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Reimagining citizen science as inclusive praxis

Jessica E. Carr[1,*], Richard Holliman[2,*], Jane Seale[3], Eileen Scanlon[4,5] and
Ruth Shaw-Williams[6]

[1]Researcher, Institute of Educational Technology, The Open University, Milton Keynes, UK
[2]Professor of Engaged Research, Faculty of Science, Technology, Engineering and Mathematics, The Open University, Milton Keynes, UK
[3]Professor of Education, Faculty of Wellness, Education and Language Studies, The Open University, Milton Keynes, UK
[4]Regius Professor of Open Education, Institute of Educational Technology, The Open University, Milton Keynes, UK
[5]Honorary Professor, Moray House School of Education, University of Edinburgh, Edinburgh, UK
[6]Group Leader, My Life My Choice Banbury Self-Advocacy Group, Technical Specialist in Bookarts and Print, Oxford Brookes University, Oxford, UK
*Correspondence: jessica.carr@open.ac.uk (JEC); richard.holliman@open.ac.uk (RH)

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Abstract

The Banbury My Life My Choice Self-Advocacy Group, Jessica Carr and three supervisors worked together to research how people with learning disabilities do citizen science. As a research group, we made our own citizen science project exploring an issue of relevance and interest to us. Using creative research methods, we learnt about research skills together and found out what research we would like to do. We then used these skills to make our own citizen science project, and we worked together to create a project of relevance to our community. This article looks at how we worked together to do our research, explores some of the challenges we faced and shows how we solved them. Our aim is to share what we have learnt to provide researchers with examples of how to work with and support people with learning disabilities to do citizen science.

Keywords citizen science; inclusive research; public engagement; learning disabilities

Key messages

- When engaging with individuals and groups that have experienced discrimination and disadvantage, researchers should ensure that they do no (more) harm. This principle acknowledges both the historical harm that has been done to these communities, and the need for university staff to build their capacity in how to engage in ways that are fair and equitable.
- To engage in ways that are fair and equitable with individuals and groups that have experienced discrimination and disadvantage, researchers should work with them throughout the research process. This should include upstream planning as the research is designed, and downstream engagement as the research proceeds through data collection, analysis and reporting.
- Focus on the positives: researchers should seek to create the conditions for equitable engagement by drawing on and enhancing the capabilities of co-researchers (as opposed to focusing on what citizen scientists struggle to do).

Introduction

People with learning disabilities have difficulties experiencing and acquiring new information, which often starts in childhood (Department of Health, 2001). Wider society can play a role in further disabling people with learning disabilities through exclusionary practices and processes (Seale et al., 2013). These issues also affect people living with other forms of disability (for example, see Kitchin, 1998).

The ‘social model of disability’

The history of disability highlights how the attitudes to this diverse community has changed over time. Originally labelled as ‘idiots’ (Idiots Act, 1886) and as ‘feebleminded’ (Royal Commission, 1908), those living with additional needs were seen as second-class citizens. A key action in transforming how people living with disabilities should be conceptualised by wider society happened in 1981 with the formation of the Disabled People’s International, who declared that:

> Disabled people have the right to equal participation in the decision-making processes of all political services and programmes that effect [sic] their lives. (Disabled People’s International, 1981: 2).

This declaration catalysed collective action, forming a movement which influenced research. The ‘social model of disability’, developed by Oliver (1990), challenged the idea that a person’s disability is a flaw, arguing that a person with a disability is disabled by the way they are perceived by society. Inclusive research developed from this movement; this methodology is rooted in the social model of disability.

Defining inclusive research

There is a strong tradition of using inclusive research methods to engage people with intellectual disabilities in research (Seale et al., 2014). Inclusive research is an umbrella term for a family of methods (for example, emancipatory research, participatory research and participatory action research) that moves away from involving people as subjects of research and instead aims to involve them as ‘instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (Walmsley and Johnson, 2003: 10). This is 'research with, not on or for', the learning-disabled community (Nind, 2008: 4). This tradition has developed as a response to influential disability activism.

In the UK, disability activists have argued that disability is a consequence of societal barriers, rather than individual impairment or difference, and they have proposed a social model of disability that calls for the removal of barriers that operate to exclude and discriminate against disabled people (Oliver, 1990; UPIAS, 1975). In the USA, Charlton (1998) wrote the generative text, *Nothing About Us Without Us: Disability oppression and empowerment*, in which he drew on interviews with disability rights activists to argue that people with disabilities know what is best for them. It follows that a key tenet of this methodological approach is the need to include people with learning disabilities in all parts of the research process, co-creating research that, 'address[es] issues which really matter to people with learning disabilities', and 'access[ing] and represent[ing] their views and experiences' (Walmsley and Johnson, 2003: 16).

These arguments resonate with people with learning disabilities who argue that they are best placed to know what needs to be researched about their lives, what the barriers are and how these barriers are experienced, and why some research questions or topics are more important than others (for example, Townson et al., 2004). A key intended outcome of inclusive research is increased opportunities for people with learning disabilities to shape their local communities, for example, by influencing health and social care service provision or decision making connected to where people with intellectual disabilities live and how they spend their time. An example of this is the growing involvement of people with learning disabilities in health and social care research funded by the UK government through the National Institute for Health and Care Research (for example, Ryan et al., 2024).

What do we mean by citizen science?

Although it was not named as such at the time, citizen science has existed in various forms for at least a hundred years (Curtis, 2015), with a small number of examples dating to the early 1700s (Siddharthan, 2024). In the 1990s, Irwin (1995: xi) defined citizen science as 'evok[ing] a science which assists the needs and concerns of citizens'. Similarly, Bonney (1996) chose to define citizen science as a research method in which non-scientists are engaged to contribute scientific data to a research project. While citizen science practices have sought to offer ways of exploring and bridging gaps between 'experts' and 'non-experts', until recently few of them sought to support marginalised communities (Montanari et al., 2021; Paleco et al., 2021; Skarlatidou and Haklay, 2021; Varga et al., 2023). As Cooper et al. (2021: 1386) note, citizen science 'participants are overwhelmingly white adults, above median income, with a college degree'.

The project discussed in this article aligns with Irwin's (1995: xi) definition, in that it 'evokes a science' by reimagining citizen science as inclusive praxis. It does so through an investigation, using surveys designed, administered and analysed by people with learning disabilities, to explore a topic of their choice, animal management. The process and outcome of this project 'assist[ed] the needs and concerns of citizens', by creating an 'easy-read' leaflet for the learning-disabled community to assist them in the care of their pets.

From research strategy to inclusive praxis

In 2019, UK Research and Innovation (UKRI, 2019), the overarching public funder for research, listed four goals in its UKRI Vision for Public Engagement:

1) engage under-represented communities and places with research and innovation
2) actively involve a wide range of people in their work
3) nurture a future generation passionate about research and innovation
4) listen to public concerns and aspirations.

Following the publication of these goals, UKRI commissioned a report to explore an equitable future for research and innovation. The report found that:

> Research organisations, such as research funders, universities and think tanks have been seen as the leading lights or 'gatekeepers' of knowledge activities. In almost every situation, they take the 'lead' in partnerships with non-research organisations. (Institute for Community Studies, 2022: 3)

In addressing the UKRI (2019) goals and Institute for Community Studies (2022) report, UKRI have funded more than 50 citizen science and community-led research projects, each with an aim to engage with more diverse communities (UKRI, 2020, 2021, 2023). While this is a welcome development, only one of these projects directly focuses on the needs of people living with disabilities. (In 2021–2, it was estimated that 24 per cent of the UK population had a disability (Kirk-Wade, 2023.) Within this wider group, there is a specific community which has yet to be engaged in a UKRI-funded citizen science or community-led project, the learning-disabled community.

Research demonstrates that, in spite of concerted calls for the ethics of engagement to be foregrounded (Medvecky, 2018; Medvecky and Leach, 2017), for epistemic justice to be considered when planning activities to ensure that under-recognised communities have fair and equitable access to knowledge (Holliman et al., 2022, 2024), for researchers involved in citizen science to prioritise 'strategic planning to advance accessibility, justice, equity, diversity and inclusion in citizen science' (Cooper et al., 2021: 1388), and for researchers to explore how minoritised people are excluded from forms of informal science learning (Dawson, 2019), the learning-disabled community has been routinely excluded from having an active voice in the planning and shared practices of citizen science. (Milner and Jumbe (2020) define 'minoritised' groups of people as those that have been, and continue to be, excluded and oppressed by dominant sections of society.) A recent review of citizen science literature confirmed that no citizen science projects working specifically with the learning-disabled community have been conducted (Carr, 2021).

Citizen science as inclusive praxis

There has been greater recognition in the field of citizen science that exclusionary practices have limited participation (Skarlatidou and Haklay, 2021), with almost no emphasis on how to support citizens with learning disabilities (Carr, 2021). The aim of this article is to explore the role that inclusive principles and practices can play in actively engaging people with learning disabilities in citizen science. We will also consider how these principles and practices could be adapted or applied to engagement involving people living with other forms of disability to promote inclusion.

Inclusive praxis is the application of inclusive research principles, by giving people with learning disabilities an opportunity to take the lead in partnership with a research organisation. In this article, we discuss and reflect on PhD research conducted by Carr (2021) with a self-advocacy group of people with learning disabilities called My Life My Choice. Jane Seale, Richard Holliman and Eileen Scanlon supervised and supported this research. We will highlight the importance of embedding inclusive research principles to design and carry out research with people with learning disabilities. We argue that this requires consideration of four main factors: (1) creativity in methods; (2) consideration of alternative practices; (3) collaboration with under-recognised communities throughout the research process; and (4) community focus, giving active voice to group needs and to what minoritised constituencies can gain from the research process.

Methods

Methods were selected to enable capacity building for the learning-disabled researchers (hereafter referred to as 'co-researchers'). There were two elements to the study: (1) capacity-building measures were introduced to support the co-researchers (the university researchers and people with learning disabilities) to engage in citizen science; and (2) the co-researchers worked collaboratively to plan and implement a citizen science project. For both elements, the overarching methodology was underpinned by the principles and methods developed by inclusive researchers (for example, Seale et al., 2014).

Selecting the methods

Inclusive researchers focus on qualitative methods, exploring how these processes can be adapted to meet the needs of the communities with whom they engage (Nind and Vinha, 2014; Walmsley and Johnson, 2003). Inclusive research studies often combine commonly used qualitative research methods, such as interviews and focus groups, with creative adaptations to 'access and represent [the co-researcher's] views and experiences' (Walmsley and Johnson, 2003: 16).

In this study, a combination of qualitative and creative methods was used, including collaging and identity boxes (Brown, 2016), alongside interviews and focus groups. The commonly used qualitative methods (interviews and focus groups) offered insights into the data collected during the creative methods (collaging and identity boxes). This offered flexibility to the co-researchers in how they contributed and supported a form of methodological triangulation (Tindall, 1994) for those who contributed to all aspects of the data collection.

Recruiting the co-researchers

A key aspect of this research was working *with* a group of people with learning disabilities to explore the concept of citizen science and to create the conditions where we would co-research a project of their choice. We engaged with 11 members (including the Group Leader) of the Banbury Self-Advocacy Group of the learning disability charity My Life My Choice.

Prior to the project, contact was made with the Group Leader, through which the outline planning for the project was developed together – a form of upstream engagement (Wilsdon and Willis, 2004).

Ten two-hour sessions, conducted monthly, were planned in outline form by the lead author and supervision team. These outline plans were negotiated, revised and agreed with the Group Leader at My Life My Choice. The first three sessions explored capacity-building measures in relation to citizen science, taking on board the expertise and lived experience of the Group Leader at My Life My Choice. The remaining sessions focused on the co-creation of a citizen science project.

Relationships between the citizens and non-disabled researchers

Walmsley (2004) identifies how the roles of non-disabled researchers are often mystified within the inclusive researcher literature. In a similar vein, it could be argued that 'the citizen' in citizen science is under-researched and under-theorised (Carr, 2021). This article aims to demystify these labels, documenting how non-disabled researchers worked alongside other co-researchers as citizen scientists. Within this project, there were five non-disabled researchers: the lead researcher (who was studying for a PhD), the Group Leader and three PhD supervisors.

The non-disabled researchers contributed to the project in complementary ways. The lead researcher's role was to work alongside the co-researchers to develop the project, and to collect and analyse data to produce a thesis (Carr, 2021). The co-researchers – citizens – were actively involved, giving voice to their expertise and experiences in shaping the research design and application, developing shared capacity in polyvocal ('many voices') approaches to research. This approach was developed in response to ethical concerns about the extractive nature of citizen science approaches (Medvecky and Leach, 2017), which all too often downplay the active nature of citizenship in favour of 'acquisitive data centred' approaches (Hall et al., 2024: 319).

Data analysis occurred in between sessions to allow for appropriate adaptations to be made in response to the co-researchers' expertise and lived experience. The Group Leader was a participant in the research, but also supported the co-researchers in their engagement with their local expertise and lived experience. The Group Leader also supported those who were not actively contributing, to facilitate ways of engaging co-researchers on their terms. The supervisors reviewed all aspects of planning, data collection and analysis, and the production of the thesis.

The lead researcher planned the sessions, and the activities within them, collected and analysed data, and adapted future sessions to reflect co-researchers' needs and capacities. These data included ethnographically informed observations through fieldnotes on co-researchers' capacity and the different types of support that were needed (Carr, 2021: 73).

Structured one-to-one interviews were also used: (1) to create a space where co-researchers could make the thinking behind their creative artefacts visible; and (2) at the end of the study, interviews replaced the originally planned evaluation methods because of the Covid-19 pandemic.

Identifying capacity needs

The first phase of the research was designed to develop rapport between the co-researchers, identify capacity needs, surface pre-existing knowledge and understanding of the sciences and citizen science, explore how the co-researchers identified as researchers, and negotiate shared definitions of key terms (research, science, citizenship). This phase used creative research methods, 'to establish an environment in which the co-researchers could learn about citizen science and how they could be citizen scientists' (Carr, 2021: 92). The creative methods included: Collage Yourself (Sinfield, 2018: 8), identity boxes (Brown, 2016) and word association (for more detail on these creative methods, see Carr, 2021). The community-specific expertise of knowledge brokers (Meyer, 2010), with the Group Leader acting as a known and trusted confidant supporting the lead researcher to establish rapport and build their capacity, was an important dimension of this early engagement.

Within inclusive research, arts and crafts are employed to support people with learning disabilities to 'convey thoughts and feelings in a way that is accessible' (Richards et al., 2019: 207). The co-researchers were briefed on what each method involved, then working on their creative artefacts and sharing them with the group through discussion. In this way, the use of creative methods offered a space where the co-researchers could explore their understanding and experiences of science and research, both individually and collectively.

One of the aims of this early work was to create a collective understanding of our shared intentions for the research. To do this, we co-created definitions of key terms, such as 'citizens', 'scientists' and 'citizen scientists'. The co-researchers then explored their identity in relation to these key terms.

Having completed the capacity-building phase, the co-researchers supported each other to undertake a citizen science project through structured and facilitated activities. This included scaffolded research training to co-create a shared understanding of research and capacity within the group. The lead researcher was an active 'participant as observer' in these processes, recording fieldnotes (Gold, 1958).

Methods for citizen science

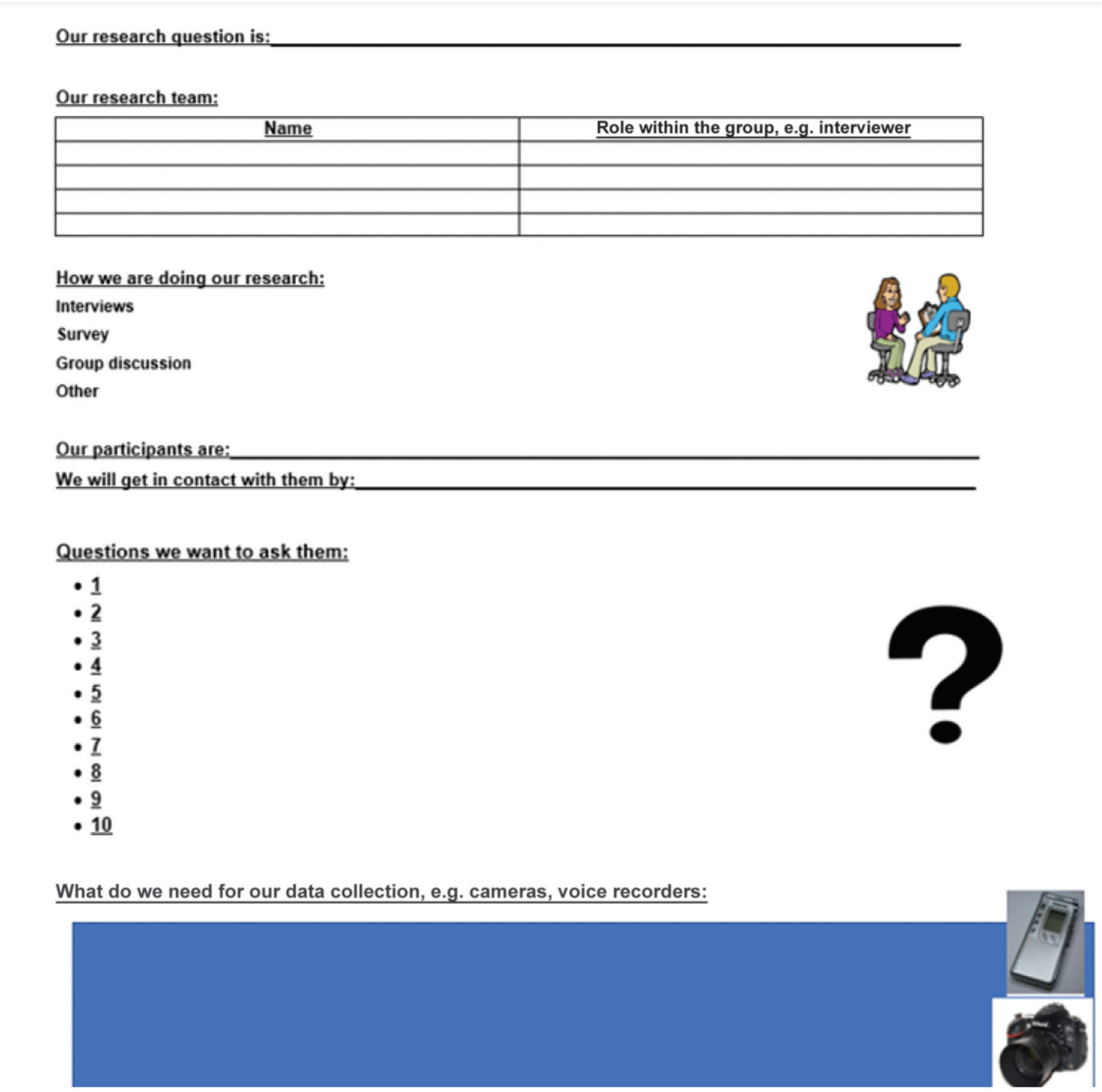
Offering citizens a choice of research topic requires shared rules of engagement (Davies, 2011). In this project, we discussed and agreed how to make this selection. We agreed to gather possibilities for our co-created research project by looking at the topics from our collages. We co-created a long list of topics, and we shortlisted them by engaging in structured discussion. We identified individual motivations for researching each topic, and how these could positively impact the learning disability community. We 'sense-checked' our thinking by exploring the pragmatic implications of researching each topic, thinking through possible research questions, data collection and so on. This approach gave voice to each of the contributors to the research project.

From these discussions, we identified three research topics (animal welfare, hate crime and health), which were of interest to the co-researchers and, potentially, to the learning disability community. Through discussions on each topic, we collaboratively developed a series of research questions. We discussed and agreed methods of data collection that the group felt confident in conducting. This approach was responsive and reflexive, co-creating the conditions where a shared goal and means of achieving it were agreed between the participants as citizens with an equivalent voice in research (Institute for Community Studies, 2022).

After these discussions, for pragmatic reasons, the group decided to reduce the number of choices. Two research topics were agreed, based on a vote: how to look after pets, and the local bus service. Both topics had direct impact on members of the group, hence their choice to investigate them. (The co-researcher leading the project on the local bus service subsequently left the group. The remaining co-researchers decided to focus on the 'pets' topic.) This collaborative research design approach reflects both upstream planning and downstream engagement with relevant publics (Holliman et al., 2017, 2022, 2024).

This process was supported by a pro forma designed to scaffold decision making in relation to research questions, data collection methods and research tools to support the research process (Figure 1).

Figure 1. Pro forma designed to scaffold decision making in research



Our research question is:______________________________

Our research team:

Name	Role within the group, e.g. interviewer

How we are doing our research:

Interviews

Survey

Group discussion

Other

Our participants are:______________________________

We will get in contact with them by:______________________________

Questions we want to ask them:

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10

What do we need for our data collection, e.g. cameras, voice recorders:

The co-researchers decided to use surveys as the data collection method, exploring veterinarians' and veterinary technicians' perspectives on the care of pets. We co-produced the survey questions by deciding what information we wanted to know regarding the care of pets. Surveys were sent to five veterinary practices in the local area.

Data analysis

Capacity building in data analysis was supported through two games, organised in a single session. The first game focused on categorising to show the co-researchers how data can be grouped. If people were part of a category, they put their hands on their head. If people were not a part of that category, they clapped their hands. The purpose of this game was to demonstrate categorisation through coding, while creating a fun and inclusive atmosphere.

In the second game, co-researchers worked with photographs, treating them as data. They were asked to work in pairs to find different ways to categorise the photographs. Through this task, the co-researchers were introduced to coded data, and they explored how to justify their decisions.

The session was concluded by discussing how data analysis could be adapted to investigate responses from the surveys of vets and vet technicians. The co-researchers decided to print off the textual responses, and to use highlighter pens to mark themes within the data (Braun and Clarke, 2019).

Results

Data collected by the non-disabled researcher about the inclusive research process consisted of written observations, creative artefacts created by the co-researchers, transcriptions of discussions and interviews. These data explored the capacity-building measures, and the process of co-creation of a citizen science project with people with learning disabilities.

Data collected by the co-researchers from vets and vet technicians consisted of survey responses.

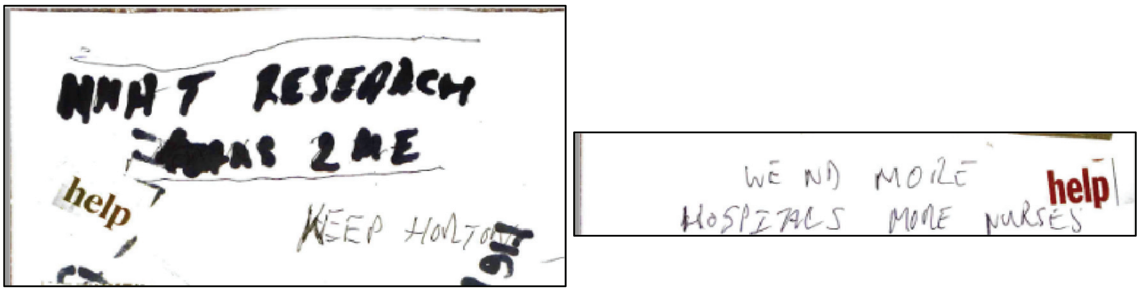
Capacity building

Creative research methods were used to investigate co-researchers' perspectives, and to co-create shared definitions of key terms. Initially, we explored 'what research means to me', using the 'Collage Yourself' method (Sinfield, 2018: 8). Co-researchers focused their collages largely on issues that affected them, highlighting their need for self-advocacy (Figure 2).

The co-researchers also identified a desire to help others outside of their community, and to advocate through them:

> **P1:** So, yeah, we need to go to more hospitals, more learning, because I was in hospital, um, even a couple of girls next to me 'cause they were in the same ward as me, even they said we need more help.

Figure 2. Extracts from two of the collages



The collages emphasised that, while the co-researchers had different motivations when engaging with research, personal relevance was key. The collages also represent how the co-researchers defined research, as identifying problems that need addressing (inquiry), and as raising awareness of the issues (dissemination).

Through the 'identity box' activity (Brown, 2016), co-researchers created their identity as citizens, by adding materials that they saw as relevant to a shoebox. The co-researchers focused on hobbies and things they liked to do. None of the co-researchers put anything about disability into the box.

However, in the ensuing discussions, issues around disability were raised, but not in the context of their identity. In the following extract, a participant describes their identity as the things that they most enjoy, only later bringing up their disability:

> **P6:** I've not got much, umm, I just, the reason why I put these in is because I love the colours of the, of the, of the sort of the tissue paper, and that's what the reason, why I put these in, because I like things that are colourful and things so. Speaking about, you know, you guys were talking about what people have got, well believe it or not I've got, I've, I've was born with a thing called, and this is no joke, I was actually born with a thing called cerebral palsy.

This links to Beart's (2005) concept that 'learning disability' is not seen as a 'salient identity' by the community. Instead, people with learning disabilities opt to identify themselves via different parts of who they are, for example, personal tastes.

Significantly, the co-researchers stated that the creative aspects of the study were some of the most enjoyable:

> **Jessica Carr (JC)** – What, what do you reckon you enjoyed the most, if you had to pick one thing that you enjoyed doing the most?
> **P8** – Uhh, uhh, I think the box. I think it was the, I think it was the box.
> **JC** – What was your favourite, why did you enjoy that?
> **P6** – Because, umm, it meant that I could sort of, uhh, choose quite a lot of different things to put into the identity box of what I used to, of what my favourite things were, sort of thing.

The influence of affective issues in learning has been discussed elsewhere, particularly in relation to collaboration (for example, Jones and Issroff, 2005). The use of creative methods provided the co-researchers with a vehicle to represent their thoughts on research in ways that built on their prior knowledge and experiences, and therefore engagement and enjoyment levels were higher. These methods also allowed for distraction, which prompted fruitful and important conversations about the citizen science project, and about our shared definitions.

By allowing individuals to explore their identity on their terms, and then engaging flexibly with the results of the activity, the types of issues that were of greatest importance to them at the time could be explored through citizen science research.

Through this capacity-building process, the co-researchers also co-created definitions of key terms within the research. This process began by defining a 'citizen'. The co-researchers broke their definition down into three categories (Figure 3).

The first category (Figure 3) documents personality traits that the co-researchers associated with a citizen. These were all positive, for example, someone who 'Helps you, working with each other, confiding' (P1). The second category emphasises the role of caring professionals as citizens, related to the co-researchers' positive experiences with these professionals. The third category represented the importance of self-advocacy (in the context of My Life My Choice) to the co-researchers' definitions and understandings of themselves as citizens: 'well we're a citizen we're sitting here doing this group' (P4). Put simply, the co-researchers conceptualised the idea of a citizen as a positive concept.

Notably, positivity is not always associated with the terms 'science' and 'scientist'. In previous research involving people with learning disabilities, the word 'science' had negative connotations: 'Do

Figure 3. Co-researchers' categorisation of a citizen

Personality traits	Caring professions	Self-advocacy
• Assertive with each other • Allocating • Working with each other • Confiding • Helps you • Looks after you	• Nurse • Doctor • Parent	• Us • This group • Being more assertive

you know what, I actually didn't like science at school, 'cause all we were doing was writing and it was sort of boring' (Carr, 2018: 30). Using terms such as 'research' can help to address negative preconceptions about science.

Through word association, the co-researchers were asked what words or phrases they associated with the term 'citizen scientist'. P1 claimed, 'one of us', which the rest of the group agreed with. This suggests that the co-researchers linked the capacity-building activities to citizen science, and that they identified as citizen scientists.

These summary findings represent some of the benefits of engaging upstream with co-researchers to surface individual experiences, and to establish shared understandings of key terminology. The co-researchers held the capacity to understand and define terms, such as 'citizen' and 'citizen scientist', and to relate them to themselves. Crucially, the capacity-building measures enabled the co-researchers and the lead researcher to build confidence in working collaboratively.

Citizen science project

Having established a shared understanding of key terminology, the co-researchers co-created their citizen science study, sharing responsibility for decision making and the outputs from the project. The research process was explored through ethnographic observation and one-to-one interviews, highlighting challenges to the co-researchers' engagement.

At points the co-researchers were distracted from the study, in the main because of issues in their personal lives which affected their ability to focus: 'The group seemed to have had a particularly difficult month; also affected the topics of discussion for the study' (Researcher fieldnotes).

By allowing space and additional time, and by exploring ways to link daily challenges to the activities, we were able to explore some of these issues through fruitful discussions. For example, in one session, we explored day-to-day life and how our experiences might affect our understanding of the term 'citizen'. In treating these 'distractions' as opportunities to identify social barriers, and by occupying a 'sheltered' space for engagement within and beyond the citizen science project (Holliman et al., 2024), the co-researchers were able to continue with their research.

A further challenge to engaging centred on the various literacies required for this citizen science project. When engaging in a citizen science project, a certain level of scientific or research literacy may be required. We tackled this from the start by introducing the capacity-building phase first, and by including research training in the citizen science project. By surfacing and utilising different skills within the group through cooperative working (Holliman and Scanlon, 2006), co-researchers supported one another to achieve a collective goal. As with any research team, we demonstrated that the whole is greater than the sum of its parts.

Figure 4. The trifold leaflet created by the co-researchers in response to the survey of vets and vet technicians

At what age does a cat or dog get vaccinated?

- Puppies are typically vaccinated at 8 -10 weeks or as early as 4-6 weeks and must have a booster at 6-12 months
- Kittens have 2 sets of vaccinations, one at nine weeks and one at 3 months old and kittens must have a booster every 12 months
- Until your kitten is fully vaccinated and neutered you must keep them indoors

How to deal with cat or dog that has anxiety?

Buy a calming spray and ask about medication from the vets. Find a safe space for them to hide. Give plenty of cuddles and strokes

My Life My Choice

My Life My Choice

Thank you for reading and we hope you found it helpful!

My Life My Choice

How to look after cats and dogs

Banbury My Life My Choice Self-Advocacy Group

Survey findings

The result of this project is not only the inclusive praxis methodology. The citizen science project delivered a trifold leaflet created by the co-researchers in response to the survey of vets and vet technicians. Through this leaflet, the co-researchers disseminated the findings of their research. They collated the answers to the surveys, conducted some additional research to explore the findings, and translated them into an accessible summary for the learning-disabled community (Figure 4).

Discussion

This article highlights the importance of understanding that minoritised communities may not have similar capacity to communities that are routinely invited to engage. Instead, citizen science organisers need to adapt their practice to co-create capacity-building opportunities for these marginalised communities, removing these 'invisible' barriers to participation through forms of collaborative and cooperative working (Dawson, 2019; Holliman et al., 2024). Furthermore, citizen science organisers need to allow time to lay the groundwork, co-creating the conditions for equitable research partnerships, and to ensure that they 'do no (more) harm' (Holliman et al., 2024; Reed et al., 2024). This can be facilitated by expert knowledge brokers (Meyers, 2010), providing opportunities for upstream discussion around capacity needs, and co-creating shared ideals and purposes for the research.

When evaluating the success of this project, interviews were conducted with the co-researchers. During these, the co-researchers identified their enjoyment of the creative activities. The data collected during the study also reflected a higher level of engagement during these activities. The creative methods employed in this research offered flexibility to both the lead researcher and the co-researchers, and they were used to enable engagement for those who may struggle with 'traditional' forms of research. We argue that citizen science organisers should consider the use of more creative activities to create shared spaces for engagement from people who do not easily communicate either verbally or through text.

Flexibility in scheduling is an important consideration to ensure that research can be conducted equitably with minoritised groups. We recognise that research projects are often subject to specific time frames, and that the above considerations take extra time to fulfil. This requires funders to adapt, allowing for more flexible time frames for inclusive approaches and partnership working with minoritised groups. Inclusive research principles (Walmsley and Johnson, 2003) require research to be co-led and co-owned by the learning-disabled community. An inclusive approach to funding calls and decision making, involving the learning-disabled community, and using their lived experiences, would provide potential for citizen science to be inclusive.

In this light, we welcome UK research funders' focus on the importance of actively involving minoritised communities with research (UKRI, 2019), with associated funding schemes foregrounding equitable approaches to citizen science and community-led research (NERC, 2021, 2023), and opportunities to co-create proposals with wider constituencies (NERC, 2023). We argue that for this approach to become more widespread, changes will need to be made to all aspects of the peer-review system for public engagement: planning for, assessment, monitoring and reporting (Holliman, et al., 2018). Practical guidance for citizen science researchers and public engagement professionals on how to support engagement with 'under-recognised communities' will help applicants and staff working for research funders, but this is lacking. For people with learning disabilities, it is completely absent. Opportunities to establish partnerships with communities is to be welcomed; focusing calls on engagement with minoritised groups and equity is another positive dimension. But we still have some way to go. Research funders, peer reviewers and assessment panels should take account of the equitable dimension of the smaller 'reach' of partnerships involving minoritised communities, the long-term nature of establishing partnerships that are not extractive, and the resource-intensive requirement of funding expert knowledge brokers.

Conclusion

This article reimagines citizen science as inclusive praxis. Cooper et al. (2021: 1388) have argued that, 'as the boundaries of inclusive citizen science expand so that no segments of society remain underserved, so too will the face, and the foci, of science'. This article has explored how this can be achieved through the engagement of a small section of the learning-disabled community, with the aim of encouraging citizen science organisers to expand their research to include this 'underserved' community. We argue that the lessons we have been learning together as we have reimagined citizen science as inclusive praxis have applicability with other constituencies, including the wider disabled community. There should be nothing about citizen science without an inclusive approach to citizens (after Charlton, 1998).

By focusing on capacity building and co-creation, the outputs of citizen science can have greater relevance to people living with learning disabilities. This article has focused largely on inclusive praxis (the process), by exploring how creative and inclusive methods can be used to create the conditions for equitable engagement. The discussion and description of the process is reflective and descriptive, in order to offer a route for others to explore.

We have demonstrated that it is possible to create the conditions for citizen science as inclusive praxis, but we argue that this should not be attempted without sensitivity and commitment. We argue that, by accessing each person's abilities, and a combination of collaboration and cooperation, the whole (co-researchers) was greater than the sum of the parts (each co-researcher). The reflexive research process created opportunities for equitable knowledge exchange by putting value on each person's 'expertise'. The data highlight how many of the co-researchers were able to reflect on their experiences and knowledge, and to use them to influence the research. The lived experiences of the co-researchers with learning disabilities were often different to those of the two non-disabled co-researchers, emphasising how this community can bring new dimensions to citizen science through their unique voices.

It seems fitting to end this article with a contribution from our co-researchers. When asked to provide feedback on the project, the co-researchers wrote the following:

> We enjoyed doing this work as a group. It was fun. We liked covering the boxes [identity boxes]. It was nice to keep us busy and keep our minds preoccupied. Doing the project made me feel good, and it was good to get the information out there and people understanding about what we were doing, getting the vets' understanding. The project made us feel happy, and we enjoyed talking to different people that we had not met before.

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My Life My Choice Banbury self-advocacy group were participating investigators on this project. They helped to design the research, collected and analysed data, and participated in discussions regarding the reporting of the research. Following the ethical procedures for informed consent agreed to at the time of the research, we have not named the co-researchers. A representative of the charity the My Life My Choice approved the final draft of this paper on behalf of the participants.

Declarations and conflicts of interest

Research ethics statement

The authors declare that research ethics approval for this article was provided by the Open University's Human Research Ethics Committee (HREC/2958/Carr).

Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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