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The Complexities and Contradictions in Participatory Research with Vulnerable Children and

Young People: A Qualitative Systematic Review

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The Complexities and Contradictions in Participatory Research with Vulnerable Children and

Young People: A Qualitative Systematic Review

Abstract

Participatory research carried out by or with children, has become a well-established and

valuable part of the research landscape investigating children's lives, views and needs. So

too has a critical agenda about its ethical implications and methodological complexities. One

criticism is that the involvement of children who may be considered 'vulnerable' or

'marginalised' has been slower to take root within mainstream participatory practice. This

means that there has been less focus on how groups such as disabled children or children

affected by abuse or neglect can shape and challenge adult-dominated types of knowledge

and decision-making that are likely to affect them. This article reports on the findings of a

qualitative systematic literature review of thirteen contemporary papers. The review was

undertaken by a UK team in 2017. The included articles explored some core ethical and

methodological issues involved in carrying out participatory research with vulnerable

children and young people. It reports on three themes: 1) The extent to which participatory

spaces could recalibrate opportunities and attention given to marginalised and silenced

groups; 2) The ways in which these children and young people could develop skills and

exercise political and moral agency through participatory activity, and, 3) How to facilitate

meaningful engagement with individuals and groups and reconcile this with a critical

appreciation of the important but limited nature of research as means of political and social

change. The review provides a unique, contemporary analysis of participatory research with

vulnerable children, illuminating in particular its conceptual complexities and contradictions,

particularly regarding power, empowerment and voice. Its overall utility and interest is

augmented by the disciplinary and geographical breadth of the included articles, rendering it relevant to many contexts and countries.

Keywords

Empowerment; engagement, co-research; children; participatory; peer-research; young people; vulnerable.

Highlights

- Complexity is an inherent feature of participatory research with children and young people

- Power, empowerment and voice are useful concepts in critiquing participatory approaches

- Participatory spaces can recalibrate attention given to marginalised and silenced groups

- Vulnerable children and young people can exercise agency through participatory activity

1. Introduction: The rise of the children's rights agenda

The past twenty to thirty years have seen exponential shifts worldwide as regards the rights of children. The UN Convention on the Rights of the Child (UNCRC) (UNICEF 1989) is regarded widely as the foundation for children's relationships with the adult, institutional, and governmental contexts in which they live (Lundy, 2007). Internationally, the Convention enshrines the rights of children (defined as any person under 18 years old – see Table 1 for definitions) across a range of areas relating to their lives. These include children's rights to education, play, health, and privacy, as well as their right to an adequate standard of living and to be protected from all forms of abuse, neglect, and violence. Article 12 cements an expectation that adults will meaningfully seek out, engage with, and respond to the views of children in all matters that affect them. It also reinforces a broader conceptualisation of children's experiences - and their knowledge about their experiences - as being unique and valuable.

[Insert Table 1]

Underpinned by legislative and policy changes stemming mainly from widespread adoption of the UNCRC, the relationship between adults and children has, in many countries, also shaped a re-conceptualisation of children as social agents, who actively engage with the political, social, and economic spheres in which they live (Prout, 2005). Assuming that children are autonomous and capable - unless identified otherwise - uproots ideas about the dependency of children on adults for protection and guidance. This, in turn, subtly disrupts some power dynamics between adults and children. It challenges, for example, implicit and explicit perceptions of children as vulnerable and unable to make informed decisions about their future. It also questions assumptions about adults' roles as proxies and guardians for children, particularly when there may be conflict between the rights and needs of a child and a given (often parental) adult (Nuffield Council on Bioethics, 2015).

2. The ascendancy of participatory research with children

Set against the backdrop of children's rights, approaches to hearing and respecting the 'voice' of children in research have seen a corresponding, and significant shift over recent years (Lundy et al. 2011). Taylor and Green (2008) talk of the 'increasing ascendancy' of children in research, who are now regarded as children in their own rights as opposed to mini adults. Participatory work has moved from specialist to mainstream research practice across a broad range of academic disciplines among those interested in the lives, views and wellbeing of children and young people (Kim, 2016). Kellett (2005) referred to this as a new research paradigm for the 21ˢᵗ century and this has consequently swelled the literature regarding researching with children, for example Alderson (2001), Alderson and Morrow (2011), Bradbury-Jones (2014), Coad (2012), Coad and Evans (2008), Kellett (2010; 2011), Kellett et al. (2004), Lundy and McEvoy (2012). This literature has brought with it a new discourse with which researchers have had to become familiar.

2.1. Unravelling the terminology

The participatory research landscape encompasses different intellectual, ethical and practical agendas. Along with the rapid pace of innovation in the field, this has resulted in considerable definitional confusion and conflation about what participatory research is (and should be). Correspondingly, it can be difficult to unravel the multiplicity of terms associated with participatory approaches.

'Co-production' is a central concept that underpins debates about different types of participatory approaches. Ostrom (1996) proposed the idea of co-production to refer to the processes whereby people from outside an organisation contribute to its production or

services. Subsequently, the concept has been used to describe the contribution of service users to the provision of services (Realpe & Wallace 2010). In attempting to disentangle the nature of co-production, there have been a number of analyses, including a systematic review of 122 articles and books on the subject (Voorberg et al. 2015). In terms of research, co-production forms the basis of participatory approaches, and some argue that it has become:

> *A terminological 'catch-all' for numerous participatory, action, community-based and collaborative research approaches, each of which have distinct (and sometime competing) histories, traditions, logics, rationales and methods* (Thomas-Hughes 2017, p. 2).

Co-production in research has attracted its own analyses, for example that of Hewison and colleagues (2012), again with the purpose of understanding the concept more fully. Heaton et al. (2016) talk of co-production as theory. However, for the purpose of this article, co-production is taken as the underpinning principle on which participatory research is based.

Within the wider field of participatory research there is a baffling array of terminology used, for example, co-design, engaged research, participatory action research and co-constructed research (Horner, 2016). In a helpful analysis, Bishop (2014) defines participatory research as a particular form of research that signifies the active involvement of participants in research, beyond providing data. She discusses the subtle but important differences between research *on, with* and *by* children. Over the past twenty years, there has been a marked trend towards the latter of these approaches. Broadly, research with and by children takes place when children are trained and supported to conduct their own research as co-researchers: when they play a significant and equivalent role to adult researchers, and are involved in some or all stages of the research process. Bishop proposes that the last two categories are *participatory research* and for the sake of consistency in this review, we also adopt that language.

2.2. Issues in participatory research with children

As the research community has developed more experience of using participatory approaches, an informed and critical agenda to improve it has also emerged. It is increasingly recognised that participatory research with children is ethically, methodologically, and practically complex: it is a 'messy reality' and one that lacks clear and reflexive reporting about the challenges as well as the advantages (Fox, 2013; McCarry, 2012; Bishop 2014; Thomas-Hughes 2017), and is replete with 'issues and ambiguities' (Yorke & Swords, 2012, p.96). Common problems include securing additional time and resources to carry out work that is often relationship-based and responsive in nature, and, recognising that those children who do participate are not and should not be expected to be 'representative' of a larger group (INVOLVE, 2016; Uprichard, 2016). Another challenge of participatory research with children is the questionability of their contributions as equal and equivalent, when the interpretation and dissemination of participatory research is still overwhelmingly carried out by adult researchers (McLaughlin, 2006).

There is tailored guidance about how to carry out research with children (INVOLVE, 2016a; Kirby, 2004), examples of research are available (Blackburn, Hanley & Staley, 2010) and there is specific advice about issues of remuneration (INVOLVE, 2016b). Nevertheless, the volume of guidance and examples available to research with children remains substantially smaller than that of adult work. Because the field is developing so quickly, there are few systematic or critical evaluations of the quality or impact of participatory research with children, particularly those who are most vulnerable.

3. Participatory research with vulnerable children

Participatory research has become a popular choice for those researching with particularly vulnerable or marginalised children. This includes but is not limited to, disabled children, children who have experienced abuse or neglect, and children who identify as Lesbian, Gay, Bisexual, Transgender or Queer (LGBTQ). Led or co-developed with children, participatory research is often creative and flexible, facilitating the meaningful inclusion of children with complex or additional social and communication needs (Bailey et al. 2015). It explicitly acknowledges and seeks to address the unequal and imperfect ways in which some types of (adult-dominated) knowledge are legitimised and prioritised.

For children whose needs are complex or uncommon – and who may have had difficult or damaging relationships with adults – participatory approaches go some way to valuing and making visible their unique experiences and insights. As with the wider field of participatory research, there is an emerging body of literature that captures the specific advances and challenges of research with these groups, for example vulnerable children in Ireland (Yorke & Swords 2012); those in hospital (Bishop 2014); and mental health settings (Graham et al. 2014); and disabled children and young people (Bailey et al. 2015). As researchers with a keen interest in engaging with vulnerable and marginalised populations - particularly children –we have reflected on the challenges of participatory research relevant to *all* children, and begun to question what this means for those who might experience greater vulnerability and marginalisation than others. We had undertaken participatory research with looked-after young people (those in out of home care) and we knew intuitively, experientially and theoretically of the issues concerned. But we were left with an uneasy curiosity regarding how we might understand the issues more systematically. This reflective stance was the genesis for the review reported in this article.

The aim of the review was to identify, synthesise, and critically examine published literature that reported on the methodological, ethical and practical issues involved in carrying out participatory research with vulnerable or marginalised children. Our aim was to map the landscape of this rapidly growing and increasingly complicated field and to identify some of the central methodological, ethical, and practical issues reported by researchers. With limited guidance and critical reflection on participatory research with vulnerable children and young people, we considered it timely to review and reflect on work being carried out in this field and to contribute new understandings regarding the complexities of such research.

4. Review questions

In participatory research with vulnerable children and young people:

1. What rationale do researchers put forward for adopting a participatory approach?

2. What language do researchers use to describe the positioning of the children and young people within their research?

3. What are the reported ethical, methodological and pragmatic issues encountered in the research process?

4. How might a synthesis of literature inform future directions in this field?

5. A qualitative systematic review

We embarked on the review without a fixed approach regarding the specific methodological angle through which we might approach the literature. This is because we were open to what it might hold. It was evident very early in the process following the initial search results that a significant majority of relevant articles reported on qualitative studies. This is perhaps unsurprising given the discursive and reflective nature of our review question. Also, although not exclusively so, participatory approaches tend to be qualitatively focused. We

decided, therefore, to only include articles reporting on qualitative studies and in line with

Grant and Booth's (2009) typology of reviews, we have named this as a qualitative

systematic review.

Systematic reviews of qualitative evidence have developed considerably – both in their

prevalence and quality – over the past ten years, as they 'catch up' with the more established

canon of meta-statistical reviews, often used to integrate clinical and experimental study data

(Gough, Oliver & Thomas, 2017). This is in part a reflection of the increased use of

qualitative methods in health and social research. It also reflects a need to make transparent

the methods and, as a result, to defend the rigour of qualitative work (Higgins & Green, 2011;

Hannes, 2012). Relevant to our review, Gough et al (2017) point out that qualitative reviews

have potential to lead to new theoretical and conceptual innovations; a point to which we will

return.

5.1. Identification of articles

The first systematic search for relevant articles took place in September 2017. We

interrogated six electronic databases: Cumulative Index of Nursing and Allied Health

Literature (CINAHL); Embase; Health Management Information Consortium (HMIC),

Institute of Statistical Information (ISI) Proceedings of conferences and seminars; Medline

and Scopus. Given the significant volume of articles published in relation to participatory

research with children and the rapid pace of innovation, we only searched for those published

after the year 2000. We only included articles published in the English language as we did

not have the resources or linguistic skills to review articles in other languages. We

acknowledge that these pragmatic decisions may have limited the number of articles included

in our analysis and the range of cultural and social perspectives encompassed in the review

process. In October 2017, we carried out additional 'hand-searching' of relevant journals to identify literature that was not picked up or indexed within major search databases.

Search terms were identified during an extended scoping exercise, carried out prior to the systematic screening of papers in relation to our inclusion/ exclusion criteria. We explored a range of terms that were of potential relevance in addressing our review questions. We then tested these terms and phrases to develop an informed understanding of their definitional and conceptual scope within the contemporary inter-disciplinary literature. When carrying out the systematic review, we used a range of paired search terms in conjunction with Boolean operators in the search strategy. To identify literature relating to children and young people, we used the terms 'child/ren', 'youth' or 'teen/ager', 'adolescen/t/ce' and 'young people'. To identify literature that reported on or discussed co-research, we used the terms 'participat/ion/y', 'engage/ment', 'involve/ment', 'partner/ship', cooperat/ion/ ate' and co-research'. We were only interested in studies that had engaged with children who could be considered vulnerable or marginalised in some way (over and above the inherent vulnerability of all children by virtue of age). We recognise that 'vulnerability' and 'marginalisation' are complex and contested concepts: a point that is explored in critical detail within our findings. However, at the point of retrieving papers we included studies, for example, with and for children in care and/or who have experienced abuse, neglect or violence; disabled children; children with illness/mental health issues; LGBTQ young people. In short, studies that worked with children with often unique and sometimes complex needs or experiences that may not be well-represented by the larger body of co-research literature.

The inclusion/ exclusion criteria captured papers that were of potential relevance in answering our initial review questions (see Table 2). Informed by our exploratory scoping

exercise, the criteria also reflect pragmatic considerations about how to carry out a critical and focused review in a field that is vast and rapidly-developing. With this in mind, we included papers that reported on empirical studies *and* contained a substantial critical or reflective element. This narrow focus captured papers that gave considerable attention to examining some of the specific and often inter-twined ethical and methodological issues involved in carrying out co-research with vulnerable or marginalised children and young people. Reviewing and synthesising papers with this critical focus would, we thought, be of unique and considerable value to those people interested in and an involved in this type of work. We did not quality appraise the included studies. This is because we were interested specifically in researchers' reporting of methodological and ethical issues within their studies, rather than their findings.   In addition, while our searches had put limits regarding publication date, due to the volume of articles retrieved, we subsequently imposed an additional limit to articles published since 2012. We justified this on the grounds that only the most up-to-date material would make its way into the review. This may mean that we have excluded some important articles published prior to this date, but the advantage lies in the contemporaneity of the included articles.

[Insert Table 2]

 [Insert Figure 1]

Figure 1 shows the flow of articles through the review process, with decisions at each stage being agreed by two of the team [CB-J and LI] and verified by a third reviewer where necessary [JT]. The searches retrieved 2129 records and we identified a further seven through hand searching. After removing duplicates there were 1585 records. After screening the title and abstract of these 1585 records, we identified 178 titles of potential relevance in addressing the review questions. That so many papers were excluded at this stage reflects the

large number of empirical papers about participatory research with children. It also speaks to the large number of papers that reported on issues of participation, representation and vulnerability in research with children participants; this in contrast to an explicit focus on co-research or participatory research with children. After retrieving and appraising copies of all relevant papers, we excluded 158, leaving 13 for inclusion in the review.

[Insert Table 3]

5.2. Data abstraction and analysis

We used Table 3 as the starting point for our analysis, extracting information from each article according to the table headings. The headings were constructed with reference to the review questions, ensuring overall coherence in the review design. To some extent, the a priori framework imposed a degree of deduction to the early stages of our analytic process. Grant and Booth (2009) propose that qualitative systematic reviews typically employ thematic analysis. Aligning with this convention, in tandem with the development of Table 3, we undertook an inductive, thematic analysis of each individual article, followed by a full analysis across all included articles. This followed more of an iterative, than linear process, with frequent ventures back into articles that had already been analysed to check the completeness of themes. CB-J and LI undertook the initial analysis and this was checked by JT who had read full copies of each article. JT added an additional layer of rigour to the process by checking the final themes presented here, with the initial thematic analysis of individual articles. This robust analytic process led to the construction of three themes: Marginalisation and Silenced Voice; Empowerment and Power; Inclusion and Influence.

6. Review findings

6.1. Article profile (with reference to Table 3)

The 13 articles included in this review are drawn from a wide scope internationally: Australia, Canada, Finland, India, Papua New Guinea, South Africa, Sri Lanka, UK and USA. This was an interesting and welcome finding given the limitations of our review in capturing only English-language papers. The aspects of vulnerability addressed were wide ranging: Children in a psychiatric setting; Disabled children and young people; Sexuality; Socially excluded youth; Young carers; Young people in care; Young people living in communities with violence, substance misuse and HIV; Young women with IPV experiences.

The claimed reasons for adopting a participatory approach fell broadly into two camps: methodological and ethical. In the first grouping participatory research was seen to increase the relevance, novelty and integrity of the research findings (Greco et al. 2017; Mitchell et al. 2017; Noone et al. 2016; Thomas-Hughes 2014; Vaughan 2014). In terms of ethics, a strong discourse was concerned with the equalising of power differences (Greco et al. 2017; Stevenson 2014; Taylor et al. 2014; Törrönen & Vornanen 2014; Wernick et al. 2014) and giving voice (Aldridge 2012; Chappell et al. 2014; Iwasaki et al. 2014; Stevenson 2014; Taylor et al. 2014; Wickenden & Kembhavi-Tam 2014).

We were interested in the positioning of children and young people within the research. In other words, we were curious about how researchers described the role of the children and young people in their studies. In Table 2 we captured this under 'level of participation'. Two groups were discerned: For one group, engagement was focused at certain points, such as informing the research agenda (Iwasaki et al. 2014); project planning and decision making (Thomas-Hughes 2017); data generation (Greco et al. 2017; Wickenden & Kembhavi-Tam 2014); data analysis (Aldridge 2012; Stevenson 2014); and dissemination (Stevenson 2014). The other cluster of articles described the participation of children and young people from the

onset of the project, through to dissemination (often including co-authorship) (Chappell et al. 2014; Mitchell et al. 2017; Noone et al. 2016; Taylor et al. 2014; Törrönen & Vornanen 2014; Vaughan 2014; Wernick et al. 2014).

6.2. Inductively derived three themes

6.2.1. Marginalisation and silenced voice

Marginalisation, discrimination and exclusion are the motivations for researchers engaging in participatory research with vulnerable children and young people. Marginalised youth are systematically prevented from accessing opportunities and resources that are available to others (Iwasaki et al. 2014; Thomas-Hughes 2017) and therefore working with them as equal partners helps ensure their involvement is meaningful (Mitchell et al. 2017). There is a perennial problem of the exclusion of disabled children and young people in research generally (Chappell et al. 2014; Wickenden & Kembhavi-Tam 2014), and those with learning disabilities specifically (Aldridge 2012; Stevenson 2014).

The issue of silenced voice among vulnerable children and young people in research was evident across the studies included in the review. As observed by Aldridge (2012), children who are unwilling or feel unable to verbalise their experiences are likely to be excluded from research. Participation was seen as a way of addressing marginalisation (Noone et al. 2016; Stevenson 2014). Arguing for the positive relationship between participatory research and voice, Wickenden and Kembhavi-Tam (2014, p.401) suggest:

> *Research with rather than about children recognises that given appropriate opportunities, they have and can express their own views, and these are often different from those of proxies such as parents or professionals who might previously have answered for them.*

However, in a problematising of the language (and concepts) that underpin ideas about 'voice', Chappell et al. (2014) argue that the claim that participatory research *gives* voice assumes that those involved with the research have no voice in the first place. This, they suggest, merely reinforces and perpetuates hierarchies in the research process. They argue instead that in this context, vulnerable children and young people are not given voice but rather they '*exercise their own voices in participatory research spaces*' (Chappell et al. 2014, p.389). Capturing the ownership and exercise of voice, Thomas-Hughes (2017) describes how she sought to recognise the young women in her study as autonomous individuals, capable of initiating and regulating their own voices.

6.2.2. Empowerment and power

Used in tandem with voice in almost all the included studies, was the issue of empowerment as a reason to undertake participatory research and/or a positive outcome of the processes involved (Greco et al. 2017; Iwasaki et al. 2014; Noone et al. 2016; Thomas-Hughes 2017; Vaughan 2014; Wernick et al. 2014). However, like voice, there was a problematising of the notion among some researchers. Wickenden and Kembhavi-Tam (2014) propose that the exact meaning of participation and its relationship with empowerment is problematic. Arguing that it is neither absolute, nor complete, Aldridge (2012, p.56) suggests that it is more appropriate to make claims of '*degrees of empowerment only*'. Similarly, empowerment should not be seen as a linear process leading to permanent agency, but rather a network of relations in the research process (Chappell et al. 2014). On a practical level – and reinforcing the problems with both voice and empowerment – Vaughan (2014) reported that the young people in her study in Papua New Guinea who were living in communities facing a range of challenges such as violence, substance misuse and HIV, had developed critical thinking and psychological empowerment, but it was difficult for them to put this into action. They found

it difficult to garner support for their plans. Vaughan describes this as '*contexts of disinterest and division [that] limit young people's praxis*' (Vaughan 2014, p.188). We pick up on this later.

Power relationship between adult researchers and children and young people as researchers was a prominent theme across all included studies. Participatory research challenges the status of the adult researcher and shifts the power dynamic (Greco et al. 2017; Taylor et al. 2014; Törrönen & Vornanen 2014). Some researchers described how the participatory methods themselves were a powerful medium for children and young people. For example, on the issue of photovoice, Wickenden and Kembhavi-Tam (2014) claim that the camera imparts an element of control among the child or young person using it, regarding what, when and how they choose to photograph. The young women in Thomas-Hughes' (2017) study, exercised their power by changing from reflexive journals to video recordings.

Like voice and empowerment, power is a troubled notion and Chappell and colleagues (2014) were again amongst those to illuminate some issues. They propose that although co-researchers' complete involvement is useful, applying it to youth with disabilities raises some difficulties. They suggest that some youths with disabilities are used to having their lives controlled and surveyed by adults and might find the equal footing difficult to accept (Chappell et al. 2014). Similarly, in relation to disabled children, Wickenden and Kembhavi-Tam (2014) illuminate the cultural factors in particular contexts may inform what disabled children expect or feel they are allowed to do or discuss. Being invited to choose, criticise or offer opinions, may they suggest, be unfamiliar to many. Additionally, there may be questions about rights to co-authorship (Stevenson 2014) and complexities may arise as regards expectations of children and young people on the adult researcher. In this Thomas-

Hughes (2017) argues that under issues of obligation and power, we cannot fail to recognise the perceived power to give or withhold future opportunities, such as involvement in other projects, references for jobs etcetera.

The contemporary, insider knowledge of being a child or young person is a powerful possession for children and young people and is one that cannot be eroded (although it can be silenced or abused). This was a much-cited reason for undertaking participatory research. Linking this to voice, Stevenson (2014, p.23) observes:

> *The silenced are not just incidental to the curiosity of the researcher but are the masters of inquiry into the underlying causes of the events in their world.*

The notion of being masters of their own world was supported across several included studies. Stevenson (2014) uses the term 'local expertise' in relation to people with intellectual disability and Wernick et al. (2014) describe how youth in their study were seen as experts in their own lives. Taylor et al. (2014) claim that without doubt, working with young people as peer researchers yielded a level of insight that would have been difficult to achieve with an adult, outsider researcher. Trustworthiness of findings (Mitchell et al. 2017) and more representative data (Thomas-Hughes 2017) are other claimed advantages. Such advantages arise due to the proximity of experiences and mutual understandings between the children and young people taking part. This can however be problematic. For example, Törrönen and Vornanen (2014) report that the co-researchers in their study were deeply involved in the same experiences as the young people they interviewed and although this created opportunities for positive contributions (such as quality insights already discussed), it could also be problematic if they were exposed to upsetting or emotive information – such as details of traumatic experiences - in the process of interviewing.

6.3.3 Inclusion and influence

The need for inclusive, adaptable research designs and methods was referred to in a number of studies. Aldridge (2012) cautioned that there is a danger that vulnerable children will be excluded from studies if methods are not adaptable and if researchers do not understand or employ appropriate methodologies to allow such children to participate. Wernick et al. (2014, p.63) talk of 'establishing accessible practices' that foster participation of youth with diverse backgrounds and experiences, which is particularly important for marginalised youth. Wickenden and Kembhavi-Tam (2014) have a great deal to say on the matter of inclusion in terms of research with disabled children. They propose that adaptations that are a necessity for some children often benefit other children too, so an inclusive rather than 'special' approach might serve to maximise everyone's participation. Furthermore, they argue that practical adaptations are required in many studies in order to be inclusive and without this:

> *Rhetoric about inclusion of disabled children in research is likely to be at best tokenistic and at worst ethically untenable as it may exacerbate their excluded position* (Wickenden & Kembhavi-Tam 2014, p.414).

Echoing this, and extending to vulnerable children and young people more broadly, Thomas-Hughes (2017) offers the reminder that when collaborating with young people in research we need to ensure that we don't simply replicate the vulnerabilities and disadvantages that they experience in other areas of their lives, such as excluding or patronising them.

Across the included studies there was considerable focus on the practical skills acquisition, training and support of children and young people within participatory research that foster their inclusion (Iwasaki et al. 2014; Taylor et al. 2014; Törrönen & Vornanen 2014). Keeping language simple and preparing developmentally appropriate training in research design and data analysis are required in some studies (Wernick et al. 2014). Given the power relations

already discussed, fostering respectful relationships is crucial and these need to be underpinned by genuine efforts if the inclusion is not to be undermined. For example, disabled children are very alert to being underestimated and are quick to detect being patronised (Wickenden & Kembhavi-Tam 2014). Thomas-Hughes (2017) reports how her relationships with young women in her study were imbued with intense value. She argues that this is important for a young person, particularly one who has experienced trauma, because being valued is often something that is missing in their lives.

Given the scope of our review, it is unsurprising that the need for protection was discussed by many researchers. This emphasis was underpinned by a commitment to include vulnerable children and young people in ways that were both meaningful and did not risk causing them harm. It is important to bear in mind the vulnerability of peer researchers as having the same risk factors or vulnerabilities as those they are researching (Taylor et al. 2014). Thomas-Hughes (2017) reported that she was 'chronically concerned' that the young women in her study may retrospectively regret the sharing of stories publicly about their intimate partner violence (IPV) experiences. She explains that she had not aimed to foreground their stories of IPV but for some women there was a sense of moral imperative that their stories should be used to raise awareness of IPV. This example highlights the careful balancing of autonomy and protection in the inclusion of children and young people in such research. There are strategies to promote safety and protection, including debrief and the presence of a known and trusted support worker (Taylor et al. 2014; Törrönen & Vornanen 2014). This level of support may assist in unearthing any potentially hidden impacts on the children and young people. Two studies in our review identified the 'burden' of involvement in terms of time and competing roles. Chappell et al. (2014) report on the challenges of different self-positions, for example of one co-researcher experiencing tensions

between being 'the niece of a sick uncle' and 'a co-researcher'. Similarly, children's identities and roles as carers, researchers and pupils were at times conflicting and constraining (Aldridge 2012).

The potential for participatory research to have political and practice influence was a strong theme and as Törrönen and Vornanen (2014) point out, the approach provides an opportunity to strengthen links between young people, policies and practices. Iwasaki et al. (2014) observed that fragmentation and discrimination of services contribute to poor outcomes for youth who live with high risk and marginalised conditions. They argue that transformational change at a systems level is required to meet their needs and that their study contributed to this by identifying the key components of a framework for engagement. Similarly, Wernick et al. (2014) propose that the approach provides youth with the communication tools to reach what they call 'powerholders'. They report that their own study was able to move adults to participate in a change strategy that focused on youth as experts.

Vaughan (2014) talks of the need for participatory methodologies to move beyond creating safe social spaces to develop 'in-between spaces' with the intent of motivating powerful others to support and participate in transformative efforts. Demonstrating this in her own study, she shows how exhibitions of photo-stories provided an 'in-between' space that brought the young people into contact with community leaders. She does however caution against over claimed political influence of participatory approaches; it has its limitations:

> *The limitations to the change that small participatory initiatives can achieve, however, does reinforce that 'participation' is not a panacea by which the structural violence experienced by marginalised youth can be remedied. Redressing structural violence does, in addition, require structural change.* (Vaughan 2014, p. 191).

Although Vaughan talks specifically of violence, addressing the structural basis of power and inequity in its multiple forms is required at societal level if pervasive and enduring inequalities facing vulnerable children and young people are to be addressed.

7. Limitations

This review has provided valuable new insights in the field of participatory research with children and young people that will be of benefit to researchers across a range of health and social science disciplines. It does however have some limitations that can be considered broadly as methodological and conceptual. Conceptually we have taken some risks with focusing on 'vulnerable children and young people'. Firstly, the included studies focus on an array of vulnerabilities and we may be criticised for assuming homogeneity across and within these different groups. This is not our intention and we acknowledge the considerable heterogeneity that exists. Secondly (and similarly), our categorisation of children and young people who may be considered vulnerable is open to debate. We know that not all disabled children or LGBTQ youth, for example, consider themselves vulnerable. As Woodgate and colleagues (2017) observe, those living with stigma and discrimination might rightly complain that '*People try and label me as someone I'm not*'. However, our review findings show that issues of vulnerability, voice, empowerment etc, are relevant to children and young people across the groups included in the review.

Methodologically, only two of the articles reported on the inclusion of young children, with children as young as eight years old (Greco et al. 2017; Wickenden & Kembhavi-Tam 2014). With the exception of Aldridge (2012) where the young carers' ages are not provided, the remaining articles are with young people. This may be explained by our focus on vulnerability, with some issues such as sexuality, drug use, IPV etcetera being relevant to

older children and youth. However, we see this as a limitation and suggest the need for further reviews that capture the perspectives of younger, vulnerable children. Additionally, the review included only 13 articles. This is because we imposed tight inclusion criteria to ensure the sharp focus of the review. The disadvantage is that some of the patterns and complexities that we have begun to unearth in the review may create only a partial picture, for example the rationale for participation and the descriptions of children and young people's involvement. This does of course open opportunity for further analyses. We excluded some potentially important articles, some from well-published researchers in the field of participatory research with children. Although such work did not make it into the review, we have utilised much of it in the discussion.

8.   Discussion

From our review, the *raison d'être* for undertaking participatory research with vulnerable children and young people is to seek to equalise power relations and provide opportunity for empowerment and voice. Other researchers have alluded to its inherent opportunities for empowerment (Kellett et al. 2004; Kellett 2010) among children and young people in general. But as Yorke and Swords (2012) suggest, while participatory research may well have a range of benefits for *all* children, the returns are probably greater for vulnerable children. Other researchers have supported this, with Graham et al. (2014) referring to the capacity for shared power with youth in the context of mental health, and Bradbury-Jones and colleagues (2015) reporting on the strengthening of curriculum vitae and opportunities for future employability for the looked-after young people in their study.

Echoing this, our review articles have shown for example, that disabled children and young people (Chappell et al. 2014; Wickenden & Kembhavi-Tam 2014; Stevenson 2014) and those

who are socially marginalised (Iwasaki et al. 2014; Mitchell et al. 2017; Noone et al. 2016) are at risk of being excluded from research generally, and even more so from participatory approaches. It is thus intuitively appealing to foreground the empowering nature of the process, but there are some conceptual and practical sticking points.

8.1. Problems with power and empowerment

Firstly, power is a contested concept, with different meanings in different contexts. Kuokkanen and Leino-Kilpi (2000) postulated that power has its roots in three traditions (critical social theory, organisational and management; social psychology), which means it is far from a concept with homogenous meanings. Indeed, Bradbury-Jones and colleagues (2008) argued that when post-structural approaches are added to the mix, power can be understood variously. Similarly, empowerment is nebulous and over-used and like power, risks over-simplification. So what does this mean for our review findings, where power and empowerment are cornerstone?

Amongst our included articles, there was considerable evidence of problematising of power, empowerment and voice. To that end, the naïve acceptance of them as being inherently positive or indeed even achievable was challenged. Chappell et al. (2014) argued that vulnerable children and young people cannot be *given* voice; they already have a voice that they need to be supported to exercise. This accords with Foucault's conception of power as pervasive and within us all; what is needed is the conditions in which it can be exercised:

> *Power is not exercised simply as an obligation or a prohibition on those who 'do not*
>
> *have it'; it invests them, is transmitted by them and through them; it exerts pressure*
>
> *upon them, just as they themselves, in their struggle against it, resist the grip it has on*
>
> *them* (Foucault 1995, p. 27).

It is important to recognise that for children and young people choosing not to participate, not to speak, and to reject ways of thinking and describing used by adults, can be crucial signifiers of what they mean and think. In this way Lewis (2010) suggests that their 'silence' is as important as their 'voice'. From a Foucauldian perspective then, this can be understood as exercising silence.

In terms of empowerment, in one of the included articles, Aldridge (2012) highlighted the relativeness of empowerment, as only ever being partial. The notion of 'degrees of empowerment' is helpful in challenging assumptions about empowerment as some form of panacea. With this realistic viewpoint, adopting Chandler's definition of empowerment as '*to enable to act*' (1992, p. 65), we turn attention to how researchers can support the children and young people in their participatory research to be enabled to act, however partial this may be in reality.

8.2. Lessons for participatory research

Our review has unearthed the complexities of participatory research with vulnerable children and young people and thus, has responded well to our first three review questions. In the concluding discussion we turn to our final question by exploring the lessons our review findings hold for future directions in this field.

8.2.1 Being included and being over-researched

The thorny issue of children and young people's perceived competence to make decisions about themselves is as relevant to research as it is to practice (Alderson 2007). This will undoubtedly account for why particular groups of children and young people are under-represented in participatory research (Bradbury-Jones 2014). As Lundy and colleagues

(2011) point out, there remains a significant disparity between participatory research with older and more articulate (perhaps more privileged) children, than those who are young and less articulate. This is certainly an issue reflected in this review that we have acknowledged in the limitations.

Also, children with more complex social and communications needs, for example children with disability, children in care, etcetera are less visible in participatory research (Lundy et al, 2011). Similarly, in their review of disabled children as partners in research, Bailey et al. (2014) found few studies that involved children from minority ethnic groups and those with the most complex impairments. Conversely, and somewhat paradoxically, there is a need to guard against over-inclusion of certain groups (Damon et al. 2017; Koen et al. 2017; Yorke & Swords, 2012). Lessons for participatory researchers are to think creatively in terms of how to engage with children and young people at the margins, lest they experience even greater exclusion than they do in their everyday lives.

8.2.2. *The power of vulnerable children and young people*

A number of articles in the review referred to the political persuasiveness of participatory approaches. Wernick and colleagues (2014) talk of 'powerholders', as being those in traditional positions of authority, such as policy makers. Yet turning again to Foucault, we might challenge the notion of who it is that holds power. He argued that power takes a capillary form. In other words, like capillary blood, it flows in both directions and:

> *reaches into the very grain of individuals, touches their bodies and inserts itself into*
>
> *their actions and attitudes, their discourses, learning processes and everyday lives*
>
> (Foucault 1980, p. 39).

From this perspective, power resides in all of us, but it is the exercise of power that is crucial. Lessons for participatory research then, are to view the vulnerable children and young people as powerful agents, capable of exerting political influence. In that way, the vulnerability ceases to be a stigmatising burden, but rather a source of power and political leverage. The participatory research becomes a vehicle through which to exercise the power that always exists, but requires the right conditions for enactment.

9. Conclusions

The field of participatory research is developing rapidly and there are few systematic or critical evaluations of the quality or impact of participatory research with children, particularly those who are most vulnerable. In that sense, our review can be regarded as making an important contribution. Gough et al. (2017) propose that qualitative reviews have potential to lead to new theoretical and conceptual knowledge. We believe this to be the case for our review. It provides a unique, contemporary analysis of participatory research with vulnerable children, illuminating in particular its conceptual complexities and contradictions, particularly regarding power, empowerment and voice. Its overall utility and interest is augmented by the disciplinary and geographical breadth of the included articles, rendering it relevant to many contexts and countries.

Addressing the structural basis of power and inequity in its multiple forms is required at societal level if pervasive and enduring inequalities facing vulnerable children and young people are to be addressed. The articles in this review have all contributed to that agenda in some way by foregrounding the voices of children and young people who are marginalised by virtue of sexuality, impairment, violence and abuse, ill-health, a caring role. The combined insights from these studies provide an important contribution to understanding and developing this important field of research.

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Table 1: Definitions of children and young people

We have adopted the UN definitions of children and young people – which are internationally recognised and widely adopted. A child is a person under the age of 18 year unless the laws of a country set the legal definition of childhood in that state as younger (UNCRC, 1989). Reference to 'youth', 'young adults' or 'young people' is those between the ages of 15 and 24 years (UN, 2013).

Table 2: Inclusion/ exclusion criteria of reviewed literature

Inclusion	1. Empirical, qualitative study.
	2. Explores research carried out with children or led by children. This may be defined as co-research, participatory research, participatory action research, peer research or another synonym.
	3. Focuses on an aspect of vulnerability/marginalisation. This includes: children in care and/or who have experienced abuse, neglect or violence; disabled children; children with illness/mental health issues; LGBTQ young people.
	4. A significant focus of the paper is critical or evaluative, discussing and/ or reflecting on participatory research with children (e.g. ethical, methodological, practical challenges and issues).
Exclusion	1. Discussion papers, literature reviews, mixed-methods studies, conference abstracts, books, book chapters, conference posters and other 'grey literature'.
	2. Research reports on the findings of a participatory study without significant focus on the ethical, methodological, practical challenges and issues.
	3. Explores general ethical and methodological issues about children 'participating' in research (e.g. recruitment, engagement, ethics, etc.).

Table 3: Included articles

Article details	Country	Type of vulnerability	Study design	Level of participation	Rationale for participatory approach	Reported advantages	Reported challenges
Aldridge, J. (2012) The participation of vulnerable children in photographic research. *Visual Studies*, 27(1), 48–58.	UK	Young carers	Photovoice project with sixteen young carers (age not stated), each of whom was caring for a parent (or parents) with serious mental health issues	Thematic analysis	Uncovers the silent and hidden aspects of children's lives	Using visual participatory methods moves away from adult-orientated perspectives to 'see' directly into participants' lives. Gives participants direct entry into dialogues with key stakeholders such as policy makers and practitioners who can help transform their lives Empowering	Ethical considerations of exploitation and intrusion Confidentiality, consent and privacy Issues of power Conflicting roles of children as carers, researchers and pupils
Chappell, P., Rule, P., Dlamini, M. and Nkala, N. (2014) Troubling	South Africa	Disabled youth	Three of the 22 young participants (aged 15-20 years) selected and trained	Co-researcher training Data collection	Ability to exercise voice in participatory research spaces	Shifts adult-youth research relations Co-construction	Troubled issues of power and empowerment

power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa. *Childhood,* 21(3), 385-399.			as co-researchers Focus group discussions and individual interviews	Data analysis Co-authorship		of knowledge Learning about self and research	Tensions between different self-positions Difficulties of disabled youth accepting equal footing
Greco, V., Lambert, H. C., & Park, M. (2017) Being visible: PhotoVoice as assessment for children in a school-based psychiatric setting. *Scandinavian Journal of Occupational Therapy*, 24(3), 222-232.	Canada	Children in a school based psychiatric setting	Photovoice using ethnographic methods conducted within an overarching narrative-phenomenological conceptual framework Included four children aged eight-12 years as co-researchers 1. Audio-taped narrative interview conducted by adult researcher with each participant 2. Participant observation by the adult researcher on each participant 3. Participants attended nine weekly sessions to create a life book 4. The participants were provided with	Photovoice sessions Production of life books	Empowers and highlights the unique experiences of vulnerable groups	Engages and empowers children in articulating what matters in their everyday lives Results in novel, child-generated information	Ethical restrictions regarding use of photography

			cameras Data analysis was conducted by the adult researchers				
Iwasaki, Y., Springett, J., Dashora, P., McLaughlin, A. M. and McHugh, T. L. (2014) Youth-Guided Youth Engagement: Participatory Action Research (PAR) With High-Risk, Marginalized Youth, *Child and Youth Services,* 35(4), 316-342.	Canada	High risk youth living in marginalised conditions such as poverty, homelessness, social exclusion, mental health challenges, foster care, abusive behaviours, school drop-out	Participatory Action Research with 16 youth leaders (aged 16-24 years)	Youth led meetings Setting agenda for meetings Development of a framework for youth engagement	Honours and highlights the voices of high risk/marginalised youth Mobilises youth into systems change	Empowerment Opportunities Learning Creates a sense of community Leads to meaningful and useful outcomes	Disconnect and distrust among youth
Mitchell, K., Durante, S. E., Pellatt, K., Richardson, C. G., Mathias, S. and Buxton, J. A. (2017) Naloxone and the Inner City Youth Experience (NICYE): A community-based participatory research study examining young	Canada	Inner city youth and Take Home Naloxone programs	Community based participatory research using a phenomenological approach. Two peer researchers recruited (aged 19-25 years)	Training on research methods Research design Focus groups and individual interviews Data interpretation Dissemination	Increases relevance and assists in more culturally appropriate data collection, analysis and dissemination	Trustworthiness of findings enhanced Creation of relevant and acceptable knowledge dissemination tools	Qualitative data analysis software may be too complex

people's perceptions of the BC take home naloxone program, *Harm Reduction Journal,* 14(1).							
Noone, J., Sullivan, M., McKinnis, N. C., Allen, T. L., Regalado, C. and Esqueda, T. (2016) Latino youth participation in community-based participatory research to reduce teen pregnancy disparities, *Children and Youth Services Review,* 63, 36-39.	United States	Latino youth	Community-based participatory project incorporating photovoice, focus groups and theatre. Two high school and two college students recruited to the project selected from 29 applicants (aged 14-24 years).	Coordination and planning Data collection and analysis Dissemination Co-authorship	Can enhance the integrity and validity of the research and add context and relevance to the process	Authentic engagement with youth Insider knowledge of the young people Empowerment Personal benefit and reward Career development	Conflicting commitments of the youth involved Adapting to new situations to incorporate youths' voice Hesitancy for youth to speak out in public
Stevenson, M. (2014) Participatory Data Analysis Alongside Co-researchers who have Down Syndrome, *Journal of Applied Research in Intellectual Disabilities,* 27(1), 23-33.	Australia	Young adults with Down syndrome	An Emancipatory Disability Research study using textual data from a participatory action research project. Involved three co-researchers aged 20-26 years.	Coding and thematic analysis Presentation at conferences and university seminars	Provides an enabling methodological framework Draws on the local expertise of the co-researchers Ensures that co-researchers' voices are heard	Demonstrates the abilities of the co-researchers Learning research skills Exercise of power	Support is needed for some young people with intellectual disability Raises questions about co-authorship

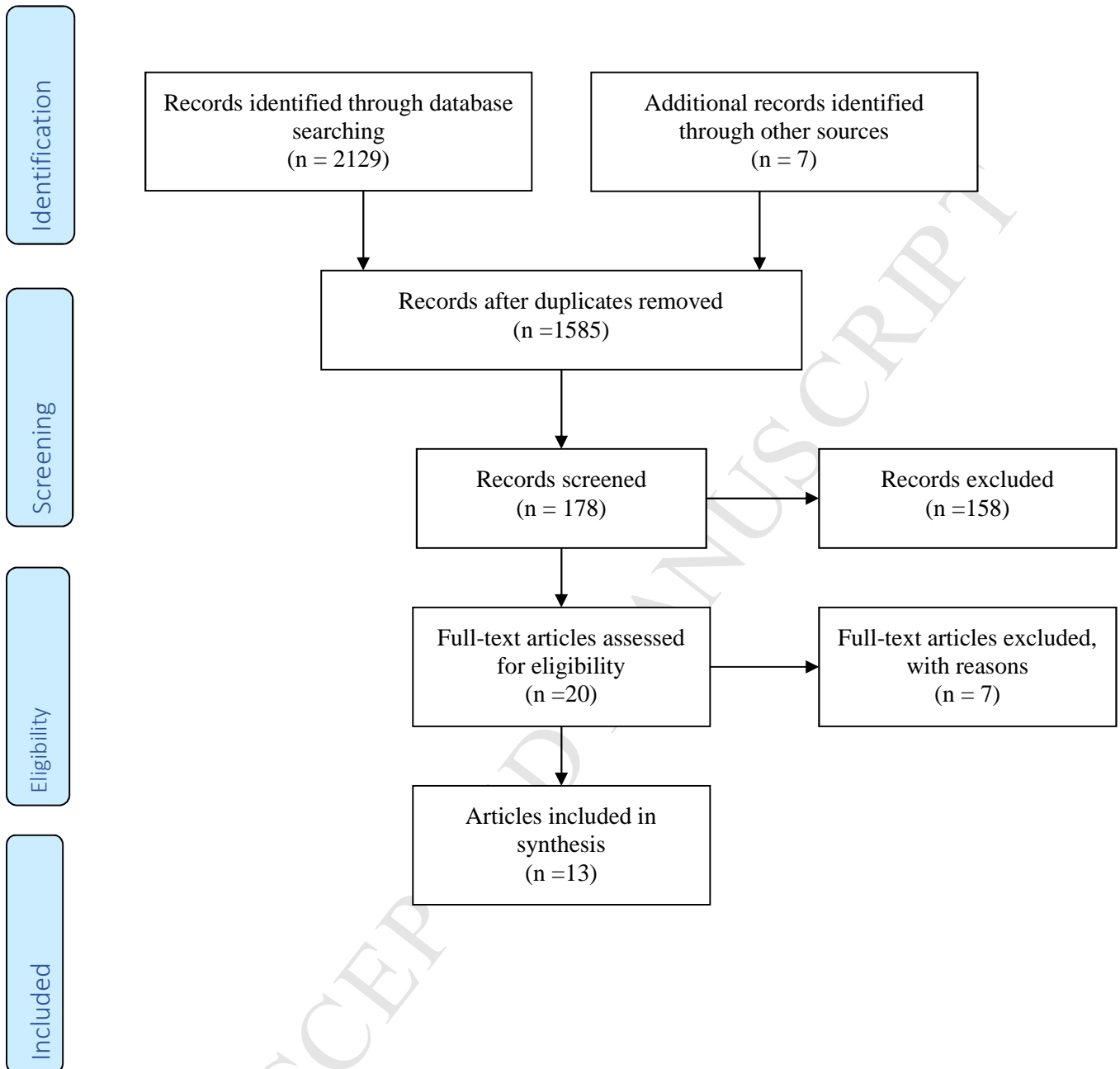|							
Taylor, J., Bradbury-Jones, C., Hunter, H., Sanford, K., Rahilly, T. & Ibrahim, N. (2014) Young people's experiences of going missing from care: a qualitative investigation using peer researchers. *Child Abuse Review*. 23, 387–401.	UK	Young people in care	A qualitative study using Critical Incident Technique focus group interviews. Two young people recruited as peer researchers (aged 20 and 22 years)	Peer researcher training Research design Data collection Data analysis Dissemination Co-authorship	Research on children's experiences is often reported from the adult's perspective rather than allowing children to have a voice	Gains meaningful insights from respondents of a similar age who have shared common experiences The presence of peer researchers during the focus group interviews adds a layer of support for participants Development of new skills for peer researchers	Training for co-researchers may be inadequate Peer researchers are vulnerable and need support and protection Power imbalance
Thomas-Hughes, H. (2017). Ethical 'mess' in co-produced research: reflections from a UK-based case study. *International Journal of Social Research Methodology*, 1-12.	UK	Young women with Intimate Partner Violence experiences	Fourteen young women (aged 13-23 years) involved in workshops	Co-writing of ethical approval Planning future workshops Project decision making	Represents marginalised groups Produces more representative data Provides opportunities for capacity building and empowerment	Ability to exercise power Establishes mutual, respectful relationships	Obligation and power Consent and data storage Anonymisation and privacy Avoiding tokenism and exploitation
Törrönen, M. L. and Vornanen, R. H. (2014) Young People Leaving Care: Participatory Research to	Finland	Young people leaving care	Participatory research design employing care-leaving peers as co-researchers, comprising 10 young people	Research design Data collection Interpretation of data	Based on principles of empowerment	Provides possibilities for better understandings from a user's perspective	Adults may have authoritarian positions Potential manipulation

Improve Child Welfare Practices and the Rights of Children and Young People, *Australian Social Work,* 67(1), 135-150.			(average age 22 years)	Disseminated of results		Challenges traditional understandings of expertise and knowledge production Abandons the assumption that the adult researcher knows best Provides an effective means of empowering young people to develop research skills	Resistance of professionals to listen to young people Waning of co-researchers' enthusiasm and activity as study progresses Inexpert interviewing skills of the co-researchers
Vaughan, C. (2014) Participatory research with youth: Idealising safe social spaces or building transformative links in difficult environments? *Journal of Health Psychology,* 19(1), 184-192.	Papua New Guinea	Young people living in communities that face a range of health challenges including violence, substance misuse and HIV	Photovoice with three pre-existing youth groups 38 participants, with an average age of 22 years	Training of participants as co-researchers and photographers in workshops Photography, refection and discussion cycles Illustrations shown in local exhibition	Produces co-constructed, new understandings of the world Brings different actors into dialogue with each other	Develops a safe, dialogical space Psychological empowerment Development of confidence Creates an affective impact of the young people's photo-stories on others	Critical thinking does not inevitably lead to critical action
Wernick, L. J., Woodford, M. R. and Kulick, A. (2014) LGBTQQ Youth Using	USA	LGBTQQ youth	Participatory Action Research and theatre Focus groups and semi structured	Designing and executing the study Developing	Provides opportunity for marginalised groups to analyse systems of oppression through reflection, consciousness-	Increases the theoretical sensitivity of data collection and facilitates rapport	Highly technical processes may be involved

Participatory Action Research and Theater to Effect Change: Moving Adult Decision-Makers to Create Youth-Centered Change', *Journal of Community Practice,* 22(1-2), 47-66.			interviews Two participants from the 25 young people who participated (aged 15-22 years) were trained as youth researchers	research questions Data collection Data analysis Report and article writing	raising and building power	among participants Accessible, flexible practices can foster participation When combined, theatre and participatory action research can empower LGTTQQ youth to create institutional change Provides youth with the communication tools to reach powerholders	
Wickenden, M. and Kembhavi-Tam, G. (2014) Ask us too! Doing participatory research with disabled children in the global south, *Childhood,* 21(3), 400-417.	India and Sri Lanka	Disabled children	Study 1 (India): An exploratory qualitative study using photography (37 participants aged 11-18 years) Study 2 (Sri Lanka): A pilot study. Two children's meetings held in each of four locations with children aged eight-18 years.	Study 1: Participants given cameras, asked to take photographs, followed by group discussions a week later. Piloting of four activities with each of the groups.	Removes barriers to the perspectives being heard	Reinforces the message that disabled children can and should actively participate in research	Information and consent Risks of tokenism Practical adaptations are required to facilitate inclusion Impairment related factors Cultural and contextual factors

							Adult researcher skills

Figure 1: PRISMA Flowchart

Identification

Records identified through database searching
(n = 2129)

Additional records identified through other sources
(n = 7)

Screening

Records after duplicates removed
(n =1585)

Records screened
(n = 178)

Records excluded
(n =158)

Eligibility

Full-text articles assessed for eligibility
(n =20)

Full-text articles excluded, with reasons
(n = 7)

Included

Articles included in synthesis
(n =13)