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# Scope and continuum of participatory research

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## ABSTRACT

As wider social and societal changes have led to moves towards equality as a response to a better understanding of inequalities, ethical considerations in research are now more consciously focussed on power dynamics. As a consequence, participatory research methods have gained traction. Simultaneously, artistic and creative methods are used within such projects to such an extent that arts-based, creative research has become equated with participatory research. In this article, I draw on three case studies to pursue three arguments: Firstly, I argue that the current understanding of community-based participatory action research is not the only potential for participatory methods, and indeed should not be. Depending on the design participatory research needs to be seen as a continuum from being minimally participatory to being fully egalitarian, whereby realistically most participatory research designs are situated somewhere in between the two with the level of participation changing throughout the process. Secondly, I argue that the employment of arts-based methods for data collection or dissemination does not automatically translate into a participatory research design. Thirdly, I argue that for ethical reasons researchers should not aim for fully egalitarian research to maintain participants' interests and wellbeing.

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## Introduction

Since the second half of the twentieth century, wider social and societal changes have led to moves towards equality for women and ethnic minorities as a response to a better understanding of inequalities. Within research, too, ethical considerations have become more consciously focussed on power dynamics between researchers and research participants (e.g. Wilkinson 1998; Smyth and Williamson 2004). As a consequence, participatory research methods (e.g. Cornwall and Jewkes 1995; Clark 2001) have emerged in order to ensure that the hierarchical barriers between researchers and participants are addressed. More specifically, participatory action research (e.g. McIntyre 2007; Kemmis, McTaggart, and Nixon 2013) and community-based participatory research (e.g. Satcher 2005; Hacker 2013) have developed. With arts, artistic and creative methods (Kara 2015; Mannay 2015) being used within such projects to such an extent that arts-based, creative research has become equated with participatory research.

In my contribution, I pursue three arguments drawing on my work in, on and with participatory research: Firstly, I argue that the current understanding of community-based participatory action

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research is not the only potential for participatory methods, and indeed should not be. Depending on the design participatory research needs to be seen as a continuum from being minimally participatory to being fully egalitarian, whereby realistically most participatory research designs are situated somewhere in between the two. Secondly, I argue that the employment of arts-based methods for data collection or dissemination does not automatically translate into a participatory research design. The use of artistic and creative methods certainly breaks down some of the hierarchical structure between researchers and participants, but participatory research is more than a means to transcend power dynamics. Thirdly, I argue that for ethical reasons researchers should, in fact, not aim for fully egalitarian research to maintain participants' interests and wellbeing. In building these three interrelated arguments I refer to three different research contexts as case studies. All three case studies come out of my own research and teaching practice, but have been chosen specifically as the participatory elements in the projects cover different research stages. Case study 1 refers to a practice-based enquiry within a teacher education programme that led to the creation of new methods to teach the reflective practice. This project was initiated by the students and co-led in an environment where the lecturers and student teachers were all seen as learners in a community of practice. Case study 2 considers the development of new forms of assessment as part of an undergraduate module. This project developed organically between me as a research-based educator and my students as we all struggled with the constraints of an essay as a summative assessment within a module that propagates multimodal forms of communication. Case study 3 reports on the research 'The construction of academic identity under the influence of fibromyalgia', where participatory and arts-based methods were employed to develop a deeper understanding of individuals' lived experiences.

## Participatory research – definition and history

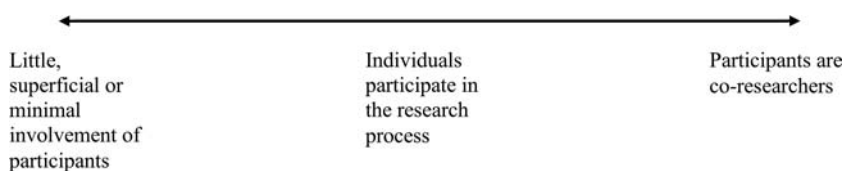
Research methodologies and methods are notoriously difficult to define, not least because frameworks are interconnected and because individual researchers use their particular disciplinary backgrounds, understanding and conventions to mould approaches to their specific contexts. Over time, therefore, boundaries shift and definitions are adjusted. The underlying principle of participatory research relates to questions of hierarchy, power and location of knowledge (see McTaggart 1991, 1997; Cornwall and Jewkes 1995; Selener 1997). In more traditional research designs, the researcher plays a central role in developing understanding about a topic or phenomenon through collecting data, which will then be analysed to foster scholarly debates for the benefit of the academic community. Participatory research in its originally intended form, by contrast, recognizes the expertise of research participants and consequently seeks to engage such individuals through handing over some responsibility within the research process. Implicit in this distinction between conventional and participatory research lie the questions of whose research it is and what the purpose of the research is. Participatory research is considered as political and activist (Selener 1997) as its primary purpose is not to provide scholarly enlightenment, but practical outcomes and actions. With the development of participatory research, this emphasis on outcomes and actions has abated. Initially, however, this definition of participatory research developed from Lewin's (1946, 1947) description of action research as an iterative, spiralling process of observation, reflection and action. Indeed, some scholars still use the terms participatory action research or PAR (e.g. Kemmis and McTaggart 2005; Kemmis, McTaggart, and Nixon 2013; Lawson et al. 2015; Chevalier and Buckles 2019) to emphasize the role of reflection and action within participatory research. However, participatory research is more than merely the reflective work of a collaborative group leading to actions; it is the taking charge of and responsibility for the research process. To this extent, we need to distinguish between the concepts of involvement and participation. The involvement of expert participants, such as patients in health research or consumers in market research (e.g. Beresford 2002; Boote, Telford, and Cooper 2002; Trivedi and Wykes 2002) cannot be equated to participate as equal partners. Where involvement allows researchers to take into account the views of

participants without handing over the reins of and to the research itself, true and full participation requires the participants to (1) have a role in setting the agenda of inquiry, (2) take part in the data collection and analysis and (3) have control over the use of outcome and the whole process (Tandon 1988, 13). These very clearly defined criteria are unfortunately often not considered or met, with most participatory research designs masking as participation what in reality and all honesty is involvement in order to tokenistically fulfil demands of stakeholders or funders, for example (McLaughlin 2010), and often participatory research is presented as demanding participation of participants where, in fact, there is only involvement (MacLeod, Lewis, and Robertson 2014).

However, as mentioned at the outset, research methods and methodologies cannot be packed neatly into categories, as they develop, shape and are shaped by the researchers using them. Within the field of agriculture, for example, participatory research is presented as a continuum encompassing contractual, consultative forms of participation as well as collaborative and collegiate forms (Biggs 1989) with the researcher's influence over the project ranging from high to low. In the moment of the research practice, areas of responsibility and power shift throughout the entire process (Woelk 1992) and it has been argued that this 'relational and uncertain nature of participation' (Rix et al. 2020, 13) must be formally recognized and accepted within the paradigm of participatory research. Consequently, during the process of research, participation is located somewhere on the continuum between fully egalitarian work with participants as co-researchers and the limited involvement of participants as supporters or advisors (see Figure 1).

In reality, the simplified scheme presented in Figure 1 is insufficient in explaining the full scope of participatory research, as participation varies across the different stages of research, especially as participatory research has become so widespread it is now commonly used in all disciplines. The popularity of participatory research is reflected in the number of relevant publications having increased tenfold from the 1990s to the 2010s. In addition to discussions of the benefits and challenges of employing participatory research as a methodology, there are numerous publications reporting results and findings from empirical work having used participatory research. What such discourses are missing, however, are considerations of what I hinted at above: that participatory research is not a single, unified methodology, but a problematic approach to research, which continues to make assumptions about knowledge-production and the value and worth of research. On the one hand, participants are required to be fully involved in and engaged with the research projects, but on the other hand, they may not necessarily have the relevant experience required to understand methodological and ethical decisions and their consequences (see von Unger 2012). Where children are involved, research projects are most often designed and conceived by adults, so that basic assumptions, hypotheses and research questions are also formulated from an adult perspective, and often with adults as the audience in mind (see Waller and Bitou 2011). A notable exception is reported by Flewitt et al. (2018), where the principles of participatory research and pedagogy were central to the study.

The late 2010s were further characterized by an ever-so-slow increase in social understanding that in many cases particular kinds of knowledge(s) and knowledge productions have been and still are being favoured. Movements towards decolonizing curricula and research have, in turn, resulted in the heightened interest in Indigenous methods and knowledge production, and more participatory research, in particular where community-based work is concerned. At times the research approach



**Figure 1.** Continuum of participatory research.

may not include an explicit description of the participatory element employed, especially where the research approach is described as ethnographical. van den Scott (2018), for example, describes how following her move to Arviat, Nunavut, she commenced a research project and took on the role of a researcher within the Inuit community she herself was a member of. The way how she was particularly sensitive to the Inuits' views and the Elders' decisions, and how she specifically sought out their advice and support, suggests that this was not a typical ethnography using face-to-face interviews, this was a co-production of knowledge that involved individuals from the community at the different stages of the research. Where the participation started and ended and how much power and control were awarded to individuals at each stage is not described. What does emerge, however, is that the joint participation in community activities and tasks, such as sewing seal-skin boots (van den Scott 2018, 30) allowed for a level of closeness that would otherwise not have been possible. This relationship between tasks, creative work and arts-based methods and participatory research will be explored in more detail in the following section.

### **Creative and arts-based methods in participatory research**

Similar to the rise of participatory research, arts-based research practices, arts-based and creative methods in social science research have also experienced an upturn in the recent decades. With this increased interest frameworks of arts-based and creative research have developed over time, and there is now no single method or approach that clearly defines arts-based or creative research. Whether the research is defined as 'arts-inquiring pedagogy, arts-based inquiry, arts-informed inquiry, arts-informing inquiry, arts-engaging inquiry, and arts-related evaluation', for example, depends on the focus of the enquiry and the positionality of the artist-practitioner-researcher (Savin-Baden and Wimpenny 2014, 5). Consequently, the use of the terms creative and arts-based methods in relation to arts-based research is also determined by a researcher's own perspective on the role of the arts within the research. As someone who is primarily a social science researcher rather than an artist practitioner, and whose focus is to include arts as an optional form of expression rather than the focus of the enquiry, I use the arts-based and creative as interchangeable terms to signify methods and approaches to research that draws on artistic and playful forms of expression.

Arts-based research originated in the 1970s in and from arts-based therapies, such as writing therapies or creative arts therapies (Leavy 2015). During the therapy-based work, however, it became soon evident that the arts not only offer therapeutic and cathartic tools for reflections and emotional outlets for individuals but also spoke to audiences in ways that were radically different from traditional and conventional research approaches. Arts-based inquiries are now often considered as 'futuristic, socially responsible and useful in addressing social inequities' (Finley 2008, 71). Through their powers for expression, evocation and illumination (Barone and Eisner 2011) the arts lend themselves towards exploring experiences and expressing feelings and emotions or other concepts that would be otherwise difficult to verbalize. Further, the arts can personally touch audiences and draw in individuals, which in turn helps to raise awareness of and for wider social and societal issues and results in action. Arts-based methods are therefore founded on a 'radical, politically grounded statement about social justice and control over the production and dissemination of knowledge' (Finley 2008, 71). In this sense, arts-based inquiries are not all-too-different or all-too-distant from the foundational principles of participatory research. In both instances, the researcher seeks to minimize hierarchy, to reduce power-differentials and to call for action.

The wealth of research employing arts-based or creative methods becomes apparent when considering the most recent systematic literature reviews. Having defined their inclusion criteria, Driessnack and Furukawa (2012) reviewed 116 articles relating to arts-based research with children between the ages of seven and twelve, Fraser and al Sayah (2011) explored thirty articles reporting on health research projects using arts-based methods, Coemans and Hannes (2017) reviewed 131 publications covering community-based inquiries with vulnerable populations, and De Jager et al.

(2017) considered 23 studies in 25 articles relating to digital storytelling in research. With the exception of De Jager et al.'s (2017) review, which specifically focused on digital storytelling, the reviews focus on the wide variety of arts-based methods ranging from the use of drawings, photographs, graphics, artefacts to poetry and theatre.

Discussing the individual findings in detail would go far beyond the scope of this particular article, so suffice it to say that scholars recognize limitations of conventional research methods and methodologies and therefore call for more embodied and sensory approaches to research. In response, readily applied methods include elicitation approaches (Bagnoli 2009), artistic workshops (Tarr, Gonzalez-Polledo, and Cornish 2018), visual materials (Mason and Davies 2009), photo-elicitation (Orr and Phoenix 2015) and metaphors (Nind and Vinha 2016) combined with interviews and narrative approaches. These methods are often not applied consciously and confidently but have been used tentatively in the hope of fruitful outcomes in the form of different, more interesting, richer data (see reports of Guell and Ogilvie 2015; Nind and Vinha 2016). It is this richness of data that researchers readily comment on when they consider creative or arts-based methods. Similarly, researchers further discuss the changing dynamics and increased responsibility handed over to participants as another unforeseen and unplanned consequence of having used creative or arts-based methods. It appears that the mere employment of creativity and the arts lead to researchers believing that they have engaged in participatory research (see Mand 2012; Greyson, O'Brien, and Shovelier 2017).

Creativity and arts-based methods do support the reduction of hierarchy and power differentials between participants and researchers, and this is indeed one element of arts-based methods, as we have seen above. However, it is all-too-easy to ignore the three basic principles of participatory research as laid out above: that participants (1) have a role in setting the agenda of inquiry, (2) take part in the data collection and analysis and (3) have to control over the use of outcome and the whole process (Tandon 1988, 13). I do not wish to discredit the accomplishments of the reports mentioned above. I would merely like to highlight that the introduction of creative or arts-based methods does not necessarily guarantee the participants having a role of responsibility and control in the research process. In the following sections of this article, I will outline how difficult it is to ensure and guarantee the participatory elements within creative and arts-based research projects.

### **Case study 1: new methods to teach reflective practice**

This case study refers to a practice-based enquiry within the Secondary Teacher Education Programme managed and delivered collaboratively by the UCL Institute of Education and the Institute of Ismaili Studies between 2007 and 2017 that led to the creation of new methods to teach the reflective practice.

Teacher education courses in westernized countries across the globe require student teachers to engage with reflections (Richardson 1990), often through formal learning logs and reflective diaries (Kaasila and Lauriala 2012; Toom, Husu, and Patrikainen 2015), to learn and practise reflections in action and on action (Schön 1983). The idea is that these reflective practises will help student teachers develop skills for determining personal strengths and weaknesses and thus improve their professional practices (see for example Korthagen 1999; Spilková 2001; Fox et al. 2015). In reality, reflective practice is notoriously difficult to teach (Rogers 2001) because of the vagueness of the concept itself, but also because of the requirement for the student to be open to engaging in and with reflections and the need for intentionality of solving a concern or issue.

The Secondary Teacher Education Programme was no different from other teacher education programmes in that it also required student teachers to maintain a reflective diary. Student teachers on this programme were asked to engage with reflective models, such as those by Gibbs (1988), Rolfe, Freshwater, and Jasper (2001), Kolb (1984) and Brookfield (1995). The particularity of the Secondary Teacher Education Programme was that students from all over the world were recruited to come to London for a two-year course to obtain two Master's degrees, after which they would return to their

home countries to be employed as teachers in community-based faith schools. With such a condensed and compressed time to gain a significant understanding of teaching and learning theories and to acquire practical strategies for the classroom, the teaching methods employed by the lecturers on the course were largely through modelling. Lecturers practically delivered masters' levels contents using pedagogical approaches and methods typically associated with secondary school classrooms to demonstrate how to best teach using appropriate questioning techniques, classroom management strategies, assessment and feedback methods and the like.

It was therefore probably not surprising that student teachers started challenging the approaches associated with reflective models as too repetitive and boring for the student teachers themselves, and too advanced, therefore wholly inappropriate for a secondary school environment. The question 'Is there a way to make reflections more exciting?' (Brown 2019a, 5) initiated a long discussion around the impact and worth of reflections leading the student teachers to conclude that the benefits for reflections throughout the learning process outweighed the challenges. As a consequence, student teachers were keen to introduce some forms of reflections in their own teaching practices. But it was evident that reflective practices needed to change if they were to be appealing and meaningful to teenagers. As a result, the students initiated and co-led the project to develop creative methods for reflection in an environment where the lecturers and student teachers were all seen as learners in a community of practice (Lave and Wenger 1991). The outcomes were activities using drawing, model making and metaphorical representations (Brown, Jafferani, and Pattharwala 2018, 2019).

## **Case study 2: assessments: letting students decide**

Case study 2 relates to the development of new forms of assessment as part of an undergraduate module. Since 2017 I have been module leader for the undergraduate module 'Literacy, Language and Communication' that is delivered as an optional module for the BA Education Studies programme at UCL Institute of Education. The purpose of the module is to introduce students to a range of disciplinary perspectives on learning-related literacy practices in formal and informal education settings, including digital environments. It aims to provide students with key ideas in studies of literacy and language that explore the potentials of contemporary forms of communication for learning and working in diverse contexts. The module emphasizes the kinds of work we as humans engage in when we read and communicate and how our use of language and literacy practices changes depending on the settings and contexts, we find ourselves in. As such, the key components to the module are the provisional and collaborative nature of literacy practices alongside the multimodal approach to communication, especially in the contemporary world of social media platforms. Despite the originality and topicality of the content, the summative assignment that is worth 70% of the overall module grade is an essay of 2,000 words, which appears to be entirely at odds with the module content.

When I first introduced the assignment modalities, one student raised this discrepancy between what the module teaches and what it assesses, which led to a detailed discussion around leading by example and 'walking the walk'. As a result, a research project developed organically between me as a research-based educator and my students, as we all struggled with the constraints of an essay as a summative assessment within a module that propagates multimodal forms of communication. Unfortunately, programme validation documents and quality assurance benchmarks did not allow for radical rethinking and reworking, so students and I decided to work together on developing guidelines around assessments that would allow for multimodal communication and arts-based projects but would still meet the criteria for the academic, scholarly assessment of a first-year undergraduate module in Education Studies.

Similar to case study 1, the framework for this project was a participatory approach within the context of students as partners in learning (see Dunne and Roos Zandstra 2011; Cook-Sather, Bovill, and Felten 2014; Healey, Flint, and Harrington 2014; Bovill and Felten 2016), where students were asked to take charge of and responsibility for their own learning and indeed their own

assessment. Within the scope of assessment criteria, validation documentation and quality assurance benchmarks, students were allowed to explore their chosen topics through multimodal, creative, arts-based approaches. Although not many students took up the offer in the first year, the initial exploratory and experimental project has gained traction and has led to a greater variety of submissions, such as a board game or a banana bread (Brown, Morea-Ghergu, and Onwuka 2020).

### Case study 3: representations in fibromyalgia research

Case study 3 reports on the research 'The construction of academic identity under the influence of fibromyalgia', where participatory and arts-based methods were employed to develop a deeper understanding of individuals' lived experiences (Brown 2018a). Fibromyalgia is a complex condition that is characterized by widespread, persistent pain, cognitive dysfunctions, sleep disturbances and psychological disorders (White and Harth 2001). The complexity of fibromyalgia is further compounded by the fact that symptoms wax and wane and shift and move from one day to the next, and sometimes even within hours, which makes it a contested condition amongst the general public as well as amongst the medical professionals (Ehrlich 2003; Wolfe 2009). In addition to the complexity of fibromyalgia itself, there is the difficulty of verbalizing experiences, as human understanding in itself is embodied (Finlay 2008, 2015; Eccleston 2016) and metaphorical (Lakoff and Johnson 2003) and because language is often described as insufficient, especially where descriptions of pain are concerned (Scarry 1985; Sontag 2003). As a result, I drew on arts-based work and participatory approaches, when I developed the concept of identity boxes (Brown 2019b).

Essentially, participants were given a question and were asked to find objects to represent the answer, which they would then put into a box. Participants then took a photograph of the box with the object(s) and emailed that to me with a very brief statement of what the object is and what it stands for. I then released the next question. In total there were five questions: 'Who are you?', 'What affects you?', 'How do others see you?', 'What role does fibromyalgia play?' and 'What is life with fibromyalgia like?'. Once I had received the final photograph, the participant and I organized a video-conference call via Skype (Brown 2018b), which would enable us to conduct an interview as a detailed conversation between the researcher and the participant (Brinkmann and Kvale 2015) with the aim that the researcher would be making sense of the participant making sense of their experience (Smith, Flowers, and Larkin 2012).

The data in this project was therefore a multitude of forms of communication from the participants, which included texts, sketches, drawings, poems, song lists, photographs and objects alongside the transcript from the recorded conversations. Analysis in this research followed the principles of iterative, inductive, semantic, reflexive thematic analysis (Braun and Clarke 2006, 2019; Brown 2019c) combined with analytical approaches commonly used within and borrowed from visual methodologies (Prosser 1998; Rose 2016).

### The relationship between participant engagement and arts-based methods

Considering these three case studies, we now have to ask ourselves about the relationship between the arts-based methods and the participatory approaches to the individual projects. In the following two figures detail an overview of participant engagement (Figure 2) and the use of arts-based

	Formulation of research question	Data collection or generation	Data analysis	Dissemination of findings
Case study 1	+	+	-	+
Case study 2	+	-	-	+
Case study 3	-	+	+	-

**Figure 2.** Summary of participant engagement in the three case studies presented.



	Formulation of research question	Data collection or generation	Data analysis	Dissemination of findings
Case study 1	–	+	–	–
Case study 2	–	–	–	–
Case study 3	–	+	+	+

**Figure 3.** Overview of inclusion of arts-based approaches in the three case studies.

methods (Figure 3) in each of the three case studies. As in all three case studies I had decided on the overarching research design and had set the agenda for the projects, I limit the design stage here to the formulation of the research question.

The juxtaposition of the two summaries in Figures 2 and 3 provides an insight into the relationship between arts-based methods and participatory elements. Subjectively, case studies 1 and 2 may appear more participatory in the sense that students were partners in learning, took charge of the research question and were involved in the dissemination of findings. However, in terms of the engagement of participants case study 3 is equally participatory, albeit in different stages of the research process. Case study 2 is an example of affording responsibility, supporting empowerment and offering agency within the constraints of existing frameworks and the fact that as the module leader I had a better, deeper, more fine-tuned understanding of learning objectives and how they could be met. In short, it is the responsibility of the researcher to ensure that in participatory research the participants' best interests are foregrounded, that participants' health and wellbeing are tended to and that participants do not come to any harm, which in case study 2 was the students' attainment in the assessments.

Figure 3 highlights the lack of arts-based work in case study 2, whereas case study 3 is more arts-based and artistic than case study 1, even. The inclusion of an embodied, arts-based approach to dissemination in case study 3 did not automatically result in or ensure participatory and egalitarian dissemination. In this particular case, I as the researcher held the control over what would be disseminated and how with the installation output being member-checked rather than co-created (see Brown 2019b). With this brief analysis in mind, how shall we define participatory research; does it matter and if, then why?

### The scope and continuum of participatory research

The role and significance of participatory research within the context of educational research, and social science research more widely, is indisputable, especially within the scope, contexts and discourses of decolonization. However, the danger in participatory studies is that researchers are not consciously aware of their roles, responsibilities and the impact they have on the projects because they involve participants *at some level* or *to some extent*. The advent of arts-based and creative methods has exacerbated this concern because the co-creation of a collage *appears* to be reducing the power hierarchy between the researcher and their participants. The relationship between participation and arts-based approaches is also referred to in a recent report that emphasizes the greater need for flexibility, the depth of insights afforded and the 'tensions around support, power and voice' that are revealed (Seale et al. 2021, 18). Participatory research is and should be more than a means to transcend power dynamics. Participatory research enables participants to be involved in, to take charge of and responsible for the research process. This does not mean that participants are required to be involved at every stage, but it does mean that the researcher needs to position themselves reflexively, transparently and critically (see Brown 2019b) within that process.

Conscious positioning and reflexive awareness are particularly important when it comes to research settings with vulnerable, othered or marginalized participants or younger children (see

Gristy 2015). Handing the reins to the research over to the participants comes with the responsibility of ensuring no harm or disadvantage comes to the participants in the process. For example, in case study 2, it would have been all too easy to let students 'run' with an idea, but that would have borne the risk of students potentially failing the assessment because they would not necessarily have had a detailed understanding of assessment criteria and benchmarks. Although I had been keen to enable empowerment and to create a participatory environment, I was very conscious that despite the high levels of engagement on the part of the students, the *control* over the project was still mine. In this sense, the participatory work in case study 2 did not at all transcend the power dynamic between my student-researcher-partners and the researcher-me; and it had not been intended to, either.

With this, let me return to the starting point of this article. Participatory research offers much more to the research process than the current understanding of community-based participatory action research may suggest. By actively employing participant agency participatory research can build on detailed insider knowledge and insights from lived experiences throughout all stages of the research process. Indeed, the beauty of participatory research is its affordance in creating contexts, where research participants can get involved in and advocate for causes that are important to them through means that are suitable for a given project. As such, participatory research should be seen as flexible and mouldable to fit particular research objectives. Yet, it needs to be said that the use of arts-based methods within a research project does not automatically make for participatory research. Collecting data through arts-based approaches, for example, would still mean that the researcher stipulates what kind of data is created and how it is shared. Similarly, the dissemination phase of case study 3 highlights how I as a researcher maintained full command over the final representations of data. Ultimately, the participants' wellbeing remains the responsibility of the researcher, and so participatory research is not and should not be the complete cession of control or power. This is particularly true in studies where the participants getting involved are untrained in research, which could lead to methodological, philosophical or ethical errors in the processes of data collection and analysis, thereby potentially derailing entire research. Defining participatory research is therefore not so much for the researcher to provide a specific theoretical outlook, as it is to frame and make transparent the researcher's positionality and role.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

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