

Article

# Participatory Research and the Ethics of Anonymisation

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**Abstract:** Research in the UK is increasingly regulated by ethics review committees (RECs) which require researchers to seek ethics approval before commencing research. These RECs routinely expect researchers to anonymise data as part of standard ethical research practice. However, the anonymisation of data may sit in tension with participatory approaches to research which prioritise shared ownership of the research. In particular, the need to make decisions relating to ethics prior to the start of research makes it difficult for researchers to meaningfully share decision-making power with their participants—a fundamental principle of participatory approaches. This paper uses a participatory research study as a case study to explore this tension. In the study, the decision to anonymise data was made as part of the ethics approval process. However, over the course of the study, the researcher questioned whether this was the correct decision for this study. In order to afford researchers the flexibility required to involve participants in decision making, this paper argues for a dialogic and situational approach to ethics regulation. Allowing researchers to delay key decisions would mean that researchers could involve participants in the decision-making process rather than purely informing them of the results of decisions made on their behalf.

**Keywords:** participatory research; anonymisation; ethics



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## 1. Introduction

Ethics regulatory bodies routinely expect researchers to anonymise data. Alongside this, there is an increasing recognition of the benefits of participatory approaches to research, which challenge the extractive and exploitative hierarchical power structures of traditional research methods. Anonymisation can sit in tension with participatory approaches as it restricts the degree to which participants can meaningfully claim ownership of the research. In some instances, anonymisation is clearly vital, such as when participation may put participants at risk, whereas in other circumstances, it can be considered a form of silencing, eliminating the participants' voices and identities from the research. This paper critically examines this tension through an example of a participatory research study. It explores whether anonymisation may be antithetical to participatory approaches which prioritise co-creation of research rather than the centring of the researcher.

This paper draws on an account of participatory research as a case study to illustrate the tension between the routine anonymisation of data and a participatory approach from two perspectives. First, in order to be awarded ethical clearance, the decision to anonymise data must be made before the study could begin and therefore made on behalf of participants. Second, anonymising data raises questions surrounding participant ownership and acknowledgement. I use this study as an illustration of the broader debate, and as such, this article is not an empirical paper per se. The study itself made use of a steering committee, recruited from participants involved in first phase of data collection, and involved a photo-voice element, alongside remote in-depth interviews. The question of anonymisation arose not only regarding the contributions of the steering committee, but also with other members of the study, particularly pupils, who wanted to feel like their voices were heard. This challenged the value of anonymisation within the context of a study in which participant voice and empowerment were considered integral.

The British Educational Research Association (BERA) ethical guidelines [1] state explicitly that there may be different legitimate understandings and applications of their principles, and this acknowledgement leaves room for individual negotiation. However, research studies in the UK tend to be regulated by research ethics committees (RECs) situated within institutions. Whereas these committees develop their regulations from guidelines, such as BERA's, they can only ever imperfectly translate these into practice. Following REC's procedures, while clearly necessary, can, in some instances, distort a researcher's approach to ethical decision making. This runs the risk of front-loading ethical decision making, often fixing a researcher to a set of pre-agreed regulations before the study commences. I make the case for an attempt to actively support ongoing ethical reflection in research by allowing researchers to delay certain decisions, with later review. This builds into the ethics review process a space to re-evaluate and re-negotiate ethical decisions as a study progresses. Revisiting ethical regulations during a study may give researchers both the flexibility to adapt their processes as the situation requires, and to emphasise the continual and processual nature of ethical research practice. In particular, this might allow researchers and participants to discuss the question of anonymisation during the research process, giving voice and acknowledgement to participants who participated as co-researchers.

## 2. Literature Review

### 2.1. Participatory Research

Participatory research sets out to explicitly challenge the exploitative (in this instance, the word 'exploitative' refers to the well-covered criticism that much research benefits the researcher more than the participants (e.g., [2])), extractive (extractive refers to the process of extracting data and the lack of ownership that participants then have over the data following this (e.g., [3])) and paternalistic ('paternalistic' means restricting freedoms of individuals, supposedly in their best interest, and challenges the tendency for researchers who make decisions on behalf of participants (e.g., [4])) nature of traditional research methods [5,6]. In particular, participatory research prioritises shared ownership, seeking to co-produce meaningful and impactful research that is relevant to the lives of participants [7]. There is significant overlap between participatory approaches to research and the ideals of democracy [8–10]. In particular, the sharing of power, such that everyone involved has the opportunity to direct the research, is foundational to participatory approaches.

Groundwater-Smith et al. [11] suggested that most ethical issues revolve around relationships between researchers and participants. Since participatory research seeks explicitly to redefine researcher–participant relationships, it raises additional ethical considerations relating both to the treatment of participants and the quality of the research. The debate surrounding issues of quality in qualitative research is not new in the literature [12,13]. Participatory research, in particular, raises a challenge to the traditional meanings of reliability and validity, as it does not aim for generalisability and objectivity. Bergold and Thomas [14], in their seminal paper on participatory research, articulated this as follows:

*This situation changes radically when the relationship between the participants is put on a participatory footing. In this case, the perspectives of the various partners and their differences of opinion are important for the process of discovery; objectivity and neutrality must be replaced by reflective subjectivity. (p. 202)*

In this quote, Bergold and Thomas explicitly shift away from the pursuit of objectivity. Participatory research cannot be objective as it relies heavily on the subjective experiences of participants. Like much qualitative research, participatory research does not seek to minimise subjectivity. Instead, it recognises that much of what we think of as data or evidence is subjective to a greater or lesser degree. In this case, the aim is not to reduce subjectivity per se, but to understand it more clearly. Reflective subjectivity captures the recognition that while objectivity is not the primary aim, being aware of the ways in which individual positions and biases may influence data production is an integral element of high-quality research.

This paper focuses predominantly on the process of anonymisation, which spans both the treatment of individuals and issues of quality. From the perspectives of ethics regarding the treatment of participants, deciding whether to anonymise data can be seen as a balancing of participants' ownership of the data with protection from potential harms. Regarding issues of quality, anonymisation can be argued either to give participants the freedom to express themselves without fear of reprisal, and hence to increase reliability, or conversely to allow researchers and participants to make claims that are only weakly substantiated, hidden behind the screen of anonymity. Both themes are picked up again in the discussion.

The word 'participate' has roots in Latin, with 'pars', meaning 'part' and 'capere', meaning 'to take' [15]. The combination of these in 'participare', meant both to participate, 'taking part', and to share, 'taking a part'. These two meanings of the word illustrate my understanding of participatory research. On the surface, participation is about engagement, about *taking part* in the research process. Having participants engage meaningfully with the research process lends credibility and validity to the research findings. On a deeper level, participation is about the ownership of the research process, *taking a part* of the decision-making power. This means framing the participants as co-researchers who are not just sites of data extraction but active producers of that knowledge. It involves sharing the power and control that the researcher has over much of the research process. It is this lens, participation as taking part and taking a part, as engagement and ownership, that I will use in this paper to explore the place of anonymisation in participatory ethics.

Ownership is a concept which is regularly associated with participatory approaches, although it is rarely explicitly defined [16]. Whereas there are clear etymological links to the concept of emancipation (literally meaning to come out of ownership [17]), in the case of the research process, 'ownership' is often linked to ideas of power and control—power to shape the research and control over decisions and process [18]. In this paper, I use the term 'ownership' to reflect whether individuals are able to recognise their own contributions to the research. Through this, I recognise that data in participatory research is co-produced, and seek to highlight that both researcher and participant have significant roles in data production and analysis. In seeking to share ownership of the research, I illustrate a desire to emphasise the contributions made by participants.

When undertaking research, researchers make decisions relating to their beliefs about the nature of reality (ontology), values (axiology) and the nature of knowledge (epistemology), even if they are unaware that they are doing so [19]. Borrowed from work by Kuhn, researchers commonly refer to these concepts as a research paradigm. Defined by Guba and Lincoln [20], a paradigm is a 'basic belief system, based on ontological, epistemological and methodological assumptions' (p. 107). Heron and Reason [21] went as far as to suggest a participatory paradigm, which they proposed as a development of Guba and Lincoln's work. They argued that 'knowing presupposes mutual participative awareness', building on a constructivist paradigm to emphasise the participatory nature of knowledge generation. In particular, they critiqued the view of a paradigm as comprising of only ontological, axiological and epistemological considerations. They argued that these three elements address matter of truth and reality but ignore questions of worth or value. They argued that it is important to consider what the fundamental purpose of inquiry is and suggested that ultimately it must be to promote human flourishing in one form or another. In this paradigm, inquiry is carried out to eventually bring about change in the world, and this implies participation and engagement. Whereas this paper treats participatory research as a methodological approach and not a distinct paradigm, this discussion adds weight to the argument that recognising the co-construction of research data participatory approaches allow insight into the meaning of data that may otherwise be inaccessible to researchers [22].

## 2.2. Ethics Regulation

Research is increasingly regulated by ethics review boards, often at the levels of individual institutions who develop their procedures from common guidelines [23]. This heightened regulation stems from an increased awareness of the potential harms of research and, consequentially, the need for improved protection of research participants. However, many of the foundational principles of ethical review processes are developed from work in biomedical research ethics, and some researchers argue that these principles are at odds with research in the social sciences, which is more emergent and continuously negotiated [24]. In particular, some researchers argue that current review process tend to engender an understanding of ethics as a discrete event that occurs prior to data-collection. They argue that ethical review process, therefore, actively hinder the continual reflection which is necessary for ethical research practice in the social sciences [25,26]. Fundamentally, there is a difference between practice in medicine and practice in education that is reflected in the nature of the duty of care that researchers and practitioners have over their participants, patients or pupils. In medicine, the potential harms of an intervention are arguably more severe, and medical ethics has had to contend with serious abuses of researcher power (see, for example, the Tuskegee trial [27]). Whereas educational practices themselves have often been harmful [28], there is less of a history of the harmful effects of educational research. In particular, the nature of interventions and of researcher–participant relationships in medical and educational research is fundamentally different, with educational research tending to proceed in a less predictable fashion. Having said this, there is also an increasing push in the medical field to re-evaluate ethical procedures to reflect the shift away from purely biomedical approaches [29,30].

Current ethical procedures are understandably concerned with the safety of the participants, but often fail to address concerns regarding the wellbeing of the researcher [31]. This highlights the unidirectional understanding of ethics promoted by review processes, where researchers are seen as having a paternalistic duty of care over their research participants. In reality, much research, specifically when it is qualitative or participatory in nature, is considerably more relational than this model implies. Participatory research deliberately blurs the boundary between researcher and researched. In this instance, it feels appropriate to reconsider traditional approaches to ethics regulation that better reflect this relationship.

Ethical decision making is not a case of following a set of universally agreed moral norms. If it were, then IRBs and RECs would be all that was required for ethical research practice [32]. Instead, ethical choices arise throughout the research process and must be continually made and re-made over the course of any study. In the case of research that is part of a programme of study, such as master's or doctoral research, there is an added need to see the research as a form of training for the researcher (this is arguably true for all research, as researchers are continually developing their practice). It is not the case that researchers can learn a set of guidelines to follow and, from then onward, be certain that the research they carry out will be ethical. It is therefore important to develop regulatory procedures that more truthfully reflect the reality of ethical research practices. Mackworth-Young et al.'s [29] recommendation of reflexive 'ethics-in-practice', and Simons and Usher's [33] description of 'situated ethics' are both examples of researchers who have recognised that many ethical dilemmas arise during research and that it is not always possible to find solutions to them beforehand. In particular, Glen's [34] discussion of 'integrity in action' research aligns well with participatory approaches to research. These approaches caution against seeing ethical considerations as predictable problems which can be solved through the application of predetermined universal moral principles. Instead, they propose an approach to ethical research that is reflexive and context-dependent, requiring the researcher to adapt and adjust their approach depending on the circumstances.

## 2.3. The Ethics of Anonymisation

Much of the literature and discussion of ethics have understandably focused on the role of the researcher. Ethical decisions are made by the researcher, often on behalf of

participants, who are framed as passive and in need of protection from harm [35,36]. From this perspective, anonymisation is usually justified as part of a researcher's 'duty of care' for their participants [37]. Considering the two elements of participation I introduced earlier, engagement and ownership, we could reasonably suggest that anonymisation is needed to facilitate engagement—participants who may feel nervous or worried about engaging in the research may be reassured that their contributions will not be traceable to them. This is of particular importance when researching sensitive issues or working with marginalised populations. However, paternalistic and occasionally naïve assumptions about the power dynamics of the research process are inherent in this justification. In particular, by making the decision regarding anonymisation prior to recruitment or data collection, researchers assume the right to make these decisions on behalf of the researched.

Anonymisation of research data is seen as crucial to maintain the privacy of research participants. In some instances, this may also be necessary as a mechanism to protect them for harm if, for example, the data collected are sensitive or could potentially be used for discrimination. In particular, anonymisation in these instances is framed in such a way as to protect participants and to facilitate their engagement in the research process. Much of the literature in this area describes the fact that true anonymisation is likely to be impossible, particularly in the age of the internet [38]. In addition, some literature points to the tension between removing identifying information while retaining the contextual data necessary to fully understand the evidence [39]. The discussion of these challenges occasionally points to the consent process, stressing that participants must be fully informed of the potential for identification and of the details of what the anonymisation process will be [40]. There seems to be less of a discussion surrounding the potential of asking participants whether and how they wish to have their privacy protected. In decisions regarding anonymisation, participants tend to be framed as passive and vulnerable, with much of the debate focused on how to inform them of the decisions that have been made rather than how to involve them in making the decisions.

Participatory research takes as axiomatic that shared ownership of research increases the relevance and impact of research. Kellet et al., in their research with young people in care, recognised the importance of children as researchers to ensure research reflected their priorities and experiences [41,42]. Although the researchers included young people in the care system, the research participants were still anonymised in order to ensure that the children 'felt safe and protected' [42] (p. 10). Framing anonymisation as important to support engagement in research may be true in many instances. The ideals of participatory research surely require researchers to at least question this assumption and, where possible, involve participants in the decision making regarding how and whether their data will be adapted.

If we accept the lens I have proposed for participation as both engagement and ownership, then it is this second element of the participatory approach which sits most obviously in tension with the practice of anonymisation. To what degree can a researcher meaningfully claim shared ownership of a piece of research when only their name appears on the final publication? Some studies have attempted to acknowledge participants, such as Fox et al., who included a written acknowledgement at the start of their chapter [43], and Baird et al., where participants were named authors and had written chapters of their own [44]. These represent examples of work that acknowledge significant contributions of participants, but there still seems to be a gap when it comes to studies which publish non-anonymised data from participants who were not necessarily involved in writing.

Conversely, Liabo and Roberts [45] reflected on their decision to refuse a participant's request to have their contribution acknowledged by name in their research. Tellingly, they reported that that had made the decision regarding anonymisation as part of their application for ethics clearance prior to the start of the study: "The young person's request that s/he be named therefore went against a requirement of the study's approval." (p. 6).

This flexibility is afforded to them as they are unregulated by ethical review boards. Instead, they are governed only by their professional integrity. I do not suggest that ethics

review processes are unnecessary but argue that surely there are instances where the data generated by an interview or survey are not particularly sensitive and where participants could reasonably request their contribution to the research projects to be acknowledged. I know from personal experience as a teacher who took part in several research studies that I often felt somewhat cheated when I contributed well-thought-out responses to interviews or surveys for which the only credit went to the researcher.

### 3. Materials and Methods

#### 3.1. *The Study*

The study focused on the intersection of educational assessment practices, perceptions of success and identity. The participants included 17 school pupils, 7 teachers and 6 policy-makers. School pupils were deliberately oversampled to privilege their contributions to the research. School-based participants were recruited from state-funded secondary schools in London, and policymakers were recruited from a range of institutions involved in the design, delivery and regulation of examinations. The study primarily used intensive interviews as a method of data collection, but pupils were also offered the chance to complete a photo-voice project prior the interviews if they wished to. For further details of the study itself and its findings, the full thesis can be found in the Oxford research archive (ORA) [46].

#### 3.2. *The Participatory Approach*

The study took a participatory approach, in particular, through the use of photo-voice as a mechanism of data collection and through the recruitment of a steering committee. The photo-voice project involved asking pupils to take or collect images that represented their understanding of the meaning of success. Through these photos and images, pupils could portray what success looked like from their perspective. These images were submitted to me before the interviews, and interviews then started with pupils taking through these images. This exemplified my participatory approach as it facilitated both engagement and ownership. Pupils were supported to engage meaningfully in the interviews by taking some time to think about the content of the interviews beforehand. They were also given some ownership of the research in that by submitting images, they set the direction of the interview within the boundaries of taking about success. Similarly, the steering committee illustrated the dual nature of participation. The steering committee was made up of three pupils, a teacher and a policymaker, all recruited from the first round of data collection, as well as my supervisor. The steering committee met twice during the research. In these meetings, I presented my initial analysis. Participants reflected on their experience of being in the study and helped adapt my methods for future rounds of data collection. In addition, they offered insight and additional analysis to help guide the progress of the study.

Although it was not a primary focus of the study, research ethics were regularly discussed, both with my supervisor and the steering committee. I talked through the study with participants before interviews and sent transcripts that I had written with participants after the interviews. During the design of this research study, I consulted the British Educational Research Association ethical guidelines [1] and the University of Oxford's Central University Research Ethics Committee guidelines [47], in particular, those pertaining to research with young people. Regarding anonymisation, my perception was that this was assumed as the best practice, and my MSc module on research methods and ethics seemed to imply this. Notably, my ethical application included how I would ensure confidentiality, rather than a discussion as to whether this was the appropriate choice.

### 4. Results

This paper draws on a research study as a case study to illustrate the discussion. The study content was not specifically focused on the idea of anonymisation. As such, this 'results' section reports on findings and impressions drawn from conversations with participants that occurred before, during and after the interviews, as well as in the steering committee. As such, I do not present these results as objective, but rather as illustrations of

the broader discussion that occurred. In future studies, I recommend centring these results as a distinct research question if the debate is to be further progressed.

#### 4.1. Power

The participants in this study ranged from school children, who I would argue held less power than I did in our interactions, to senior policymakers with whom the power dynamic was clearly hazier. However, in discussions around the process of data anonymisation, participants in positions of relative power tended to be more in favour of anonymisation—I sent a transcript of the interview to each participant after I had finished transcribing it, and policymakers were the only ones to respond asking for clarification about certain parts of the interview which they felt might make them identifiable. They were also quick to point out that their responses did not necessarily represent their ‘official’ position and regularly clashed with their perceptions of the cultures at their institutions or the views of their colleagues. School pupils, however, were more ambivalent, feeling that it was unlikely that my thesis would be read by anyone they knew. Even if it was, they stood by their contributions which they felt were accurate representations of their views.

Anonymisation often is justified as protecting more marginalised participants. In this instance, is it instead protecting those who have more power and hence ‘more to lose’ from their contributions? By extension, does anonymisation in instances where participants are experts in the subject matter and in positions to bring about meaningful change allow individuals to contribute without being held accountable to their contributions? If a policymaker makes a claim about the failings of a particular policy initiative, do they then have a responsibility to act from their position to change it? Anonymity allows participants to speak candidly and facilitates *engagement* in this sense. However, in allowing participants to speak without repercussion, anonymisation may reduce their *ownership* over their contributions and therefore their responsibility to use their positions to act on their views.

Schools were understandably hesitant to allow me access to school pupils, particularly as interviews were carried out remotely. Schools have a duty of care for their pupils and, as such, wanted to make sure that pupils’ privacy would be respected (although several schools also asked for teachers to sit in on interviews, which is perhaps contradictory to their desire for privacy). In contrast, throughout the recruitment and interview process, I witnessed enthusiasm and engagement from pupils. Many pupils reported enjoying and learning from the photo-voice projects. Several pupils also reflected on the importance of these conversations, suggesting that teachers and policymakers did not often hear their views. For these pupils who often seemed to feel disempowered by their educational experience, this was an opportunity to be heard. Whereas schools and researchers were keen to protect students, it is worth considering whether, in so doing, we restrict their opportunities to engage in research which they consider to be valuable.

#### 4.2. Acknowledgement

Participatory research frames participants as active contributors to the research. In particular, it requires researchers to reflect on the nature of their relationship with participants [48]. Participants give researchers the gift of their experience and insight. This is as true of experts, as it is with novices, who can be thought of as experts of their own experiences. With teachers and policymakers, the process of data collection and analysis was merged during interviews. The ideas raised were ones which they all had a degree of familiarity with. Therefore, discussion moved quickly beyond the sharing of data and into reflective analysis. It is naïve to claim that I carried out data analysis by myself—it seems clear that analysis was a collaborative effort which started during the interviews. It feels somewhat disingenuous to relegate participants to merely ‘sources of data’ and elevate my own contribution to that of researcher and analyst. This is particularly true when considering the contributions of participants who sat on the steering committee.

However, by anonymising the participants and including only my own name, there is an implication that I carried out the more cerebral work myself.

Regarding the pupils who participated, the research is empty and colourless without their insight. As the primary subject of the research, the pupils' experiences give life to the claims made. School pupils were given the option of carrying out a photovoice project in the build-up to the interviews, an option which the majority (13 out of 17 pupils) decided to take. This meant that pupils arrived at the interviews having already thought about the ideas I would be raising in the interviews. Many of them had spent considerable time preparing for the interviews and, in some cases, wondered whether they would be able to have their names attached to choice quotes which they had spent time formulating. One pupil had even developed a system of categorisation for her responses, meaning the analysis had started even before the interview. At one level, this makes me confident in the participatory nature of the research. On the other, by anonymising her contribution, did I take credit for the emotional and intellectual labour that she has put into this project?

## 5. Discussion

In order to carry out my research, I had to first gain ethics approval from my University's research ethics committee. Only once I had gained approval could I begin the process of recruiting participants to the study. This meant that many key ethical decisions had to be made before any engagement with participants. There is an implication in this that it is possible to predict, by and large, the way in which research will proceed. This tidy description is not representative of the reality of research, which is always a much messier and more reflexive process [49]. Ethical decision making takes place at every stage of the research process, from design to dissemination. This is particularly true of participatory research, which prioritises flexibility so that participants can have some power in shaping the research. In the case of my research, I had already made certain decisions regarding the anonymisation of data before I contacted schools. However, after speaking with pupils, I came to question the value of anonymisation and wished that I had been able to delay the making of that decision until after I had spoken with the pupils.

Alongside this, the research carried out was part of my MSc studies. Whereas I believe that the research was important in its own right, it also represented a training in research methods for me. Master's and doctoral research studies are opportunities for researchers to develop and hone their research skills. An integral element of that is their ethical practice—the ability to make and reflect on ethical decisions at every stage of the research. Very few researchers believe themselves to be unethical researchers, yet there are examples of unethical research being carried out. Although it is by no means the primary purpose of ethics review processes, it is worth considering whether a procedure which engenders continual reflection through a more dialogic approach to regulation could facilitate greater reflection and, therefore, the better development of ethical researchers.

I would argue for a dialogic, contextual and situational approach to anonymisation. Rather than fixing a researcher to a set of pre-agreed regulations before the study commences, allowing researchers to delay certain decisions would be a step toward an ethics regulatory procedure in which ethical decisions must be re-evaluated and re-negotiated. This adds a processual element to ethics regulatory procedures as a way of building in reflexive practice. Revisiting ethical regulations during a study may give researchers both the flexibility to adapt their processes as the situation requires, and to emphasise the continual and processual nature of ethical research practice. In particular, this might allow researchers and participants to discuss the question of anonymisation during the research process, giving voice and acknowledgement to participants who participated as co-researchers.

### 5.1. *Research Is a Privilege, Not a Right*

One of the fundamental ethical factors that researchers must consider is what is the value of the research—why is the research worth undertaking and who will benefit? An important personal motivation for this research was that it was a requirement for

the successful completion of my MSc. In this way, even though it was well intentioned, there was an element of the research that was exploitative. Limes-Taylor Henderson and Esposito made this clear when they reflected that researchers ‘probably need our subjects/participants more than they need us.’ [50] (p. 887). It is important for researchers to recognise that the research they carry out is a privilege, granted to them by their participants, and not a right that they have. This is implied, but not always made explicit, in the ideals of participatory research, which emphasise the importance of the research participants.

One attempt to ensure the benefits of the research extended beyond helping me acquire a qualification involved the design of the methods of data collection. Participatory and creative methods can be enjoyable and empowering, representing an opportunity for participants to benefit from participation [14,51]. Many of the participants in this study felt that they had benefitted from the process in terms of their own personal learning. In addition, some participants felt that they had contributed to what they perceived as an important and meaningful study. The BERA guidelines refer to “*an ethic of respect*” [1] (p. 5, emphasis in original) and emphasises ‘trust’ between the researcher and participant as an essential element of ethical research practice. Participants need to trust that the researcher is capable of doing a good job of the research in order to produce something that is worthwhile. Shared ownership of a study can help build this element of trust. O’Neill described the need to put yourself in a position of vulnerability to demonstrate yourself as trustworthy, in order to be trusted [52]. Giving up some power over the research that you carry out and resisting the urge to think of it as *your* research can be a way of demonstrating that vulnerability and building trust between the researcher and researched. In particular, by offering participants the opportunity to attach their names to the research, a researcher can more clearly share the ownership and recognise the privilege that has been granted to them.

### 5.2. Voice and Power

My research involved young people, a group who, in particular, are often framed as passive and vulnerable in the ethics literature [53]. Part of the study design included the oversampling of school pupils compared to other groups. This was in part to reflect that their contributions have occasionally tended to be reduced in the wider literature. My aim was to privilege their voice and contribution to the research. Many pupils recognised this and reported feeling glad for the opportunity to have their voice heard in a context where they often felt overlooked and ignored. When pupils made these comments, I felt conflicted. On the one hand, I was pleased they felt that this represented an opportunity to be heard. On the other, I wondered whether I was merely contributing to their silencing by providing the illusion of voice. Ultimately, their voices were only heard by me, and as much as I attempted to represent their experience, I presented the evidence they provided as part of my own research project. I deliberately oversampled pupils to privilege their experiences, but by removing their names and identities, did I in some way erase their contributions?

By reducing participant ownership of the data, participants become less accountable for the data and less invested in holding researchers accountable. Walford [54] argues that the anonymisation of data can be seen as a way for researchers to make conclusions based on insufficient or uncertain data:

*Researchers are able to hide poor evidence behind the pseudonyms without those researched being able to make a challenge.* (p. 100)

Ensuring research is rigorous and accurately reflects the evidence is an ethical issue. It is worth reflecting whether naming participants would increase the degree to which researchers feel accountable to their participants. In carrying out all research, researchers have a degree of obligation to their participants, and this is perhaps made even more explicit when those participants are named contributors to a study.

Participatory research does not seek to reduce the degree to which researchers must consider the potential risks for the participants by handing over responsibility [55]. Lundy [56] described children’s voice as a right but not a duty. By this, she meant that as adults, we

have a responsibility to provide opportunities for children to be heard, but that children do not have to speak up if they do not wish to. This echoes the discussion I am attempting to illuminate regarding anonymisation. If we are asking participants to offer their thoughts, insights or experiences, then could we not make a similar argument that they have a right, but not a duty, to have their name attached to it? The argument that I make is not that we should stop practicing the anonymisation of data, but that we have a responsibility to provide research participants with the opportunity to be named if they wish.

### 5.3. Anonymisation and Participatory Research

Gordon [57] questioned whether requiring anonymity is a form of silencing which, rather than empowering participants, erases their identity. Rather than giving voice to individuals who are routinely overlooked, anonymisation may act to separate individuals from their contributions. Participation is about sharing ownership, whereas anonymisation can be conceptualised as keeping ownership—as the researcher, I own the data. By making the decision to anonymise data without discussing the options with participants, I went against the ideals of shared ownership and decision-making power, which is a necessary element of participatory research [58]. Beresford [59] reflects on challenges she faced obtaining ethical clearance for a study in which anonymisation was framed as optional, highlighting that it is routinely expected by ethics review boards as part of standard ethical practice. As both a novice researcher and a researcher attached to an institution which requires ethical clearance before recruitment can begin, I felt the need to make the decision to anonymise data on behalf of the participants, and importantly, before I could involve them.

Participatory research brings two major challenges into ethical review and regulation. First, the emergent and unpredictable nature of the research makes it not only impossible to foresee all the ethical dilemmas that may arise, but the ‘correct’ decision in each case may also vary depending on the specific situation and context [60]. Second, participatory research deliberately blurs the boundary between the researcher and the researched. Most ethics review processes focus on the role and actions of the researcher, and prioritise the protection of the researched. When the power structures are less hierarchical, this focus may need to be reconsidered. These two challenges are well illustrated by the decision of whether to anonymise data. Whereas there may be good reasons both for and against anonymisation, it is disingenuous to claim a participatory approach without involving participants in this decision where possible.

## 6. Conclusions

This paper adds to the discussion regarding the role of ethics review processes, particularly with less traditional research approaches, such as participatory research. There has already been much critique of institutional review boards (IRBs) in the USA and research ethics committees (RECs) in the UK, specifically regarding their role in regulating qualitative and innovative research approaches [10,32]. This critique has often been aimed at the higher-level, broader principles which underpin the regulatory process. This article seeks to add to the debate by focusing on the practice of anonymisation and by illustrating the arguments through a case study of a participatory research study carried out with pupils, teachers and policymakers in England. The article has not provided definitive solutions as such, but makes the case for a reflexive and dialogic approach to ethics regulation, which would both facilitate continued reflection by the researcher as well as support the development of ethical decision-making skills. This paper uses the routine anonymisation of participant data as an illustration of two ways in which participatory research may not be fully compatible with research ethics review purposes—sharing decision-making power and sharing ownership.

Participatory research requires researchers to recognise participants as active and capable contributors in the research and, as such, to share decision making with them as much as possible. Requiring ethical decisions to be made before ethical clearance is given,

such as whether and how to anonymise data, restricts researcher's ability to share this decision with participants. Furthermore, it is worth considering whether it is possible to claim shared ownership by attaching only the researcher's name to the research. Whereas I do not argue that data should not be anonymised, in some instances, it may not be necessary. By allowing this decision to be delayed until later in the research process, we can offer researchers the flexibility to determine, alongside their participants, whether the increased protection afforded by anonymisation is worth the decreased ownership that the participants have of the research.

An overly simplistic understanding of power relationships in research leads to a paternalistic approach ethics that seeks to protect participants from harm but does so without involving them in the decision-making process. This is illustrated by the case of the anonymisation of research data. This is purported to protect participants from harm, but arguably, in some instances, better protects participants already in positions of relative power. In the research I carried out, school pupils, in particular, were excited to have their opinions heard, and reported that as a significant benefit of taking part in the research. Would naming pupils allow them greater ownership of the research and the evidence that they have contributed? If researchers are carrying out research in a participatory manner, surely these decisions must be made with participants where possible. Allowing researchers to delay key decisions would help move toward an ethics process where participants are involved in making decisions rather than merely informed about what has already been decided on their behalf.

This suggestion for a flexible, dynamic and iterative approach reflects BERA's latest guidelines [1], but RECs seem to be lagging behind in adapting their ethics review procedures, which still promote static and discrete understandings of ethical practice [61]. Reflexive ethics regulation should be a process which supports researchers to continue to reflect on ethical dilemmas throughout their study rather than becoming another bureaucratic hoop to jump through. Brooks et al. [62] differentiated between foundational 'principles' and practical 'implications' of ethical research practice, arguing that it is not possible to set down a coherent set of rules or instructions that researchers can follow to ensure that their research is ethical. They do not go as far as other authors who have criticised ethical regulatory bodies for preventing researchers from developing their own ethical practice, but they do caution that the current practice risks front-loading ethical decisions and does not necessarily engender ongoing ethical reflection. Ethical considerations do not end with approval from a research ethics committee. Therefore, procedures should not be designed to suggest that [63]. However, rather than simply removing ethical regulation, as some academics have argued for [64], I instead would argue for a process of ethics review that reflects the processual and reflexive nature of ethical research practice [65]. In particular, this must allow researchers to delay decision making until later stages where necessary. This would allow research participants to be involved in the decision-making process, which is necessary for participatory research.

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