for the care and well-being of children are called upon in research to account for them, particularly when the subject matter is particularly sensitive as in, for example, Alkon and colleagues' (2003) research on the value of mental health consultation in pre-school child care centres. Alkon and colleagues draw on insight from questionnaires and interviews with managers of mental health agencies, and questionnaires and focus groups with teachers in the child care centres. Through this they build up a picture arguing for a continuation and further development of forms of mental health consultations and support alongside high quality child care environments. Although they do not include the perspectives of children directly, the study concludes that these services will enhance children's social and emotional development.

Research on children, such as that by Alkon *et al.* can be legitimate given that those who live or work with children do have an intimate knowledge of their lives, which can inform views on the acceptability of the healthcare services they receive. It can also be argued that even in research which does not speak directly with children, their own presence can come through the research. In our own previous work, which was also on a sensitive subject about pre-school children, the children were also not directly involved as participants (Mclaughlin *et al.* 2008). The main focal point was on those who might be described as holding informal forms of expertise around the child from their position as main care-givers – in this case, parents. The research question explored the experience of support (formal and informal) for families, and how parents felt these shaped family life. Because the research was with families of very young babies and infants, to capture a time from when some of the earliest questions around each child's health were raised, we believed it would not be possible to include accounts of the children themselves. However, although the children's own perspectives, in

their own words, were not included, children were nevertheless present in the research. Rather than invisible, fieldwork observations and parents' stories of their children reveal ways in which their children interact and respond to the world, and how they often find ways to resist the efforts of adults around them, no matter how well intentioned, to control them. For example, one of the parents spoke about ways in which her child played and discovered her body in new ways that were a revelation to her parents and proved, if that was necessary, how important she was as an individual above and beyond her disabling condition (Mclaughlin *et al.* 2008, p. 75).

A great deal of insight into children's worlds can be found in research on them, even though they are not involved directly as participants. However, we cannot escape the issue that each adult-representative is providing their interpretation of what they think are the issues for the child and what is best for them. Thus, what children want, think, worry and dream about are ultimately filtered through multi-lenses of adult-orientated concerns and claims making. Children remain objects framed by an adult-centric worldview, a mode of engagement for understanding children's lives that continues to dominate much research today (Qvortrup 1997). Some writers have gone as far to see this approach as a form of adult-centric 'imperialism', or colonization (Cahan *et al.* 1993, p. 194) of the known child. On its own therefore research which is on children is rarely sufficient to meet the needs of providing a space to fully engage with children's perspectives. This has led, in part, towards an increasing focus on doing research *with* and *by* children.

Research with children

There is an increasing concern that the omission of children's perspectives may either mis-identify their needs and/or focus on the needs of the adults (providers or carers) who interpret their needs (Fox & Berrick 2007). Researchers working across disciplines, such as sociology, anthropology, critical geography and social history have sought new ways of working with children directly (Greig & Taylor 1999; Valentine 1999; Christensen & James 2000). Much has been carried out to redirect the research gaze towards recognizing and valuing children's accounts of the world. The first stage in doing so is to incorporate children's perspectives alongside adult-accounts (Sweetling 2001). The value of this work is the potential for acknowledging differences and tensions between the accounts of adults and children. It actively engages with differences in standpoint between adult and child and ways in which each party may at times make contradictory claims. Bauman and colleagues (2006) interviewed children and mothers to look at ways in which children may take on roles usually held by adults, such as when they become the carer for their own parent/s. Their analysis compared interviews with the children and their mothers; one of their main findings was that the children tended to feel they had more influence on their mother's decisions than was acknowledged by their mothers.

The second stage of this approach focuses only on children. Methodologies have been developed that are appropriate to their cultural lives, local understandings and social position. The impetus for much of this work draws on arguments within the sociology of childhood which revision children as social agents in their own right (James & Prout 1997; Scott *et al.* 1998). Of particular influence has been the work by Nordic childhood researchers, such as Jens Qvortrup and Pia Christensen, which puts children at the heart of research, and acknowledges that children exist as social interlocutors, engaged in their worlds and involved in shaping it (Solberg 1997). They, alongside their British counterparts, such as Allison James and Sue Scott, argue it is important to hear children because they are likely to have very different things to say about their lives and those around them.

Research with children can raise new insights into children's worlds, and into their relationship with the adult world around them. These alternative perspectives and concerns may not fit with adult-assumptions about what their priorities may be. In their review of research with children looking at experiences of care systems, Fox and Berrick (2007) identify key points children highlight, in contrast to the priorities of care providers. They refer to Wilson's (unpublished) study, for example, of children in the US foster care system, which showed how (perhaps surprisingly) the ability to establish meaningful friendships became one of the greatest concerns in a context associated with rupture and uncertainty for the children. The top-down approach of the care system, however, took little account of individual friendship bonds, and was instead focused on assessments of care and notions of safety at a more remote level. As Wilson identified, children's perceptions of risk, safety and security have implications for their physical and psychological well-being both in the short and long term. Children, framed here as 'the clients', raise awareness of how important it is for adult-led services to 'get it right' both for children and for wider society.

The value of research that seeks to understand children's ways of knowing from the perspective of the child is evident. Such engagement asks us to rethink the nature of childhood itself. Through finding ways to hear children, childhood can be recognized as something children 'do' rather than simply 'be' (Solberg 1996, 1997). Research with children reveals social and

cultural processes in which they are constituted, shaped and formed. This approach occurs when the agenda is set by the adult researcher, while the point of focus is directed at the child. However, this is not always a straightforward hierarchy, a reflection which can in itself tell us a lot about both children's ways of being in wider social and cultural contexts, and the way power may be experienced and negotiated. The challenge for the adult researcher is to find ways into children's visions of life. This is not a simple process as demonstrated in Davis and colleagues' (1994) ethnographic research with disabled children. Here additional resources, such as time and the development of new skills, were needed to offer insight into ways children communicated and interacted with other children, teaching staff and their environment. By attending different classes with each child, and talking to them about everyday experiences during breaks the researcher developed ways to 'get to know' individual children. The emerging complex relationship between researcher and child thus became very different from relationships the child was likely to have with other adults in the school setting.

Davis's approach enabled him to see the school in different ways and challenge his own previously held assumptions about authority and agency, very much dominated by adult (in this case, teacher) understandings. This new relationship, however, held many new challenges for the adult-researcher trying to access children's lives, and Davis found himself placed in situations where his adult status came with assumptions of authority when, for example, a teacher left him little option but to take control of a child's hands in a musical lesson. Moments like these offer glimpses into ways in which adults are themselves shaped and defined against our understandings of children. Doing research with children, then, not only engages with notions of childhood but may also offer up new perspectives on adulthood that may be revealed along the way (Christensen 2004). Furthermore, with this comes opportunity for deeper reflection on the dynamics of everyday interactions.

It is important to recognize that these new insights into children's worlds remain in the main framed by adult concerns – namely those of the research team (Christensen 2004). Just as research *on* children is clearly adult-led, so research *with* children can not, and indeed does not make claim to be child-led. Research approaches, questionnaires, interview schedules, conceptual frameworks, analysis and disseminations remain the domain of researchers. Wording might be tweaked to reflect children's interests and culture, such as in the language used in questionnaires for child respondents to complete (Coad & Evans 2008), but control of which words are chosen and which questions are asked ultimately remains the responsibility of the researcher. Hence, adult researchers are the organizers, interpreters and authoritative voice on children's worlds. This in itself is not necessarily problematic: adult researchers are drawing on their research experience and expertise to develop appropriate research questions and methodologies. Nevertheless, there is research, which we now turn to, that seeks to go further in exploring what active role children can play in shaping research agendas, as well as research findings.

Research by children

One way to strip away a further layer of adult-researcher control is by enabling children to take on the role of researcher themselves – this is what we mean here as a basic principle of research *by* children. Participatory research actively encourages participants to set the research agenda (Kostanski & Gullone 2007). By taking the research agenda to the subject, participatory approaches encourage an equitable relationship between research parties that is particularly appropriate when engaging with marginal groups, such as children (Cornwall & Jewkes 1995; Vander Stoep *et al*. 1999). Children are able to initiate and direct research, and thereby set the research agenda (Alderson 2001). Participatory research provides space in which, to a greater or lesser extent, participants are able to design the research, direct the analysis and/or shape dissemination. This approach to research, like the other approaches detailed above, started out from the standpoint of adults and adult-worlds. However, with the growing child-orientated agenda informing and shaping new research, it is increasingly aimed at enabling children to influence research that is about them (Thomas & O'Kane 1998; Alderson 2001).

Just as there are a multitude of research approaches and methods available to researchers working on and with children, so research that can be said to be by children may do so in many ways and at several different junctures in the research process. Alderson (2001) identifies a spectrum of approaches involving children as co-researchers across each point in the process of both quantitative and qualitative research: in everyday encounters; as research participants; helping to plan research questions; collecting data; involved in analysis; and, publicizing findings. None of these preclude adult involvement. Research that is, for example, planned, carried out, analysed and reported by children could have been inspired, guided and shaped by adults. Participatory approaches open up junctures for negotiation across the life-course of a research project. This offers new opportunities to appreciate children's perspectives appropriate to ethical principles, with less interference and filtering out through adult concerns and priorities (Thomas & O'Kane

1998). Furthermore, there are advantages beyond ethics: by opening up the research agenda to children as far as possible, strengthens claims to reliability and validity in areas of study relevant to them (West 1997).

Some of these advantages can be recognized in work that opens up health-related research processes to particularly vulnerable groups of children, such as those from ethnically and socio-economically diverse populations (Nesman 2007; Claudio & Stingone 2008). Two case studies discussed by Coad and Evans (2008) illuminate ways in children may be involved at multiple points in the research process including data analysis and dissemination. One was with a research group of six young people (12–21 years) in Yorkshire, who were trained as peer-researchers to look at issues around bullying. In this study, the child and young person-led research team planned, collected and undertook data analysis with adults taking on the role of facilitator to support this involvement. The other case study involved children (10–16 years) as an advisory group on a project to identify children's views on a purpose-built children's hospital unit. In this study, adults collected data, and trained and supported the children through the process of defining the research questions, planning the project, collecting and analysing the data, writing up and disseminating the findings. Coad and Evans suggest adoption of a pragmatic framework, one characterized by negotiation and openness of approach, will facilitate the partnership between adult researchers and children. They point to benefits of involving children this way to enable a greater understanding of children's perspectives, and help prioritize children's agendas in policy and practice. However, they also identify challenges in taking this approach on, including recognizing the need to support children fully through each process and building in the additional time this will take, and the need to remain reflexively critical of the way power operates across research relationships that place new demands on children and researchers alike, for example, requiring children to be objective when analysing highly subjective data.

It is clear participatory approaches can break down cultural distinctions between children's lived worlds and adult assumptions, through the mediation of research processes and understanding. However, it is important to bear in mind that this does not, in itself, place each party (child and adult co-researcher) on an equal footing consistently throughout the research life-course. Questions remain about how negotiations are organized, and who makes decisions and when. Processes of power and questions of representation remain issues in participatory research just as they do in other ways of working with children. To incorporate participatory methods in a meaningful way, takes time to develop, establish and maintain along with an ethical commitment to dismantle forces that otherwise remove choice from children and silence them, and more needs to be carried out to critically reflect ways in which these processes continue to shape research relationships at all levels (Birch & Miller 2002; Kellett & Ward 2008; Kellett 2009). How far, then, can it be truly said that children are in control of this form of research?

Although participatory research is associated with ethical practice, in research where participants are disproportionately disadvantaged, it is not in itself a guarantee of removing the risk of further exploitation in the process of research. Schenk and colleagues (2006) point out that extra precautions are required to protect children and ensure safeguards are introduced so as to avoid placing too great a burden on them in the research process, or compromising either their safety or well-being. Once again, perhaps inevitably, there is a time when the adult researcher takes back control – whether it be at the point of agreeing to work in a certain way, or when the research is written up for dissemination, or in having greater responsibility to ensure the children are protected and not placed in harm's way. This is not necessarily a problem – it seems appropriate that though these processes may be negotiated, ultimately there is a need for the adult researcher to take due responsibility. By acknowledging this inherent power and responsibility differential, ways of working this through are opened up for debate.

Participatory approaches encourage recognition of and critical engagement in ways in which power continues to operate and shape research processes. Challenges in so doing are likely to be felt more keenly when participants are particularly vulnerable, as in the case of children with chronic health issues. Participatory methods rely on an open, clear and consistent flow of communication across and between co-researchers. This is not unique to research with children included as co-researchers, as the discussion above around research on and with children demonstrates, communication is a fundamental issue for any research and part of the foundation for any claims to knowing. The need to ensure productive modes of communication between children and adult researchers perhaps helps explain why there is relatively few participatory studies involving children with alternative communication and/or severe, multiple disabilities. This suggests that more needs to be carried out to find ways to develop techniques to enable communication and participation. It is across these very engagements, in which structures of power and marginalization are revealed and challenged, where participatory methods are, arguably, most appropriate. It is likely that those deemed the most remote and difficult to reach are also likely to hold some of the most crucial

insight, and offer the most troubling viewpoints to the experience of childhood and the way power structures operate to exclude some more than others.

Closing discussion

The purpose of mapping out this continuum in the paper is not to promote any one approach over and above another. Instead our aim is to consider the varied potentials and risks of different approaches in order to aid researchers' evaluation of what is possible and legitimate in the context of the topic being explored, the children whose lives are being considered and the aims of the research. Nor is the continuum presented here intended to suggest that researchers must stick to a single approach throughout the research process. Indeed during the life-course of a single research project, approaches may change over time and across stages. For example, initial research ideas may come from children themselves (i.e. *by* children), the children may take a role in developing the research design (i.e. *with* children), fieldwork may involve a range of methods including quantitative questionnaires and non-participatory observations organized by (adult) researchers (i.e. *on* children), while children may be invited to give feedback on analysis (i.e. *with* children), and then be involved in a variety of ways to develop strategies for dissemination in which they may also be encouraged to take part in (i.e. *on, with and by* children).

What lies behind many of the studies we have drawn from here is a clear shift from only viewing children as the objects of research study. In a context where we are acutely aware of children's rights and policy agendas of inclusion in decision making, it is a requirement that research on children's experiences within healthcare asks in what way children can come to the fore as actors with something to say and contribute to how we explore those experiences. Moving in such directions complicates the research process, but in a productive fashion. It does require new innovative methodological approaches, which creatively emerge from and engage with children's varied forms of reflecting on their lives and position in the world. The need for creativity and innovation in methods is particularly important when working with disabled children, where questions of communication problems or comprehension difficulties, do need to be addressed, but not in such a way that they simply become a reason to avoid developing strategies which can work well with such children.

One final comment, which needs further discussion within health research and its management, revolves around ethics and processes of formal ethics regulation. Formal ethics regulation within structures, such as the National Health Service National Research Service has a tendency to think of children as inherently vulnerable and in need of paternalistic protection. The knock-on effect is a precautionary approach, which at times leads researchers to being conservative in what they propose to do with children. The danger is that such adult concerns around children's apparent vulnerabilities can reduce their opportunities for inclusion and reinforce their marginalized position in society (Qvortrup 1994; Kitzinger 1997). However, if we take on board arguments presented here which reposition children as legitimate social actors who have agency and an ability to assert their own values and perspectives, is vulnerability and protection always the appropriate place to begin when considering their involvement in research? Is a better starting point to recognize what they can bring to the research process? Equally, ethics regulation tends to be guided by criteria focused on age and development stages. Too rigid or mechanistic approaches to age and development are likely to rob both the regulator and the researcher of the space and scope to develop the appropriate fieldwork approach for the particular children they are working with, whose abilities, talents and imagination will not be a simple product of age and development.

Key messages

- If the perspectives of children themselves are to be included in healthcare research, then we need to think through the appropriate ways to do so.
- Considering how to involve children in research benefits from understanding childhood as a complex social phenomenon and political construct.
- Current research approaches to working with children can be distinguished as research *on* children, research *with* children and research *by* children.
- There are practical strategies that are successful at enabling research with children who are often seen as not capable of being involved in research, because they are too young, or too disabled or too difficult to reach.
- In a context where we are acutely aware of children's rights and policy agendas of inclusion in decision making, it is a requirement that research on children's experiences within health care asks in what way children can come to the fore as actors with something to say.

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