



# Reflecting on (the challenge of) conducting participatory research as a research-degree student

Kris Southby\* – *Leeds Beckett University*

## Abstract

Participatory research appeals to notions of community empowerment and of generating more valid data grounded in the lived experiences of communities. For research-degree students, however, implementing such an approach can complicate an already challenging endeavour. Participatory research may juxtapose the institutional mechanisms surrounding a research degree and provide practical barriers to research-degree students. Reflecting on my own experience attempting to conduct a piece of participatory research for my doctoral research, this article concludes that participation should be viewed as an expansive concept and that any meaningful attempt to progress along a continuum of participation should be recognized and encouraged.

**Keywords:** participatory research; learning disability; postgraduate research

## Key messages

- Participatory research is a distinct approach to research that involves members of the community in the research process and is thought to lead to more valid and insightful data and yield more beneficial outcomes for those involved.
- Conducting participatory research may be more difficult for research-degree students than traditional approaches to research, complicating an already challenging endeavour.
- Participatory research should be viewed as a continuum rather than a dichotomy, and therefore any attempt at doing research 'participatorially' should be welcomed and encouraged.

## Introduction

Participatory research differs from 'traditional' social research in that the community of interest who would otherwise only be sources of data are involved in the research process, possibly contributing to decision-making, project planning, research design, data collection and analysis, and dissemination. The notion of incorporating research subjects into the research process alongside trained researchers can be traced back to the work of social psychologist Kurt Lewin (1946), who first wrote about involving participants in a circle of planning, action and fact-finding. As a distinct approach to research, participatory research emerged in the 1970s as a response to concerns about

the pursuit of traditional 'top-down' research. Participatory methods developed as a system by which communities could work towards change (Pain and Francis, 2003). In this sense, participatory research became more than a methodology – it became a political statement and a 'theory of knowledge' that 'affirms people's right and ability to have a say in decisions which affect them' (Reason and Bradbury, 2006: 10). Participatory methods can be a means by which community members are given a voice, their concerns raised and inequalities made clear (Gold, 1998). Participatory research 'empowers people to be a part of building knowledge, provides a voice for community members and expands the research lens from one academic researcher to be shared with participants' (Bourke, 2009: 470). Although still not yet part of the academic mainstream, including lay people as more than just research subjects is gaining popularity and credibility (Pain *et al.*, 2013; Povee *et al.*, 2014; McDonald and Stack, 2016) and can be thought to have 'come in from the cold' (Klocker, 2012: 149).

Participatory research appeals to a belief that, compared to a traditional research paradigm, involving research subjects in the research process will lead to more valid and insightful data, yield higher responses, make research more accessible, accountable and relevant to people's lives and more likely to lead to change (Israel *et al.*, 1998; Bourke, 2009; Povee *et al.*, 2014; McDonald and Stack, 2016). It also responds to broader critiques regarding the detached, hierarchical and exploitative nature of traditional research relationships, which can have little benefit for the research subjects (Klocker, 2012). Participatory research is thought to benefit participants in terms of empowerment, developing new skills and confidence, promoting engagement with the wider community, confronting stigma and promoting political/community activism (Povee *et al.*, 2014; McDonald and Stack, 2016). However, despite the solid justifications for participatory research and the increasing body of participatory research projects that have been developed across multiple disciplines over the past decades, there are few published accounts of the process of conducting participatory research to inform future research projects (Povee *et al.*, 2014). There is even less information available for early-career researchers or research-degree students wishing to pursue participatory research (Strnadova *et al.*, 2014).

Written from a 'reflexive practitioner perspective' (Sense, 2006: 2), this article explores the experience of conducting participatory research as a research-degree student. I examine my own experience as a doctoral student setting off to conduct a piece of participatory research to explore the potential for Association Football (football) fandom to be a route for social inclusion for people with a learning disability in the UK (Southby, 2013). As one of the most historically excluded and stigmatized groups in social research and society more generally, working with people with a learning disability brings into focus both the attraction of participatory research and the difficulties of delivering a project for research students.

Following this introduction, the paper draws on relevant evidence to provide a short discussion of what participatory research is, surmising that the participation of subjects forms a continuum, rather than a dichotomous classification. The methodology I developed for my research is critiqued against other examples of student participatory research and participatory research with people with a learning disability. The challenges I faced in developing a participatory methodology as a research-degree student – or, to put it another way, the reasons my research did not fall further along the participatory continuum – are then discussed. The final discussion reflects on the work I was able to do. While my PhD project may not have been as participatory as other examples of research-degree student participatory research or participatory research carried out with people with a learning disability, I am satisfied it

was conducted as participatorally as possible in the circumstances I faced. The article will hopefully 'illuminate some practise dilemmas' (Sense, 2006: 2) for future research-degree students wanting to implement a participatory approach.

## The spectrum of participatory research

Participatory research views those being researched not simply as sources of data but as integral to the research process, contributing to 'the decision making and conduct of the research', such as in project planning, research design and data collection, analysis and dissemination (Bourke, 2009: 458; Clark *et al.*, 2009; McDonald and Stack, 2016). Implementing such an approach involves a realignment of the traditional researcher–participant relationship and a transfer of power (such as to make decisions and to control the process) from the 'researcher' to the 'participant' (Northway, 1998; Povee *et al.*, 2014). A key feature of participatory research is the attitude of the researcher (Cornwall and Jewkes, 1995; Northway, 1998). Stalker (1998) articulates three core beliefs of participatory research, that: (1) the conventional research relationship of researcher as 'expert' and informant as 'object of investigation' is inequitable, (2) that people have the right to be consulted/involved in research relating to their own lives and (3) that the quality of research improves when people are involved in research concerning their own lives. Ultimately it is about understanding and respecting the people the research is about and engaging in an alternative epistemology and ontology from traditional research processes (Pain *et al.*, 2013).

Beyond the aim of establishing more equal relationships between 'researchers' and 'participants', there are very few strict rules about what constitutes participatory research; participation can occur at different levels and in unpredictable ways (Pain and Francis, 2003). Numerous protocols have developed in different fields. Examples include: 'participatory appraisal', 'participatory rural appraisal', 'rapid rural appraisal', 'participatory action research', 'cooperative enquiry', 'emancipatory action research', 'appreciative enquiry', 'feminist participatory research' and 'community-based participatory research'. Participatory research has not been limited to the types of qualitative methods typically associated with capturing 'voice' in a community setting. Turk *et al.* (2012), for example, reported on involving people with a learning disability in the process of a large quantitative survey. This variety of terminology and methodology has led to some concerns that 'participation' is becoming an umbrella term, even a cliché, which may be used to refer to different things (Bigby *et al.*, 2014) and that undermines the credibility of the process (Cornwall and Jewkes, 1995). This has led to a binary distinction between 'morally good research ... and morally bad [participatory] research' (Klocker, 2012: 157), and ranks of different levels of 'participation'. Efforts that do not achieve the ideal standard of participatory research risk being labelled as inauthentic, impure, 'diluted', a 'process of vulgarization' (De Toma, 1996: 4) or 'sterile and unsatisfactory' (Mayo, 2001: 279).

However, given that a lot is asked of participatory research – to be distinctive, to answer questions other research cannot, to support campaigns, to train and develop new skills and to empower and change lives – the expansiveness of the concept and what it means to do it well should be encouraged (Nind and Vinha, 2012: 108). While attempts at participatory research may often fall short of their desired goals, being puritanical or dogmatic about what is and is not 'participatory research' only serves as a straightjacket for well-meaning researchers and research that may produce valuable results (Walmsley, 2001; Kesby *et al.*, 2005; Bourke, 2009; Pain *et al.*, 2013; Bigby *et al.*, 2014; Strnadova and Cumming, 2014). Rather than being a dichotomy of 'participatory'

and 'non-participatory', participatory approaches should instead be conceptualized as being on a continuum of varying degrees of involvement and control for participants (Povee et al., 2014). To paraphrase Cornwall and Jewkes (1995), we should move away from 'participatory research' to thinking about 'doing research participatorally'.

## An overview of my PhD research process: Conducting research 'participatorally'

The principals of participatory research complement the disability rights movement (McDonald and Stack, 2016) and in learning disability research there is a growing body of literature recounting projects involving people with a learning disability in research processes (Bigby et al., 2014; Strnadova et al., 2014). Authors describe the process as 'participatory' (Atkinson, 2005), 'collaborative' (McClimens, 2008), 'co-researching' (Redmond, 2005), 'cooperative' (Schoeters et al., 2005), 'partnership' (Williams et al., 2005) and 'people led' (Townson et al., 2004). Sample (1996), Booth and Booth (2003) and Burke et al. (2003), for example, all describe involving people with a learning disability in group decision-making processes about the research in order to develop participation. Valade (2008) describes a participatory action research project where she supported a small group of people with a learning disability to discuss their problems with the local transport system, identify possible causes, points where pressure might be applied and advocate for change to institutional and political representatives. More recently, Northway et al. (2015) outline the involvement of people with intellectual disability (including volunteer members of the research advisory group) to support their project, making many of the key decisions at all stages of the project.

I first became aware of participatory research reading Barnes and Mercer's (1997) book *Doing Disability Research*. As a then master's student, fresh from undergraduate study and becoming increasingly aware of, and interested in, social justice, learning of a research paradigm explicitly intended to include and empower people was revelatory. Conducting a piece of participatory research felt like a way to directly benefit people with a learning disability, rather than just indirectly supporting them through written reports and publications – which may not even be read – and it was in this mode of research that I wanted to conduct my PhD. I felt that prioritizing distance and separation from the subject would have raised ethical and epistemological concerns. In my research proposal I wrote confidently that a participatory approach would be adopted in order to overcome the historical exploitation and marginalization of people with a learning disability from social research. I stated that an advisory group of people with a learning disability would be established at the beginning of the project and 'continuously consulted to help guide the researcher and inform the appropriateness of the methods employed'.

I felt that I was forging a new path and that my research would be beneficial for people with a learning disability in both process and outcomes. Other PhD students (in other fields) have also been drawn to participatory research's appeal of meaningful collaboration with marginalized groups. Khobzi and Flicker (2010), for example, had an interest in participatory methods, health inequality and social justice, and so were motivated to become allies of, and undertake community-based participatory research with, young people with HIV/AIDS and young transgender people in Ontario, Canada. Likewise, Klocker (2012: 151) was concerned about being a 'colonising western researcher' investigating child domestic work in Tanzania during her doctoral study and so participatory methods emerged as a way towards culturally relevant, sensitive action. Burgess (2006) also developed a participatory approach to explore what mattered to

nurse practitioners in the primary care team setting and how they can contribute to the advancement of inter-professional collaboration. In comparison to these authors, the research I conducted to explore the potential for social inclusion of football fandom for people with a learning disability fell further back on the participatory continuum and fell short of the participatory ideal I set out to achieve.

To begin with, the focus of my research was not identified by the community of interest (that is, people with a learning disability) but by me, sitting at my desk reading academic texts and policy documents. A close family member of mine has a learning disability, and both he and I like football. As such, like Burgess (2006), who describes herself as a 'community leader' following years working as the director of a community health care centre, I may be considered part of the learning disability-football fan milieu and able to offer some insight into that experience. But ultimately, I wrote and submitted the research proposal without any involvement from the 'community'. In comparison, Khobzi and Flicker (2010) both worked on PhD projects already defined by communities who had a hand in conceptualizing thesis questions, and Klocker (2012) involved her 'co-researchers' in defining research aims.

The second deviation from the planned participatory approach was not having a research steering group comprised of people with a learning disability with whom to discuss process issues and reflect on the findings. Instead, I made all the strategic and practical decisions throughout the research and analysed the accumulated data independently. In comparison, Seymour and Garbutt (1998), Khobzi and Flicker (2010) and Klocker (2012) all established project steering groups of partners who met periodically to discuss research questions, recruitment, data analysis and dissemination.

In terms of data collection, I used a mix of qualitative methods, including semi-structured interviews, participant observation and photovoice with football fans with a learning disability. Semi-structured interviews were also conducted with family members of the people with a learning disability involved in the research and relevant stakeholders from football clubs and football governing bodies. Like Khobzi and Flicker (2010) and Seymour and Garbutt (1998) I completed the interviews myself, whereas Klocker (2012) involved her 'co-researchers' in data collection. The use of photovoice in my research did introduce a participatory element, as participants with a learning disability had the opportunity to exert some control over the data collected (Povee *et al.*, 2014).

The use of photovoice also enabled participants with a learning disability to be somewhat involved in the data analysis by selecting images that were important to them, which we then discussed. Beyond this, participants were not involved in any of the analysis of interview data, which I completed myself. In comparison, other PhD student researchers have developed more participatory data analysis processes, either through involving participants in the coding of interview data (Klocker, 2012) or corroborating their interpretations with steering groups (Seymour and Garbutt, 1998; Khobzi and Flicker, 2010).

While I was not able to involve participants in all of the practical elements of the research – formulating research questions, data collection, data analysis – throughout the process I attempted to maintain a 'participatory attitude'. Hunt's (1966) critique of social research that does not set out to empower participants with disabilities acted as a strong reminder of the need to be thoughtful about my own role in the project. While I was in charge of the research process, I did not claim to be a completely "'detached", "balanced", "unbiased" social scientist': I was not purely working on my 'own side' (Hunt, 1981: 39). Rather, working explicitly from a position informed by the cultural model of disability, I remained mindful that people with a learning disability

have barriers imposed upon them by their social situation and not only by their own impairments (Beresford and Boxall, 2012). In practice, this meant giving participants with a learning disability the respect they deserved (in line with their non-disabled peers) to express their own narratives. For example, during the interpretation and exploration of interview data I was aware not to filter out the participants' voices and give them meaning in my – the researcher's – terms. Moreover, whenever there appeared to be a conflict of interests between myself and the participants (such as, in organizing meetings), the needs of participants always came first. Like Northway (1998), I was also open with participants that I would benefit from the encounter by receiving a PhD. Participants were happy to take part and seemed to enjoy being involved in the research, although this information was not formally captured/measured.

Overall, the participation of people with a learning disability in my research can be thought to have occurred in a 'shallow' (Biggs, 1989) and informal manner (Nind and Vinha, 2012) in comparison to other examples of participatory research conducted by PhD students (Seymour and Garbutt, 1998; Khobzi and Flicker, 2010; Klocker, 2012) and learning disability researchers (Valade, 2008; Northway *et al.*, 2015), where participation occurred at 'deeper' and more formal levels. That is to say, while I had proposed to work in a participatory way, in practice the involvement of participants was worked out in the moment in response to certain challenges rather than planned out and rule bound from the beginning. Participation was 'nominally consultative rather than collaborative' (Fawcett and Hearn, 2004: 214). I fulfilled the 'traditional' researcher role and the people with a learning disability who were involved were afforded the same status as those people without a learning disability who took part as 'participants'. While I could play down my involvement in the research in order for the project to appear more participatory, this would only serve to camouflage any power imbalances behind 'a rhetoric of participation' (Walmsley, 2004: 66). I hope that being explicit about who did what, and what did not work, might enable others to learn from my experience, rather than make the same mistakes.

My experience and that of other research students demonstrates the diversity of research that can be done 'participatorally', reinforcing the view that participatory research is a continuum. While some examples may have been able to involve participants, all have been completed in the spirit of wanting to involve and empower people in decisions that affect them in order to bring about positive change. I would have liked to have involved people with a learning disability more in my research, but this was not possible at the time.

## The challenges of participatory research as a research-degree student

Having completed a piece of participatory research for her doctoral dissertation, Klocker (2012: 150) is critical of what she perceives as a prevailing discourse warning research-degree students against participatory research, castigating the creation of an environment where 'only the "bravest" students dare mesh the two'. However, while no social research is straightforward, working effectively in partnership with local people does create challenges on top of those experienced by non-participatory researchers (Cornwall and Jewkes, 1995; Lister *et al.*, 2003; Bourke, 2009; Clark *et al.*, 2009; Khobzi and Flicker, 2010). Research degrees, which are 'complex, often chaotic and sometimes messy ... at the best of times' (Byrne-Armstrong *et al.*, 2001: vii), are therefore made more difficult by participatory procedures.



I experienced a number of challenges in attempting to conduct participatory research for my PhD that I believe would not have occurred – or, at least, I may not have been aware of – had I followed a non-participatory path. These challenges were not mutually exclusive but overlapped and interacted with one another. Where I was not able to overcome these challenges, my research had to take a step back along the participatory continuum and adopt more ‘traditional’ procedures. While I was not able to overcome every challenge and so my research was not as participatory as I had planned, I am still satisfied with the results. I feel the research was conducted as participatorially as possible in the research context, and considering my personal circumstances.

## Adhering to the standards and procedures of an individualistic academy

In academia, knowledge and the power to create new knowledge has traditionally been deemed to be held by individual ‘experts’ who have undergone recognized training and accreditation; prizes, degrees, funding, titles, and accolades are awarded to individuals in recognition of work they have done and for the contributions they have made. Research may be carried out in teams, but only with colleagues whose expertise has been equally validated and only on external objects of enquiry. This ideology carries over into research (and non-research) degrees, which are intended to assess an individual’s competency with regard to a specific topic or subject and come imbued with set criteria to be met and procedures to be followed. Such an individualistic construction of knowledge, however, contrasts with participatory research’s emphasis on a ‘bottom-up’ approach (Cornwall and Jewkes, 1995; Northway, 1998; Seymour and Garbutt, 1998). In blurring the boundaries between the roles of ‘researcher’ and ‘participant’, anyone setting off down a participatory path is – deliberately or not – subverting the accepted (and possibly expected) path of a research-degree student. Some research students may have the confidence to be able to negotiate the path between individualistic academic procedures and collaborative working in order to implement participatory ideals. However, I had reservations about upsetting the apple cart. In parallel with the experience of Pain *et al.* (2013) of introducing participation into undergraduate teaching, I felt that in order for all the necessary material to be covered, participants could not be fully involved.

The contradiction between academic process and participatory research can be seen during the research proposal stage and while seeking ethical approval for study. The research proposal is, by definition, drawn up and submitted prior to the research taking place. As such, research students will most likely have formulated a research question and designed a methodology before even entering the field to engage with participants, meaning that participants will be excluded from this process. This may be overcome if prospective students are already embedded in the field, such as Coy (2006: 420), who describes how her participatory research project with young women in local authority care was ‘incorporated into [her] everyday work’ as an outreach worker, or if students are joining an existing larger research project taking place in the community, such as Khobzi and Flicker (2010). Coming straight from full-time undergraduate and then master’s study, I was not already embedded in the community nor was I looking to join an existing project. It is possible to build uncertainty into a research proposal to allow for future negotiation with the community (Klocker, 2012). However, this approach felt very uneasy for me. Relying on the proposal to grant me access to further study –

and funding – I felt I had to clearly predefine every aspect of my research; not doing so felt like too much of a gamble.

Participatory research also challenges university research ethics procedures in ways that non-participatory research does not (Pain, 2009; Northway *et al.*, 2015). While traditional approaches to research ethics favour keeping participants, especially those deemed ‘vulnerable’, at arm’s length, participatory research explicitly challenges this ‘first do no harm’ dogma by insisting that objects of inquiry be involved in the process. Participatory research does not disregard research ethics altogether. Rather, ethical issues – informed consent, confidentiality, anonymity, data protection – are valued differently and addressed through processes of dialogue and open discussion between researchers and participants. Northway *et al.* (2015) have successfully involved people with a learning disability in the research ethics process but describe the experience as quite daunting and as requiring adjustments by the research team and ethics committee in terms of processes, presentation of information and timing. As someone with considerably less experience than Professor Northway and team, the thought of changing the ethics procedure to suit a participatory approach was anathema to me and so I shied away from this action in favour of conforming to the more traditional approach. I feel, however, that I was able to instil my participatory ethos through the ethics application, particularly in presenting participants with a learning disability not as wholly vulnerable participants unable to express their own voice or give consent but as individuals whose contribution will be valued and respected.

## Fear of failure

The competing agendas and priorities of individualistic academic structures and participatory research create a dilemma for research students. Research students retaining too much power in the research process potentially jeopardizes any attempt at participation (Burgess, 2006). On the other hand, realigning power too far into the hands of participants runs the risk of a student’s work being regarded as lacking rigour, reliability and academic credibility and, at worst, might lead to the risk of failing the degree (Cornwall and Jewkes, 1995; Seymour and Garbutt, 1998: 3; Campbell, 2002; Pain and Francis, 2003). During the process of conducting the research, I was acutely aware that the project was part of a research degree intended to test *my* skills and competencies and my requirement to prepare and produce a substantial piece of original research. Like Seymour and Garbutt (1998: 11), I was concerned with having to ‘display [my] expert status’. As such, the concessions I made to a participatory ideal were, I felt, necessary compromises with the aim of securing a PhD (Seymour and Garbutt, 1998). (Admittedly, I made some greater concessions than did Seymour and Garbutt (1998)).

‘Failure’ – or, at least, the fear of failure – may be problematic for students as it is the one thing they are encouraged not to do (Pain *et al.*, 2013). Ultimately, my attempt to deliver participation was not something that I needed to attain in order to get a pass mark. In this sense, this approach was similar to the attempts of Pain *et al.* (2013) to get undergraduate students to take part in participatory action research projects with local community groups, where projects that ‘failed’ in terms of degrees of participation did not receive lower marks. Conversely, Klocker (2012) overcame the institutional demands associated with being a research student to demonstrate the legitimacy of her participatory action research by developing two bodies of work: one reflecting the participatory-action element of her work and one being a separate thesis. This is not



something I thought about doing at the time or, on reflection, would have had the capacity to do.

## Sharing control

In order for participatory research to be an empowering experience for participants, the power to make decisions and control the research process must be shared by researchers. Some researchers have gone to extraordinary lengths to share power and control. Williams (1999), for example, describes her work with a Bristol self-advocacy group working on its own agenda, undertaking interviews and sharing in the generation of theory. Other researchers may not be able to cope with feelings of uncertainty and losing professional power and control (Povee *et al.*, 2014). An extract from the research diary of Povee *et al.* (2014), in reference to a steering group meeting, demonstrates the ambiguity of research conducted participatorally:

This was not what I was expecting. In my mind I imagined everyone sitting around quietly, exchanging ideas and asking questions. It did not happen like that at all, it was complete chaos. I was trying to talk to the group about how to use the cameras and I had one Member tugging on my shirt and dismantling my pens. I feel as though the project is completely derailed. I think my expectations were unrealistic. I was being naïve to think that this project would be easy.

(Povee *et al.*, 2014: 903)

I retained most, if not all, of the 'power' during my PhD research. Participants had, for example, a choice to take part in the project or not, and a choice of what to photograph during photovoice, but this procedure was established on my terms. I was not prepared to risk not 'getting it right' (that is, failing my degree) by handing over the 'power of decision making' to participants (Lister *et al.*, 2003; Bourke, 2009: 458).

Having completed undergraduate study and a postgraduate degree in social research methods I feel that I was too ingrained in the 'traditional' approach to research. While these courses did not preach a positivist approach to research, within the techniques and skills learnt it was implicit that research would be controlled by a trained researcher. As such, having to deconstruct what I understood social research to be and tolerate greater uncertainty and a redefinition of my role (Moore *et al.*, 1998; Povee *et al.*, 2014) in order to pursue participatory research was, at the time, insurmountable for me.

Those that report greater success sharing control to delivery participatory research, 'credit building relationships, setting up structures that value and enable equity, experienced community members, and scientist flexibility' (McDonald and Stack, 2016: 201). Despite the advancement of participatory research in recent decades, there is still a balancing act to be performed between principals and pragmatics (Nind and Vinha, 2012), especially where research students are involved. Clark *et al.* (2009: 13) describe how they did not 'hand over the stick' entirely to participants. While some may criticize their method in this regard, given the nature of research funding and academic necessity an alternative is to say that an honest attempt at participation of a kind is better than no attempt at all.

## Inexperience

Research degrees, even at doctoral level, aim to provide a training ground for researchers, professional development, experience undertaking research projects, mentoring, attending conferences and presenting work for critical review (Strnadova *et al.*, 2014) and also to 'ensure the flow of highly qualified people' (Economic and Social Research Council, 2016). The implied inexperience of research-degree students may be at odds with the reality of participatory research, where the majority of successful projects are completed by experienced researchers (Pain *et al.*, 2013) or by those with experience in the field (McDonald and Stack, 2016). Having come to my PhD straight from full-time undergraduate and then master's studies, with no experience of full-time employment in the field, a lack of experience was a considerable limiting factor in my pursuit of participatory research. In order to prevent a struggle, I was interested in making the project as easy to manage and complete as possible.

Research-degree students are not left to flounder unaided. A package of support to help them along the way is usually provided, including one-to-one supervision, peer-support networks, instructional texts, and taught courses. Working with a supervisor with experience of, or affiliated to, a community-based participatory research project is seen as a contributing factor towards successful participatory research for research-degree students (Khobzi and Flicker, 2010). However, depending on the field of study it may not always be possible to find a supervisor sufficiently experienced to guide a student through. The absence of an 'expert guide' was not a problem for Klocker (2012) as her supervisors, although not participatory researchers, had the confidence to let her navigate a way through and offered an outside perspective. My difficulty in delivering a participatory project is not intended to be a criticism of my supervisors, who I am sure would have been able to support me through the particulars of a participatory PhD. Rather, more generally, the 'training' I had received up to my PhD had not prepared me for the challenges of participatory research. Again, this is not intended to be a criticism of my institution – had I been more insistent on pursuing a participatory ideal, appropriate support might have been provided – but it is perhaps a reflection on the individualistic construction of knowledge discussed previously.

Guidance for budding participatory research students might also be taken from instructional texts and practical guides about how to conduct participatory research in its many forms. However, this was not appropriate for me. At the time when I was studying, all the resources identified seemed to be aimed at experienced researchers, well versed in conducting and managing 'traditional' research projects, looking to move into a participatory sphere. I would have liked a text describing participatory research for someone with no experience of conducting social research.

## Competing priorities

Unlike 'traditional' research methodologies, undertaking participatory research requires research students to work with, and be accountable to, community partners, as well as their supervisors, examiners and themselves (Khobzi and Flicker, 2010). This introduces potential issues of competing priorities, shifting agendas, negotiating role boundaries and authorship (Bourke, 2009). I shied away from engaging participants for fear that it might compromise the validity of academic evidence and complicate timescales.

Participatory research not only subverts the research–researched relationship but also the supervisor–researcher relationship. No longer are supervisors guiding or

assisting a single student during their project; they can potentially become embroiled with a whole community of 'researchers'. If a student's supervisor is not as amicable as Klocker's (2012), the relationship could break down and, at worst, fail altogether.

## Time and effort

It seems fairly widely accepted that participatory research requires a greater investment of time and resources than non-participatory research – time and effort to develop relationships, maintain contact and sustain involvement. Povee *et al.* (2014), for example, describe visiting their research site every fortnight for a year to support participants. Also, participants are not likely to 'be empowered, liberated and transformed on our schedules' (Maguire, 1993: 175) and so a greater flexibility in timescales is needed. This extra time and effort is often used as a stick to discourage research students from pursuing participatory research (Moss, 2009; Pain *et al.*, 2013); not completing my thesis on time was certainly a concern of mine.

Conversely, reflecting on her experience, Klocker (2012) suggests that a PhD is the perfect time to embark on a participatory project because any time invested building relationships at the beginning of the project is likely to pay off when participants relieve the burden of data collection and analysis from the researcher, and because researchers are unlikely to have such time again to devote to one endeavour in an academic career. However, for me, engaging in participatory activities would have resulted in duplication rather than reduction of work. Such duplication is demonstrated by Klocker (2012) herself, who produced two final outputs from her work, a co-authored report with participants and her thesis.

## Working with people with a learning disability

It is also the case that, despite the potential benefits, communities may not always want, or be able, to participate in research. With regard to people with a learning disability, it is difficult to develop research partnerships that are accessible, inclusive and adequately resourced (McDonald and Stack, 2016). People with a learning disability often require additional accommodations to participate in research. While I have a history of working with people with a learning disability outside of research, at the time of carrying out my PhD I felt that I did not have sufficient experience of conducting research to allow me to involve people with a learning disability extensively in the process.

Moreover, as with other communities, it can be difficult to involve the community of interest in the research proposal because, on the one hand, non-researchers rarely see the world in terms of research questions and, on the other, the community may not want to be involved. With regard to working with people with a learning disability, for example, Ward and Simons (1998: 131) have suggested that 'not everyone ... is able or willing to be involved' in research. Ward and Trigler (2001: 58), as well as others (Atkinson *et al.*, 2000; McCarthy and Millard, 2003; Lennox *et al.*, 2005), suggest that inappropriately expecting people with a learning disability to propose research topics or draw out implications from an array of information, for example, has created practical 'methodological problems' and 'compromised results'. Such an approach may fail to recognize the reality of impairment for some people with a learning disability, ignoring the actual skills and knowledge they have or do not have at their disposal (Walmsley and Johnson, 2003).

## Discussion and conclusion

This paper has explored my experience of attempting to conduct a piece of participatory research into the potential for football fandom to be a route to social inclusion for people with a learning disability. It has examined my use of semi-structured interviews, participant observation and photovoice to involve people with a learning disability in data collection, as well as my 'participatory ethos', recognizing the right of people with a learning disability to be involved in decisions affecting their lives. My failure to involve people with a learning disability in a steering group, research proposal, data analysis or dissemination has been critiqued in comparison to other PhD researchers who were able to more meaningfully involve participants in their research processes (Seymour and Garbutt, 1998; Khobzi and Flicker, 2010; Klocker, 2012).

The paper has reflected on the challenges I faced in attempting a piece of participatory research. The focus of participatory research on collective decision-making and empowerment challenges the individualistic construction of knowledge dominant in the academy, upon which research degrees are built. I was more concerned with getting it 'right', in terms of adhering to the criteria for passing my degree, than in involving people with a learning disability in meaningful participation. As an inexperienced researcher being assessed on my work, I did not feel capable of giving up control of the process because of the ramification this may have had for the timescale, aims and objectives, and outcomes of the work.

While the research I completed deviated from what I had originally proposed and what I would have liked to achieve, on reflection I am satisfied with my conduct and what was achieved. This is because the goals of participatory research are lofty, especially in the context of a research degree (Seymour and Garbutt, 1998; Klocker, 2012; Pain *et al.*, 2013). There are numerous examples of researchers falling short of their participatory intentions for a variety of practical reasons. To paraphrase Seymour and Garbutt (1998), compromises were made in my project because of the overriding aim of securing a PhD. I feel that participants were engaged as fully as possible in the research process in line with my relative (in)experience at the time as a social researcher.

This may lead some to the conclusion that participatory research is incompatible with the research-degree process. However, the position throughout this paper has been that participatory research is not an absolute state but a continuum of potential involvement – a set of philosophies, principles and practises with which to critically engage (Seymour and Garbutt, 1998; Pain *et al.*, 2013). Some researchers – student or otherwise – may exhibit great skill and effort in fully engaging members of the community in the research process, while others fall short of such ambitions but nonetheless produce research that is useful and meaningful (Maguire, 1993; Pain *et al.*, 2013). Such attempts should not be castigated because, in the words of Kesby *et al.* (2005: 245), 'the road to doing things differently has to start somewhere'.

In relation to research degrees, given that the process represents a training environment, an important question is what students do with the skills they have acquired once the degree is completed (Seymour and Garbutt, 1998). Following completion of my PhD, I have gone on to work for a national charitable organization as a researcher and now as a researcher in a university. My interest in, and passion for, social justice, particularly around learning disability, has only increased through these experiences. In my current role I have been involved in a number of research projects utilizing participatory methodologies to a greater extent than I was able to during my PhD. Without the 'lesser' experience gained as a research-degree student, the work

I have since been able to complete alongside members of the community would not have been possible.

## Notes on the contributor

Since completing his PhD in 2013, Kris Southby has worked for a national learning disability charity as a research and employment coordinator. Since 2014 he has worked as a researcher in the Centre for Health Promotion Research at Leeds Beckett University. His research interests broadly concern learning disability, particularly issues around social inclusion/exclusion, leisure and volunteering.

## References

- Atkinson, D. (2005) 'Research as social work: Participatory research in learning disability'. *British Journal of Social Work*, 35 (4), 425–34.
- Atkinson, D., McCarthy, M., Walmsley, J. et al. (eds) (2000) *Good Times, Bad Times: Women with learning difficulties telling their stories*. Kidderminster: BILD.
- Barnes, C. and Mercer, G. (eds) (1997) *Doing Disability Research*. Leeds: The Disability Press.
- Beresford, P. and Boxall, K. (2012) 'Service users, social work education and knowledge for social work practice'. *Social Work Education*, 31 (2), 155–67.
- Bigby, C., Frawley, P. and Ramcharan, P. (2014) 'Conceptualizing inclusive research with people with intellectual disability'. *Journal of Applied Research in Intellectual Disabilities*, 27 (1), 3–12.
- Biggs, S. (1989) 'Resource-poor farmer participation in research: A synthesis of experiences from nine national agricultural research systems' (OFCOR Comparative Study Paper 3). The Hague: International Service for National Agricultural Research.
- Booth, T. and Booth, W. (2003) 'In the frame: Photovoice and mothers with learning difficulties'. *Disability & Society*, 18 (4), 431–42.
- Bourke, L. (2009) 'Reflecting on doing participatory research in health: Participation and power'. *International Journal of Social Research Methodology*, 12 (5), 457–74.
- Burgess, J. (2006) 'Participatory action research: First-person perspectives of a graduate student'. *Action Research*, 4 (4), 419–37.
- Burke, A., McMillan, J. and Cummins, L. (2003) 'Setting up participatory research: A discussion of the initial stages'. *British Journal of Learning Disabilities*, 31 (2), 65–9.
- Byrne-Armstrong, H., Higgs, J. and Horsfall, D. (2001) *Critical Moments in Qualitative Research*. Oxford: Butterworth.
- Campbell, J. (2002) 'A critical appraisal of participatory methods in development research'. *International Journal of Social Research Methodology*, 5 (1), 19–29.
- Clark, A., Holland, C., Katz, J. and Peace, S. (2009) 'Learning to see: Lessons from a participatory observation research project in public spaces'. *International Journal of Social Research Methodology*, 12 (4), 345–60.
- Cornwall, A. and Jewkes, R. (1995) 'What is participatory research?' *Social Science & Medicine*, 41 (12), 1, 667–76.
- Coy, M. (2006) 'This morning I'm a researcher, this afternoon I'm an outreach worker: Ethical dilemmas in practitioner research'. *International Journal of Social Research Methodology*, 9 (5), 419–31.
- de Toma, C. (1996) 'Sharing experiences of participation in Latin America: A workshop report'. *Participatory Learning and Action Notes: Special Issue on Children's Participation*, 25, 4–5.
- Economic and Social Research Council (2016) 'Doctoral Training Centres'. Online. [www.esrc.ac.uk/skills-and-careers/studentships/doctoral-training-centres/](http://www.esrc.ac.uk/skills-and-careers/studentships/doctoral-training-centres/) (accessed 1 August 2016).
- Fawcett, B. and Hearn, J. (2004) 'Researching others: Epistemology, experience, standpoints and participation'. *International Journal of Social Research Methodology*, 7 (3), 201–18.
- Gold, N. (1998) 'Using participatory research to help promote the physical and mental health of female social workers in child welfare'. *Child Welfare*, 77 (6), 701–24.
- Hunt, P. (1966) *Stigma: The experience of disability*. London: Geoffrey Chapman.
- Hunt, P. (1981) 'Settling accounts with the parasite people: A critique of "A life apart" by E.J. Miller and G.V. Wynne'. *Disability Challenge*, 1, 37–50.

- Israel, B., Schultz, A., Parker, E. and Becker, A. (1998) 'Review of community-based research: Assessing partnership approaches to improve public health'. *Annual Review of Public Health*, 19, 173–202.
- Kesby, M., Kindon, S. and Pain, R. (2005) 'Participatory research'. In Flowerdew, R. (ed.) *Methods in Human Geography: A guide for students doing a research project*. London: Pearson, 144–66.
- Khobzi, N. and Flicker, S. (2010) 'Lessons learned from undertaking community-based participatory research dissertations: The trials and triumphs of two junior health scholars'. *Progress in Community Health Partnerships: Research, Education and Action*, 4 (4), 347–56.
- Klocker, N. (2012) 'Doing participatory action research and doing a PhD: Words of encouragement for prospective students'. *Journal of Geography in Higher Education*, 36 (1), 149–63.
- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D.M. and Boyle, F. (2005) 'Beating the barriers: Recruitment of people with intellectual disability to participate in research'. *Journal of Intellectual Disability Research*, 49 (4), 296–305.
- Lewin, K. (1946) 'Action research and minority problems'. *Journal of Social Issues*, 2 (4), 34–46.
- Lister, S., Mitchell, W., Sloper, P. and Roberts, K. (2003) 'Participation and partnerships in research: Listening to the ideas and experiences of a parent carer'. *International Journal of Social Research Methodology*, 6 (2), 159–65.
- Maguire, P. (1993) 'Challenges, contradictions and celebrations: Attempting participatory research as a doctoral student'. In Park, P., Brydon-Miller, M., Hall, B. and Jackson, T. (eds) *Voices of Change: Participatory research in the United States and Canada*. Westport, CT: Bergin & Garvey, 157–76.
- Mayo, M. (2001) 'Children's and young people's participation in development in the South and urban regeneration in the North'. *Progress in Development Studies*, 1 (4), 279–93.
- McCarthy, M. and Millard, L. (2003) 'Discussing the menopause with women with learning disabilities'. *British Journal of Learning Disabilities*, 31 (1), 9–17.
- McClimens, A. (2008) 'This is my truth, tell me yours: Exploring the internal tensions within collaborative learning disability research'. *British Journal of Learning Disabilities*, 36 (4), 271–6.
- McDonald, K.E. and Stack, E. (2016) 'You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities'. *Disability and Health Journal*, 9 (2), 201–7.
- Moore, M., Beazley, S. and Maelzer, J. (1998) *Researching Disability Issues*. Buckingham: Open University Press.
- Moss, P. (2009) 'Positioning a feminist supervisor in graduate supervision'. *Journal of Geography in Higher Education*, 33 (1), 67–80.
- Nind, M. and Vinha, H. (2012) 'Doing research inclusively: Bridges to multiple possibilities in inclusive research'. *British Journal of Learning Disabilities*, 42 (2), 102–9.
- Northway, R. (1998) 'Engaging in participatory research: Some personal reflections'. *Journal of Intellectual Disabilities*, 2 (3), 144–9.
- Northway, R., Howarth, J. and Evans, L. (2015) 'Participatory research, people with intellectual disabilities and ethical approval: Making reasonable adjustments to enable participation'. *Journal of Clinical Nursing*, 24 (4), 573–81.
- Pain, R. (2009) 'Commentary: Working across distant spaces: Connecting participatory action research and teaching'. *Journal of Geography in Higher Education*, 33 (1), 81–7.
- Pain, R. and Francis, P. (2003) 'Reflections on participatory research'. *Area*, 35 (1), 46–54.
- Pain, R., Finn, M., Bouveng, R. and Ngobe, G. (2013) 'Productive tensions – Engaging geography students in participatory action research with communities'. *Journal of Geography in Higher Education*, 37 (1), 28–43.
- Povee, K., Bishop, B.J. and Roberts, L.D. (2014) 'The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities'. *Disability & Society*, 29 (6), 893–907.
- Reason, P. and Bradbury, H. (2006) 'Introduction: Inquiry and participation in search of a world worthy of human aspiration'. In Reason, P. and Bradbury, H. (eds) *Handbook of Action Research*. London: SAGE, 1–14.
- Redmond, M. (2005) 'Co-researching with adults with learning disabilities: Roles, responsibilities and boundaries'. *Qualitative Social Work: Research and Practise*, 4 (1), 75–86.
- Sample, P. (1996) 'Beginnings: Participatory action research and adults with developmental disabilities'. *Disability & Society*, 11 (3), 317–32.
- Schoeters, L., Schellhout, P., Roets, G., Van Hove, G., Townson, L., Chapman, R. and Buchanan, I. (2005) 'Partnership working between university researchers and self-advocacy organizations: "A way forward for inclusion?" in England and "Fine feathers make a fine bird" in Flanders'. *Journal of Intellectual Disabilities*, 9 (4), 345–57.



- Sense, A. (2006) 'Driving the bus from the rear passenger seat: Control dilemmas of participative action research'. *International Journal of Social Research Methodology*, 9 (1), 1–13.
- Seymour, J. and Garbutt, R. (1998) "'Do we all get a PhD?" Attempting emancipatory research relating to disability in an academic environment'. Paper presented at the British Sociological Association Conference, Edinburgh.
- Southby, K. (2013) 'Social inclusion through football fandom: Opportunities for learning-disabled people'. *Sport in Society*, 16 (10), 1,386–403.
- Stalker, K. (1998) 'Some ethical and methodological issues in research with people with learning difficulties'. *Disability & Society*, 13 (1), 5–19.
- Strnadova, I. and Cumming, T. (2014) 'People with intellectual disabilities conducting research: New directions for inclusive research'. *Journal of Applied Research in Intellectual Disability*, 27 (1), 1–2.
- Strnadova, I., Cumming, T., Knox, M., Parmenter, T. and Welcome to Our Class Research Group (2014) 'Building an inclusive research team: The importance of team building and skills training'. *Journal of Applied Research in Intellectual Disability*, 27 (1), 13–22.
- Townson, L., Macauley, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., Eardley, M. and McNulty, N. (2004) 'We are all in the same boat: Doing "people-led research"'. *British Journal of Learning Disabilities*, 32 (2), 72–6.
- Turk, V., Leer, G., Burchell, S., Khatram, S., Corney, R. and Rowlands, G. (2012) 'Adults with intellectual disabilities and their carers as researchers and participants in a RCT'. *Journal of Applied Research in Intellectual Disabilities*, 25 (1), 1–10.
- Valade, R. (2008) *Participatory Action Research with Adults with Intellectual Disabilities: "Oh my God! Look out world!"* Saarbrücken: VDM Verlag.
- Walmsley, J. (2001) 'Normalisation, emancipatory research and inclusive research in learning disability'. *Disability & Society*, 16 (2), 187–205.
- Walmsley, J. (2004) 'Inclusive learning disability research: The (non-disabled) researcher's role'. *British Journal of Learning Disabilities*, 32 (2), 65–71.
- Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities: Past, present and futures*. London: Jessica Kingsley.
- Ward, K. and Trigler, L. (2001) 'Reflections on participatory action research with people who have developmental disabilities'. *Mental Retardation*, 39 (1), 57–9.
- Ward, L. and Simons, K. (1998) 'Practising partnership: Involving people with learning difficulties in research'. *British Journal of Learning Disabilities*, 26 (4), 128–31.
- Williams, V. (1999) 'Researching together'. *British Journal of Learning Disabilities*, 27 (2), 48–51.
- Williams, V., Simons, K. and Swindon People First Research Team (2005) 'More researching together: The role of non-disabled researchers in working with People First members'. *British Journal of Learning Disabilities*, 33 (1), 6–14.