

SAGE Research Methods Cases in Social Science Ethics

Case Submission for Consideration

Case Title

Anonymity in participatory research: Is it attainable? Is it desirable?

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Discipline: Ethics [please do not alter]

Sub-discipline

[[Click here to select discipline](#)] **Health, social sciences**

Academic Level

Intermediate Undergraduate Useful to people doing masters' dissertation in global health and other areas where participatory methods are common

Contributor Biographies

Kristin Liabo is a senior research fellow at the University of Exeter Medical School where she heads up a team that supports and initiates patient and public contributions to research planning and implementation. Kristin has a background in childhood research, evidence-based policy and practice, and qualitative research that employs participatory methods.

Helen Roberts is Professor of Child Health Research at UCL Great Ormond Street Institute of Child Health. Although a career academic, she spent a decade leading R&D in the children's charity Barnardo's and a further period seconded to a government department. Her research interests include inequalities in health and what can be done about them, and research-informed advocacy.

Published Articles

Liabo K, McKenna C, Ingold A, Roberts H. Leaving foster and residential care: A participatory study of care leavers' experiences of health and social care transitions. *Child: care, health and development* 2017, 43(2): 182-91, DOI: 10.1111/cch.12426

Abstract

Patient perspectives in multi-disciplinary study teams can add to the relevance, quality and application of research (Shippee et al., 2013). In the UK, ethics committees tend to distinguish patient and citizen involvement from research participation. This means that when researchers ask patients or citizens for *advice* on a study, or invite them to collaborate with the study team, they do not need ethical approval. This puts their input on a similar footing to clinicians, other practitioners, academics and policy makers. But there are times when people's input into study design and implementation derives from their participation as research 'subjects'. This is more likely to be common in qualitative research, where a researcher's interaction with participants may result in collaboration on data collection and analysis.

Drawing on a study with young people leaving foster and residential care, this case study describes what we did when a research participant wanted to be acknowledged by name. This request challenged the principle of anonymity which ethics committees and researchers commonly expect to be afforded to, and welcomed by, participants. We declined the request on two grounds. Firstly, the commitments we had made in our application for ethics approval; secondly, our concern that naming one participant might breach the confidentiality of those who preferred to remain anonymous.

Here, we ask whether it is possible to conduct fully anonymised participatory research and suggest that involvement of patients and citizens as research advisors carries challenges to established conventions.

241 words

Learning Outcomes

By the end of this case students should be able to

1. Understand that ethical dilemmas in research frequently have no single correct response (British Sociological Association, 2017).
2. Consider what they might do if their planned research were to raise similar difficulties to those described in this case.
3. Explore how they might apply ethical perspectives, sometimes described as an ‘ethical radar’ (Skånfors, 2009) to their planning and analysis of participatory research.

Case Study

Currently 2,872 words

Project Overview and Context

Imagine a young person, Ava. She is 17 years old and has been in foster care for the last 8 years. Before that, she lived with her mum and step-father. At the age of 9, and as a result of neglect, she went into foster care for 6 months while social services looked for something more permanent. Her first placement broke down when a younger foster sibling struggled to cope with sharing their foster parents’ attention. Ava moved to another placement, which broke down when it turned out that she was allergic to the family dog. Her third placement, from the age 12, has been ok, but the foster parents also care for Ava’s younger half-siblings. They are currently sharing a room and at ages 3, 5 and 6, they will soon require more space. This means that Ava will need to move out when she turns 18. Since she was 13, Ava has been regularly attending a paediatric clinic to help her manage her diabetes. She knows the consultant and nurses well. In the past year she has also attended a service to help her with her struggles with depression and anxiety. She knows that when she turns 18 she will need to go to an adult diabetes clinic in a different hospital to the one she has used for years. At much the same time, she will need a mental health assessment to find out whether she is eligible for adult mental health services. She is also changing social worker because she is transitioning from children’s social care to the leaving care service. All of this involves a lot of disruption for someone only just approaching independent living as a young adult.

The example of Ava is fictional, but not atypical. It is inspired by stories we were told by young people in a study that focused on young people’s experiences of transitioning out of children’s health and social care services when they turn 18 and enter adulthood (Liabo, McKenna, Ingold, & Roberts, 2017). Because we were interested in young people’s experiences, we were keen to ensure that young people, with similar experiences to Ava, could have the chance to shape our study so that it would focus on the questions they thought most pressing during this period in their lives. This study forms the background for our case example.

Research Practicalities

We carried out this research in a local authority where we had a good research relationship with a participation project for children and young people in foster and residential care. This project is led by a social worker who actively supports foster children and young people having a say in local policies and practices. For example, young people sit on interview panels to recruit social workers and do ‘mystery shopping’ to check out whether local frontline services are young-people-friendly and approachable.

Before starting our study, we liaised with the manager of the participation project before meeting two young people involved there to explain what we wanted to do. They supported the plan and wanted to be part of it. Both young people told us how difficult it can be to approach your 18th birthday knowing that you are likely to have to move to live by yourself, and start using health services you may know nothing about.

Once the study began, young people were first approached by a staff member at the participation project, or their transition support worker in social care (known as a personal advisor). They were told about the study and asked whether they wanted to find out more and come to a meeting or be interviewed. If a young person was interested, they were met by a researcher who explained the project while going through a study information sheet. If they agreed to take part, they would fill in a step-by-step consent form where they were asked to consent or decline to a list of items including the ways that data might be used by the researchers, one of which emphasized confidentiality:

Do you know that everything said in the meeting/interview will be confidential (private)?

Data used in our report will be anonymized (private and confidential).

The consent form was much longer, but these two points have the greatest relevance for the dilemma we are about to describe.

Research Design

Following our initial meeting with the young people and project staff we designed a participatory study with qualitative methods, working with young people and interviewing professionals in key agencies. By ‘participatory’ we mean that we wanted to make sure that young people could influence both the conduct and focus of the study. This research was exploratory in that there is only a slender body of literature on young people’s experiences of multiple service transitions. We were open to the possibility that our questions might not be the ones most important to them and wanted to hear what young people thought we *should* focus on.

We spoke to young people in a set of group meetings, each focusing on an aspect of the transition from children’s services. In these meetings young people participated in a

combination of conventional focus group discussions and activities were they chose images or symbols that related to the transition period. These images were then used to prompt further discussions. At one meeting for example, young people cut photographs from magazines and newspapers to create a collage of their transitions from children's services. In another meeting young people were encouraged to use props that reminded them of central aspects of service provision during transition, or to come up with items that would symbolize an opinion or point they wanted to make. For example they identified the symbol of a 'key' to illustrate that the most pressing issue for most of them during the transition period was where they were going to live. The props were used to engage young people with a range of abilities, languages and backgrounds, and encourage them to initiate focal points for discussion.

These meetings were supplemented by individual interviews with the young people who wanted to speak to the researchers on their own in addition to, or instead of, in group meetings. In these interviews, we asked young people about their current situation, their experiences of service transition and their thoughts on becoming an adult.

Participatory aspects of the design included activities as well as a meeting where young people commented on the research plan, and ongoing consultation to make sure that we were focusing on the aspects of transition that they saw as most important. We also invited young people to suggest questions or topics that we could use when interviewing professionals, and which professionals, or professional groups they recommended we interview.

Ethical Dilemma

Twenty-four young people participated in the study, and seven of them attended both group meetings and individual interviews. Nine only gave individual interviews, and eight only attended group meetings. While they all received services from the same local authority children's services, they did not all know one another, but some were friends.

Young people were candid in the group meetings about their views of services, but generally reserved stories about their own health and transitions for individual interviews. Some described difficult experiences relating to foster placements, treatment by health and social care staff, and reasons for going into care. Some, but not all, had fractured relationships with their families. Everyone spoke of at least one professional who had seen their need for support, and gone the extra mile to provide it. We could not have carried out our study without the young people's willingness to share these stories.

Towards the end of the study one of the young people who had been at the information meeting where we first presented the project with our research idea, and who had come to two meetings and given an individual interview, asked to be acknowledged for their input by name.

As researchers, we tend to see a confidentiality clause as being primarily there to protect participants from being identified. Confidentiality is a central principle in most research. In the print media, while there is a preference for real names for real people, individuals are sometimes accorded privacy ('a trusted source') or where they are sources of very sensitive information their identities may be protected. In comparison, research participation is usually confidential by default and researchers normally design their information sheets and consent forms with this commitment in mind.

Actively involving participants in shaping the design and focus of a study is far from new in sociological research, with examples of participants influencing the research focus as a result of their interactions with researchers (Christensen, 2004; Roberts, Smith, & Bryce, 1993), where they helped to collect data (Foote Whyte, 1981; Orlandella, 1981), or where members of a research team were themselves members of the field they were researching (Ash, Bellew, Davies, Newman, & Richardson, 1997). For example, the sociologist Howard Becker was a musician when he conducted fieldwork on dance musicians (Becker, 1963). This level of participation, and thereby influence from personal experience on the research, has come somewhat later to health services and clinical research, but once adopted, has been adopted vigorously.¹ As an example, Rosamund Snow, a diabetes patient, researched a training programme for patients with diabetes (Snow, Humphrey, & Sandall, 2013).

Our study was reviewed by an ethics committee in advance of us setting out in the field, and followed what have become standard principles for research: informed written consent, confidentiality, and clarity that participants could leave the study at any time. These principles initially emerged in relation to biomedical research, but as awareness grew that any research involving human subjects has the potential for harm, it has become usual in academic research in the UK for all participants to be given the option to refuse to consent to research and, if they participate, to be protected by confidentiality except in well-defined circumstances.

Since it is difficult to guarantee confidentiality in a group meeting, the ethics committee that reviewed our study was concerned about the confidentiality of the young people who would participate in this part of our study. They asked us to speak about confidentiality during recruitment, and emphasise it on our information sheet. The young person's request that s/he be named therefore went against a requirement of the study's approval.

In addition to our formal agreements with the ethics committee, we were concerned that naming one study participant would risk identifying others. At the request of our key gatekeepers, we also withhold the names of these professionals and the local authority where the study was conducted. Young people, some of whom had good reason to protect their identities, had told us their stories on the understanding that their data would not be linked to their names.

¹ <https://www.nihr.ac.uk/patients-and-public/>

Our dilemma largely derived from the fact that through our research methods and the study design we had actively encouraged participants to take ownership of the research. We had asked their opinions on what we should focus on, who we should interview, and what we should ask. We had encouraged them to create collages that we would go on to use in our dissemination activities. A young person asking to be acknowledged by name for their input into the study indicated that we had achieved our participatory aim, but this challenged another principle of research: confidentiality.

Resolution of the Dilemma

The young person first put their wish to be named as a contributor to the research to one of the researchers. They explained that this would need to be discussed with the wider team. We discussed the pros and cons of naming the participant, and implications for other people who had taken part. We considered including the young people interviewed in these discussions, but did not want them to feel under subtle pressure to overturn the confidentiality they had been promised.

The principal investigator took the dilemma to a closed professional workshop where she had been invited to discuss ethical challenges in research with looked after young people. Another participant at the meeting described a similar situation where a group of elderly people had been interviewed about extraordinary experiences in their pasts. They too had asked to forgo anonymity and wanted to be named, which did eventually happen. Whilst discussing the case with others did not solve our dilemma, it helped us crystallise what was important to consider in our particular study context.

Unlike our colleagues who had supported a request to forgo anonymity when it was requested by an entire group, we concluded that the sensitive information shared by the young people, in response to a promise of confidentiality, weighed towards retaining full confidentiality. We were also influenced by the power of the media in creating or covering narratives which could be damaging to individuals. Some years ago, a doctor writing in a medical journal had described a child with multiple disabilities, suggesting that a reason the parents had not wanted to let their child die may have been because s/he brought in considerable financial benefits. Not long afterwards, the family was traced by a newspaper. This was before the days of social media – but was a salutary lesson in how some sections of the press can be quick to trace individuals through a few details, even if professionals do not intend to breach confidentiality.

Our decision on how to respond was based on consultation with research colleagues and reflection on our past experiences. We informed the young person that we did not feel that we could acknowledge their input by name, and explained our reasons. As a compromise we offered all participants a certificate, in hard copy, acknowledging their participation. The participation project is not named on the certificate and so the study could have been conducted anywhere. Having a certificate was a sign of their contribution, which we deemed to outweigh the minimal risk of identification from these documents.

Practical Lessons Learned

Both authors have a record of working with participatory methods and have published with research participants in the past (Liabo & Gray, 2008; Liabo, Gray, & Mulcahy, 2012; Roberts, Rice, Smith, & Bryce, 1994; Roberts, Smith, Campbell, & Rice, 2010). We recognise the a-symmetrical relationship in the case we describe here, where academic colleagues are acknowledged by name (or by referencing their publications) and a young person who has made a contribution, along with others, is not.

It is tempting to conclude that this case example illustrates no more than a need for clear differentiation between research participants and service user advisors in participatory research. This conclusion would, however, overlook the strengths of methodologies where research participants influence the trajectory of the research from conception to dissemination. Our research was strengthened by its participatory elements and our experience has changed our own practices so that in future our participatory research will start with a discussion about confidentiality and the ways in which contributions might be recognised.

One workaround could have been to acknowledge by name people who want to be recognised formally for their help with study design, research focus or implementation, without referring to them also being participants in the research study, thus retaining anonymity for all research participants. With hindsight, we might have applied this to our own study. However, even this risks identifying members of a population some of whom will actively prefer anonymity.

We are aware that the young people we study are almost certainly more conversant than us of the risks and benefits of social media – and would be expert commentators on where the balance might lie for those of us who do research. This does not, of course, imply that there would be only one view. We fed back our initial findings to a group of care leavers before wider dissemination. We showed one quotation where a young person had felt strongly that since the status of being (or having been) in care could influence some professional decisions in a positive direction, in-care status should be readily available in health and social care records. Others took the opposite view, which was that having been in care was potentially stigmatising and that after leaving care, young people themselves should decide what could be shared on a case by case basis. This discussion strengthened our resolve to try to ensure that we try to identify problematic issues upfront.

Conclusions

Between us, the authors of this case study have a good deal of experience of participation and involvement in research (Curtis, Liabo, Roberts, & Barker, 2004; Liabo, 2016; Roberts, 1981, 2000; Roberts et al., 1993; Stewart & Liabo, 2012). That we are still learning lessons shows

that not every problem can be foreseen, and how much can depend on the context of the research.

Progress in this area comes through reflective research practice. Researching populations who are deemed to be vulnerable, who may be very different from us or who may have similar experiences requires relationship-building. This tends to generate complex ethical and moral dilemmas (British Sociological Association, 2017). Planning for these is not always possible, but engaging with them as they arise and reflectively, following the completion of fieldwork, helps us discover new paths towards an ethically sound research practice.

Exercises and Discussion Questions

1. What was the aim of the research study on which this case example was based?
2. What makes research 'participatory'?
3. Why might researchers aim to be participatory?
4. What is the ethical dilemma described here? How did it arise?
5. What would you have done in our place?
6. Can you think of a research study where a participatory approach might be unethical?
7. A journalist asking similar questions to us could have used the names of the people they spoke to. What makes research different from journalism?
8. Design a consent form for a piece of research with children and young people aged 12-16 some of whom have mild learning disabilities.

Further Readings

Beazley H, Bessell S, Ennew J, Waterson R (2009). The right to be properly researched: research with children in a messy, real world. *Children's Geographies*, 7(4): 365-378

Christensen P (2004). Children's participation in ethnographic research: issues of power and representation. *Children & Society*, 18: 165-76

Morgan H, Thompson J, Crossland N, Dykes F, Hoddinott P and the 'BIBS' study team (2016). Combining PPI with qualitative research to engage 'hard-to-reach' populations: service user groups as co-applicants on a platform study for a trial. *Research Involvement and Engagement*, 2(7)

Renold E, Holland S, Ross NJ, Hillman A (2008). 'Becoming participant' Problematizing 'informed consent' in participatory research with young people in care. *Qualitative Social Work*, 7(4), 427-47

Sammons HM, Wright K, Young B, Farsides B (2016) Research with children and young people: not on them. *Archives of Disease in Childhood*, 101(12): 1086-88

Thomas N (2012) Love, rights and solidarity: studying children's participation using Honneth's theory of recognition. *Childhood*, 19(4), 453-466

Thomas N, O'Kane C (1998) When children's wishes and feelings clash with their 'best interests'. *The International Journal of Children's Rights*, 6: 137-54

Web Resources

<http://ethicsguidebook.ac.uk/Research-with-children-105>

<http://childethics.com/>

<http://www.open.ac.uk/researchprojects/childrens-research-centre/research-children-young-people>

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References

- Ash, A., Bellew, J., Davies, M., Newman, T., & Richardson, L. (1997). Everybody in? The experience of disabled students in further education. *Disability & Society*, 12(4), 605-621.
- Becker, H. (1963). *Outsiders: Studies in the sociology of deviance*. New York, NY: The Free Press.
- British Sociological Association. (2017). *Statement of Ethical Practice*. Retrieved from Belmont, Durham:
- Christensen, P. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children & Society*, 18, 165-176.
- Curtis, K., Liabo, K., Roberts, H., & Barker, M. (2004). Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, 7, 149-156.
- Foote Whyte, W. (1981). *Street corner society: The social structure of an Italian slum*. Chicago and London: The University of Chicago Press.
- Liabo, K. (2016). Care leavers' involvement in research: an ethnographic case study on impact. *Qualitative Social Work, Online early*.
- Liabo, K., & Gray, K. (2008). Working together to produce a systematic review. *INVOLVE Newsletter, Conference 2008*, 8-9.
- Liabo, K., Gray, K., & Mulcahy, D. (2012). A systematic review of interventions to support looked after children in school. *Child & Family Social Work*.
- Liabo, K., McKenna, C., Ingold, A., & Roberts, H. (2017). Leaving foster or residential care: a participatory study of care leavers' experiences of health and social care transitions. *Child: Care, Health and Development*, 43(2), 182-191. doi:10.1111/cch.12426
- Orlandella, A. R. (1981). The Whyte impact on an underdog. In W. Foote Whyte (Ed.), *Street corner society: The social structure of an Italian slum*. Chicago: The University of Chicago Press. (Reprinted from: In File).
- Roberts, H. (1981). Women and their doctors: power and powerlessness in the research process. In H. Roberts (Ed.), *Doing feminist research* (pp. 7-29). London: Routledge & Kegan Paul. (Reprinted from: Not in File).
- Roberts, H. (2000). Listening to children: and hearing them. In P. Christensen & A. James (Eds.), *Research with children*. London: Falmer Press. (Reprinted from: In File).
- Roberts, H., Rice, C., Smith, S. J., & Bryce, C. (1994). It's like teaching your child to swim in a pool full of alligators. In J. Popay & G. Williams (Eds.), *Researching the People's Health*. London: Routledge.
- Roberts, H., Smith, S., & Bryce, C. (1993). Prevention is better ... *Sociology of Health & Illness*, 15(4), 447-463.
- Roberts, H., Smith, S. J., Campbell, B., & Rice, C. (2010). Safety as a social value: Revisiting a participatory case study in Scotland. In M. Kirst, N. Schaefer-McDaniel, S. Hwang, & P. O'Campo (Eds.), *Converging disciplines: a transdisciplinary approach to urban health problems*. New York: Springer.
- Shippee, N. D., Domecq Garces, J. P., Lopez, P., Wang, Z., Elraiyah, T. A., Nabhan, M., . . . Murad, M. H. (2013). Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations*, 18, 1151-1166.
- Skånfors, L. (2009). Ethics in child research: children's agency and researchers' 'ethical radar'. *Childhoods Today*, 3(1), 1-22.
- Snow, R., Humphrey, C., & Sandall, J. (2013). What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a

qualitative patient-led study. *BMJ Open*, 3, e003583. doi:10.1136/bmjopen-2013-003583

Stewart, R., & Liabo, K. (2012). Involvement in research without compromising research quality. *Journal of Health Services Research and Policy*, 17(4), 248-251.