

RESEARCH ARTICLE

Co-production with “vulnerable” groups: Balancing protection and participation

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Abstract

Background and aim: This paper explores the tension between participation and protection at a time when professionals are encouraged to engage patients and citizens in both the “R” (research) and the “D” (development) of services. Concerns to protect groups perceived as “vulnerable” can mean that not everyone is afforded the same opportunity to participate.

Methods: Our data draw on the literature and secondary analysis of a study designed to explore the experiences of young peoples' transitions from health and social care to adult services. In seeking ethics approval, tensions between protection and participation were evident, and once the study was concluded, we reviewed group and individual interview transcripts, team email correspondence, and research notes. We considered aspects of participation, co-production, involvement, and research design in relation to the ethics concerns raised.

Findings: In terms of privacy and confidentiality, young people were skilled at setting their own boundaries. Whilst young people leaving foster and residential care are frequently perceived as vulnerable, those in our study asserted their agency and desire to be “visible.” Some experienced conditions aimed at protecting their confidentiality or safety as oppressive.

Conclusion: The risk reduction strategies that often underpin ethics approval processes can also carry risks. Limiting opportunities to play a part in research for people who may already be excluded on age, health, language, or other grounds reduces the range of lay knowledge on which we can draw, limits generalisability, and potentially adds to damaging social exclusion. Learning how to participate effectively is a life skill.

KEYWORDS

care leavers, co-production, ethics, participation, vulnerability, young people

1 | INTRODUCTION AND BACKGROUND

Proponents of evidence-based medicine and others in the health community have sought to conduct research, which first identify and then respond to patient and citizen priorities,¹ a position well recognised for some time by social scientists.²⁻⁴ Involvement at an individual and community level is increasingly seen as a key component of research⁵⁻⁸ on the grounds that research questions influenced or led by citizens, patients, or carers are likely to increase acceptability and applicability.⁹

This paper draws on both the literature and a recently completed primary study to explore the tension between protection and participation in research that includes groups or individuals viewed as “vulnerable,” and ethical considerations of “protection.” Our case example is from a qualitative study of young people's experiences of transitioning out of health and social care children's services in a growing policy context of calls for more co-production in health and social care research.^{10,11} Whilst our focus was young people, including those with learning disabilities and unaccompanied child migrants, this discussion also resonates with research with other groups considered

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vulnerable to exploitation or coercion through ethnicity, gender, or old age.¹²⁻¹⁷ Ethnographic work, including work with children, has highlighted the active role that research participants can play in shaping both research and the interpretation of findings.¹⁸ Well-conducted qualitative research can be designed with a participatory core, where researchers respond to a community's request for research or community members become research advisors.¹⁹⁻²¹

Work of this kind is increasingly referred to as “co-production.” This is a multifaceted concept, acknowledged as potentially “woolly”²² with roots in, and applications to, a number of disciplines.¹¹ In health research, it generally involves collaboration between researchers, health professionals and patients, carers, or citizens. The latter group is increasingly recognised as important, as they can bring different kinds of knowledge to the table.¹⁰ By designing research *with* lay people (“experts by experience”) and professionals, researchers can address the questions most salient to those who use services, improve the acceptability of interventions, and gain a better understanding of the kinds of outcomes most valued. Moves towards co-production in health research in many parts of the world have been viewed as a welcome trend towards the democratisation of public and personal decision making, though this may not always play out as expected. Aspirations for co-production fail if only those “answers” that are a good “fit” with researchers' or clinicians' paradigms are incorporated, and anything else explained or airbrushed away.

Following a shameful history of unethical research, ethics frameworks have often tended to emphasise participants' rights to protection over their rights to participate.²³ Those seen as “vulnerable” may be excluded from research because of concerns that participation could have a detrimental effect on their well-being or for a different—also unethical—reason, simply on the grounds of additional time, difficulty, or costs of including people who do not speak English, have a learning disability, or are considered too young or too old.^{24,25} Participation in research is primarily exercised as the right to give or refuse consent,²⁶ but some who might want to participate in research or involvement do not have the opportunity even to refuse.²⁷

Children and young people are almost invariably considered vulnerable on the basis of their developmental understanding. Rhodes,²⁶ for example, suggests that even in older children, “practical reasoning is not fully developed and ... deviates significantly from mature judgement” (p28). Challenges from the sociology of childhood meanwhile demonstrate that children can have a deep understanding of the consequences of their actions or inactions, not necessarily in line with their chronological age.²⁸⁻³⁰ Recent work on children's participation in biomedical research refers to contexts that make them more or less vulnerable, and suggests that involving them as partners in research may in fact be protective through identifying ways in which they might feel better supported and less prone to vulnerability.³¹

2 | THE CASE EXAMPLE

2.1 | Funding, study rationale, and setting

The “parent” study on which our case example draws explored young people and practitioners' experiences of managing multiple transitions

from children's to adult services in health and social care.³² It was funded by the English Department of Health. In line with the Department's ambitions to increase young people's participation,³³ we wanted our study to provide young people with an opportunity to influence the conduct and focus of the research.³⁴

Details of the study design, methods, and core findings can be found elsewhere.³² In brief, we had for some years worked with a participation group for looked after children and care leavers in an inner city social services department.³² Building on this, we held an initial meeting with the professional lead and young people in the group to discuss whether our proposed work might be of interest. As the group is regularly approached for advice or research requests, they had a genuine choice as to whether to accept or decline the chance to find out more. The young people told us that transitions (the focus of our study) were a priority for them, and they supported our study idea.

We envisaged 3 ways of addressing our participatory aims: a further meeting where the research plan would be reviewed and adapted in the light of young people's views; young people working as co-researchers interviewing professionals involved in transition care and implementation; and young people conducting an add-on study, exploring in more depth an aspect of transition that interested them.

2.2 | Ethics application

Our study covered transitions in health, education, and social care. Given our population (young people leaving foster and residential care) and setting (Children's Services), we applied for approval from a Social Care Research Ethics Committee. Since a study design for participatory research is more fluid than that of, for instance, a trial, we described how we planned to apply an “ethical radar”³⁵ throughout the study with ethics conduct and consent seen as negotiated and ongoing, starting before researchers enter the field and continuing during the dissemination process after the formal end of the study.³⁶ We described how we would be alert to non-verbal as well as verbal signs of withdrawal of consent during data collection, and that participants would be reminded of the voluntary nature of the study. We had arrangements in place were any of the participants to show signs of distress and an independent person they could approach should they have a complaint. Children, whatever their age or ability, are skilled at indicating their disinclination to engage in an activity, as any parent can confirm. Consent can vary across a single encounter, with a researcher needing to adjust a line of enquiry on the basis of participants' responses.³⁷

With hindsight, our commitment in our original ethics application to a flexible design with ongoing consent might be viewed as naive given well-described obstacles to research with looked after children.^{27,38} Our optimism lay in the policy-oriented focus of our research and the priority on participation in policy documents.³⁹⁻⁴¹ We confidently expected that our established practice links with the participation project and a growing prioritisation of patient and community involvement and engagement in the UK research funding environment^{42,43} would lend support to our approach.

The ethics committee had concerns about our research, particularly in relation to the potential intrusiveness of asking young people leaving the care system about transitions. They expressed worries about peoples' capacity to consent and asked us to emphasise that confidentiality could not be assured in a group. Further concerns were raised in relation to our aim to offer young people the opportunity to invite professionals to be interviewed by them. Any additional work led by young people would, we were told, require a further full ethics application.

In response to both the committee's requests and our own reflections, we modified our involvement plans, and the research was approved. We held 5 research meetings and 16 individual interviews with 24 young people (aged 16-24) and interviewed 11 practitioners. The young people who were about to leave, or had already left foster or residential care, were ethnically diverse, and 17 of them described use of health care services over and above the health team co-located with social services.

3 | ETHICS IN PRACTICE

Our experience of the ethics process encouraged us to fine-tune our ethical practices in the course of the research. During the study and afterwards, we read and reread interview transcripts, team email correspondence, and research diaries to consider challenges in relation to protection and participation.

3.1 | Consent

Reluctance or refusal to take part in research can be regarded as a form of agency.⁴⁴ In this case with initial recruitment undertaken by a third party (the service in which most of the research was based), participants were able to exclude themselves before formal recruitment, as well as at any point in the process.

Young people were given assurances of confidentiality and generally filled in our consent forms without comment, although some negotiated in advance, or during an interview, on what they would or would not be willing to cover. The interviewers emphasised this before starting:

AI: Thank you so much for agreeing to be interviewed, before you ... you know, before today you made it really clear to me that you didn't want to answer any questions about reasons for coming into care or that sort of aspect of things

YP: Uh-huh.

AI: ... which I won't touch on and I wouldn't have ... anyway.

YP: Yeah.

AI: I'm only interested in what you want to share.

(Individual interview, young person age 20)

In an interview with a young person with learning disabilities, it was clear that the young person had taken on board the information provided.

As we went through the information sheet, he seemed very engaged, nodded and at times repeated what I had

said. He seemed very interested in how to contact [named person on consent sheet] to complain, commenting that it said she would not usually be at her phone and email being a better way to contact her... [He] seemed to appreciate [being given] the opportunity not to answer something, and volunteered the answer "I will just say 'pass'" - and he did do this very clearly on two occasions during the interview (first when asked about moving from his mother's house, and then when asked about a move from primary to secondary school). (Research notes)

That this young person followed through with the agreement to "pass" when he did not want to talk about something can be seen in his interview transcript:

YP: Don't want to talk about it.

KL: You don't want to talk about that.

YP: Pass.

(Individual interview, young person aged 21)

The young people also set boundaries for us. The context for the interviews may have helped them to do so. They were almost all conducted at the participation project or leaving care service, and there was always a worker they knew on the site, but not in the room. Some young people had met the researchers at earlier group interviews and based their decision to take part in individual interviews on that encounter. These contextual factors may have contributed to research participants' sense of agency.

Because of the concerns of the ethics committee, our consent form and formal procedures were extensive. Some concerns raised by the ethics committee were echoed in the research process, some not. The suggestion that groups might not be a good place to discuss transition experiences was only partly supported in practice. Most young people participated actively; others were more guarded but did not appear reluctant to participate in general. Two who were quiet in one group returned to later meetings and gave individual interviews. Young people used the group meetings and individual interviews in different ways that complemented one other much as we had expected. In groups, participants discussed their views on the transition system and generalised from their experiences to comment on practices and policies. In individual interviews, they were more candid and often told their personal stories.

Not only did the young people take part willingly, and on their own terms; some also questioned the ethical framework for the study. A specific request by the ethics committee was that the consent form included the following (Figure 1).


	If you tell us something that makes us think you or someone else might be hurt, we will need to tell a worker or another person you trust. We would talk to you first.	
	YES	NO
We might also need to tell another professional.		

FIGURE 1 From the consent form

This was queried at an early meeting. Since we were taking consent at the time, the exchange was not audio recorded, but our research notes read:

[young person] was keen to participate and having discussed the project, was going through each box on the consent sheet. When they came to the one on breaching confidentiality, [name] felt that this was unfair since s/he was now an adult and had moved out of the care system. We explained that without a signature, we could not continue. They signed. This suggests that a system designed to protect may be experienced as coercive. (Research notes)

Discussing this later, the research team reflected that we had not been asked to (nor had we suggested) including a similar warning for the professionals interviewed, though our duties as researchers and citizens would have been similar were we to have been concerned about potential harm.

3.2 | Anonymity

We used pseudonyms chosen by the young people during our analysis and, after discussion with our gatekeepers, further anonymised our population during the dissemination phase. No personal data have been retained by the research team. But anonymity, often linked to confidentiality in research, could be seen as unfair:

YP, a student, wanted to be acknowledged by name in the report. As academics, we are used to acknowledging colleagues by name.... We have made a commitment to anonymity with the ethics committee and it would be difficult to go back on this, particularly since naming one person would breach anonymity for the group. (Research notes)

This example of someone wanting to “breach” their own anonymity (discussed in more detail elsewhere)⁴⁵ illustrates the way in which a professional perspective on ethics can be challenging or even feel undermining to a research participant.

Although some participatory aspects of our work were reduced during the ethics approval process, we continued to ask for feedback from participants during the fieldwork, including feedback on the way we were conducting the study. And whilst we did not gain ethics approval for young people to interview practitioners, we did ask for their views on who we should interview and what we should ask.

At a meeting where we presented young people with our interim findings, one was enthusiastic about seeing her own words in the report:

KL: Have you got any comments on the way we've done this kind of thing?
 YP1: No. I like the way that you didn't write the person's name but I recognised my one straightaway so ...

KL: Does that worry you..?
 YP1: No, it's actually good

(Group meeting)

Another presentation to academics, policy makers, and practitioners was filmed and shown at a dissemination event for the young people at the participation project.⁴⁶ Again, young people and practitioners welcomed our reliance on direct quotations with their views foregrounded.

3.3 | Ethics as a process, not an event

We aimed to approach young people with sensitivity:

... before the recording starts I tell them that although they have given consent they can ask to stop at any time ... they can either tell me and I will move on or [they can] just look down or away and I will move on without any discussion. If there is time at the end of the interview I say something like “I have asked you lots of questions is there anything you would like to ask me”? ... I always arrive at least 30 minutes beforehand to allow me get past the reception and to quietly set up and establish myself in the room - open windows - let staff know I am using the room (Interviewer's email, advising a new colleague before her first interview)

The ethics committee and a peer reviewer of our ethics application emphasised the well-documented mental health needs among care leavers, which was indeed evident in our study population. Some interviews were emotionally charged, as young people shared their stories. The question here is whether potentially difficult or upsetting issues should lead to individuals being denied the choice of whether to consent or decline participation, or whether the more salient problem is how spaces can be created in a research context for a young person to talk safely, with mechanisms in place for further support if needed. An example from our case report can be seen in one researcher's notes to another. A young person, aged 17, had described having regular counselling. The note describes how the interviewer ended the encounter:

when finished I stayed in the room for about 30 minutes as the yp txted her friends. I needed to see her adjust back to the normal way she presented herself - cheery/chatty. When she arranged to meet up with a friend to do revision together I felt fine leaving ... I just felt I could not say cheerily at the end of the interview “thanks so much, bye”. Equally I did not want to make small talk. So I busied myself making notes etc. (Interviewer's email, advising colleague before an interview)

This warm approach was repeated in other interviews:

YP: Oh my god, that's sad. I still want to cry, yeah. [Gets upset]
 AI: Oh would you like to stop?
 YP: [Whispers] It's fine.

AI: Okay. Take your time and remember you don't have to talk. It's obviously very upsetting for you and I'm assuming, yeah, it was a very frightening time?

YP: Mm hm.

(Interview with young person aged 19)

Incidents such as the one below, after a young person had said more than they intended, illustrate the "ethical radar" applied in practice³⁵:

YP: Slight slip of the tongue.

AI: You know you're looking away, if you don't want to talk about anything, you know I've said it before, you don't have to talk about anything

(Interview with young person aged 24)

These excerpts and reflections are a reminder that in practice, ethics guidelines provide tools rather than rules that researchers can draw on in the field.

4 | DISCUSSION

Ethics committees in the United Kingdom tend to distinguish between qualitative research (usually collecting and analysing interview data) and "involving" people in research decision making (patient and public involvement and engagement), with qualitative research needing ethics approval and involvement not. This distinction is not always clear but is primarily signified by the roles given to (or taken by) participants in informing the study design and development (involvement) or taking part as respondents and providers of data (research). A recent paper in a quite different area (smoking and breastfeeding) illustrates how involvement and qualitative research can enhance each other by embedding involvement within the qualitative research design.⁴⁷ Our plan to include young people in interviewing practitioners was based on a belief that this could enhance our understanding of what matters to young people, because they would be invested in the questions.

The term "vulnerable" is ill-defined, often used to delineate between "us" (the strong) and "them" (the weak).⁴⁸ Whilst it is important to build in protection for those more likely to be exploited, it becomes problematic if "protection" trumps peoples' wish to participate, or choice of whether to participate or not. Our data indicates that "visibility" may be one motivation for people to take part in research,⁴⁹ just as others have found that recognition can be a motivator for citizen participation.⁵⁰ "Protection" can have unintended consequences when it excludes people, who because of their membership of a group, are considered vulnerable *per se*. If those identified as vulnerable are given no chance to exercise their views, research findings risk being distorted by an over-reliance on proxy sources of evidence or no evidence. "Protection" from involvement can deny those defined as vulnerable the right to expression, and risk marginalisation and exploitation.⁴⁴ On the other hand, given that some citizens are (or are seen as) more susceptible to compliance without a full understanding of the consequences, ethics considerations need to consider the research context.⁵¹ Schoolchildren, for instance, may find it difficult to exclude themselves from classroom-based research, whatever their capacity to consent.

Our reflections explore what happens when young people involved in a participatory study come up against the ethics framework for the study. As such, we offer a modest contribution to a body of social science on the balance between protection and paternalism, and autonomy, participation, and self-determination in research ethics.^{52,53} Along with others,^{35,54,55} this case example demonstrates that young people can and do set their own boundaries. They did not, for example, offer details of their health history in group meetings but often chose to do so in individual interviews. In group meetings, young people provided insights into how they experienced and understood systems set up to provide them with transitional support, without giving sensitive information about themselves or others. Some challenged aspects of our ethics framework designed to protect them, perceiving it as oppressive or discriminatory in relation to confidentiality on potential harm, and recognition by name.

Locating individuals within "vulnerable" groups on the basis of shared characteristics risks overlooking their strengths and exacerbating exclusion from the mainstream. Some people deemed vulnerable may have good reason to make their story (even if not themselves as individuals) "visible."⁵⁶ Whilst there is a growing awareness of the need to listen to children and young people to safeguard them, some attempts to expose historical abuse and exploitation continue to be discounted precisely on the grounds that the young people involved are "vulnerable," and their accounts considered unreliable. Whilst there are good examples of children and young people with (for instance) learning disabilities being included in research, they are all too frequently excluded, or it falls to parents, journalists, or activists to expose vulnerabilities imposed by systems that discount them.⁵⁷

Participating in research has the potential to expose participants, irrespective of background,⁵² to feelings of vulnerability. Given that young people are often seen as adults in the making rather than people capable of exercising agency, they may be treated as less capable of understanding the consequences of their actions.²⁶ Much debate on research ethics focuses on informed consent, and the extent to which people can be autonomous and fully informed when signing up to participate in research.^{26,51,52,58} Our data provide an illustration of the importance of the relationship between the researcher and the researched in offering both protection and participation. Gaining ethics approval is just the start.⁵⁹ The next step is to establish a research context within which full or partial withdrawal of consent is enabled. We found that participatory ambitions for research participants viewed as vulnerable can challenge (or be challenged by) ethics frameworks. Our experiences resonate with theoretical work on "recognition"^{56,60} based on the Hegelian notion that who we are—our identity—is formed through recognition or non-recognition by others. From this perspective, struggles for participation by marginalised groups are struggles for recognition. Barriers to participation or involvement form obstacles to voice and recognition of that voice, reinforcing inequalities.

5 | STUDY LIMITATIONS

The study from which this paper derives did not set out to explore ethics. Most of the young people we recruited were involved in an

active participation project in a children's services department. This, combined with generally good support and the colocation of Children's Services and health service provision for young people leaving care, means that this may not be typical. As such, these are preliminary findings from an exploratory study and further research is needed to explore ethics in practice.

6 | CONCLUSION

Procedures to gain ethical approval can leave researchers considering approval as "ethics done" rather than "ethics started." We do not challenge the importance of protecting research participants and recognise that qualitative "talking" studies have the potential to be harmful. Our findings chime with others that show that protection and participation go hand in hand. Drawing on a theory of recognition^{56,60} and applying this to research ethics can be helpful in understanding how we can develop a concept of research ethics that incorporates participation and protection. We do not believe it is possible to achieve the latter without the former. Participation is essential to protection. It is through participation that young people learn to exercise rights and responsibilities, understand the health care system, and navigate the adult world. Participation can support cognitive health⁶¹ and enable self-protection.⁶² The challenge for ethics committees and researchers is to promote and conduct inclusive research that responds to participants' needs to have their participation well supported.

The people participating in this research may not have defined themselves as "active citizens," but initiatives to engage young people in co-production are framed within a citizenship discourse consistent with the governmental ambitions to increase their participation.³³ Since nearly every study will raise unforeseen ethical issues, what is as important as the approval letter from an ethics committee is an expectation that as problems arise, researchers will operate an "ethics radar."³⁵ This includes discussing difficulties with colleagues and, where appropriate, participants and feeding back to ethics committees.

There are a number of parties to be "protected" in research studies—the institutions conducting the research, researchers, and participants. Ensuring that the interests of latter are not trumped by the former is itself an ethical issue. Viewing children as citizens, rather than trainee adults or citizens in the making, is part of that process.

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CONFLICT OF INTERESTS

None declared.

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