Voices for Inclusive Activity:
A co-produced Participatory Action Research project exploring more accessible and inclusive ways of evaluating disabled people's participation in sport and physical activity

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“I feel like just shoving everyone in with everyone else with disabilities is like, you're not looking at someone for their individual, who they are, and that's all we want. That's all I feel like you and me, we've ever wanted, someone to just look at us for exactly who we are and appreciate all the things we can do.”

Co-researcher Fiona interviewing
a research participant, 05/04/22
(Included with consent)

Abstract

Disabled people and those with long-term health conditions are less likely than the general population to participate in sport and physical activity. Sport and physical activity have the potential to transform lives, but existing tools used to evaluate disabled people’s participation in such occupations are typically inaccessible and not inclusive of varied ways and means of participation. Consequently, sport and physical activity programmes struggle to demonstrate impact and ensure future sustainability. This can perpetuate inequalities in access to sport and physical activity for disabled people, violating occupational rights and perpetuating occupational injustice. Injustice is also apparent within traditional research and evaluation approaches that produce knowledge ‘about’, rather than in collaboration ‘with’, disabled people. This PhD focuses on the Voices for Inclusive Activity research project, within which an initial seven co-researchers, including five disabled people and one family carer, worked together to explore more accessible and inclusive ways of evaluating disabled people’s participation in sport and physical activity. Co-researchers used principles of co-production to design and implement a research project involving two categories of participants: funders, providers and related organisations with interest in disability sport and physical activity; and users and non-users of disability sport and physical activity. Co-researchers were involved in all aspects of the research process, from designing research questions and participant information, to carrying out data collection and elements of data analysis, determining recommendations, next steps and calling for action. Co-researchers also worked together to develop accessible forms of dissemination, which have included co-produced presentations and discussions with interest holders, audio podcasts and subtitled videocasts. Methodological learnings acknowledge exclusions and opportunities for innovation in an online participatory action research approach, congruence between this approach and occupational therapy theory, practice and occupational justice, and may also offer guidance for the pursuit of participatory forms of evaluation involving disabled people.

Keywords: *disability; sport; physical activity; evaluation; participation; participatory action research; co-production; occupational justice*

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Thank you to supervisors, Dr Anna Pettican, Professor Ewen Speed, Dr Paul Freeman and Professor Valerie Gladwell for your unfailing support, guidance and learning throughout the entirety of this journey. Thank you to Anna, in particular, for going above and beyond to get me through to this point (including motivational voice notes!). Thank you for blazing the trail and your patience as I follow you along the way.

I cannot thank enough the friends and family who have supported me throughout this process. Nick, although I think you'll be glad this part is over, you have continued to be my rock throughout. For Martha who was just a mere dot when this process

began and Bronwyn who has joined us on the way, I hope they know that girls can do anything, even if/when they are fortunate to become mothers. But I cannot fail to acknowledge the privilege of support from my own dear mum, Pauline Howard, who has appeared at the drop of a hat and never fails to put others before herself. Your dogged determination to overcome your own challenges has been beyond inspiring. It is for that reason that this thesis is wholly dedicated to you. As I submit this in the 10th year since he was taken too soon, I hope dad would be proud of what we have both achieved.

Covid-19 impact statement

When the worldwide Covid-19 pandemic was declared in March 2020, I was in the first year, six months into this PhD project. The initial scoping exercise had been completed, and I was in the midst of writing an initial draft of the literature review. While plans were being made for the recruitment of the steering group of co-researchers, no recruitment had yet been undertaken. With social distancing measures in place across the UK, it was not possible to start meeting with potential co-researchers in person. Some of the people I hoped to work with would have been included within the group of people most at risk from complications relating to Covid-19 and had been recommended to remain isolated for a period of 12 weeks. The whole plan required a re-think. As a result, the group of co-researchers was established online, and our project was entirely planned and prepared using monthly online Zoom meetings of two hours each. As will be further explored in *Chapter 5, The Voices for Inclusive Activity project,* methods had to be planned for online data collection. While this project is not the one originally envisaged and with the benefit of hindsight, aspects would have been handled differently, there have also been learnings about conducting research in different ways. These are explored within *Chapter 7: Methodological Learning.*

In parallel, during this unique time, efforts to address inequalities in sport and physical activity were being hampered in many ways as Covid-19 had an unprecedented effect on almost everyone’s way of life. Access to physical activity was even more restricted than usual for disabled people (Activity Alliance, 2021). For those not considered clinically vulnerable and able to leave their home, permitted forms of exercise were a walk, run, cycle from home (the suggestion of wheeling was not offered) (GOV UK, 2020). Access to usual facilities, clubs, groups and team sports, multi-sports, Boccia, swimming and other accessible activities was curtailed. For those unable to leave their home, suggestions were provided from organisations using the platform of Sport England’s campaign focused on remaining active within this space, *Join the Movement* (Sport England, 2020). However, as an online platform, this required access to technology and the internet. As highlighted by the Digital Poverty Alliance, the online world remains particularly inaccessible to disabled people (Allman, 2022).

Even now, almost five years on from this time, figures from Activity Alliance demonstrate how the pandemic has resulted in a perceived legacy of reduced opportunities for disabled people (Activity Alliance, 2024). This is compounded by the cost of living crisis, which has had a significant impact on disabled people and 39% of disabled people have stated how this has reduced their levels of physical activity (Veruete-McKay *et al.*, 2023).

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Thesis structure

This thesis describes a Participatory Action Research (PAR) project undertaken with a steering group of co-researchers who worked together using principles of co-production to explore accessible and inclusive evaluation of disability sport and physical activity participation.

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3. Conceptual Framework
4. Methodology
5. The Voices for Inclusive Activity Research Project
6. Research Findings from Data Collection
7. Methodological Learning
8. Reflection: Discussion and Conclusions

Separated into eight chapters, Chapter 1 introduces the background and policy context to the study, and reports how the issue was first identified. Chapter 2 details the *Literature Review* and scoping exercise, seeking to explore what evidence exists to inform the evaluation of disability sport and physical activity from both published literature and practice. Chapter 3, on the guiding *Conceptual Framework*, sets the scene for the collaborative research process. The nature of PAR is explored within Chapter 4 on *Methodology*, within which details are shared of how the scoping exercise led to the building of networks and establishment of a steering group of co-researchers. The project undertaken by this group, self-titled *Voices for Inclusive Activity,* is outlined within Chapter 5, including the collaborative process of research planning and participatory approaches to data collection and analysis. Our research findings are outlined in Chapter 6, while *Methodological Learning* from our process of working together is contained within Chapter 7. Finally, Chapter 8 explores the outcomes of this research including the forming of recommendations, further action and collaborative dissemination, with an associated discussion. Reflections are included on the implications for accessible and inclusive evaluation, participatory approaches to research and the individuals involved in the project. An accessible summary of this thesis can be found in Appendix 1.

Throughout the thesis, methodological reflections puncture the text, demonstrating the process of reflexivity undertaken during the project. This thesis recounts a PAR project with cycles of planning, action and reflection. The writing of this thesis as a personal account of the process of the research has also included all aspects of Lewin’s Action Research model (Lewin, 1946), including planning (of the projects, of sessions), acting (facilitating discussion groups, preparing resources after discussions, following up on actions), observing (of co-researcher discussion and interaction) and reflecting (in my reflective field diary).

As an Occupational Therapist, I draw on the theoretical underpinnings of my profession throughout, including a person’s human rights to engagement in meaningful occupation, including sport and physical activity. This right to access occupations without barriers is termed occupational justice, a concept drawn from social justice that will be further explored in Chapter 3: *Conceptual Framework*.

Confidentiality and anonymity

Within this thesis, the four co-researchers who remained with the project for the duration are identified by their real names, in line with their wishes. Within participatory research, it is acknowledged that people may wish their experiences and contributions to be acknowledged (Boddy, 2016). As collaborators in the design and delivery of this research, their involvement was not subject to ethical approval and they were provided with the choice on whether they would like to be named within any dissemination work. All chose to be identifiable, enabling due recognition of their contribution to the project. The names of the two co-researchers who left the process after project planning are not named, but their contributions are noted.

The research participants from which we collected data, however, are afforded anonymity in line with the requirements of institutional ethical standards. As such, they are identified by pseudonyms. It is also recognised that there can be limits to anonymity and confidentiality within PAR, particularly when working with high profile individuals or organisations, as is the case within this research (Boddy, 2016). While I have attempted to anonymise these contributions, the limits to this were openly discussed within the relevant interviews.

Language and terminology

The use of I/we personal pronouns

At points within this thesis where I describe the work I've undertaken solely, I will use the personal pronoun 'I'. Elsewhere, when describing collective work undertaken by co-researchers within discussion groups and as part of the Voices for Inclusive Activity project, I will switch to using the plural personal pronoun of 'we'.

Glossary of terms

This thesis includes a variety of terms relating to participatory methodologies, processes and theoretical concepts, which are explained below.

Action research

This is an umbrella term for a set of collaborative approaches to research, where researchers work with local interest holders to create knowledge and action for change (Greenwood and Levin, 2007).

Collaborator

I have deliberately selected to use the terminology of 'collaborator' as opposed to 'gatekeeper' within this project, to accurately reflect the role I believe was adopted within this project by the person who supported recruitment of co-researchers and some participants. The term gatekeeper often has negative associations; a gatekeeper may limit, prevent or block access to a community as much as facilitate it

(Henderson, McLean and Kinnear, 2022). Collaborator is a term more representative of the nature of the supportive and facilitative relationship that the collaborator had with this project, to understand and meet the requirements for recruitment and ensure that the people involved were best supported.

Community-Based Participatory Research (CBPR)

A collaborative research approach facilitating partnership between members of a community, organisations and researchers throughout all aspects of the research process (Partin, 2006).

Co-production

A broad term that primarily describes a way of working in partnership with interest holders to design new or different ways of doing things. It can occur in a variety of contexts, for example designing or improving services, or in the context of co-produced research, creating knowledge that will benefit the interest holders involved (McLean *et al*., 2023).

Co-researcher

Throughout the project and within this thesis, the steering group involved in the planning and conduct of the Voices for Inclusive Activity project are referred to as co-researchers, within which I include myself. This is a term present in existing literature on PAR projects (St. John *et al*., 2019). When we discussed how to describe ourselves within this project, co-researchers felt it emphasised the active, collaborative and cooperative nature of our work together. They are more than ‘participants’, although we use this term for the people who we have engaged within our research project. Where participatory research is conducted within health and social care settings, co-researchers are sometimes described as being ‘patients’ or ‘service users’, but this would not be appropriate in this case as neither of these descriptors is accurate and there is no need to medicalise their experience within this project. The use of the term co-researchers has been critiqued by Watson (2020) as undermining the role of disabled people within the process of participatory research, but this is where co-researchers were separate to researchers. In this study, we are all co-researchers (Watson, 2020).

d/Deaf

This format is used when referring to people with hearing loss. People within the Deaf community (capital D) may see themselves as culturally deaf rather than disabled. People who are deaf (lower case d) identify with the medical categorisation of hearing loss, but do not consider themselves part of the Deaf community, and may not use BSL as their first language, if at all (Shakespeare, 2018).

Disabled people/person

Throughout this thesis I use the terminology ‘disabled people/person’ rather than ‘people/person with a disability’. Although opinions differ, even among co-researchers within this project (as discussed in section 5.2), I made a conscious decision for thesis authorship to use the recognised preferred term in the UK, emphasising through a Social Model lens that a person is disabled by society (Shakespeare, 2018).

Emancipatory research

An alternative, critical approach to undertaking disability research that demands “transformation of the material and social relations of research production,” where disabled people control all aspects of research about disability, including the process, funding and overarching research agenda (Barnes, 2002).

Interest holders

This term has been used in a broad sense to include anyone with a vested interest in this project, including partners, organisations and policy makers. It is an alternative to the term ‘stakeholder’, which has been subject to critique for its potential to perpetuate inequalities (Reed *et al.*, 2024). I also avoided the term ‘stakeholders’ to describe the disabled people involved in driving and enacting this PAR project, as it would fail to emphasise the active involvement of disabled people (Williams *et al.*, 2021b). They are described as co-researchers instead.

Learning disability/disabilities

The terms intellectual disability/disabilities are often used internationally, whereas I will retain reference to learning disabilities for consistency with preferred terminology in the UK (Shakespeare, 2018).

Occupational justice

A concept that is related to social justice, but is particularly concerned with fair and equitable access to engagement in meaningful occupations, with recognition of the impact of this engagement on health (Durocher, Gibson and Rappolt, 2014).

Participatory Action Research

A political, democratic and emancipatory form of action research viewed as a form of social action, where those most affected by an issue are the ones to investigate and use their findings to create change (Grimwood, 2016).

Patient and public involvement (PPI)

Situated primarily within health research, this describes the involvement of members of the public, services users or patients within the research process. While there is guidance for researchers and clinicians wanting to undertake research ‘with’ rather than ‘on’ or ‘to’ people, there is not a set approach or level of involvement required (NIHR, 2021).

Knowledge transfer/translation

An approach to ensuring the findings from research are used in practice. As noted by Wimpenny (2013), it is: “A collaborative means of making the best use of knowledge resulting from theory, policy and research evidence to ensure delivery of best practice to clients and carers to improve health outcomes” (Wimpenny, 2013, p. 3).

Transformative paradigm

A philosophical worldview that provides a framework for addressing issues of societal inequality and injustice by requiring that power and privilege is problematised at each stage of the research process, and the recognition that realities are shaped by social, political, cultural, economic and racial/ethnic values (Mertens, 2007).

Chapter 1 Introduction and Context

1.1 Topic introduction

Disabled people and those with long-term health conditions are reportedly twice as likely to be described as physically inactive (40.8%) than the general population (20.7%) (Activity Alliance, 2024; Sport England, 2024), despite having rights to full and active lives, with participation in a wide range of occupations (United Nations, 2007; World Federation of Occupational Therapists, 2019). Figures also show disparity between the number of disabled people who would like to participate in sport and physical activity on a regular basis and the number who actually do so (Activity Alliance, 2024). With disabled people less likely to access the wealth of health and wellbeing benefits that come from being physically active, this has particular consequences in terms of health and wellbeing (Smith *et al.*, 2018). Within the discipline of occupational science, the barriers that deny a person's right to meaningful and health-giving occupation are termed occupational injustice, a concept that will be further explored within section 3.6.

However, the aforementioned figures are unlikely a true representation of the picture of activity and inactivity in disabled people. These statistics are taken from the most recent report on Sport England's annual *Active Lives Survey* (Sport England, 2024), the methodological approach of which involves distribution of an invitation letter to a randomly selected sample of households in England. People are required to self-selectively participate by entering a password online, with an option of a paper questionnaire. The mechanisms of this survey are problematic and have potential to exclude many disabled people, including people with cognitive impairment or learning disabilities, living at home or in supported living settings, who may not be able to understand the request or respond to the invitation or the standard questioning contained with the survey, with or without the support of others. Disabled people are also more likely to be digitally excluded (Allman, 2022). Additionally, the Active Lives Survey is used to judge whether a person is active against World Health Organisation guidelines, adopted within the UK Chief Medical Officers' Physical Activity Guidelines (Smith *et al.*, 2018; Davies *et al.*, 2019; Bull *et al.*, 2020).

Being active is described as completing 150 minutes of activity per week of moderate intensity, of a minimum 10 minutes per episode, with additional recommendations for strength-based training (Figure 1.1) (Smith *et al.*, 2019). As will be problematised within this thesis, these guidelines are not achievable or accessible for many disabled people, or reflective of different ways and means of being active.

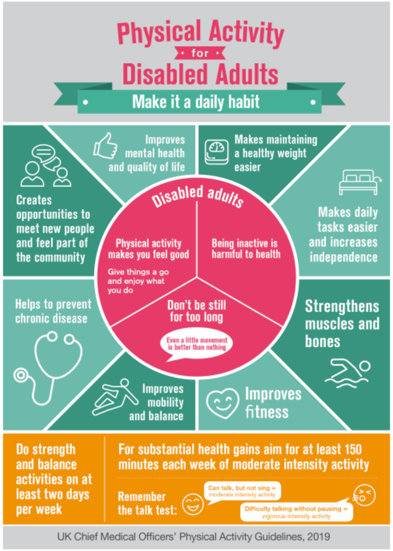


Figure 1.1: UK Chief Medical Officers' Physical Activity Guidelines for disabled adults (Smith et al., 2019)

Disability sport and physical activity providers also face issues with completing project-level evaluations of disabled people’s participation. Current approaches to evaluating physical activity in disabled people focus on recording of performance aspects through use of objective devices such as accelerometers, which are not widely available or applicable to community participation, or self-report tools including the *International Physical Activity Questionnaire (IPAQ)* (Appendix 2.1) (Heath and Levine, 2022), among others, that are inappropriate or inaccessible to many users. The IPAQ includes questioning that may be considered ableist, such as asking how far people walk, how often they ride a bike or dance, which are activities that may not be accessible to all in their traditional form. Again, these tools judge activity levels against published guidelines.

It is asserted that, without consistent impact evaluation data, it is unknown how disabled people’s participation changes over time, how it is affected by involvement with different organisations or participation in particular interventions, and we cannot know what action is required to improve the conditions of participation to enable more disabled people to realise the wider benefits of regular physical activity (Martin Ginis *et al.*, 2021). This situation perpetuates inequalities in sport and physical activity participation among marginalised groups, particularly because the collection of valid participation data is often used for new and ongoing funding decisions and is central to appraising whether public money has been spent appropriately (Mansfield, 2016). This, therefore, creates problems with issues of sustainability for projects supporting disabled people to be more active. Ineffective evaluation of disabled people’s participation in sport and physical activity therefore creates barriers to participation, with potential to result in occupational injustice.

However, the relevance, usefulness and possibility of collecting consistent and comparative data across the spectrum of disabled people's experiences is also problematised within this thesis, as it is reflective of wider issues. Most vitally, as a consequence of non-inclusive collection methods and resulting gaps in data, individual experiences cannot be explored, meaning disabled people do not have a voice. Whilst acknowledging that sport and physical activity have the potential to further marginalise certain groups and reinforce stereotypes, what will be explored in this thesis is how it can also be a site for resistance and change (Mackintosh and Medcalf, 2019). This project, which is focused on establishing more accessible and inclusive methods of evaluating participation, aims to address these inequalities. It will do this by embracing throughout the principle of 'Nothing about us without us', including disabled people in a process of Participatory Action Research (PAR) (Charlton, 1998).

1.2 Background

1.2.1 Inclusive sport and physical activity: policy context

Public Health England's *Everybody Active, Every Day* report highlighted the public health cost of inactivity, with particular reference to disabled people (Public Heath England, 2014). Published the following year, the UK Government's (2015) strategy document, *Sporting Future* announced a change in direction for the funding of sport and physical activity within the United Kingdom (Department for Culture Media and Sport and UK Government, 2015). Judgement of success was to move beyond participation numbers, to consider five key outcomes: physical wellbeing, mental wellbeing, individual development, social and community development and economic development, in recognition of the wider benefits of being physically active, and *Sporting Future* identified that a new system of evaluation would be required to assess against these outcomes. To support organisations conducting project-level evaluations, Sport England, the UK Government's arms-length body with responsibility for sport and physical activity in England, provided the *Evaluation Framework* that included a standard *Question Bank*, containing tools including the *Short Active Lives Survey* (Appendix 2.2), *International Physical Activity Questionnaire (IPAQ)* (Appendix 2.1) and *Single Item Measure* (SIM) (Appendix 2.3) (Milton *et al.*, 2017; Sport England, 2019). The framework was designed to help organisations clearly define objectives, measure outcomes effectively, and link these outcomes to broader strategic goals. With funding tied to and, indeed, prioritised for those who can demonstrate these outcomes, organisations were guided towards this system of measurement to secure their ongoing sustainability.

Published in 2016, the Sport England strategy *Towards An Active Nation* (Sport England, 2016) set out how the organisation would prioritise its work towards the achievement of the five outcomes for a wider range of activities and a more diverse selection of the population. Funding was specifically directed to groups less likely to participate in sport (from grassroots upwards), including disabled people. The commitment to tackling inequalities in sport and physical activity and reaching new participants was further strengthened with the publication of Sport England's updated strategy document in 2021, *Uniting the Movement: A 10-year vision to transform lives and communities through sport and physical activity* (Sport England, 2021). Since the publication of this strategy, Sport England has retired use of the aforementioned *Evaluation Framework* and *Question Bank* and has proposed a new approach to evaluation and insight that prioritises learning and collaboration (Sport England, 2022). This PhD began in 2019 to consider more accessible and inclusive approaches to evaluation of disability sport and physical activity. While this development from Sport England is a positive move, the effects of this approach remain to be seen in its implementation at community level and the participation of disabled people in sport and physical activity. The *Active Lives Survey* also continues to exclude the perspectives of disabled people. The issue of accessible and inclusive evaluation remains prescient.

1.2.2 Problem identification

There is no consistent approach to collecting information in an accessible way from all disabled people about the sport and physical activity they are undertaking, including what they are doing, how often, the level of intensity and how long they are taking part (Martin Ginis *et al.*, 2021), but additionally, why they do it and what they get out of participating. This is problematic for disability sport and physical activity providers who want to be able to demonstrate the value of their activity for disabled people.

This issue was identified in 2018 by Boccia England, the national governing body for Boccia in England, when they commissioned a report to identify a suitable outcome measure to support them to evaluate participation in Boccia against the aforementioned five key physical activity outcomes identified by the UK Government (Department for Culture Media and Sport and UK Government, 2015; Pettican, 2018b). Boccia is specifically designed as an inclusive and accessible sport open to people of all abilities and levels of mobility. All players compete from a seated position, whether wheelchair or chair, equipment such as ball ramps can be used, it can be played in a range of formats outside of official competitions, and the rules of play are intended to be easy to understand (Pettican and Barrett, 2017). Within the Boccia England report, it was identified that the measures recommended at that time to evaluate participation, within Sport England's *Evaluation Framework* (Sport England, 2019), were not specific enough to participation in Boccia. The recommended tools focused on activities such as walking and cycling, failing to recognise different ways and means of participating, and the lack of accessibility in format and design prevented some from completing the survey (Pettican, 2019).

While Sport England is moving away from its *Evaluation Framework* towards a new approach to evaluation, the issues identified within Boccia England's report provided the original impetus for this project. However, Boccia England are not alone in identifying measurement of physical activity with a disabled population as an issue; it has also been highlighted as a research priority in regards to the physical activity of people with multiple sclerosis (Motl *et al.*, 2015). The position previously adopted by Sport England was, and still is, indicative of prevailing social mores regarding the inclusion of disabled people in sport and physical activity and wider society. More recent examples, from literature and practice, are explored within Chapter 2: *Literature Review.*

1.3 Summary

This chapter has introduced the background and context for this PhD study exploring more accessible and inclusive ways of evaluating disabled people's participation in sport and physical activity. As has been explored, current approaches are not demonstrating a true picture of disabled people’s levels of activity and inactivity, which has implications for the availability, breadth and appropriateness of future opportunities for participation. This barrier to participation has potential to result in occupational injustice. The chapter has introduced the policy context that underlies this issue and the resulting project justification, but further exploration is now required of current practice and existing evidence. In the next chapter the context will be further explored through a review of supporting literature, presented alongside initial thoughts of interest holders on this issue, gathered through a participatory scoping exercise.

Chapter 2 Literature Review

2.1 Introduction

This chapter establishes the context for this study through published literature, which has been identified and appraised on an ongoing basis since the project started in 2019. This body of literature and the themes within are explored alongside the scoping exercise that was undertaken between October 2019 and February 2020, utilising a participatory approach to engage with key interest holders to improve understanding of the issues with evaluating disability sport and physical activity. This gathering of information occurred concurrently with initial efforts to gather and appraise published evidence for the literature review, and references practical and experiential perspectives on the evaluation of disabled people's participation in sport and physical activity. Presenting this information here, alongside published literature, is a deliberate tactic to avoid privileging certain types of information over the experiences of disabled people and those working with the everyday reality of supporting their participation in sport and physical activity.

2.2 The pursuit of epistemic justice

Within Participatory Action Research (PAR), lived experience and knowledge are valued and central to the co-creation of useful knowledge (Kramer-Roy, 2015). For this study, this ethos was applied from the earliest stages of scoping and information gathering, with value placed on different sources of knowledge from beyond academia and institutions, to integrate the insight of disabled people and those supporting their participation in sport and physical activity. It is not appropriate to suggest that peer reviewed literature be ignored altogether, as it is not the case that everything is produced from the perspective of an academic conversation among academics, nor without involvement of disabled people. There is not a binary distinction between academic sources of knowledge and practice-based knowledge as there are exemplars of research involving disabled people. However, it is important to acknowledge that there continues to be variation in levels of disabled people's involvement in research, across the levels described within Arnstein's ladder of involvement (Arnstein, 1969). Arnstein's (1969) ladder depicts non-participatory levels at its base (i.e. manipulation, therapy), with tokenism (i.e. informing, consultation, placation) on the middle levels, with research practices that enable citizen power at the ladder's pinnacle (i.e. partnership, delegated power, citizen control). A critical approach is therefore required to how knowledge is produced, who produces it and how this influences the framing of research problems. The power inequalities generated and maintained by traditional research approaches with non-participatory or tokenistic involvement do produce hierarchies of knowledge and oppression can be reproduced – history can be repeated (Egid *et al.*, 2021; Fernandez *et al.*, 2021).

While recognising there is not a binary between knowledge sources, the approach within this literature review chapter to bring together published literature and experiential knowledge draws some inspiration from the knowledge mobilisation approaches. Discussed by Langley, Wolstenholme and Cooke (2018), such approaches prioritise knowledge co-creation for addressing difficult issues in health and social care, bringing together and 'mobilising' different forms of stakeholder/interest holder and research knowledge into actionable and tangible products, tools and objects, to address the gap between research and practice (Langley, Wolstenholme and Cooke, 2018). This approach intends to place value on tacit knowledge, lived experience and 'know how', with awareness that those holding tacit knowledge, experience or 'know how' can often unknowingly keep it hidden, unaware of its value (Langley, Wolstenholme and Cooke, 2018).

Also important to draw from are current discourses on decolonializing knowledge production. Recognition and action is required regarding the effects of colonialism on research and how power has been used to create hierarchies of knowledge and difference, where alternative ways of knowing have been marginalised and deemed illegitimate and invalid by dominant Western knowledge systems (Udah, 2024). The researcher has a responsibility to create a space for change to happen through active solidarity and 'defiance' with marginalised groups, where they are recognised as experts in their own experience and can contribute actively to knowledge and theory generation (Udah, 2024). As noted by Udah (2024), this pursuit of epistemic justice is not only relevant to research with indigenous populations, but also offers learning on centring the experiences and perspectives of all other marginalised groups, who have been dehumanised by systems of knowledge production that have devalued and delegitimised their forms of thinking and being in the world (Udah, 2024).

2.3 Scoping exercise

A scoping exercise was undertaken between October 2019 and February 2020, utilising a participatory approach to engage with key interest holders to improve understanding of the issues with evaluating disability sport and physical activity.

The scoping exercise involved a series of discussions held with five local and national sports bodies, six disability sports projects, four national charities operating sports programmes and representatives from two evaluation companies that had evaluated two of the charity sports programmes. In most cases, these discussions were held in person, by travelling to either the organisation’s offices or the location where sport and physical activity was taking place. It was felt important to join people and organisations in their own spaces, as part of developing a participatory approach, to learn about the people, environments and activities that make up the research context. The locations of sport and physical activity were mostly based within the East of England and gave me the opportunity to experience and participate with disabled people in inclusive sport and physical activity sessions, including Boccia, tennis, wheelchair basketball and riding a doughnut ring down a ski slope.

One aim of the scoping activity was to begin to build relationships with potential interest holders; as part of the participatory approach, the process developed from contact with one initial interest holder, who brokered introductions, from which further suggestions followed. The intention was not to collect research data, but to begin building an impression of the system surrounding disability sport and physical activity, and how it is evaluated. As such, these were informal visits and discussions, with no set research process or requirement for ethical approval. However, I still ensured that representatives were aware that this information would be used to determine what tools and evaluation approaches were currently being used and I have anonymised their contributions. Discussions were predominantly unstructured; the only consistent questions were to ask how participation was being evaluated, whether any tools were being used and any issues that were being experienced.

2.3.1 Issues with evaluation of disability sport and physical activity

All respondents recognised the difficulty with evaluating participation in an inclusive and accessible way and had responded to this challenge in different ways. Keeping in mind the limitations of speaking with a small selection of people and organisations, four key issues identified from scoping exercise discussions, will be discussed in turn:

- Purpose of evaluating activities and interventions
- Difficulties in using validated tools: content relevance and design
- Delivery of evaluation
- Complex and cognitive impairment.

Purpose of evaluating activities and interventions

A discussion between an activity leader and a participant/volunteer during this exercise highlighted how they felt that evaluation is often completed not for the benefit of the person themselves, but for the organisation or, more often, to satisfy funding investors. Evaluation was mostly required to evidence the effective use of allocated grants, often in the hope of securing further funds, either for project sustainability or further innovations. Organisations also wanted to know, for their own operations, what was working and what did not. Some projects have developed ways for participants to map their own progress, but it was recognised that this is not always included within evaluation.

Difficulties in using validated tools: content relevance and design

A number of representatives from disability charities shared the view that, regardless of whether a tool is validated, if it is not appropriate for the audience, then responses are meaningless. Whether the tool is inaccessible in its current form or adapted in a way that affects its validity, the possibilities of data aggregation and comparison are limited.

There were two particular issues raised: firstly, the questions being asked and the relevance of the subject and, secondly, the way the questions were being asked. Some questionnaires include terminology or concepts that need a lot of explanation. Additionally, survey techniques, such as alternating between positive and negative statements that are designed to prevent people rushing through and marking the same option, may be overly challenging for some people with learning disabilities or cognitive impairment.

Some organisations had trialled different evaluation tools without success, citing issues with accessibility but also lack of direct relevance to their specific sport or physical activity, with particular difficulties mapping a relationship between the outcomes measured and the outcomes from their intervention. Many organisations reported difficulties with the requirement to use standardised tools. One disability sport and physical activity provider described difficulties in using one particular tool, the EQ-5D, to evaluate their practice (EuroQol Research Foundation, 2009). This tool requires participants to use visual rating scales, which have previously been noted to be difficult to interpret by people with moderate to complex learning disabilities, due to the abstract nature of rating one's health on a numerical scale (Hartley and Maclean, 2006). The questionnaire requests participants to self-report ability using five rating levels across five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, with no specific mention of sport or physical activity. It is very difficult to see how this could be used to evaluate participation or to correlate any outcomes with a particular activity.

A funding organisation gave examples of where they had worked with organisations to adapt standardised tools, as they were not accessible to participants in their existing form. In one example, an existing survey tool was redesigned to ensure accessibility for Deaf British Sign Language users, for whom spoken or written English may be their second or third language. Additional issues related to the capacity of evaluators to collect data; while it was felt face-to-face evaluation would be most effective for engaging with this audience, due to the resource intensive nature of this approach, the survey was instead adapted for self-report, including visual elements to support accessibility. A second organisation had adapted the topic of questions being asked within a standardised questionnaire, for example, stating that a 'continuous walk' can be done using mobility aids, including a walking stick, wheelchair or walker, whereas a cycle ride may be completed using a hand-bike or other adapted vehicle. Another organisation had adapted the way information is displayed and how questions are asked. More fundamental changes in design included simplified language, the use of symbols, large text and strategic highlighting, large ticks and crosses and number scales to circle, adapted for those with altered cognitive function or ability to write. These changes could potentially make this questionnaire more accessible to others beside the intended audience. Again, addressing issues with the format of questionnaires, other organisations had opted to provide evidence through alternative methods such as case studies. While the rationale had been accepted by funders, this still creates the issue of lack of comparable data for later funding applications, where funding bodies make decisions based on existing data with the intention of deciding ‘fairly’ on distribution of further funding.

Although adaptation of a standardised tool in this way would affect the ability to provide valid data, it was determined to be a more fruitful approach than having no data at all. This points to tensions evident in current practice between accessibility and perceived rigour within data collection.

Delivery of evaluation

The person required to deliver the evaluation may be a third party delivering an activity, who may not have the time, skills or incentive to complete an evaluation. Those expected to administer evaluation might be volunteers or paid for the delivery of the activity but not for its evaluation. Any time or effort spent on evaluation has the potential to detract from activity delivery.

In some cases, there was a reported reluctance around the asking of certain questions (e.g. socioeconomic status, mental health, anxiety and social isolation), and how these weren’t considered in line with the best interests of participants.

Related to this was the concept of safeguarding: whether organisations are able to provide further support if issues are raised in relation to a difficult question being asked. Staff completing the evaluation with the person might not be trained to deal with the fallout from asking such questions. One representative from a disability charity shared concerns that asking questions about loneliness, in particular, could be triggering without providing follow-up support, with a negative impact on mental health. The need for trust between the person delivering and completing evaluation was mentioned; especially when working with people with learning disabilities or mental health issues, who may be reluctant to answer certain questions.

One Disabled People's User Led Organisation (DPULO) described the process of engaging with an evaluation company to develop an accessible appraisal of a project to increase disabled people's participation in sport and physical activity. The evaluation approach was co-produced with disabled people and designed to be inclusive and not impairment specific. While this is a more inclusive approach, it is also recognised as resource intense in the time and money required to involve evaluation professionals and also, while the resulting evaluation tool was accessible and enabled local sports coordinators to get to know participants, it was lengthy and not quick to administer.

Complex and cognitive impairment

A consistent issue was methods for evaluating outcomes for people with the most complex impairments, and those with cognitive impairment. People with limited recall, for example, may be unable to report back on previous participation, or find it difficult to rate themselves on a scale, as this requires abstract rather than concrete thought. One anecdotal example cited a physical activity project with care home residents, where validated tools could not be used with those with impaired cognition, and a range of simpler voting methods, such as raising hands, had to be adapted for use. Some people may also be vulnerable to coercion and the phrasing of a question may lead towards a specific response. In some cases, proxy report was permitted, although there were examples given where the responses were seemingly shaped by the carer rather than the participant's experience.

An organisation supporting people with complex disabilities described an observational tool they had developed, in the absence of any tool to support self-report of physical activity experiences for people with severe impairment. The tool required an observer to comment on three aspects: social interaction with other participants and the activity instructor, the development of new skills, and observed changes in behaviour, for example communication, expression or confidence. One of the key issues highlighted was the impractical amount of time required to complete this evaluation each week, for just three people observed. There is also difficulty regarding who completes the questionnaire: if the observation is intended to be undertaken by someone expected to know the person, perhaps a support worker. However, there is difficulty noted in inter-rater reliability with different staff attending each week and high staff turnover in the social care sector: the person may not know the person or their baseline. Observer perception may vary greatly from participant experience, and it doesn't enable a person to share their own perspective.

2.4 Literature review

2.4.1 Literature review design

This literature review was undertaken using a scoping study design, enabling an exploration of the boundaries of the topic and the range of literature available (Booth *et al.*, 2022). It bears some relation to the design of a scoping review. These are often used as a preliminary to a systematic review but can also stand alone as a quick, efficient means of surveying a large volume of existing evidence for identifying broad themes and patterns, potential gaps and for developing research questions and proposals (Rumrill, Fitzgerald and Merchant, 2010). Elements of a scoping review approach are appropriate for this topic, as it is complex and not easily defined within a single question with set parameters; initial searches revealed that a range of approaches and types of sources would need to be considered. It is particularly appropriate for mapping a field of literature that is potentially broad, complex and has not necessarily been reviewed in this way before (Arksey and O'Malley, 2005).

While not as methodologically rigorous as a systematic review of the literature, a scoping review can still be described as 'systematic' when conducted through a rigorous and transparent process such as the one recommended by Arksey and O'Malley (2005), which involves first defining the research question, searching for relevant literature, developing inclusion and exclusion criteria to select sources, charting the data and then collating, summarising and reporting the results (Arksey and O'Malley, 2005). A scoping review can be policy focused and combine research and non-research data, so this type of literature review can sit well alongside the existing scoping exercise (Rumrill, Fitzgerald and Merchant, 2010).

However, a scoping review is a specific method usually used as an initial survey of the literature and does not venture to discuss the quality of evidence presented (Arksey and O'Malley, 2005). Therefore, while the literature review presented here adheres to the aforementioned process steps, it goes one step further in appraising the quality of the evidence. The process followed will now be documented.

2.4.2 Literature review search strategy

An initial literature search was first conducted on various occasions between October 2019 and July 2020 and repeated at regular intervals until December 2024, to capture any new literature. The aim of the literature review was to retrieve journal articles related to the evaluation of disabled people's participation in sport and physical activity. The literature review question was refined over this time from an issue focused on tools for evaluation to an eventual definition that considers evaluation more broadly:

What evidence is there to inform the evaluation of disabled people's participation in sport and physical activity?

Both the PICO and SPICE framework were trialled to establish search terms (see Figures 2.1 and 2.2) (Booth *et al.*, 2022). Search terms were refined as searches progressed, more relevant articles were identified and deeper reading uncovered alternative descriptors (See *Literature search strategy* in Appendix 3.1). When used separately, the PICO and SPICE tools failed to capture all elements needed to establish terms relevant for this issue. For example, PICO includes reference to the outcome of participation from disabled people’s engagement with sport and physical activity, whereas SPICE included the reference to evaluation.

P	Disabled people
I	Sport and physical activity
C	(no comparison)
O	Participation

Figure 2.1: The PICO framework used to establish literature search terms

S	Worldwide
P	Disabled people
I	Sport and physical activity
C	(no comparison)
E	Outcome measures/evaluation

Figure 2.2: The SPICE framework used to establish literature search terms

Across both tools, the population is defined as “disabled people”, with the key words of disabled/disability and impairment truncated to capture alternative terms. As outlined in the *Glossary of terms* (page 25) I am using this descriptor throughout the thesis. The appropriateness of a ‘catch-all’ term and the challenges of representation across all potential impairments and disabilities will be discussed in the section on terminology in Chapter 3: *Conceptual Framework*.

The concepts of “physical activity” and “sport” were included as the intervention; the former to capture activities that do not meet definitions of the latter. The term “exercise” was trialled but removed, as the search was skewed by papers focused on physical therapy or ‘prescribed’ exercise interventions. Within both frameworks, the Comparison element was not relevant. Although the Outcome is not included within the SPICE framework, the term “participation” was initially added to the question after initial searches revealed the prevalence of this term within relevant search results, helping to retrieve measures of participation rather than other outcomes. Again, the term participation will be further defined within the terminology section in Chapter 3: *Conceptual Framework*. However, while it is a useful concept for narrowing search results, it was found superfluous within the search strategy to find tools specifically relating to sport and physical activity participation.

Adding the E of ‘Evaluation’ was also essential to narrow the search to papers mentioning approaches to evaluation, including an outcome, survey, tool or questionnaire. Although I am concerned that considering evaluation only in terms of tools, measures and questionnaires may be limiting, for the purposes of this search it enabled me to capture existing examples of evaluation in practice, because current practice of evaluation is predominantly through measurement tools and questionnaires. In refining the search, the word “scale” was removed in relation to evaluation and outcome methods, due to too many results that were not participation specific.

A final search was conducted in December 2024 to ensure capture of all relevant articles using the following query, linking terms using Boolean operators:

> **[Disab*] AND [Sport OR “Physical activity”] AND [Evaluation OR Outcome OR survey OR tool OR questionnaire OR instrument OR measure OR assessment]**

The above search string was adapted for use within EBSCOhost to search the databases MEDLINE Ultimate, CINAHL Ultimate, eBook Collection, APA PsychARTICLES, APA PsycINFO and SPORTDiscuss; Web of Science, Wiley Online Library, SAGE Journals, Taylor and Francis, JStor and OT Seeker were searched independently.

Previous searches had included ‘inclus*’ in relation to the population but yielded too many results in relation to inclusion criteria. Initially I placed disab* to appear in the title to ensure articles were disability specific but repeated searches revealed the need for all key terms to be mentioned in the title of the article for the result to be of significance i.e., relevant to disabled population, sport and physical activity participation and evaluation or outcome measurement; many unhelpful results were otherwise included. Where possible, the limiters of English language, publication within the last 10 years and peer review were applied.

The search on EBSCOhost yielded 185 results, reduced to 99 with duplicates removed and application of the *Inclusion and exclusion criteria* listed in Appendix 3.2. Titles and abstracts were screened for relevance, to ensure the article mentioned or was concerned with the use of a physical activity tool, scale or questionnaire with disabled people or people with a long-term condition. Articles removed included those concerned with competitive or para sport participation, disability classification in sport, assessment scales that were not related to physical activity, assessments of participation that were not physical activity specific. This resulted in 33 full text articles to review.

The same search, limiters and procedure was applied to Web of Science, resulting in 101 documents, narrowed to 42 after title and abstract review. Wiley Online Library resulted in 57 results, narrowed to 17 after title and abstract review. A Sage Journals search revealed 24 results, but none were directly relevant to the literature search question. From the Taylor and Francis database, 77 results were retrieved, narrowed to 11 after abstract review. Searches of JStor and OT Seeker yielded no results. After search results from all databases were collated with duplicates removed, 72 articles remained. Web of Science and Scopus were also searched using this strategy but additionally employed for citation snowballing and tracking. Hand searching was undertaken by using reference lists of key articles and relevant authors.

An additional 92 results were identified through snowballing and other sources. With duplicates removed, 121 articles remained for full text review. Additional literature identified during the process of the search, including policy and strategy documents, have been included within the background and concept definition sections, in order to discuss and appraise the context for this study. Full text review of the identified 121 articles was undertaken, using the *Literature review inclusion and exclusion criteria* outlined in Appendix 3.2. Articles were included if they sought to answer the literature review question by adding to the evidence of how disability sport and physical activity is evaluated.

Articles about tools, devices or other methods for measuring sport and physical activity in disabled people and/or people with long-term conditions were included, along with those about the evaluation of disability sport and physical activity programmes or schemes, whereas time limited interventions that were clinic-based or in the context of treatment for or recovery from a specific health condition were not. Articles where the term disability is used in reference to specific health conditions (e.g. back pain, femoral fracture) or an older adult population were also excluded, along with any article focused purely on the evaluation of physical fitness. The article had to concern disabled people and those with long-term conditions, as opposed to short-term conditions or recovery from treatment. However, the focus had to be recreational activity, so articles concerned with para or competitive athletes and their participation were removed. Programmes that were evaluated using purely academic methods that wouldn't be generally applicable in practical, real world settings, such as Randomised Control Trials, were excluded. Tools concerned with measuring barriers or facilitators to participation (e.g. parental support) or measuring the behaviour of support professionals in physical activity support, or parental orientation to sport and physical activity were removed from the list, as were any articles concerned with access to facilities. Articles from participants of all ages were included, so as not to exclude any learning from relevant articles involving disabled children. Articles had to be written in the English language to enable the full text review. Studies concerned with the validation of measurement tools into different languages were also excluded, as their focus was on the impact of the translation rather than other aspects of the tool's use. The initial search was for peer reviewed journal articles, but some conference presentation abstracts appeared within search results after being published in special editions. These were excluded, as were any copies of tools not situated within explanatory literature. Tools specific to measuring motivation for participation, or articles about evaluating participation in general, rather than specifically in sport and/or physical activity were excluded, along with articles about measuring or assessing participation of non-disabled people. Also excluded were articles that were focused on experiences of participation that were not primarily concerned with how this was evaluated.

2.4.3 Literature review results

A total of 45 articles remained for inclusion within this literature review after full text review, details of which can be in Appendix 3.3 *Literature review search results*. An approach was taken to consider different conceptualisations of evaluation within disability sport and physical activity and the range of approaches that might be taken. Articles were divided into broad categories in terms of their relationship to evaluation, including population level measurement of physical activity, and individual monitoring using subjective self-reporting tools or objective device-based measurement. Approaches to programme evaluations were also included, which tend to take a mixed methods or predominantly qualitative approach.

Enabling comparisons with how data is collected by organisations such as Sport England in the UK, five articles concerned population-level measurement of physical activity in disabled people; these concerned respectively, disabled adults in Australia (Hassett *et al*., 2021), adults with physical or sensory impairments in the Netherlands (de Hollander and Proper, 2018), and children and adolescents with disabilities in France (Aubert *et al*., 2023), while another offered comparisons across 15 European countries regarding the activity levels of adolescents with long-term illnesses or disabilities (Ng *et al*., 2017). A final article in this category involved a systematic review of physical activity levels and how they were measured in adults with learning disabilities (Dairo *et al*., 2016).

Seven articles concerned the use of different devices for evaluation, five of which concerned their usage in adults with learning disabilities. Devices included ActiHeart (Moss and Czyz, 2018), ActivPAL (Lynch *et al.*, 2025), accelerometers (Dairo, Collett and Dawes, 2017), and accelerometers and pedometers (Ptomey *et al*., 2017) and Activ8 (Lankhorst *et al*., 2019), the latter being trialled with young people who are ambulatory and have motor disability. A scoping review concerned a range of device-based instruments for ambulatory adults with physical disabilities and/or chronic diseases: (Brandenbarg *et al.*, 2023) and a systematic review related to accelerometer usage (Leung, Siebert and Yun, 2017).

Nine articles concern evaluations of different disability sport and physical activity programmes and activities, concerning a range of audiences: people with dementia (Ovenden, Dening and Beer, 2019), disabled children and young people (Willis *et al.*, 2018), children with learning disabilities (Pochstein, 2022), children who use wheelchairs (Carter *et al*., 2014), adults with visual impairment (Strongman *et al*., 2023), physically disabled adults (Schmid, Short and Nigg, 2019; Matthews, Seaman and Bremer, 2023; Berthiaume *et al.*, 2024), and people with learning disabilities (Dixon-Ibarra *et al.*, 2018). Programme evaluations were primarily included within this review with the intention of offering an alternative perspective to the use of evaluation tools and questionnaires and for the potential to consider alternative methodologies and approaches to evaluation. As the focus of this literature review is to explore evidence relating to evaluation, commentary focuses predominantly on the mechanisms employed for evaluation and application of these, rather than attention to the outcomes of intervention or specific results discussed, unless this is relevant to process.

One article looked broadly at the reliability and validity of self-reporting of physical activity in adults with learning disabilities (Johnson, Yun and McCubbin, 2014). Twenty-three articles concerned the use of specified outcome measurement tools, 7 of which included a range of different self-assessment methods and objective measurements across groups including disabled children and young people (Ross *et al.*, 2016; Ross, Case and Leung, 2016; White *et al.*, 2016), people who use a wheelchair (Lankhorst *et al.*, 2020), people with dementia (Farina *et al.*, 2019), adults with learning disabilities (Firkin, Obrusnikova and Koch, 2024) and people with severe mental illness (Soundy *et al.*, 2014). Six articles involved the International Physical Activity Questionnaire (IPAQ), in people with bipolar disorder (Vancampfort *et al.*, 2016), schizophrenia (Duncan *et al.*, 2017), adolescents and young adults with visual impairment (Wrzesińska *et al.*, 2018), disabled adults (Clina *et al.*, 2023, 2024) and people with learning disabilities (Lynch *et al.*, 2024). Two articles concerned use of the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), one for people with Parkinson’s (Jimenez-Pardo *et al.*, 2015) and one for disabled people (Tyagi and Mattu, 2016). One article focused on the Measure of Experiential Aspects of Participation (MeEAP) for disabled adults (Caron *et al.*, 2019); another the five-item Simple physical Activity Questionnaire (SIMPAQ) for people with mental illness (Rosenbaum *et al.*, 2020). One involved the Physical Activity Enjoyment Scale (PACES) for people with functional limitations (Murrock, Bekhet and Zauszniewski,

2016) and another explored measurement of activity in wheelchair users using the PARA-SCI, LTPAQ-SCI, PADS, PASIPD and device-based measurement (Nightingale *et al*., 2017). One study involved adapting the Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury for use in individuals with disabilities (i.e., the LTPAQ-D) (Gee *et al*., 2024) and another the Adapted Short QUestionnaire to ASsess Health-enhancing physical activity in disabled adults (Adapted-SQUASH) (Seves *et al*., 2021). A final article concerned the development of the Learning Disability Physical Activity Questionnaire (LDPAQ) (Pakravan, Ghazirad and Shaddel, 2022).

2.5 Thematic discussion

The next section will involve a narrative synthesis of the literature highlighting six themes across the body of articles in relation to the evidence they provide for the evaluation of disability sport and physical activity (Figure 2.3).

Figure 2.3: Literature review themes

The first theme problematises the aim to assess disabled people against physical activity guidelines, considering population-level surveillance and the two predominant approaches of self-report and device-based measurement. In recognition that most studies take an impairment-focused approach, the challenges of inclusion are then explored, before considering the exclusion of people with the most severe impairments from evaluation research, and the pros and cons of proxy reporting. Consideration of alternative physical activity outcomes, aside from performance levels, are then examined through relevant literature, before the final theme that refers to the burden of evaluation approaches to disability sport and physical activity providers.

2.5.1 Assessment against physical activity guidelines

The majority of the papers within this review that discuss quantitative measurement of physical activity levels make reference to measurement against the World Health Organisation (WHO) physical activity guidelines, which recommend a minimum of 150 minutes of moderate to vigorous intensity physical activity a week, along with muscle strength straining on two or more days per week of at least moderate intensity (Bull *et al.*, 2020). Although this guidance is based on data from non-disabled people, in the UK it was supported by a Public Health England rapid evidence review on physical activity for general health benefits in disabled adults (Smith *et al.*, 2018). Yet, as this review will demonstrate, measurement of physical activity levels in relation to this guidance is problematic across all impairment groups.

Articles about population-level measurement of disability sport and physical activity have been included to consider approaches from other countries at a similar level to Sport England’s adoption of the Evaluation Framework, introduced within Chapter 1:

Introduction and Context. One of the tools recommended for use within the framework is the IPAQ, which has featured heavily within this literature review, and was specifically designed for assessing quantity of physical activity at a population level and to allow for cross-country comparisons (Rosenbaum *et al.*, 2020). Similarly to the approach of tools within the Evaluation Framework, the following articles focus on evaluation of physical activity against measures of frequency, intensity and duration of performance taken from published physical activity guidelines that prioritise the quantity rather than quality of participation.

Aubert *et al*.'s (2023) article identifies a method, the Active Healthy Kids Global Alliance Report Card, to monitor activity levels of French children and adolescents with disabilities, emphasising the need to include this group within national surveillance of physical activity levels in order to highlight inactivity and the need for interventions. Also exploring physical activity in young people, Ng *et al*. (2017) compare activity levels of adolescents with long-term illnesses or disabilities across 15 European countries; as with other population level studies of physical activity, these were judged against international guidelines for recommended levels of participation. The authors note variation in how physical activity is measured but also, similar to Aubert *et al*. (2023), note how data for young people with disabilities are most often excluded. For their study, the authors examined data from the *2013/2014 World Health Organization Collaborative Cross-national Health Behavior in School-aged Children* (HBSC) study, which involved 15 European countries. Physical activity within this study was measured through a single question focused on the number of days within the past week that respondents were active for at least 60 minutes per day. They give a range of examples of what physical activity might be, but there are no specific adaptive options mentioned. There are significant limitations within this methodology; some expressly identified by the authors and others not. The respondents had to answer unaided, without support, with the potential for inaccuracy, although there is no breakdown of impairment type so it is difficult to judge what kind of support may have been required. They note that self-report is deemed appropriate for collection of information from large populations and how everyone was asked the same questions in the same way, but do not seem to acknowledge the potential for some people needing tailored support to understand and answer.

In comparison to the Aubert *et al.* (2023) study that does not identify impairment at all, De Hollander and Proper's (2018) paper includes some interesting points regarding how disability is defined. The study used data from the 2012 delivery of the Dutch Public Health monitor survey, which is undertaken every four years to monitor the health and lifestyle of adults living in the Netherlands, and to examine the physical activity levels of Dutch disabled adults against World Health Organisation physical activity guidelines. Levels of physical activity were measured using the Short QUestionnaire to Asses Health enhancing physical activity (SQUASH), which asks people to self-report the number of days per week and average amount of time per day they engage in leisure time activities (e.g. gardening and sports), household activities, activity at work and school, and commuting activities. People with physical and sensory impairments were identified based on their provision of assistive devices and on health professional assessment, although these methods weren't entirely reliable for exclusion of some categories due to how wheelchairs and hearing aids are funded. I would argue there may be other exclusions including people who choose not to have equipment or self-fund, or those who have not received any official form of health professional diagnosis. The authors note as a strength in their study the use of data around assistive devices provided by healthcare insurance companies as a more objective and accurate way of determining physical or sensory impairment rather than self-report, which is a very medicalised approach to viewing and categorising disability and removes the agency of self-identification. They do, however, note that even those identified as disabled through objective measures do not always experience limitations or identify as being disabled. While the authors note some limitations of the Public Health Monitor survey in that it requires a selective response, there is no questioning of the mechanisms used within the survey itself, and who may have been excluded by the methodology employed, for example, people with cognitive impairment or learning disabilities, or those living in residential settings.

The aforementioned SQUASH questionnaire has since been adapted by the team who wrote another paper in this review (Seves *et al.*, 2021). Seves *et al.* (2021) explored the test-retest reliability and concurrent validity features of the Adapted-SQUASH, having created this tool from reflection that when measuring activity levels, disabled people may have a different perceived intensity of activities; they may be perceived as more intense, cost more energy and pain. This is a point also noted by Clina *et al.* (2023) in their discussion around adapting the IPAQ. In addition, Seves *et al*. (2021) included examples of physical activities that may be more relevant to wheelchair users, including wheelchair sports and hand cycling, along with questions about wheelchair propulsion. The tool is reported to be adapted for disabled adults, although this is used to refer to physical disability and/or chronic disease that impairs mobility, rather than any other form of cognitive of sensory impairment. In tests against an ActiHeart activity monitor, the Adapted-SQUASH was found to be acceptable for self-report of physical activity in large populations but not at an individual level, where issues included the tendency to over-estimate time being active and difficulty recalling activity intensity with accuracy. Additionally, wheelchair users were excluded from the study described, because the ActiHeart could not be reliably tested within wheelchair users and it is asserted that this likely affected responses to the adapted questions about wheelchair sports and handcycling. The authors noted some of the barriers to physical activity in disabled people that might affect measurements of frequency of activities, but these were assertions of the researchers rather than anything that could have been recorded with the use of this tool.

Studies involving objective measurement of physical activity using wearable devices are prescient to this theme, for their focus on outcomes related to frequency, intensity and duration of activity. While devices have been found to be accurate measures of frequency, intensity and duration of physical activity, beneficial in reducing response and recall bias (Moss and Czyz, 2018), there are limitations in their use that should be acknowledged; upper body activities are not easily measured with these tools, many cannot be used for water-based activities or are not reliable for activities such as cycling, they do not provide information on the context of activities and they can be more time and cost-intensive to use than questionnaire tools (Vancampfort *et al.*, 2016; Farina *et al.*, 2019).

As seen within studies reported by Rosenbaum *et al.* (2020) and Vancampfort *et al*. (2016), many use self-report measures (such as questionnaires), sometimes with assistance of proxy reporting, to compare with outcomes from wearable devices (such as accelerometers that capture motion and pedometers that count steps), in recognition of these being the most common current methods for assessing physical activity in disabled people (Brandenbarg *et al.*, 2023). It is also notable that the studies discussed here tend to take an impairment-based focus, separating people with learning disabilities from people with physical impairments who are either ambulant or wheelchair users. Nightingale *et al.* (2017) and Lankhorst *et al.* (2020) explored the validity and reliability of objective device-based measurement in wheelchair users, with considerations to ideal placement of sensors. Nightingale *et al.* (2017) noted devices to be lacking in their ability to detect alternative movement patterns and musculature in people who use wheelchairs, but solutions continue to be developed and trialled in research settings (Nightingale *et al.*, 2017). Technology within this area is fast moving and this is noted as a challenge within Lankhorst *et al.'s* (2020) systematic review, as new devices are continually being developed with their validity unknown. They found moderate evidence for a positive rating of criterion validity for some devices measuring the intensity and type of physical activity, and good evidence for a positive rating of criterion validity for a range of devices measuring type of physical activity.

With Leung, Siebert and Yun's (2017) systematic review in mind, any papers concerning use of accelerometers with people with learning disabilities should be considered with a note of caution. Their main finding was inconsistency in protocols and procedures followed within studies using accelerometers to measure physical activity in people with learning disabilities, which prevented data comparison, but can also point to inaccuracies in the levels of physical activity being reported using these methods (Leung, Siebert and Yun, 2017). One particular recommendation is the use of external reminders including diaries and posters to prompt participants to wear the device. Also exploring the use of devices within adults with mild to moderate learning disabilities (although without limiting to older adults) across an 18-month period of intervention, Ptomey *et al.* (2017) observed from their 149 participants aged over 18 some difficulties in adhering to the protocols involved in wearing a waist-worn ActiGraph accelerometer belt and difficulties in the accurate recording of data on the number of steps taken each day – 60% of the recorded data was considered not plausible. This may relate to the long time period of the study, but also to how, while all participants needed to have a caregiver to support their participation in the study. While they were able to remind the person to wear and record their daily steps, but were asked not to write down the number of steps for them, regardless of whether they required support to do this. Participants needed to be ambulant and to be able to communicate preferences, wants and needs, through spoken or sign language or AAC, but people with more profound learning disabilities were excluded.

A more recent scoping review explored literature around the measurement properties of device-based physical activity instruments in ambulatory adults with physical disabilities and/or chronic diseases (Brandenbarg *et al.*, 2023). Brandenbarg *et al*. (2023) identified a range of devices in use, mostly ActiGraph and Fitbit, and determined a large variability in research on their measurement properties. They also noted variation in physical activity outcomes measured, critiquing the reliance of step count as a measure that does not consider other forms of activity or consider intensity of activity, and the authors comment how devices cannot demonstrate a full picture of physical activity outcomes.

Other difficulties with device-based measurement are reported by Lankhorst *et al.* (2019) regarding their study aimed at quantifying physical activity in 10 young people who are ambulatory with a motor disability (cerebral palsy or spina bifida) in comparison with 10 typically developing young people. This study focused on use of the thigh-worn accelerometery-based Activ8 activity monitor, and whether it was valid for differentiating between static and dynamic physical activities in everyday life (tested at home or at school). For participants with cerebral palsy or spinal bifida, it was found that the device could determine levels of activity between static/dynamic but was unable to determine specific activities or postures, possibly resulting from the physicality (potentially hip angle, crouched posture or gait) of those participants; it was also noted that the young people included had relatively mild forms of physical impairment. This reflects observations elsewhere that issues with sensitivity to movements can be problematic in recording activity in people with alternative gait patterns (Gee *et al.*, 2024). Also studying children and young people with physical impairment, White *et al.* (2016) conducted a systematic review to explore the reliability and validity of physical activity instruments, comparing data around usage of a range of self-report activity diaries and tools with objective measurement devices, including accelerometers, Uptimers, pedometers and motion sensors. They found the evidence for self-report tools lacking in this population, recommending use instead of objective devices. They note approaches such as these as vital to evaluating community-based physical activity programmes.

Although device-based approaches appear less reliable for longer term interventions, as outlined above (Ptomey *et al.*, 2017), or wheelchair users (Nightingale *et al.*, 2017), the majority of included studies appear to suggest their reliability in quantifying physical activity across a range of populations of disabled adults and young people. However, it should be noted that some studies occurred in controlled research environments rather than real world settings; as found by Ptomey *et al.*, (2017) and Leung, Siebert and Yun (2017), this can affect adherence to usage protocols for some participants.

2.5.2 Inclusive or impairment-specific approaches

The majority of studies looking at measurement tools (predominantly focusing on self-report tools or objective measurement devices such as accelerometers or pedometers) explore impairment-specific groups, focusing on people with learning disabilities or those with physical impairment or who are ambulant. Both Nightingale *et al.* (2017) and Lankhorst *et al.* (2020), previously mentioned in relation to device-based measurement, note the challenges in measuring physical activity and energy use in people who use wheelchairs, where there are not clear guidelines regarding methods and approaches. Nightingale *et al.* (2017) note three self-report tools used with this population: Physical Activity and Disability Survey (PADS), Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) and the 3-Day Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI). The PADS (Rimmer, Riley and Rubin, 2001), is a tool for measurement of weekly activity. While this tool asks people to specify their own activities, exercises and household activities, the frequency and duration of these, it also asks about time spent indoors, time sitting and includes an intrusive set of demographic questions, such as household income, receipt of disability benefits and marital status. This may be usual practice for large evaluations but may not suit the needs of smaller projects looking to evaluate the impact of their sessions. The tool is designed to be administered as a semi-structured interview of 30 to 40 minutes, so is incredibly time intensive, especially if multiple participants need to be interviewed, along with the required attention span of the person subject to the evaluation. The PADS has previously been found reliable and valid for use with people with neurological conditions and other chronic health conditions (Rimmer, Riley and Rubin, 2001; Kayes *et al.*, 2007). The PASIPD (Washburn *et al*., 2002), designed for people with physical and sensory impairments, is more accessible in terms of the language used, the activities considered and their adaptation (e.g. how often did you walk, wheel, push outside your home; specifying cycling as leg or hand; including wheelchair push-ups). It considers a range of activities undertaken including leisure, household and occupational activities, and also measures inactivity, although it does require recall of the duration of each activity.

Tyagi and Mattu (2016) and Jimenez-Pardo *et al.* (2015) also explored the PASIPD, but without comparison to objective devices, and the latter suggest this as a possible route for future research. From their study of 82 disabled people, Tyagi and Mattu (2016) report the PASIPD to be useful for evaluating the association between physical activity, chronic disease and functional outcomes and note it to be easy to use and score, although do concede that it might not always provide a useful measure of activity. A positive aspect of their study was the diversity within their study participants of people with physical, cognitive and sensory impairments.

Jimenez-Pardo *et al.* (2015) found the PASIPD to be a reliable measure of physical activity for their 63 participants with Parkinson's, where there was previously no specific instrument evaluated for use in this population. It is noted that this tool measures alternative forms of activity including household work, gardening and caregiving activities, making it more inclusive of forms of exercise that may be more prevalent within the demographic of study (in this case, people with Parkinson's aged 52-87). One point lacking from this study is consideration of the variability of Parkinson's for individuals; beyond simply stating a diagnosis it would have been useful to know how long people had been living with this progressive condition and to have more detail about their functional status. It was noted that just over 25% of respondents required support to complete the PASIPD, which could be indicative of support needs regarding physical or cognitive function. A potential limitation of self-selection bias is suggested by the recruitment method, where those without the cognitive or physical function to respond without support were not able to respond to the study invitation. It was also noted that activities that included use of a wheelchair were removed from the PASIPD template distributed, for the reported reason that these activities were not relevant within the population of people with Parkinson's, yet I would argue that those with severe disease progression may indeed be wheelchair users. These are important considerations in whether all people with Parkinson's can be heard using this tool.

Within their systematic review, Lankhorst *et al.* (2020) note the PASIPD and the PARA-SCI as the most promising self-report tools for assessing physical activity levels in wheelchair users, the latter specifically for those with spinal cord injury. Nightingale *et al.* (2017) noted the latter, designed specifically for those with spinal cord injury and most likely wheelchair users, to demonstrate the best reliability and validity of the three tools in this population, but it takes time to complete (20-45 minutes) by telephone interview and relies on accuracy of recall. However, as is noted within this paper, the issues with administration including the time it takes and the need for an interviewer led to the developers of the PARA-SCI to develop the Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPAQ-SCI). This is a much shorter questionnaire that requires self-reporting of the minutes of different intensities of leisure time physical activity from the previous seven days. However, it does not measure other activities of daily living. Additionally, in their systematic review, Lankhorst *et al.* (2020) did not find reasonable evidence to support usage of the LTPAQ-SCI with this population. The LTPAQ-SCI has more recently been adapted into the LTPAQ-D, for a broader population of disabled people with physical and/or sensory impairment. Gee *et al.'s* (2024) paper explores the nature of this adaptation, the construct and content validity and the test-retest reliability of this tool. In their justification for a new tool, Gee *et al*. (2024) mention the limitations of other tools: the lack of reference to exercise intensity in the PADS, the inability to accurately specify time spent on physical activity in the PASIPD, due to categorical responses, how this tool measures against data from non-disabled people, and the lack of a self-report measure that measures across all aspects of frequency, intensity, duration or type of activity. Because the LTPAQ-SCI measures all of these aspects, it was felt appropriate for adaptation for people with physical and/or sensory impairments. It is noted that involvement in the full study required ability to travel to the laboratory to complete fitness tests, those unable to do this completed questionnaires only. Although it is not confirmed within the paper, this approach had the potential to exclude experiences of those with access needs, and potentially the most severe forms of impairment; consideration of learning and developmental disabilities is also absent.

Recent work has been undertaken to adapt the IPAQ to be acceptable for use in people with physical disabilities, with changes including more inclusive examples of physical activity for manual and powered wheelchair users (e.g. handcycling, muscle stretching and shoulder retractions), rephrasing walking to the use of a wheelchair (walk/roll/push), and sitting time to sedentary time with an accompanying definition (Clina *et al.*, 2023). Within their paper reporting the adaptation process, Clina *et al.* (2023) assert an imperative to adapt existing tools to be inclusive of disabled people, rather than create new tools for disabled people alone, such as those previously described (PASIPD, PADS, PARA-SCI, LTPAQ-SCI). However, it is noted that they only consider physical impairment in their adaptation. In the conclusions of the follow-up paper confirming the reliability and validity of the adapted IPAQ, Clina *et al.* (2024) note that this approach enables the IPAQ to be used for comparison of activity levels for people with and without disabilities. In their conclusions they note a contribution being made to literature on inclusion science, as the research was inclusive of people with disabilities and people without, and it would be beneficial to have a tool that is applicable to both populations. However, I would also question the inclusivity of methodology: the adapted tool was compared with objectively measured step count, which is an interesting choice when changes have been made to make the adapted IPAQ more applicable to wheelchair users. The authors acknowledge this exclusion because of the current lack of consistent device-based measurement for wheelchair users. In addition, the limitation is acknowledged within the paper by Clina *et al.* (2023) that the tool is not inclusive of all disabled people as only physical impairment was considered in the adaptation. In their description of the changes made to the tool, I disagree with the authors' assertion that activities in the IPAQ such as walking, digging or climbing may not be relevant to disabled people, as the latter two, at least, can be adapted if required.

Administration of the IPAQ (long-form) was adapted for use within a study of self-reported physical activity of 122 adolescents and young adults with visual impairment (Wrzesińska *et al.*, 2018). Specific changes were made to the format of the questionnaire; large-font documents were prepared for people who were visually impaired, and blind people were administered the questionnaire in an interview, and both were found to be reliable approaches with this group. It should be noted, however, that there were no co-morbidities in this group that could have potentially affected survey administration: a non-inclusive approach is noted in that any mental, intellectual or physical disability or wheelchair-use excluded participants from the study.

A number of studies commented on the lack of self-reported tools demonstrated as valid for use with adults with learning disabilities, often accompanied by the argument that better measurement would enable monitoring of progress towards reducing inequalities in access to physical activity (Johnson, Yun and McCubbin, 2014). The development of the Learning Disability Physical Activity Questionnaire (LDPAQ) is reported by Pakravan, Ghazirad and Shaddel (2022) in response to their perceived need for a tool specific for use within this population, noting the difficulties with communication experienced by people with learning disabilities that can affect their ability to respond to verbally administered tools. The authors report the previous adaptation of the IPAQ into the IPAQ-ID, noting the IPAQ to be the closest, most appropriate tool currently available for people with learning disabilities, but criticise the IPAQ-ID for its reliance on proxy reporting. The LDPAQ was designed for people with mild, moderate and severe learning disabilities to be able to use themselves, taking a concise, Easy Read, picture-based format and was tested in a range of community and inpatient settings. It was designed to be applicable to wheelchair users, but there is no comment on its applicability to those with profound impairment. The authors note how that, in addition to measuring activity, it enables further conversation about participants' interests and activities they might enjoy. The LDPAQ is a promising development but does not yet seem to have been subject to further testing of validity or reliability or adopted for widespread use, with a search for published articles relating to the tool yielding no further results.

Current focus remains on use of existing tools in people with learning disabilities. Inactivity rather than activity behaviours was the focus of Lynch *et al.*'s (2024) study exploring self-report by people with learning disabilities, which employed the IPAQ-SF alongside the Rapid Assessment of Physical Activity (RAPA) questionnaire, noting both to be validated for use within this population. The outcome measures were either self-reported or proxy reported. While both measures demonstrated low activity levels, additional comment was made regarding the IPAQ-SF being potentially too complex for use by this population because of the requirement for recall and perceived complexity of questions.

A similar argument is posed by Soundy *et al.* (2014) within their narrative synthesis exploring physical activity measures, although in this instance concentrating on people with severe mental illness. From the studies identified, they noted shortcomings in how and why particular measures were selected for use, but how further work is needed to validate tools with people with severe mental illness. Particularly difficulties in self-report measurement identified with this population include potential cognitive impairments, such as short attention span, issues with comprehension, information retrieval and reporting, and tools may require recall of information over an extended period (Soundy *et al.*, 2014). Vancampfort *et al*. (2016) and also Rosenbaum *et al.* (2020) suggest that variability in mood and other mental health symptoms may also affect self-report response. The latter also note the potential for difficulties in accurately recalling intensity of activity (Rosenbaum *et al.*, 2020).

Both Soundy *et al.* (2014) and Vancampfort *et al*. (2016) note the potential for tools not to capture activity that is unstructured and/or of a low intensity; the study reported by the latter involved use of the IPAQ with 20 participants with the specific diagnosis of bipolar disorder. Vancampfort *et al*. (2016) found inaccuracies in self-reporting of energy expenditure when compared with data measured by a Sensewear armband and concluded that the IPAQ should be used with caution in this population. Noting the lack of self-reported physical activity measures for people experiencing mental illness, Rosenbaum *et al.* (2020) report on the development and reliability of a simple, deliberately quick to administer, five-item physical activity questionnaire (SIMPAQ) in this population. It asks respondents to recall time spent 1) in bed overnight, 2) sedentary, 3) walking, 4) exercising and 5) engaged in incidental activity over the past 7 days. While it was found to be reliable and valid in comparison with ActiGraph accelerometer data, it is designed as a clinical tool intended for administration by healthcare professionals, which limits its applicability to a disability sport and physical activity context. The SIMPAQ tool appears to require a great deal of activity recall and does not take account of those with physical impairments by specifying walking as one of the measures, although participants within this study were not observed to have any issues with being administered the tool. However, as might be expected, inaccuracies with self-report were noted in people with cognitive impairment. The authors note how existing tools such as the IPAQ are not sensitive to short durations of physical activity, under 10 minutes, that may be beneficial to mental health; Vancampfort *et al*. (2016) made similar observations within their study cohort and suggest further work is needed to address the failure of this tool to capture the lowest intensities and durations of unstructured and incidental physical activity that may still provide benefit.

Assessment of sitting time using the IPAQ was of particular interest in a study involving people with Schizophrenia reported by Duncan *et al.* (2019), with intention of exploring ways of reducing this time as a low intensity means of increasing activity. However, in comparing survey outcomes with accelerometer data, they found the tool unsuitable for this purpose, as levels of sedentary behaviour were underestimated. They also question the wording of the question asking about sitting, rather than considering other sedentary postures such as lying/reclining. Issues with data comparison resulting from a high level of ‘don’t know/not sure’ responses was noted in this study. Potentially, this could be reflective of issues with self-reporting in this population, attributed to possible memory impairment, deficits in attention and executive function, symptoms of apathy and lack of motivation to recall and report, and the level of effort attributed to everyday activities.

2.5.3 Exclusion of people with severe impairment from evaluation

Self-report remains the most cost-effective measure of physical activity at a population level (White *et al.*, 2016) and is reportedly less burdensome to participants and administrators (Clina *et al.*, 2024), although I would argue there is potential burden if the tool is not easily accessible to the individual being surveyed. Additional limitations are noted in participant recall bias, use of scales that are not comparative with other measures or do not provide information about the four domains of physical activity that can be measured with objective devices: frequency, intensity, time or type of activity (FITT) (Soundy *et al.*, 2014). It has also been noted within a number of papers that self-report may not be sensitive to the recall of light or unstructured physical activities (Soundy *et al.*, 2007; Farina *et al.*, 2019; Seves *et al.*, 2021).

There is acknowledgement within this literature review of the inaccessibility of existing evaluation approaches to participants within literature review; across all methodological approaches there were examples of the exclusion of people with the most severe forms of impairment. Ptomey *et al.* (2017) had specific requirements for participants to be able to communicate preferences, wants and needs, either through spoken or sign language or AAC but this, nevertheless, excluded people with the most severe impairment from participating. Participants within Lankhorst *et al.'s* (2019) study exploring the use of device-based measurement included disabled young people with cerebral palsy and spina bifida, but all were ambulant and were acknowledged to have relatively mild forms of impairment. Leung, Siebert and Yun (2017) note the frequency with which people with severe learning disabilities are excluded from research, asserting that this is potentially due to cognitive function and the challenges this poses to data collection. However, the authors note how this limits full understanding of activity levels in people with learning disabilities and necessitates the development of user-friendly and inclusive measurement protocols for the use of accelerometer devices.

Adults living in institutional settings and those not able to communicate verbally were excluded from the study described by Hassett *et al.* (2021), which involved a cross-sectional national survey of the leisure time physical activity participation of adults with and without a disability in Australia. The telephone-based AusPlay survey is on a par with the Sport England administered Active Lives Survey in that it was developed by Sport Australia with the aim of gaining a population-level understanding of sport and physical activity participation. Disability is determined by asking whether the person has: “A disability or physical condition that restricts his or her life in some way and has lasted or is likely to last for at least 6 months” (Hassett *et al.*, 2021). Participants are then asked what sport and physical activities they have participated in within the previous 12 months, up to 10 activities, starting with the one they have participated in the most. They are then asked to remember how many times they have taken part over the past year, and how long they took part on the most recent episode of participation. As with other aforementioned population-level studies, these responses are then compared with physical activity guidelines. Aside from the need for verbal communication for a telephone-based interview, the task itself requires significant capacity to recall activity over the previous 12 months.

Inability to verbalise responses also excluded non-verbal people with severe learning disabilities in a study described by Dixon-Ibarra *et al.* (2018). The authors discuss a qualitative evaluation involving interviews with 12 people with learning disabilities who undertook a programme to promote physical activity in their group home setting. The authors note that participants were selected based on the mild nature of their impairment and ability to communicate in an interview. One site of intervention did not have a participant interviewed because all residents had severe learning disabilities and were non-verbal, so were not able to communicate their responses using the selected method. Staff were interviewed instead, and voices were therefore excluded using this methodology. This again reflects concerns raised within the scoping exercise about the lack of recognition of the perspectives of people with the most severe and complex impairment.

The perspectives of participants were almost entirely absent from the programme evaluation described by Matthews, Seaman and Bremer (2023), of an 8-week virtual physical activity programme for people with learning disabilities. Occurring in Autumn 2020 during the restrictions of the Covid-19 pandemic, access to the programme and to the evaluation relied on the technical skills of participants and their carers and the study took a mixed methods case study approach, incorporating the use of tools for measuring demographic data (Washington Group Short Set of Questions on Disability), emotional functioning (Pediatric Quality of Life Inventory), physical literacy (PLAYparent) and the IPAQ-A for physical activity, along with surveys and interviews. The authors acknowledge limitations in the use of survey tools, specifically the potential for inaccuracies resulting from miscommunication or different interpretations of the questions. Access to the study was limited to participants who had the cognitive and language ability to read, write and speak, or who had a carer who could do this on their behalf, and it is noted that all surveys and questionnaires were completed by carers, bar one participant of the 15 involved in full data collection, who was able to do this themselves. Interviews did involve participants alongside their carers, although they are described within the text as caregiver interviews, so it is unclear how much the participant themselves was involved. It should be noted that some of the participants (6 of 15) were children, but as other examples demonstrate, creativity with methods can enable more thorough participation. Alongside their traditional methods of interviews, focus groups and participant observation, Carter *et al.* (2014) also designed a series of activity packs and group surveys for engaging disabled children in their research, enabling inclusion of those with a range of cognitive and functional abilities, with additional support provided, as required, to ensure their ability to contribute their thoughts and feelings about the wheelchair sports club being evaluated. The activity pack included an information sheet, stickers, colouring pencils and activity sheets that encouraged them to: “Draw a picture with a wheelchair in it; write a story about a child and a wheelchair; and write down three brilliant things you can do in a wheelchair” (Carter *et al.*, 2014, p. 941). The group interviews enabled them to speak or write their responses.

Dairo is lead author on two papers within this review that both reflect on the absence of people with severe to profound learning disabilities within evaluation studies (Dairo *et al.*, 2016; Dairo, Collett and Dawes, 2017). The lack of inclusion of people with the most severe levels of impairment is first acknowledged within a systematic review exploring evidence relating to physical activity levels in adults with learning disabilities (Dairo *et al.*, 2016). In the 15 studies they reviewed, it was noted that most participants had mild to moderate severity of learning disability, and the authors concluded that other studies should consider those with severe and profound impairment. They also note inconsistencies in measurement of prevalence of learning disabilities, including differences across methodologies. The authors considered mechanisms of measurement in their review, which were both objective (accelerometers and pedometers) and subjective (diaries, semi-structured interviews and questionnaire surveys: International Physical Activity Questionnaire (IPAQ), Physical Activity Checklist Interview (PACI), physical activity scale, National Health and Nutrition Examination Survey (NHANES III), along with direct observation. Dairo *et al*. (2016) assert objective measures to be practical for use with people with mild to severe impairment, but that they have not been used with people with profound learning disabilities. Additionally, they note that the validity of subjective measures for use with people with learning disabilities is unclear, with only the IPAQ validated for use with this population. The authors note that different physical activity guidelines were used as outcome measures for levels of activity, which differed in whether they favoured frequency and intensity or steps per week. In total, only 9% of participants achieved the global physical activity guideline of 150 minutes of moderate to vigorous physical activity per week. This focus on measurement of performance levels of activity, with participation conceptualised in relation to performance rather than involvement or engagement, is interesting to contrast with other studies exploring outcomes valued by participants.

Firkin, Obrusnikova and Koch’s (2024) more recent scoping review synthesising approaches to quantifying physical activity and sedentary behaviour in adults with learning disabilities again noted vast diversity and inconsistency in the methodologies adopted and offered some useful considerations for future approaches. From their findings, the authors assert that attention should be paid to tailored preparation, instruction and behavioural strategies that are required when working with people with learning disabilities: these might include further consideration of the support provided, such as verbal administration of questionnaires. It is noted that many studies provided instructions for participants that relied exclusively on spoken language; providing verbal instruction may not be inclusive enough and may require supportive written information (I would add, ideally Easy Read and supported by images). The authors note the need to adapt questionnaires to be relevant, feasible and valid for adults with learning disabilities and to create strategies that enhance accuracy of both self and care-giver responses.

2.5.4 Proxy report – disempowering or an opportunity for inclusion?

Within the scoping exercise, providers expressed a desire for people with even the most severe impairment to be able to share their own experiences within evaluation, with proxy reporting as a very last resort. The following studies consider the use and accuracy of someone else responding on behalf of a participant. Focusing on 72 older adults with learning disabilities, Lynch *et al.* (2024) compared objectively measured activity levels using an accelerometer (ActivPAL) with self-reported levels using the International Physical Activity Questionnaire short form (IPAQ-SF), noting deficiencies in using the IPAQ to determine activity levels in this population. The questionnaire was administered as part of a face-to-face interview with the participant, with a proxy present if required, requiring recall of the type, intensity and quantity of physical activity undertaken within the previous 7 days. Lynch *et al.* (2024) also report on their mechanisms for informed consent, with 32% of consent responses coming from proxies, while Easy Read information and consent forms facilitated informed consent for those who were able to complete this themselves. While self-report is known to be one of the predominant methods of determining physical activity in people with learning disabilities, the authors note previous questioning of the accuracy of recall in such approaches with this population. In this case, the self-report tool overestimated moderate and vigorous levels of physical activity and underestimated mild activity, including questionnaires completed by proxy report, indicating it is not the best tool for determining activity levels in older adults with learning disabilities.

Two other studies within this review offered a comparison between the IPAQ-SF and devices in adults with learning disabilities (Dairo *et al.*, 2016; Moss and Czyz, 2018), although Dairo, Collett and Dawes (2017) found, in contrast with the more recent study from Lynch *et al.* (2024), that moderate and vigorous levels of physical activity were under rather than overestimated. Dairo, Collett and Dawes (2017) specifically sought to involve people with profound forms of learning disability, noting their exclusion from other research and the relationship between physical activity levels and severity of learning disability. As such, they took measures to involve such participants, including enabling space and time for the consent process and identifying, where a person lacked capacity to consent in line with the Mental Capacity Act (UK Government, 2005), a proxy decision maker was identified to consent on their behalf. Ten people were able to consent for themselves, while 10 required a proxy to consent on their behalf. The IPAQ-SF they used was adapted with pictures of physical activity and time but was either self-completed or completed by their proxy rather than involving the researcher. This recall of physical activity from the previous 7 days was compared with data from a wrist-worn accelerometer worn for the same time period. Twenty participants were included (levels of impairment profound (n = 5), severe (n = 7), moderate (n = 4) and mild (n = 4)), and they found that self and carer-reported physical activity had perfect agreement on the IPAQ-SF, asserting it to be a useful form of measuring physical activity, including people with profound learning disabilities. The accelerometers were also reliable measures, but they were less tolerated or accepted for wear.

In contrast with the aforementioned approach by Dairo, Collett and Dawes (2017) to enable involvement of people with profound and severe learning disabilities, Moss and Czyz's (2018) focus was the accuracy (or as it transpires, inaccuracy) of proxy report. Moss and Czyz (2018) found the IPAQ-SF to be inaccurate in determining physical activity levels in 58 adults with moderate to mild learning disabilities, in their exploration of agreement between proxy-report using the tool and use of the ActiHeart, a combined heart rate monitor and accelerometer. It was found that, from comparison with ActiHeart data, caregivers significantly underreported levels of physical activity using the IPAQ-SF. It is significant that all IPAQ-SF responses in this study were completed by carers on behalf of participants; the authors recognised proxy-report as a common and widely used approach and noted a desire for consistency in data collection. It is acknowledged as a limitation that caregivers may not have full awareness of activities undertaken by a person and may only be able to report their own perceptions of activity levels rather than the true performance and effort of activity undertaken. However, no comment is made on the ability or agency of participants in completing such forms themselves and there appears to be an assumption that people themselves would not be capable of accurate reporting, which is not necessarily the case. It was also noted that one participant was unable to complete a graded step test due to immobility. This signals the inclusion of ambulant people without mobility impairments, and potentially indicates the exclusion of people with profound experiences of learning disability.

Although focusing on people living with dementia, Farina *et al.* (2019) proffer the potential of proxy report to counter issues with cognitive recall in people with dementia, but note that such approaches would need validation against objective measures, as has been undertaken here by Moss and Czyz (2018). Farina *et al*.'s (2019) scoping review of physical activity measurement approaches concluded a lack of standard approach or specific tool for assessing physical activity in people with dementia. They also noted general difficulty in assessing physical activity in older adults because this population tend to participate in frequent but lower intensity and unstructured physical activity, which is more difficult to recall than structured, higher intensity activities (Farina *et al.*, 2019). All 18 studies identified used self-report questionnaires of older adults. Ten of these adapted self-report questionnaires for older adults to allow for proxy report on behalf of the person with dementia, affecting the validity of these questionnaires; there are also additional comments (as with other studies) regarding the accuracy of proxy report in knowing how much physical activity has been undertaken and at what intensity. Some mention was made of the use of device-based measurement within people with dementia, noting the potential for poor adherence to wear time. Finally, the point is also made that recall issues may not be present in some people with dementia, particularly in the earlier stages, so it should not be assumed that people with dementia require a proxy (if one is available) to report on their behalf. Farina *et al.* (2019) suggest that shortened question length, use of prompts, cued recall, and greater focus on lighter or less specific physical activities, may lead to more successful self-reporting within this population.

Returning to consider people with learning disabilities, Johnson, Yun and McCubbin (2014) instead took the more empowering approach (than proxy reporting) of assessing the convergent and discriminant validity of involving a secondary source (family member, carer or support staff) to enable 37 participants with learning disabilities to self-report themselves using the NHANES III survey, comparing responses with objective measurements of activity from accelerometers and pedometers. The NHANES III survey focuses on determining whether participants have in the past week walked, jogged or run 1 mile or more at a time without stopping, ridden a bicycle, swum, participated in aerobics or aerobic dance, other dancing, calisthenics or floor exercise, done gardening or yard work, or lifted weights, and the duration of these activities. While the devices offered better psychometric properties than self-report tools, the researchers found the use of the NHANES III survey with assistance as a reliable procedure. Issues with recall are likely to be resolved with support, although this does rely on the perspective of the supporter to also remember and know what activities have been undertaken. Additionally, there is no opportunity to specify other activities. Another critique observed is the lack of mention of complexity of learning disabilities; the procedures undertaken suggest the lack of inclusion of people with profound forms of impairment.

2.5.5 Identifying and valuing participant outcomes

Two of the qualitative programme evaluations included within this review suggest the lack of quantitative outcome measurement within their studies as a potential limitation, raising questions regarding what is viewed as valuable in terms of knowledge and linking to earlier discussions regarding epistemic justice. Using focus groups as an approach, although pre- and post- intervention, Pochstein (2022) describes their evaluation of an 8-week community-based programme enabling access to mainstream sport for children with learning disabilities (Pochstein, 2022). Their study involved 15 families, and the method is described as enabling interactive involvement of all participants and they describe the consenting process where easy language information was provided and children who could not read were read the participant information. Despite describing an open research approach that considers perspectives of all stakeholders, Pochstein (2022) suggest as a limitation that they did not use questionnaires or scales to measure outcomes in a more statistical way, suggesting a lacking in their approach that could be addressed in future. Considering their approach enabled the perspectives of participants to be heard, it is interesting that they feel more would be gained from the use of tools – although it is not suggested what tools may be most appropriate. A suggestion for the future potential use of quantifiable measurement of clinical or other outcomes is also included in the limitations offered within Ovenden, Dening and Beer’s (2019) exploration of the impact of a Boccia group on the lives of people with dementia. They conducted interviews and observations of six people with dementia, 10 carers and six organisers, and describe the process of informed consent, where carers were approached in cases where the person was deemed to lack capacity, for participant observation to be undertaken. Where people with dementia were interviewed, it is noted that responses were often briefer, although no specific details are provided on the mechanisms of the interviews – how many were conducted with people with dementia alone and how many involved caregivers speaking with or on behalf of the person with dementia. Again, there is no suggestion of what measures might be used, only that this would provide quantifiable evidence of the benefits of Boccia.

Ross, Case and Leung (2016) suggest the development of effective physical activity intervention and promotion strategies would be better supported by considering alternative and more meaningful measurement approaches that go beyond the consideration of FITT. Within their paper, Ross, Case and Leung (2016) report on work to align physical activity measures with the ICFDH Framework for childhood disability, noting a misalignment in theory and measurement practices, in that current approaches focus on a biomedical framing of physical activity in terms of objectively quantifying performance and activity levels, that assumes greater energy expenditure means better health outcomes. While this connection is not in question, they do query whether low objective scores translate to poor health, experiences or other outcomes, and low intensity may be due to particular factors that cannot easily be explained from data. The authors discuss an alternative conceptualisation of physical activity beyond the bodily experience that considers additional dimensions such as participation, to better capture and describe self-perceived experiences, engagement and the nuances of physical activity behaviour.

Following on from this study, Ross and Case were also part of a team that conducted a systematic review of conceptual and methodological approaches to considering physical activity participation in disabled children (Ross *et al.*, 2016). Within this paper they discuss the need to differentiate between physical activity engagement and participation as two separate concepts that require different measurement and note from their review that while some studies focus on measuring performance aspects of physical activity, some use alternative participation measures, such as subjective perception of involvement, inclusion or enjoyment that account for the quality of the experience, which is perhaps better described as engagement. Because there may be limitations noted in the measurement of physical activity performance in disabled children, considering additional aspects of participation enable equity in the measurement of sport and physical activity in this population.

As noted by Shirazipour and Latimer-Cheung (2020), research is lacking that considers the subjective perceptions of disabled military veterans on their desired outcomes from sport and physical activity. Understanding what makes a high-quality physical activity participation experience and what outcomes are valued was the focus of their study involving 18 disabled veterans (Shirazipour and Latimer-Cheung, 2020). The physical activity outcomes valued, identified from participant interviews, related to the psychological and social benefits of participation and opportunities for advancement. A recognised limitation of this study is that participants were involved in competitive and parasport rather than community-based exercise. While this should have excluded this study from consideration within this review according to aforementioned exclusion criteria, the paper offers useful commentary on how a focus on quantity without quality can limit understanding and evaluation of whether full and equitable participation is being achieved. Shirazipour and Latimer-Cheung (2020) refer to use of the Quality Parasport Participation Framework that can support the creation of programme conditions that promote quality of participation (Evans *et al.*, 2018), which resulted from the work to broaden the conceptualisation of participation, beyond the traditional focus on performance (Martin Ginis *et al.*, 2017). This consideration of participation as a multi-faceted construct led to the development of the Measure of Experiential Aspects of Participation for People with Physical Disabilities (MeEAP), as discussed within the paper by Caron *et al.* (2019). The authors assert that understanding the subjective experience of participation is necessary for the design of meaningful, participation-enhancing programmes (Caron *et al.*, 2019). Sport or exercise (separately) are two of the domains that this tool can be used to measure. It consists of 12 statements, two for each of the six, subjective, experiential aspects of participation that are recommended for measurement: belonging, autonomy, mastery, challenge, engagement and meaning. When delivered to evaluate sporting participation, each statement would be preceded with: “When engaging in sport, I feel…”. Responses are then given on a seven-point scale from 1 (strongly disagree) to 7 (strongly agree). Although potentially quite quick to complete, how the questions are structured and asked may prove difficult for those with a learning disability, particularly in the requirement to respond on a scale that requires abstract thought. Although proxy report is permitted, this is a disempowering approach to using a tool that offers potential for measuring physical activity beyond performance. It is noted that the tool can be used as an outcome measure or to explain broader outcomes and can be used in programme evaluation to provide insight on the conditions required to facilitate participation. The MeEAP was used to explore quality of participation as part of an ethnographic mixed-methods evaluation of an adapted paddleboard programme reported by Berthiaume *et al*. (2024), which also explored strategies for supporting meaningful engagement. Nine people with physical disabilities participated, although it is noted that the inclusive approach and lack of focus on impairment type meant that no specific questions were asked of participants regarding the nature of their disability. From the MeEAP, participants identified high-quality levels of participation, with belonginess, autonomy and engagement as particularly prescient aspects. Strategies were also proposed within the evaluation for increasing engagement and quality of participation, enabling a process of learning from evaluation.

Referring back to Caron *et al*. (2019), Berthiaume *et al*. (2024) note that sport and physical activity researchers have questioned the absence of enjoyment from these experiential aspects of participation. Enjoyment as an outcome of physical activity was specifically explored by Murrock, Bekhet and Zauszniewski (2016) in their psychometric evaluation of the Physical Activity Enjoyment Scale (PACES) in adults with functional limitations and was determined an important construct for understanding participation. Functional limitations are defined within the study as real and perceptual restrictions of the ability to carry out activities required for independent living in the community. The participants were selected from an apartment complex for disabled people, but wheelchair users were excluded. The PACES is an 18-item scale that asks people to rate how they feel about the activity using a 7-point Likert scale, from 1 (I enjoy it) to 7 (I hate it). The scoring of the questionnaire results in an overall enjoyment for physical activity score. Murrock, Bekhet and Zauszniewski (2016) found the PACES to be reliable and valid from their study of 40 adults with functional limitations undertaking a 12-week dance programme. While it is a potentially useful tool for understanding enjoyment as an aspect of participation, the limitation to this singular domain potentially limits its application.

Quality of life is another outcome that was identified within the scoping exercise in Section 2.3 to be challenging to measure. Strongman *et al*. (2023) explored the experiences of 14 people with visual impairment undertaking a mat-based Pilates programme as a ‘return to sport’ after the Covid-19 pandemic. Among other measures, qualitative surveys and interviews, the team used pre- and post-measures of quality of life (WHOQUAL_BREF), which asks 26 questions across the domains of physical health, psychological, social relationships and environment, with Likert-scale style responses ranging from very poor to very good. Following the intervention, there were no statistically significant quantitative changes in quality of life, whereas the interviews revealed additional outcomes including the value for overall function, wellbeing and mental health, the sense of community formed, independence and competence. As all measures were administered by a researcher interview, it can be assumed there were minimal accessibility issues for the use of such methods with people with visual impairments. There is no questioning regarding the applicability of the measures themselves within this study, but it is suggested that measured scores were already strong for participants pre-intervention with limited room for improvement. It is interesting to note, however, that the qualitative interviewing revealed additional aspects that were valued by participants.

One advantage of the qualitative approaches seen within the programme evaluations reviewed here is the exploration of the outcomes of participation in disability sport and physical activity that were most valued from a participant perspective. In the case of Schmid, Short and Nigg’s (2019) report on a qualitative process and outcome evaluation of non-profit organisation AccesSurf Hawai’i, which provides adaptive ocean-based sports activities to disabled children and adults and to wounded veterans, programme outcomes were not already defined. Their evaluative process enabled the exploration of outcomes that were most valued to participants (Schmid, Short and Nigg, 2019). The evaluation was conducted using a single, six-participant 120-minute focus group with the aim of exploring, using a qualitative approach, participants’ own outcomes, enabling the development of relevant programme outcomes. Participants identified a series of immediate outcomes of having fun and feeling free, and longer-term physical, mental and social outcomes of participation. The authors acknowledge this qualitative approach appropriate to a situation where outcomes are not already clearly defined but acknowledge that definition of goals will need to be determined. They recommend the creation of research-based outcome measures for future evaluation, with the starting point from a participant perspective.

Willis *et al.’s* (2018) realist approach to evaluation also explores connections between the context, the programme and the outcomes, i.e. what works, in what conditions and how (Chen, 2018; Willis *et al.*, 2018). Their evaluation of an adaptive physical activity intervention for disabled children and young people, explores ideal conditions for participation. This approach is designed to improve understanding of the mechanisms that enable participation in sport and physical activity, viewing participation as a process rather than an outcome; the study findings point to participation as the first step to a range of other outcomes as a result. As is common for a realist approach, qualitative approaches were adopted by researchers, namely ethnographic methods of participant observation, interviews and focus groups to explore the experience of 31 participants and their parents and found a range of outcomes in addition to the main goal of optimising participation, along with a number of mechanisms for enabling participation. The authors note how realist approaches can inform tailoring of interventions and policy regarding, for example, optimising participation, but also towards the achievement of additional objectives; in short, this is an approach that views evaluation as an opportunity for organisations to learn and improve, with benefit to participants as a result.

2.5.6 Accessibility of evaluation methods to providers

All papers discussing programme evaluations employed in-depth academic researcher-administered qualitative methods, including surveys, interviews and focus groups. Willis *et al*. (2018) included a range of ethnographic methods. I appreciate the focus of the literature search on peer-reviewed academic papers influences the prevalence of academic research approaches to evaluation, but some participants within the scoping exercise also recognised their previous commissioning of external academic researchers for their programme evaluations, so the inclusion here is relevant.

It is acknowledged that the type of programme evaluations described require capacity in terms of time and specific skills to complete; ethnography in particular is time intensive requiring extensive engagement in the field (Willis *et al.*, 2018). Similarly, Carter *et al.* (2014) undertook a series of qualitative activities including participant observation (10 sessions observed by a team of researchers), focus groups and interviews to explore the experience of 63 people connected with a wheelchair sports club for children, which would have taken time and expertise to plan, collect and analyse data. Such approaches are therefore not necessarily accessible to providers without commissioning external support, which reflects providers' concerns raised within the scoping exercise about their own abilities and capacity to complete evaluation tasks. Some aforementioned questionnaire tools also require administration by an interviewer and take time to complete; referring back to the PARA-SCI, which requires around 20-45 minutes (Nightingale *et al.*, 2017).

2.6 Summary and research gap

This chapter has established the current picture of evidence related to the evaluation of disability sport and physical activity from the perspective of those involved in the field, as part of the scoping exercise, and from an academic perspective from within the published literature. From both approaches to gathering information, it has been identified that it is not currently possible to evaluate the participation of disabled people in sport and physical activity in an accessible and inclusive way, using means developed in partnership with disabled people, taking account of their experiences, needs and preferred outcomes. This chapter has considered population-level measurement, objective device-based and subjective questionnaire-based approaches, and project-level evaluations. The issues highlighted within the scoping review were also reflected to some extent within the thematic discussion of published literature, particularly accessibility of approaches to participants with a range of cognitive abilities. The limitation sections of included papers were often most revealing in terms of detailing the difficulties with administering tools and the need to rely on proxy report, also in recognising, in some cases, the absence of people with the most complex forms of cognitive impairment. Questions also arose around the purpose of evaluation within the scoping exercise and within the literature review, relating to questions around what outcomes are valued; those that measure the quantitative performance of an activity or those that express the subjective experience of being involved. As seen within the scoping exercise, consideration was given to the capacity of providers in having the skills, knowledge and time to engage in complex evaluation processes.

Considering the literature review themes from an occupational science perspective, the existence of occupational injustice is present in the exclusion of people from participation in evaluation processes through failure to consider accessibility needs of individuals and the inaccessibility of the methods employed. There is also failure in many cases to consider the full range of outcomes from participation in occupations that can contribute to health and wellbeing.

Research aims and a research question cannot be articulated at this point as this was the result of a collaborative research process that will be explored later within this thesis. The following chapter will explore the theoretical and conceptual framework underpinning this work with disabled people to address the need for change.

Chapter 3 Conceptual Framework

3.1 Introduction

This chapter outlines the theory and concepts that underpin the approach taken within this thesis. Theory offers a lens through which to view the issue at hand and also influences the questions asked within the research, the type of research undertaken and methods used, and how findings are handled and interpreted (Cooper and Meadows, 2016). Additionally, such a lens can help focus any learning from the data, contributing towards calls for action or reform (Creswell, 2014); an appropriate theoretical framework will therefore support this project's focus towards change.

The chapter begins with an exploration of key concepts involved within this study: disability, evaluation, participation and physical activity. I do not offer finalised definitions here; these were starting points guiding my approach to the project, but were further discussed with co-researchers, resulting in alternative perspectives influenced by lived experience. This approach recognises fluidity in language and the influence of varying conceptual, theoretical and political standpoints.

I proceed to explore and explain the overarching paradigm that has driven my approach to this research, which draws on ideas of transformation and change. I explore the ontological and epistemological assumptions that support the Participatory Action Research (PAR) approach and introduce the theoretical lenses through which the project was shaped, primarily critical disability theory, occupational justice and epistemic justice. Some consideration is given to the notable tensions between critical disability studies and occupational therapy practice and theory.

It should be noted that the definitions of a conceptual framework and theoretical approach are aspects required of the PhD process that sit outside of co-researcher involvement; the decisions made within this chapter have been mine alone; yet they have no doubt influenced how the project was presented to co-researchers and therefore, in turn, have shaped the contributions that have been made to the Voices for Inclusive Activity project that sits within it.

3.2 Key concepts

Key terms and concepts will now be explored, namely *disability, evaluation, participation* and *physical activity.*

3.2.1 Disability

Language and terminology is key to the construction of disability; disablist language is used to separate disabled people as ‘other’ from ‘normal’ society (Marks, 1999). Issues related to definition include variation in recognition of who is disabled depending on how disability is conceptualised and how many people do not identify with the label of being a disabled person (Marks, 1999; Adams, Reiss and Serlin, 2015; Watson, 2020).

Disability Rights UK notes how there is no single definition of disability in the UK, but a number of definitions used for different purposes (Disability Rights UK, 2021). Assessments of disability (which can vary by service or benefit being claimed) can determine whether a person receives vital support or not, and this process is steeped in controversy concerning what counts as disability and who is making that decision. Impairment-focused definitions usually (but not without critique or challenge) serve the purpose of determining a person's eligibility to receive care, welfare and other support. The UK Equality Act (2010), for example, refers to disability as:

> *"A physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities." (UK Government, 2010)*

Being 'registered' as disabled with a local authority can also enable access for carer support, if required (Disability Rights UK, 2021).

Policy documents continue to use Medical Model definitions of disability; the UK Chief Medical Officer's Physical Activity Guidelines (2019), for example, refers to how barriers to society may hinder participation but not contribute to the base definition of disability:

> *"Disability refers to people who have long-term physical (e.g. spinal cord injury), sensory (e.g. visual impairment), cognitive (e.g. learning difficulties), and/or mental impairments (e.g. depression) which in interaction with various barriers may*

> *hinder their full and effective participation in society on an equal basis with others."* (Davies *et al.*, 2019, p. 46)

The World Health Organisation's *International Classification of Functioning, Disability and Health* (ICFDH) attempts to offer a universal definition of disability, as:

> *"An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)."* (World Health Organisation, 2001, p. 221)

However, despite attempts to recognise social aspects and participation, the WHO has been criticised for its impairment-based approach (Oliver and Barnes, 2012). Despite this critique, my chosen approach to considering disability (rather than defining it) was developed from the ICFDH definition for the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) (United Nations, 2007) and recognises the changing complexity of the concept, taking account of social and environmental factors alongside impairment and consideration of participation:

> *"Disability is an evolving concept and that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." (United Nations, 2007, p. 33)*

3.2.2 Evaluation

Evaluation, as a vital aspect of the occupational therapy process, is usually concerned with assessing and appraising the outcomes of an intervention, often in a way that is quantifiable (Hocking and Whalley Hammell, 2017). This definition could be applied more broadly to any intervention or programme of activity. However, I am going to frame my approach with Merten's (1999) definition of inclusive evaluation in mind, as this considers the purpose of evaluation and who it benefits, and connects with the overarching philosophical approach that will shortly be explored:

> *"Inclusive evaluation involves a systematic investigation of the merit or worth of a program or system, for the purpose of reducing uncertainty in decision making, and to facilitate positive social change for the least advantaged."* (Mertens, 1999, p. 5)

3.2.3 Participation

Participation in cultural life, recreation, leisure and sport is recognised as an Article within the aforementioned *UNCRPD* (United Nations, 2007). As an occupational therapist I am drawn to the profession's conceptualisation and definition of participation, as one of the basic tenets of our work is to enable full and meaningful participation in all aspects of life (Law, 2002). Unsurprisingly, definitions within the profession's literature take an occupational focus. In defining participation as one of the core concepts of occupational therapy, Creek (2010) extends a definition within the WHO's ICFDH but with a particular reference to activity: "Involvement in life situations through activity within a social context," (World Health Organisation, 2001; Creek, 2010). While it considers involvement as an aspect of participation, the ICFDH conceptualisation has been criticised for reliance on observable measurement of 'how much' and 'how well' a person participates, rather than their subjective experience (Engdahl-Høgåsen and Bentzen, 2023). Within the Occupational Therapy Practice Framework (OTPF, 2020), participation is defined as an outcome, with a definition that makes specific reference to personal satisfaction and meaning:

> *"Engagement in desired occupations in ways that are personally satisfying and congruent with expectations within the culture." (Boop et al., 2020, p. 67)*

Schell, Gillen and Scaffa (2014) consider specific occupations but also recognise the meaning and subjective experience of participation, which makes it my definition of choice:

> *"Involvement in life situations (e.g. self-care tasks, domestic life, education, employment, social and civic life). Participation encompasses passive participation (e.g. observing others or listening). Occupational therapists generally include additional elements such as the meaning of participation and people's subjective experience of participating."* (Schell, Gillen and Scaffa, 2014, p. 1238).

However, it will be essential to move from professional perspectives to work with co-researchers to consider what meaning participation holds for disabled people. As Hammel *et al*. (2008) note, current conceptualisations and assessments of participation focus on the performance or doing of an activity, rather than the meaning or experience. Rather than seeing how they fit with predetermined norms and standards, there is a need for disabled people to:

> *"Define and pursue participation on their own terms."*
> *(Hammel et al., 2008:1455).*

3.2.4 Physical activity

How physical activity is defined determines how it is measured, what is measured and what is important to measure. Many of the papers discussed within Chapter 2: *Literature Review* referred to a definition from Casperson, Powell and Christenson (1985), which is widely adopted within sport and physical activity research and beyond (Warms, 2006):

> *"Any bodily movement produced by skeletal muscles that results in energy expenditure" (Casperson, Powell and Christenson, 1985:126).*

Focusing on the physical aspects, this definition is firmly rooted in a biomedical perspective and its adoption within the World Health Organisation's *Global action plan on physical activity* reflects the prevalent medicalised approach to physical activity for health within the public health sphere (World Health Organisation, 2018). The increasing focus on physical activity as a 'universal panacea', a concept critiqued by Piggin (2020), can further segregate those for whom activities are not accessible. Interventions such as exercise prescriptions from General Practitioners, for example, can fail to account for the wider social determinants of health.

Decisions at a policy level can influence what activities are included and supported within a definition (Piggin, 2020). Within the UK Government's (2015) report *Sporting Future*, the distinction between sport and physical activity was removed for being "Unhelpful, outdated and irrelevant," citing how activities not traditionally defined as "sport" are still tackling inactivity and getting people moving (Department for Culture Media and Sport and UK Government 2015:27). The intention was to contribute to a wider conceptualisation of physical activity to consider daily activities such as gardening and household chores, which may provide more accessible opportunities for physical activity than organised sport. While this signalled potential for a more inclusive approach, the focus on physical activity within this thesis was guided by engagement with disability sport and physical activity providers and participants and later reaffirmed by work with co-researchers. From the scoping exercise (Section 2.3), it was identified that evaluation of recreational physical activity is most problematic, with its potential to include a wider range of participants and activities.

Arguing for a more inclusive, holistic and ethically minded approach, Piggin (2020) proposes a definition that recognises the complexity of physical activity beyond bodily experience:

> *"People moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships."*
> *(Piggin 2020:5)*

In its consideration of contextual factors, parallels might be drawn between this definition and attempts to reconceptualise disability from an individualised, impairment focus, towards consideration of the social and environmental factors that contribute to disability. There is no reference within this definition to a connection between physical activity and health, to level of activity intensity or to specific activities. This counters arguments that physical activity requires a certain level of intensity or involve particular activities to ‘count’ (as reflected within many physical activity self-report tools), which can exclude disabled people. For these reasons and its foregrounding of the importance of human experience, this definition of physical activity guides my approach to this thesis, but the meaning of physical activity for disabled people will be further explored.

3.3 The conceptual framework

3.3.1 Philosophical worldview

The philosophical worldview or paradigm provides guiding theoretical grounding, beliefs and principles that shape and guide how knowledge is considered and constructed, what are deemed appropriate methods of creating knowledge, what counts as knowledge and what is ethical in the creation of this knowledge (Creswell, 2014). The theory and nature of knowledge (epistemology) in turn informs the theoretical perspective, which then underpins the strategic process (methodology) and the techniques, procedures and processes of the research (the methods) (Crotty, 2003). This connection is illustrated in Figure 3.1, which shows the congruence from the overarching philosophical paradigm, through to key theoretical concepts and the selection of methodological approach. All of these will now be explored in turn.

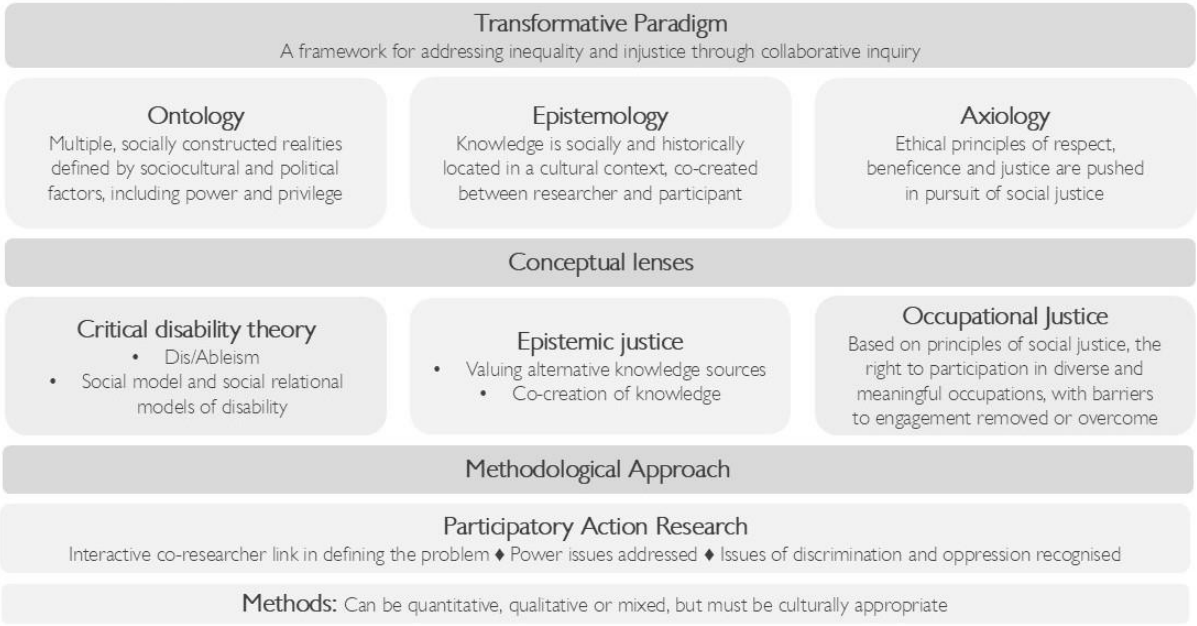


Figure 3.1: Theoretical Framework (Oliver, 1992; Mertens, 2007, 2018; Durocher, Gibson and Rappolt, 2014; Goodley *et al.*, 2019)

This study draws upon the Transformative Paradigm, an overarching philosophical paradigm that extends from the Emancipatory Paradigm, which views disability as a political problem (as opposed to an individual problem in the Positivist Paradigm and a social problem in the Interpretive Paradigm), and advocates empowering disabled people throughout the research process (Barnes, 2002; Oliver, 2002; Kramer-Roy, 2015). Working alongside disabled people is a political act and, as Oliver and Barnes (2012) demand, disability research must be emancipatory, to create change, but without reproducing the long history of oppression experienced elsewhere by disabled people, including within research (Oliver and Barnes, 2012).

The Transformative Paradigm was developed as a renaming of the Emancipatory Paradigm by Mertens in 2005 to emphasise active inclusion rather than a passive process – furthering the idea of ‘doing with’ rather than ‘doing to’ (Mertens, 2009).

Concerned with issues of power, social justice and human rights to confront discrimination and social oppression, this paradigm developed from a desire for research to do more to action change through collaboration with marginalised individuals (Mertens, 2009, 2015; Creswell, 2014; Denzin, 2017). Adopting a change-oriented worldview encourages ethically and morally sound collaborative working that avoids further marginalisation to those experiencing inequalities and imbalances of power (Mertens, 2015).

The need to do something different, to make change, was highlighted throughout the initial scoping exercise outlined in section 2.3. Disability sport and physical activity providers reported the need to adapt existing standardised tools, due to their inability to apply the survey to their specific audience or setting, because of inaccessible language or format or the irrelevance of particular questions. Such actions effectively negated the standardisation of this measure, invalidating results and the possibility of data comparison with other organisations who had used the tool differently. For other organisations, adaptation was not possible, and they were unable to use this tool at all. All were calling for a new approach to ensure they could demonstrate value and ensure sustainability of their activities.

The Transformative worldview is related to the tradition of critical enquiry, a political approach that is informed by the theory and practice of critical theory, which enables people to gain understanding of, knowledge, power and control to make practical change regarding issues affecting their own lives (Schwandt, 1997; Smith and Caddick, 2012). This study will particularly draw from the work of three areas of critical theory, critical disability studies, occupational justice and epistemic justice.

As will be explored within Chapter 4: *Methodology*, Participatory Action Research (PAR) is an appropriate research approach under the Transformative Paradigm. There is a common underlying intention of redressing oppression through action, with active involvement in decision making of marginalised people at all stages of the research process, and dissemination that is focused on enhancing social justice and human rights (Mertens, 2009; Creswell, 2014).

The selection of a paradigm is related to what the researcher perceives to be the nature and structure of reality (ontological assumptions), and the relationship between the researcher and the researched (epistemological assumptions), and this drives what is counted as being knowledge and who is privileged to provide this knowledge (Crotty, 2003; Smith and Caddick, 2012). The ontological and epistemological assumptions within this study will now be explained.

3.3.2 Ontology

The Transformative worldview draws on critical theory and intersectionality to critique how certain versions of reality and truth, what is thought to be true, are privileged based on cultural positioning, and demands examination of the influence of power and privilege on the social construction of reality, including consideration of intersecting identities such as disability (Mertens, 2009, 2015; Smith and Caddick, 2012). In common with social justice approaches to research, the positivist value of scientific neutrality is challenged within this study, where lived experience is elevated as a highly valuable contribution to the co-creation of knowledge (Johnson and Parry, 2016).

The initial scoping exercise privileged the knowledge of those working daily with disabled people to support their access to physical activity. As the research progresses, it will be vital to ensure that multiple perspectives are included, especially from people who may not otherwise be included in research, such as those with multiple and complex disabilities. So, as seen within Chapter 2, where published literature was combined with the scoping exercise experiences, it is necessary to be inclusive of other sources to reach a more balanced and authentic understanding of the research issue, in pursuit of epistemic justice (Whiteford, 2023).

3.3.3 Epistemology

Epistemology concerns what knowledge is and how it is produced. While research under a Transformative Paradigm draws on constructionism, in that meaning is not ‘discovered’ but constructed within a social context, a more critical approach is taken in pursuit of action towards social justice (Crotty, 2003). The epistemology of this approach recognises an interactive link between co-researchers and participants through co-production and how any of the co-researchers’ values cannot be separated from the joint construction of knowledge (Smith and Caddick, 2012; Mertens, 2015). From this perspective, the researcher is not considered ‘the expert’, but their place in the research and issues of power and trust must be acknowledged and addressed.

Within his text *Knowledge/Power*, Foucault asserted the intrinsic connection between knowledge and power, considering hierarchies of knowledge, how knowledge is used to exert power and control over others, and reproduced to serve its own purposes (Foucault and Gordon, 1980; Downing, 2008; Ritzer and Stepnisky, 2014). This study intends to question the traditional construction of knowledge and whose knowledge is valued. Where traditional research practices can reproduce oppression, the Transformative approach is concerned with issues of power and new ways of producing knowledge and understanding through ongoing reflection and action (Crotty, 2003).

3.4 Theoretical lenses

Theory is used to shape what is looked at and how, often described in the context of a lens through which to view the work that guides issues of importance, how questions are asked, how data is collected and interpreted (Creswell, 2014).
My work on this project is underpinned by the theoretical lenses of critical disability studies, occupational justice and epistemic justice. Critical disability studies are considered in light of differing models of disability and key thought around dis/ableism. Consideration is also given to the critique of occupational therapy from critical disability theorists, and how occupational therapists are being called by occupational justice scholars to engage with critical disability studies and challenge dis/ableism within their practice. Justice within knowledge production and enabling privileging of alternative sources of knowledge are also considered through the lens of epistemic justice.

3.4.1 Critical disability theory

Critical disability theory is an interdisciplinary update to disability studies in response to criticism that the Social Model of Disability (Section 3.4.2) was rooted in experiences of physical disability and failed to recognise intersecting identities (Marks, 1999). The intersectional approach within critical disability studies considers postcolonial, feminist, queer and crip theories among others. Such interplays are ignored if a person is defined by their impairment alone, or if disabled people are considered as a homogenous group with similar needs (Oliver and Barnes, 2012; Goodley *et al*., 2019).

A Transformative Paradigm can be integrated with critical disability studies as a theoretical lens to underpin research that aims to challenge disabling social structures and practices (Oliver and Barnes, 2012; Creswell, 2014; Watson, 2020). The Transformative Paradigm's focus on strength-based away from deficit-based approaches is an appropriate basis for disability research framed within the Social Model that challenges an impairment-based view of disability (Mertens, 2009). Although the paradigm's originator relates it to the US sociocultural perspective on disability, this holds some similarities to the Social Model in the UK, for its focus on societal oppression (Mertens, 2009).

Exploring the history and development of disability studies and disability activism is an essential grounding for working with disabled people, to begin to understand the issues they may face and theories with which they may identify. Disability studies underpinned by such theories are often undertaken in response to anger and dissatisfaction with how disabled people are treated by society (Watson, 2020). Disability activists have long challenged medicalised views of disability that describe it based on individual impairment. While disabled people will have different views on how they describe disability or how disability affects them, and the meaning of disability is widely debated, language and definitions are important as they can affect a person's view of themselves in the world and how society responds to them (Oliver and Barnes, 2012).

3.4.2 Social Model of Disability

The UK disability rights movement, spearheaded by the Union of the Physically Impaired Against Segregation (UPIAS), was instrumental during the 1970s and 1980s in attempts to redefine disability as social and political, through the UK Social Model of Disability. This was in response to the limitations of the prevailing Medical Model, within which disability is viewed as personal problem or 'tragedy' of individual impairment, to be prevented, treated and cured (Charlton, 1998; Bennett, Grossberg and Morris, 2005; Oliver and Barnes, 2012). Instead, the Social Model frames it as society that disables people, through culture, economics, attitudes, environments and contexts (including policy and political) and these are the elements that need to flex and change, rather than the individual (Oliver and Barnes, 2012). To apply this understanding to the issue of study, it is the evaluation approaches that need to be changed to be more accessible and inclusive to disabled people, rather than disabled people having to flex and fit to current disabling practice.

Sociologist Mills (1959) discussed the importance of investigating the interplay between 'personal troubles' and 'public issues' (Mills, 1959). By reframing disability away from being an individual personal tragedy but instead defined by societal barriers, which social policy or government action can either reinforce or alleviate, a base is created for collective organisation and action against shared experiences of oppression and exclusion (Marks, 1999; Oliver and Barnes, 2012). This understanding is therefore an appropriate basis for collaborative work in solidarity with disabled people.

The Social Model is not without its own critique for ignoring the emotional, psychological and embodied reality of impairment and the impact of intersecting identities and comorbidities on disabled people's experience (Oliver and Barnes, 2012; Brighton *et al.*, 2021). The Social Model relies on people to identify themselves as disabled, while avoiding medical criteria to do so, but many people do not identify themselves as disabled, or cannot ignore their impairment or bodily experience (Marks, 1999).

3.4.3 Social Relational Model of Disability

More recent conceptualisations of disability take into account the interaction between a person, their impairment and their wider physical and social context (Shakespeare, 2018). Defined by Thomas (1999), the Social Relational Model of Disability, influenced by feminist theory, aims to reflect diversity of experience, extending the Social Model to also consider the psycho-emotional as well as structural factors that serve to disable people, and critiques the Social Model's primary relevance to male wheelchair users (Thomas, 1999). This model recognises that disabled people experience the effects of their impairment, alongside the disabling effect of structural barriers, to fully function and participate in society (Medcalf and Mackintosh, 2019).

3.4.4 Dis/Ableism

Where disablism is the exclusion and oppression faced directly by disabled people in everyday life, considered a social determinant of health (Whalley Hammell, 2020), ableism is the more subtle yet equally present notion that ability is ‘the ideal’, where ability is conforming to norms in body and behaviour and functioning independently, autonomously and self-sufficiently (Goodley, 2018). These are deliberately presented in the connected format of dis/ableism, conceptualised by Goodley as the ‘dis/ability complex’ to highlight the inextricable connection between both concepts (Goodley, 2018). Both concepts are relevant within this research because the design and use of evaluation tools is inherently tied with the measurement and assessment against statistical ‘norms’, and levels of deviation from these, as will be explored within the following section.

3.5 Measurement and categorisation of disability

To consider how the participation of disabled people is evaluated, it is necessary to take a critical eye to how people are measured and, in particular, issues around how disability is identified. The naming and categorisation of disability arose with the industrial revolution of the 18th and 19th centuries; those who were unable to contribute to productivity within the newly organised structures were officially differentiated, segregated and classified as a problem (Marks, 1999; Davis, 2017a). Prior to the industrial revolution, individuals who were now considered ‘disabled’ were rarely segregated from daily life, but political concern with the health of the general population rose with the primary focus on what healthy bodies could contribute towards economic profit (Foucault and Gordon, 1980). People were now being defined by whether they could meet the demands of work; an idea that continues to pervade neoliberal political ideology (Oliver and Barnes, 2012).

The rise of official statistics in the early 19th Century contributed to an obsession with statistical deviance – that is, measurement of anything deviating from the statistical ‘norm’ of an ‘ideal’ worker without impairment; the discredited notion of eugenics also arose at this time, dehumanising any deviation from this ‘norm’ (Hacking, 1986; Marks, 1999; Davis, 2017a, 2017b). Within the text *The Order of Things*, Foucault (1966) reflects on the arbitrarily constructed rules used to order and classify the world and separate ‘normal’ from ‘abnormal’, which were not inevitable but arose from a specific sociopolitical context (Foucault, 1966). The actions of naming, labelling and categorising in relation to a norm is a mechanism of control; as new categories of people came into being, this created new ways for people to be and places for ‘types’ of people to ‘fit’ (Foucault and Gordon, 1980; Hacking, 1986; Davis, 2017b).

Within a medicalised view of disability, being able in body and mind is the ‘norm’, but normalcy is a social construction underpinned by ideology associated with neoliberalism, capitalism, individualism and eugenics (Marks, 1999; Patrick Gamboa Yao *et al.*, 2022). With the ‘norm’ as majority and dominant, those outside of this are marginalised and can experience stigma, with reduced life chances and discrimination from being see as ‘not quite human’ (Goffman, 1963). These ideas relate to the cultural model of Humanism, critiqued by Foucault (1966) and Braidotti (2013) as offering a restricted definition of what counts as human, with a single common standard of a perfectly functional physical body untroubled by the inferiority of difference (Foucault, 1966; Braidotti, 2013). Central to the disability rights movement is critique of the concept of the norm and an accompanying system of “compulsory able-bodiedness,” where being able-bodied is viewed as a “non-identity” that produces disability (McRuer, 2006, p. 2).

As a non-disabled researcher, it is vital to have an awareness of the historical construction of disability as ‘different’, ‘abnormal’ and ‘other’ (Davis, 2017a; Medcalf and Mackintosh, 2019). Not every disabled person will have received a medical diagnosis or associated impairment-based label, but they may be subject to the application of a socially constructed label resulting from perceived difference. Labels can shape a person’s way of being and behaving, influencing who they are and what they may do, they can marginalise and oppress, resulting in stigma, exclusion and even violence (Hacking, 1986; Marks, 1999; Oliver and Barnes, 2012; Ritzer and Stepnisky, 2014; Patrick Gamboa Yao *et al.*, 2022).

This partly explains why many disabled people do not identify with the label that has been applied to them (Beresford, 2005; Oliver and Barnes, 2012). This has implications for how people describe themselves and self-report within evaluation. There are particular debates around the inclusion of chronic illness, learning disability, deafness, mental health issues and the neuro-diversity affirming approach under the umbrella of disability (Wendell, 2017). Yet many people with such impairments will, according to the Social Model definition, experience the disabling effects of society (Oliver and Barnes, 2012).

Global population measurements of physical activity are challenged by lack of consistency in surveillance and monitoring regarding disability and physical activity (Martin Ginis *et al.*, 2021). Many unsuccessful attempts have been made to define, classify and categorise who is and is not disabled (Oliver and Barnes, 2012). As Shakespeare (2018) notes, how disability is measured depends on how it is defined and conceptualised, which renders the search for consistent figures an impossible task (Shakespeare, 2018). For example, a Social Model view suggests incidence and occurrence of disability is variable dependent on social context, and is therefore incompatible with consistent measurement (Marks, 1999). There are clear implications here for this project; if there is no consistency of measurement of who ‘counts’ as being a disabled person and the size of this ‘population’ within the UK, it is not statistically possible to determine the percentage of disabled people who are taking part in sport and physical activity.

3.6 Occupational justice

As a UK-based, HCPC-registered Occupational therapist, I draw on the theoretical underpinnings of my profession throughout this project. Occupational therapy is a science-based profession that supports people to overcome barriers that prevent them participating in occupations (or activities) that matter to them (Royal College of Occupational Therapists, 2024). The practice of occupational therapy is connected with *occupational science*, an interdisciplinary academic discipline concerning human occupation in all its forms (Yerxa, 1993).

An area of concern within occupational science is *occupational justice*, which considers just access and opportunity for engagement in occupation.

In light of critique of previous conceptualisations of occupational justice (Durocher, Gibson and Rappolt, 2014; Whalley Hammell, 2020), Whalley Hammell (2020) suggests to consider occupational injustice to be a: “Violation of occupational rights, due to unfair and inequitable social conditions” (Whalley Hammell, 2020, p. 5); aligning with *The World Federation of Occupational Therapists’ (WFOT) Position Statement on Occupational Therapy and Human Rights (revised):*

> *“Occupational justice is the fulfilment of the right for all people to engage in the occupations they need to survive, define as meaningful, and that contribute positively to their own well-being and the well-being of their communities.”* (World Federation of Occupational Therapists, 2019, p. 1)

The developing theorisation of occupational justice has encouraged politicisation of occupational issues and solidarity with communities who are often marginalised (Whiteford, 2023). WFOT emphasises the role occupational therapists can play in work towards the *United Nations’ Sustainable Development Goals* (World Federation of Occupational Therapists, 2018). Particularly relevant to this project are the goals of good health and wellbeing and reduced inequalities (United Nations Department of Economic and Social Affairs and Development, 2025). Hoerder, Josephsson and Kramer-Roy (2023) discuss how occupational therapists have a professional role in addressing these global challenges, with the pursuit of social justice and support of participation as a professional call and responsibility, and how occupational justice offers a perspective and framework through which to address factors that limit participation and to improve population health (Hoerder, Josephsson and Kramer-Roy, 2025).

Physical activity is an occupation that is practiced in many different forms; engagement and participation will hold various meanings and have a range of outcomes, not only health and wellbeing but also in social and community outcomes. Physical inactivity is a global health priority, but disabled people may face significant barriers to participation that deny their right to experience the health and wellbeing benefits of physical activity, resulting in occupational injustice. Attention is required to the wider social determinants of health when promoting the rights of people to engage in activities that positively impact health and wellbeing (Whalley Hammell, 2020).

This study proposes that ineffective evaluation of disabled people's participation in sport and physical activity results in occupational injustice. The privileging of certain occupations within existing sport and physical activity self-report tools, for example, walking, running and cycling within the *Short Active Lives Survey* (Appendix 2.2), relates to the idea of the socially sanctioned occupation (Kiepek *et al.*, 2019). This is an activity that is acceptable within a social context, the performance of which will conform with and reinforce social norms and expectations (Kiepek *et al.*, 2019). As found from the scoping exercise (Section 2.3), without accessible and inclusive approaches to evaluate their provision, disability sport and physical activity providers cannot contribute to an accurate picture of participation, its facilitation and barriers, or demonstrate their impact to secure ongoing funding. Loss of funding may detrimentally affect the ability of providers to continue or expand their offering, affecting the availability and sustainability of opportunities for participation. As well as being a form of occupational injustice, this issue is a social determinant of health, as social factors have contributed to inequalities in opportunity for participation in an occupation with the potential for positive effects of health and wellbeing (Whalley Hammell, 2020, 2021b).

Although many occupational therapists work with people in connection to the full range of valued occupations, including sport and physical activity, and occupational therapists were named within Sport England's workforce strategy *Working in An Active Nation* (Sport England 2018), the profession remains widely unknown within the sport and physical activity sector. Yet it has much to offer a sector seeking to be more inclusive, with understanding and skills relating to the complexities occupation, the barriers and facilitators to participation and an understanding of the social determinants of health (Department for Culture Media and Sport, 2015; Sport England, 2016). Occupational therapists can support people to overcome barriers and realise their occupational rights to engage in sport and physical activity.

3.7 Tensions between critical disability theory, occupational science and occupational therapy

The practices of health care professionals are problematised within critical disability studies for an often uncritical focus on individual impairment and practical aspects of disability for prevention and rehabilitation (Marks, 1999). Although occupational therapy emerged in the United States at the time when the American eugenics movement was growing in global support, it presented an alternative to the treatment of disabled people that aligns with the justice-oriented approach that occupational scientists are calling for a return to today (Patrick Gamboa Yao *et al.*, 2022). Yet the profession has been called out for the presence of both overt and covert ableism within practice (Doucet and Gutman, 2013; Patrick Gamboa Yao *et al.*, 2022).

Occupational therapists have been described as ‘agents of the state’ by some disabled people, with practice built on neoliberal principles of ‘fixing’ impairment that underpin and uphold ableism (Whalley Hammell, 2021a, 2023).

Occupational therapy is client-centred, but this focus on the individual and their issues or impairment is often grounded in the Medical Model of the existing healthcare system (in the UK but also beyond) and can result in failure to address issues that are rooted in oppressive social structures and systems (Patrick Gamboa Yao *et al.*, 2022). Engagement with critical disability studies would encourage occupational therapists to take a more political, justice-oriented approach to practice that draws from and beyond the Social Model of Disability and enables attention to disabling practices, language and actions (Patrick Gamboa Yao *et al.*, 2022).

The practice of rehabilitation has received particular critique for its contribution to the construction of ‘normalcy’, in its focus towards repairing or preparing for productivity (McRuer, 2006; Heffron *et al.*, 2019). There is ideological synergy here with the basis of categorisation of disability on a person’s ability to be productive.

The focus within occupational therapy on enabling independence, promoting productivity and a need to ‘fix’ people by identifying and modifying dysfunctions and deviations from ‘norms’ is essentially ableist (Whalley Hammell, 2021a). The prioritisation of independence is a case in point; the ableist idea that dependence on others is unacceptable devalues the lives of disabled people, and undermines the valuable contribution of appropriate support to meaningful participation. Moreover, thinking specifically to a sport and physical activity context, interdependence is often an essential requirement for participation.

Ableism can be present throughout the occupational therapy process, from initial information gathering and assessment in response to an assigned diagnosis, label or measure of disability, to the setting of goals and use of standardised measures of achievement that determine ability from disability and rate performance in relation to a non-disabled ‘norm’ (Heffron *et al.*, 2019; Patrick Gamboa Yao *et al.*, 2022). Categorisations of occupations also determine what occupations ‘matter’ and are important – in the same way as what is prioritised in evaluation determines what matters: as an example, the *Short Active Lives Survey* prioritises walking, running and cycling (Appendix 2.2), which are not accessible to all.

Evaluation, as a vital aspect of the occupational therapy process, is usually concerned with quantifiable assessment and appraisal of the outcomes of an intervention (Hocking and Whalley Hammell, 2017). Whalley Hamell (2021) has called on occupational therapists to critically question the profession’s reliance on quantitative outcome monitoring, based in neoliberal values that measure people against normative milestones irrelevant to many, and to look for value in qualitative methods based in experience (Whalley Hammell, 2021a). Drawing on the work of disability studies scholars, occupational scientists have found problematic the use of standardised tools to classify and rate performance for their ideological roots in colonial and eugenic practices of the industrial revolution where certain bodies were seen as superior, productive and powerful and ‘others’ were marginalised (Patrick Gamboa Yao *et al.*, 2022; Whalley Hammell, 2023).

3.8 Engaging with critical disability studies for sport and physical activity research

As the call to engage with critical disability studies is made to occupational therapists, such engagement is also demanded within the sport and physical activity research context and is starting to emerge as researchers engage more with the potential and power of sport for social change and to address inequality (Haslett and Smith, 2020). Sport and physical activity is also political in its structures and organisation and inequalities are evident in the way it can further marginalise certain groups and reinforce stereotypes (Mackintosh and Medcalf, 2019).

Haslett and Smith (2020) noted historic examples of sport being used to advocate for social change, usually driven by athletes using their profile. However, this approach has not always been welcomed from within elite disability sport, due to the belief of some disability rights activists that Paralympians do not represent the everyday realities of disability, and because the often accompanying, ableist narrative on overcoming adversity is unrealistic and unhelpful (Haslett and Smith, 2020).

Research in sport and physical activity has traditionally been framed through a Medical Model lens, but using a critical disability studies frame can challenge ableism and disablism in sport and physical activity (Haslett and Smith, 2020). This thesis will answer the call for innovative methodological approaches, such as PAR, involving collaboration with disability activists, disability sport organisations and the involvement of a range of recreational disabled athletes, along with engagement with critical disability studies to enable action towards change (Haslett and Smith, 2020).

3.9 Summary

This chapter has introduced the theoretical underpinning of this study, beginning with an initial exploration of the key concepts, which will later be further defined by co-researchers. This chapter has explored the grounding of this study in the action-focused Transformative Paradigm, to the conceptualisation of the issue of disability sport and physical activity evaluation through the lenses of critical disability studies, occupational justice and epistemic justice. Current evaluative practices are viewed as ableist, and the reliance on statistical measurement is problematic from its relation to ideas of deviance from statistical norms. This work intends to extend into practice the work of occupational justice theorists who are advocating a closer engagement of occupational therapists with critical disability studies and critiquing the occupational therapy profession's unquestioned reliance on disabling standardised assessment tools. The conceptual framework outlined within this chapter underpins a demand for action and change. The methodological approach of PAR is therefore appropriate for its focus on collective action to redress oppression, and will be further explored within the next chapter.

Chapter 4 Methodology

4.1 Introduction

This chapter is about the methodological approach of Participatory Action Research (PAR) and how it set the conditions for and underpinned the planning and conduct of the Voices for Inclusive Activity (VIA) project. This chapter builds from the theoretical underpinnings explored within Chapter 3*: Conceptual Framework* and demonstrates the congruence from a Transformative Paradigm towards a PAR approach underpinned by social, occupational and epistemic justice, which involves action towards real change. PAR is explored in light of its relevance to working with and alongside disabled people, and connections are drawn with co-production, many of the principles of which have been employed within the VIA Project. Ethical issues are discussed, and the chapter explores the recruitment and early stages of beginning to establish relationships and working practices with co-researchers. The undertaking of the VIA Project by co-researchers is explored within Chapter 5. From this point in the thesis onwards, the text is punctured with boxes outlining my own methodological reflections on the process undertaken.

4.2 Participatory Action Research

PAR is a political, democratic and emancipatory form of action research viewed as an ‘orientation to enquiry’ rather than dictating a specific process or methods for undertaking research (Grimwood, 2016). Action Research is an umbrella term for a range of approaches informed by critical social theory, all of which involve working systematically through research problems to bring change through action (Herr and Anderson 2005; Koch and Kralik 2006; Silver 2016). This approach aligns with Lewin's (1946) call for individuals to participate in research relevant to them (Lewin, 1946); while the idea that research findings should create change featured within Marx's writings on praxis (Marx, 2014). Within this study, the aim was to adopt the transformative and power-addressing Global South originated forms of PAR, with credit attributed to scholars including Fals Borda and Paulo Freire, rather than the Euro-American Action Research approach of Lewin, where the action occurred within the context of the existing structure rather than challenging it (Freire, 1972; Fals-Borda, 1987; Fals-Borda and Rahman, 1991; Grimwood, 2016; Cornish *et al.*, 2023).

The key principles of PAR are the valuing of direct experience and knowledge; mobilising this knowledge for action to make change and new knowledge; the potential for the research process to be transformative through empowering relationships and environments; and collaboration through dialogue that makes use of co-researcher skills and experience (Cornish *et al.*, 2023). Freire viewed research as a form of social action, based on the premise that: “Those who experience a phenomenon are most qualified to investigate it” (DePoy and Gitlin 2016: 161). Often, but not exclusively, used in deprived communities, this approach involves working in collaboration to investigate issues from the perspective of those affected, and to generate knowledge that may be applied for immediate social improvement (Herr and Anderson 2005; Silver 2016; Holloway and Galvin 2017). While different forms of participatory research involve community members throughout the process, the action element of PAR is vital, as is the priority on social change, underpinned by the belief that solutions already exist in the community (Cornish *et al.*, 2023). There are theoretical parallels between Freire's (1972) discussion of marginalised people being 'less human' as a result of experienced oppression and ideas around the dehumanisation of disabled people visited within Chapter 3: *Conceptual Framework* (Freire, 1972). Freire offers the suggestion that freedom from oppression is possible through a process of 'conscientization', where those affected become critically aware of the very existence and causes of oppression, and the resulting injustice (Freire, 1972). PAR is experienced through cycles of planning, action and reflection, borne from Freire's assertion that freedom from oppression requires praxis; committed involvement of those affected by this oppression within a process of reflection and transformative action 'with' and not 'for', towards liberation and 'fuller humanity' (Freire, 1972).

4.2.1 The alignment between PAR and occupational justice

The focus on enacting social justice, working with people affected by injustice and facilitating this process of 'conscientization' aligns with an occupational justice approach to practice and research. Occupational therapy is underpinned by a belief in the transformative potential of meaningful and purposeful occupations on personal or social aspects of life, health and wellbeing (Kramer-Roy, 2015; Wilcock and Hocking, 2015). Occupational therapists work in collaboration with clients, taking practical action to support participation in purposeful or meaningful occupations in pursuit of occupational justice; an approach congruent with and suited to the conduct of PAR, if the research is seen as a purposeful or meaningful occupation to the co-researchers involved (Trentham and Cockburn, 2005; Kramer-Roy, 2015). Examples of PAR undertaken by occupational therapists move beyond the theorisation of occupational justice into action, enacting this perspective and building confidence, capacity and skills in co-researchers (Bryant and Kramer-Roy, 2015; Pettican, 2018a). Occupational therapists bring professional values and skills that can support the conduct of PAR, including experience in client-centred practice, where clients can be individuals, groups or communities (Trentham and Cockburn, 2005; Kramer-Roy, 2015).

It has been questioned why a ‘professional’ is needed to raise this consciousness, why an outsider is needed for communities to realise issues and take action and the relevance of academic researchers to meet the needs of communities, as failure to address power within the process also risks reproducing and perpetuating inequalities (Kindon, Pain and Kesby, 2007a). This is where the approach taken by this ‘outsider’ must be facilitative; training in group dynamics and facilitation of group work is core to the occupational therapist’s training. The role of the facilitator is further explored within Pettican *et al.* (2022) and will be revisited in Chapter 7*: Methodological Learning*.

Participatory and community approaches are not common in sport, exercise and physical activity research, but are an increasing concern (Schinke, McGannon and Smith, 2015). There is also a growing call for co-production approaches to be used more widely within sport and physical activity research (Smith *et al.*, 2023), with some notable examples in collaboration with Disabled People’s User Led Organisations (DPULOs) (Smith and Wightman, 2021). Within research related to disability and sport and physical activity, there is a prevalent focus on studies exploring barriers to participation, where some researchers have highlighted a greater need for co-produced responses to removing barriers (Smith and Sparkes, 2020); this study is one response to that call.

4.2.2 PAR and co-production

There is no single way of conducting PAR, no prescribed methods or analytical approaches, as it can be used in many disciplines and applied in different ways (Grimwood, 2016). I found within the research and planning stage that co-production offered some potentially useful practical strategies for how to approach and conduct this project. Co-production is most commonly used within health and service provision settings to describe collaborative work involving service users in the formulation and design of user-centred services, but it is increasingly being described within other contexts including research (Cornish *et al*., 2023).

As with other forms of participatory research, alignment has been made between co-production and the person-centred values of occupational therapy (Harries, Barron and Ballinger, 2020). Referring back to Chapter 3*: Conceptual Framework*, alignment can be found between how both occupational therapy and co-production approaches require: “Deeply collaborative, power and knowledge sharing partnerships” (Whiteford, 2020, p. 682) and how this is particularly appropriate for working in ways that support the disability rights movement slogan “Nothing about us without us” (Charlton, 1998; Whiteford, 2020). In relation to research, there is potential for occupational therapists to make a strong social contribution and be catalysts for transformative change by working with people to co-produce knowledge and close the gap between evidence and practice (Whiteford, 2020).

However, warnings exist in the literature of how ‘participatory’ and ‘co-production’ have both been adopted as buzzwords in research, policy and practice, when both have been adopted in a tokenistic way. Without relevant resulting actions or outcomes or attention to addressing power, these labels are meaningless (Oliver, Kothari and Mays, 2019; Cornish *et al*., 2023).

While Cornish *et al*. (2023) describe co-production as a potential space in which PAR can be conducted, they warn the activist nature of PAR could be restricted by the institutional context within which it is occurring. Attention must be paid to power relations, who is benefiting from the outcomes of any endeavour, negotiation of boundaries and any potential conflict (Cornish *et al.*, 2023).

There is no precise definition of what co-production is or how it should be done; attempts have been described as futile and potentially restrictive, with the potential to exclude good practice, due to how specific the process can be to context (Williams *et al.*, 2020, 2021b; Beresford, Farr, Hickey, Kaur, Ocloo, *et al.*, 2021; Smith *et al.*, 2023). Broadly speaking, co-production describes a way of working that requires attention to process, with an inclusive, collaborative, mutually owned approach informed by the sharing of power, respect and trust, with flexibility and willingness to challenge assumptions and learn from each other to co-create new understandings (Atkin, Thomson and Wood, 2020). Because PAR involves a combination of research and practical action, built on a tradition of working with marginalised groups to build a collective understanding while tackling power inequalities within the process, it is an approach epistemically and practically aligned with co-production (Ocloo, 2021).

4.3 Ethical considerations

This section considers the specific nature of ethics in PAR, considering both procedural and relational ethics. Following from the latter, I discuss the considerations of involving disabled people in research, with particular focus on involving people with learning disabilities who are often excluded from the process of undertaking research (Milner and Frawley, 2019). While it would be challenging to anticipate all possible ethical dilemmas, the researcher has a responsibility to plan as far as possible to ensure any benefits of the research outweigh any risks (Boddy, 2016).

4.3.1 The ethics of PAR

The guiding principle of research ethics is the responsibility the researcher has to act for the benefit and without detriment to anyone involved within the research, following key ethical conventions and principles such as voluntary informed consent, anonymity and confidentiality, data protection and security, researcher safety, safeguarding of participants, and avoidance of harm, manipulation and deception (Schubotz, 2019; Cornish *et al*., 2023). I did not anticipate any potential harm to co-researchers as a result of participation within this project, but the principle of non-maleficence was considered throughout the process to ensure all aspects of safety were assured for those taking part (Boddy, 2016). Agency and autonomy of co-researchers and participants to make decisions regarding their participation was considered through processes supporting informed consent (Sections 4.7.2, 5.4.1 and 5.5.1), and reassurance that all were free to leave the process at any point. However, the picture is more complex within PAR, as ethics is tied to the pursuit and potential to achieve social justice and emancipation, with multiple levels of responsibility and accountability to co-researchers, collaborators, the community and the institution (Manzo and Brightbill, 2007; Johnson and Parry, 2016; Cornish *et al.*, 2023). Ethics is also further complicated by the involvement of multiple decision makers within a fluid, ever-changing process that responds to different situations, perspectives and needs, so ethics have to be considered throughout (Manzo and Brightbill, 2007).

Considering this in relation to the ethical concept of beneficence, whether project outcomes are likely to do some good and who will benefit from them (Boddy, 2016), there is potential for PAR to extend this (Manzo and Brightbill, 2007). However, this is not guaranteed; the choice to take a participatory approach may be an ethical one, but selecting the approach alone does not automatically mean it is inherently ethical; challenges will still arise, which will require attention to standard ethical principles alongside additional criteria and values, regarding the nature of relationships, power and the co-creation of knowledge (Manzo and Brightbill, 2007; Schubotz, 2019). Ethical considerations go beyond procedural and institutional aspects because of the relationships involved in conducting good quality PAR, requiring examination of relational ethics.

4.3.2 Relational ethics

Cornish *et al.* (2023) describe the concept of relational ethics, which:

> *"Situates ethics as ongoingly negotiated within the context of respectful relationships" (2023: 12).*

The development of trusting, reciprocal relationships is key, and this is further explored within Section 4.10 on co-researcher relationships. This form of ethics considers how the research is designed and managed, how knowledge is produced and applied and considers the use of inclusive approaches, dialogue, mutual respect and care, collective decision making and collaborative action (Cornish *et al.*, 2023).

To connect with the pursuit of epistemic justice, epistemological concerns about what counts as knowledge, who is involved in knowledge creation, how it will be used and who it will benefit, are all considerations of relational ethics that help guide knowledge creation towards action (Cornish *et al.*, 2023).

It was my intention within this project to ensure true involvement with potential for sustainable change, enabling co-researchers to have a sense of ownership of the research. This required a very loose initial conceptualisation of the issue at the outset of the project and a lot of change throughout, designed and controlled by co-researchers (Silver, 2016). There was also a need to manage expectations of what could be realistically achieved within the boundaries and resources of the project (Cornish *et al.*, 2023). Such an approach, and the emergent nature of relationships within it, requires transparency over decisions made, who is making them and why, and demands an ongoing process of evaluation, self-reflection and reflexivity (Pain, Kindon and Kesby, 2007; Wilson, Kenny and Dickson-Swift, 2018).

4.3.3 Institutional ethics

PAR often requires a different approach to institutional ethics to standard or traditional research approaches (Manzo and Brightbill, 2007). Following the lead of previous PAR researchers, including within my own institution (Pettican, 2018a), I did not apply for ethical approval before involvement of co-researchers, which aligns with the lack of requirement in England to obtain ethical approval to carry out PPI (Volkmer and Broomfield, 2022). Applying for institutional ethical approval before the recruitment of co-researchers would have required specification of the project process, its proposed direction and methods; it would challenge the ideal of PAR and co-production to involve people at the earliest stages of project conception, enabling them to shape the process through different iterations (Wilson, Kenny and Dickson-Swift, 2018). In addition, it would have instantly created a power imbalance between the other co-researchers and myself, not only in the need to conceptualise the project before they are involved, but also because it separates between whose involvement as a co-researcher requires approval and those whose does not (i.e. mine). Wilson, Kenny and Dickson-Swift (2018) assert an additional argument that the duty felt by ethical review bodies to protect disabled people’s involvement in research could undermine their autonomy to decide for themselves, with assumptions of vulnerability (Wilson, Kenny and Dickson-Swift, 2018). In addition, any expectation to maintain anonymity or confidentiality could go against the wishes of co-researchers to be recognised and rewarded for their efforts; not to mention the challenge of maintaining such principles within specific locations and contexts (Wilson, Kenny and Dickson-Swift, 2018).

For researchers undertaking PAR, it can be a real benefit if institutional ethics committees have a good understanding of this type of research and its intricacies; issues with institutional research infrastructure are a recognised challenge (Wilson, Kenny and Dickson-Swift, 2018; Cornish *et al.*, 2023). It is not only the ethical review process to consider; the niche, situated and contextually specific nature of knowledge created from PAR may limit the institutional support for this type of research, as the ethical concepts of generalisability and reproducibility have limited application; indeed, these could be seen as negating the value of specific local knowledge (Cornish *et al.*, 2023). However, elements of process may be useful when applied elsewhere. Cornish *et al*. (2023) recommend engaging with a network of like-minded PAR practitioners with which to share best practice on negotiating institutional barriers, but also advise cultivating a critical community that can help support accountability and sustainability (Cornish *et al*., 2023). With the benefit of institutional support in the form of PAR-experienced supervisors and an ethics reviewer also experienced in the process of PAR, it was instead the proposed research that arose from our discussions that required ethical approval to be obtained. Co-researchers shaped the documents supporting the application for institutional ethics, as outlined in Chapter 5: *The Voices for Inclusive Activity project.*

However, processes were nevertheless put in place to ensure co-researchers were informed about the type of research this was and the potential nature of their involvement, as will be explored within Section 4.7 on co-researcher recruitment.

4.4 Involving disabled people in research

This research problematises the disparities between disabled and non-disabled people's participation across domains, but with specific focus on two instances of occupational injustice:

1. Inequalities in participation: Disabled people are frequently marginalised and excluded from aspects of everyday life and subjected to patterns of activity that are detrimental to their health and well-being. Significant inequalities exist in the participation of individuals with disabilities in sport and physical activity.
2. Inequalities in knowledge production: Disabled people are frequently marginalised and omitted from processes of knowledge production (research and evaluation) and policy formulation.

There are stark disparities in health, participation in daily activities and socioeconomic status between disabled and non-disabled people (Shandra, 2018), with such inequalities also evident in research. The history of disability research in academic environments is tainted by exploitative practices that prioritise academic 'expertise' over lived experience, where researchers have power and privilege over their participants, which has served to alienate, perpetuate ableism, and failed to make a difference to the lives of disabled people (Oliver, 1992; Lester and Nusbaum, 2018; Brighton and Williams, 2019). Particularly in sport and physical activity research, criticism has remained that disabled voices are absent from research that is supposed to reflect their experiences, let alone from the process of undertaking inquiry, with preference for positivist approaches perpetuating an impairment-focused medical biomedical view of disability as an individual problem, leaving inequalities unaddressed (Oliver, 1992; Hammel *et al.*, 2008; Oliver and Barnes, 2012; Brighton and Williams, 2019; Medcalf and Mackintosh, 2019).

There is an ethical imperative to involving disabled people in research, as from exclusion, policies and practices that affect disabled people's lives are created and implemented in ways that are not meaningful, relevant or helpful. Yet listening to disabled people's voices is not enough; for research to have potential to challenge oppression and change lives, disabled people should have control over the process of knowledge production (McFarlane and Hansen, 2007; Oliver and Barnes, 2012; Shakespeare, 2017). The call from the disability rights movement for "Nothing about us without us" demands a participatory approach (Charlton, 1998). Joining with disabled people as co-researchers in this study and the processes followed are, in some ways, as important as its outcomes, influencing the relevance of findings and how useful they are. This approach is also appropriate to the focus of this enquiry. According to Hammel *et al.* (2008), collaborative research involving disabled people with different experiences is particularly relevant to exploring the meaning of participation and how it is evaluated (Hammel *et al.*, 2008).

4.4.1 Involving people with learning disabilities in research

Although it might be the intention to undertake an inclusive, 'no labels' approach to including disabled people within the production of this research study, it is vital to acknowledge how people with learning disabilities have most often been excluded from research (Seymour and Garbutt, 1998). The involvement of people with learning disabilities amplifies how the language of research has the potential to alienate those who are unfamiliar with academia, and how vital it is to ensure the process is as accessible as possible to avoid highlighting difference (Oliver and Barnes, 2012; Lester and Nusbaum, 2018).

While I was keen to redress the common exclusion of people with learning disabilities from research, I was also keen to avoid tokenism, with awareness of the additional access requirements, not only in the provision of information about the project and during the project, but also in how topics are explained and discussions are structured to enable inclusion. These strategies are further explored later regarding co-researcher recruitment (Section 4.7). As a group we will continue to be challenged to find accessible routes to disseminating our research outcomes, with potential for outlets such as accessible research articles specifically designed for people with learning disabilities (Garbutt *et al.*, 2010).

4.5 Researcher positionality and reflexivity

PAR relies on researchers being self-aware and willing to suspend any ‘expert’ role in favour of being open to learning from co-researchers, which relies on critical reflection on their own values, beliefs, priorities, motivations, actions and how they interpret findings (Manzo and Brightbill, 2007; Kramer-Roy, 2015). Because of the positioning of the facilitator as a potential ‘oppressor’, a transparent process of reflexivity is required on their relation to those they are working with and the relationships being built, with recognition that the forming of relationships can be affected by the identity and the views of the researcher (Boddy, 2016; Medcalf and Mackintosh, 2019; Fernandez *et al.*, 2021). Freire (1972) discussed the oppressor fighting alongside the oppressed in solidarity, which can only occur when the oppressor recognises the oppressed as people who have experienced injustice (Freire, 1972).

I cannot claim to be objective within this research, I was inherently involved, so I needed to be transparent with potential co-researchers from the outset of our contact about who I am and why I want to work with them on this project (Zarb, 1992). In initial discussions with potential co-researchers, most asked me about my motivations to undertake this research and where they haven't, I was honest how the pursuit of a further academic qualification is important for me, but how this is underpinned by my interest as an occupational therapist in supporting participation in meaningful activities, with a particular focus on sport and physical activity. While it is important for the researcher to reflect on their own position within the research process, it should not be assumed that power is automatically held by a researcher. Each of the co-researchers involved in this project varied in personal characteristics, background and experience of sport and physical activity. As set out in NIHR Involve's framework for considering who might be involved in research, a person may have a background that gives additional expertise alongside their lived experience (NIHR Involve, 2021). A truly inclusive approach recognises groups are not homogenous and include people with varied and intersecting identities (Ocloo, 2021). By making time to reflect together on the multiple intersections of our identities as co-researchers, we were able to consider how this may influence the process of the research (Brighton and Williams, 2019). Throughout the process of working with co-researchers I have used a reflexive diary as a means to critically reflect on decisions made; attention to this was vital to enabling genuine participation and avoiding tokenism (Zarb, 1992).

4.5.1 Being a non-disabled disability researcher

As a non-disabled researcher, I began reflecting on my positionality and suitability to conduct this research since before applying to undertake this PhD. My intentions have been to understand the impact of the privilege of my social location as a white, married, heterosexual, adult, Anglophone, cis-gendered female, currently without physical impairment or mental health issues, living in the Global North, for whom access to education has enabled a degree of social mobility. As previously referenced, there is a long history of oppression within disability research as much as in other parts of society, both in questionable conduct and the lack of involvement of disabled people in research about them (Oliver, 1992).

A researcher from a university, however junior, has the potential to be seen to hold a position of power and privilege different to those of other co-researchers. As an occupational therapist, I also reflected on discussions surrounding ableism within occupational therapy practice (Section 3.7). I have examined my own personal and professional views of disability. Some of this learning has been evident within the process:

Methodological reflection on language and terminology

I'm becoming more aware of avoiding ableist language. During the first discussion group I stopped myself before making the ableist suggestion to 'walk away from the screen' if co-researchers needed a break.

I sought resources on allyship to demonstrate my positionality within this research, using as an example, the coin model of allyship to examine unearned privileges (Nixon, 2019). I saw my role as to facilitate the group of co-researchers, with potential to advocate for the contribution they have made to the construction of knowledge (Happell and Scholz, 2018). My intention was to enable meaningful involvement more than ‘allowing voices to be heard’ or ‘giving voice’; concepts that have been rightly criticised for the implication that the researcher has the power and privilege to allow or give others the opportunity to be heard (Fairey, 2018). Although participatory research attempts to subvert and break down power relationships and ensure a more democratic approach to research, it has the potential to magnify existing power relations (Golob and Giles, 2013). Yet Golob and Giles (2013) demand a Foucauldian understanding; the research does not operate outside of power relations, but these can be harnessed to enable progress, to be productive as much as repressive, when all participants are able to exercise power.

4.5.2 PAR within the context of a PhD

The basic foundations of PAR as a collaborative and process-driven approach that takes time to establish, is instantly at odds with an academic environment that focuses on outcomes, particularly those that involve timely, individual achievement (Seymour and Garbutt, 1998; Klocker, 2012). Using this approach within the pursuit of an academic award may be viewed as a misnomer. As noted by Oliver (1992), the intention to use an emancipatory approach is not enough; researchers must make their skills available to co-researchers and join together to challenge discrimination, rather than use disabled people to reach their own goals and perpetuate oppression

(Oliver, 1992). This is also problematic in relation to Freire’s observations that PAR must not begin with the interests of the oppressor (Freire, 1972).

Seymour and Garbutt (1998) describe potential constraints of conducting PAR within an academic institution (Seymour and Garbutt, 1998). However, similar to the situation reported by Klocker (2012), I was in the facilitative position of having supervisors that were either experienced in PAR or open to its potential, and being registered with an institution that supports and legitimises this approach to knowledge creation (Klocker, 2012). Unlike Klocker, the supervisory support I had is grounded in experience, as my lead supervisor completed a PAR PhD, also from the perspective of being an Occupational Therapist (Pettican, 2018a). Other researchers within the university are either undertaking or have completed PAR PhDs, so there is a network of experiences to call upon. Allies who see this form of research as valid are recognised as a valuable form of support (Seymour and Garbutt, 1998). Fortunately, the departmental staff member with responsibility for institutional ethical approval was also experienced in PAR, so no further explanation or justification was needed for the process, aside from what is ordinarily required. I was also successful in obtaining funding for involvement payments, showing that some funders are also supportive of this approach (Appendix 11). This is also one example of reciprocity, opportunities for which I have sought throughout. For example, one of the co-researchers is aiming towards PhD study themselves, so their participation as a co-researcher may contribute towards their future learning.

When undertaking this type of research, the PhD student aims to become a member of a team, where roles and responsibilities are shared. Within this process I was not an ‘expert researcher’, instead facilitating a process where each person brings their own skills and experiences, experiential knowledge is valued, and my skills, for example in methodology or research, could be used alongside those of the other co-researchers. The sharing of research tasks is a collective effort at odds with the individual and original authorship required of a doctoral thesis and not every co-researcher will receive a PhD as a result of our research project (Seymour and Garbutt, 1998; Klocker, 2012). When one person writes a thesis about a collaborative project, it may appear this person owns this knowledge, and then has the potential to benefit individually from its creation (Zarb, 1992; Seymour and Garbutt, 1998; Klocker, 2012). This is a tension that I endeavoured to make explicit with co-researchers from the very first introduction I gave to this project, both within written and recorded information and the accompanying discussions we had, about the benefits that I may obtain personally from this research.

Aligned with Klocker’s (2012) approach, our collective PAR project is distinct from (although in many ways overlapping with) the individualised thesis writing process (Klocker, 2012). The VIA project exists with its own outcomes and associated actions while the thesis has been written about the process of undertaking the project. As such, the research project itself is detailed in a separate chapter (Chapter 5: *The Voices for Inclusive Activity project*) with findings from the project detailed in Chapter 6. Learning related to the undertaking of the project will follow in Chapter 7: *Methodological Learning.* Klocker (2012) highlights how language is crucial to determining this distinction – following their example, it will be ‘our’ project within ‘my’ thesis.

4.6 Working with co-researchers

This section outlines the approach taken to enact a PAR approach, involving disabled people as co-researchers to explore the overarching issue of more accessible and inclusive ways of evaluating disability sport and physical activity.

4.6.1 Impact of the Covid-19 pandemic on the methodological approach

The scoping exercise outlined in section 2.3 concluded in March 2020, just days before the national lockdown due to the Covid 19 pandemic. The pandemic required a change in the course of this research, as it was no longer possible to meet face-to-face to undertake a participatory project. Despite initial hesitance around using technology to engage a participatory research group, recognising that not everyone may have access to appropriate equipment and facilities or the skills or ability to use technology or participate in online video conferencing, it became clear with extended social distancing measures in place that alternative options would need to be explored. With a desire to ensure a fully accessible research process, I was concerned whether this new format may further silence those who were already underrepresented in research, such as people with cognitive impairment or learning disabilities (Mikulak *et al.*, 2023).

During planning, I consulted a series of resources (although noting the limited range of these at the time) reporting conditions for facilitation of online steering groups or co-production. As the Covid-19 pandemic progressed, one benefit at this time was the proliferation of virtual meetings and guidance that became available to support researchers seeking a means of maintaining involvement of participants in co-production and participatory research. During this time, I attended various events and meetings that were organised to enable information sharing between those looking to maintain collaborative and participatory working online.

Zoom was readily supported by the University and aligned with privacy and storage requirements, but was also selected as an appropriate platform for its recommendation by other researchers who found the whiteboard and share screen functions to be useful, along with the ability to have multiple users visible on screen (Matthews, Baird and Duchesne, 2018; Daniels *et al*., 2019). In addition, it enabled recording of video and audio, which was accessible to co-researchers after groups, although the transcript needed editing for accuracy. There were, however, potential privacy and confidentiality concerns to consider around the environment from which people participate (Collard and Teijlingen, 2016; Daniels *et al*., 2019).

For some, it is recognised that virtual methods may enable participation. For example, those who may have difficulty travelling or accessing a physical venue, who experience fluctuations in their health, who would find it more comfortable to participate from home, or indeed at the time of this project, who remained in social isolation due to the Covid-19 pandemic. At this time of national lockdown, video calling became a more familiar tool for many people to maintain contact with family, friends and the workplace. I reflected on my concerns within my reflexive diary:

Methodological reflection on the effect of the Covid-19 pandemic

I was reluctant to have an online steering group for the potential to exclude those unable to use or access the internet. In a time when disabled people's participation had curtailed more than ever before, I wondered whether this would be a positive outlet for involvement or a further demand on mental health. The group would need to be small enough enable ability, space and confidence for contribution.

Working online enables recruitment from a wider geographical pool of people unable or unwilling to travel and saves on travel costs; there is potential rigor in a wider pool of participants but online approaches may alienate those unable or unwilling to use this approach (Collard and Teijlingen, 2016; Matthews, Baird and Duchesne, 2018; Daniels *et al.*, 2019; Lember, Brandsen and Tõnurist, 2019). Although Daniels *et al.* (2019) reported on studies showing that people find interaction just as easy in an online group, there are potential issues with the flow of conversation. Lember, Brandsen and Tõnurist (2019) noted that the effectiveness and efficiency of conducting co-production online can lead to uncertainties and risks to be ignored, including potentially more tokenistic involvement (Lember, Brandsen and Tõnurist, 2019). While the issues experienced are similar to face-to-face groups, they can be more difficult to deal with and solve in an online environment; I found it useful to follow Daniels *et al.*'s (2019) guidance on being prepared with participant information, informed consent processes and the co-creation of our ways of working (Daniels *et al.*, 2019).

4.7 Co-researcher recruitment

There is no set rule book for PAR or co-production, so as part of the planning stages, I researched recommended conditions but also took influence from other sources. I aimed to recruit 8-12 participants; a manageable number recommended for cohesive group work in occupational therapy (Cole, 2018). However, when it was necessary to change to online working, I reduced these numbers to align with those suggested for working online (Daniels *et al*., 2019).

As discussed within Chapter 3: *Conceptual Framework*, my intention within this project was to ground the project in a critical perspective of disability, rejecting a limited impairment-focus that narrows the conceptualisation of what it is to be disabled (Goodley *et al.*, 2019). As such, I intended to take a non-impairment-focused approach to recruitment; to recruit people who identified as disabled, but to remove the conventional focus on diagnostic labels. Despite the focus on accessibility, inclusivity and bringing people with a range of lived experiences of disability together, discussion with the collaborator did require some consideration of impairment to enable support and access as needed. In recruitment information and discussions, I emphasised my willingness to facilitate participation on the terms of people involved, including time and location of involvement (McFarlane and Hansen, 2007). The pre-requisites for co-researchers were access to a communication device that could support video calls, the cognitive capacity to participate in and contribute to discussion groups, and participants had to be aged 18 or older to take part.

4.7.1 Engaging with a collaborator for co-researcher recruitment

Research within the Transformative Paradigm and the PAR approach are consistent in their focus on trust building in the process of entering the community (Creswell, 2014). From their own experience of participatory research, McHugh, Coppola and Sinclair (2013) describe the benefits of finding a gatekeeper; someone from the community who acts as an intermediary to be able to engage potential participants and direct initial sessions, to ensure a researcher is not within this position of 'power' (McHugh, Coppola and Sinclair, 2013). For reasons outlined within the *Glossary of terms* (page 25), I use the term collaborator in place of gatekeeper. Although they involved people with learning disabilities only, not a mixed group, Henderson, McLean and Kinnear (2022) also describe working with collaborators for recruitment, with the aim of involving people who hadn't been involved in research before; but also reflected the potential for collaborators to block access with concerns for capacity or perceived vulnerabilities (Henderson, McLean and Kinnear, 2022).

While a local organisation had been identified as a potential collaborator during the scoping phase, the Covid-19 pandemic restrictions ceased all activities at this site, and it was not a realistic potential for recruiting an online steering group. Instead, an email approach was made to another organisation involved in the scoping exercise, located further away, with a brief outline of the new steering group strategy and whether they could identify anyone who may want to be involved. Within my fieldwork journal, I reflected on my worry about whether we would find anyone interested in undertaking this process, but how the collaborator settled concerns:

Methodological reflection on initial engagement with collaborators

A single conversation can completely alter research progress. I approached a potential collaborator as a 'trusted contact' with concern about ensuring diversity in a small group, and they instantly suggested a range of people to approach. They also made some great suggestions for more accessible recruitment information.

Although a detailed description of the project was not possible due to the emergent nature of PAR, an initial outline was required to ensure the community collaborator's understanding of potential involvement for co-researchers. A telephone conversation was held with the collaborator in August 2020 to discuss this outline and potential co-researchers. After discussing the various requirements, the collaborator suggested two males and two females with varying impairments who may be interested in participating. The collaborator asked what the criteria were for accepting co-researcher involvement, but there were no criteria aside from the practical notes previously mentioned (age over 18 and access to a device for accessing video calls). I trusted the collaborator's ability to select potential co-researchers with varying lived experiences of disability and sport and physical activity. The collaborator also asked whether we would include d/Deaf people or those with visual impairment within the group. There was no reason to exclude these valuable perspectives, but there would be additional access requirements to be considered for the research process.

4.7.2 Co-researcher informed consent

A co-researcher information sheet (Appendix 4.1) was created to send to people who had expressed an initial interest in participating in the online steering group, following published guidance (National Health Research Authority, 2017; University of Essex Research and Enterprise Office, 2021). It was essential to make people aware of the expectations of this role but also to establish their expectations of the project and their expectations of me as student co-researcher, and to ensure autonomy and informed consent. Those giving their time to contribute their skills and experience to this research should know that they could withdraw at any time or come and go at any phase of the research, should they wish.

The information sheet also included details about co-researcher involvement payments. While it was intended for the group to discuss what people would want to receive in return for their time and expertise, following best practice guidance from Shaping Our Lives, a national network of service users and disabled people, and National Institute for Health and Care Research (NIHR Involve, 2018; Shaping Our Lives, 2025), co-researchers were offered the opportunity to claim an involvement payment (voucher or charity donation) for their time. If participants chose to accept a payment, they would be encouraged to discuss with their local benefits office whether any potential payment would affect their entitlement for welfare benefits. I was aware of critique of involvement payments as ‘buying’ involvement (Fernandez *et al*., 2021), but while co-researchers said they appreciated the token, it was confirmed throughout the process that this was not the sole reason for engagement. To record the process, co-researchers completed a form after each session to specify their preference for a voucher or donation (Appendix 4.2). To enable accessibility, an Easy Read version of the information sheet was created (Appendix 4.3). The information sheet was also used to create a video, and a shorter introductory video enabled a quick introduction to the project. An Easy Read video was also produced to ensure people were able to access items using the appropriate format (Appendix 4.4). The videos were uploaded to YouTube as unlisted; subtitles were included, and simpler links were created using TinyURL.com

I reflected on the process of making this information in my fieldwork journal, but also about the uncertainty I felt at this point:

Methodological reflection on creating information for co-researchers

Recording the co-researcher information sheet as a video enabled greater consideration of its accessibility: speaking the information required plainer language, but I am concerned about appearing patronising in my attempts to speak with more clarity. I have many questions right now about whether people will want to be involved, whether I am asking too much and what co-researchers will gain as a result, whether we will have enough time, and what my role will be – I am very concerned about not directing progress.

All items were sent to the collaborator for their initial feedback on the information and its accessibility. This led to changes being made, including simplifying the title slides and editing all PDFs to ensure they were accessible to screen readers. An email was then sent to the collaborator to support them with distributing information to potential co-researchers (Appendix 4.5). Boddy (2016) notes that when working with a collaborator, extra care is needed to ensure consent comes from the participant themselves (Boddy, 2016); although this consent was not associated with any ethical review requirement, I needed to ensure my process was sound. Consent was therefore sought during an introductory conversation with potential co-researchers.

4.7.3 Introductory conversations with potential co-researchers

The project guidance was supported by an initial individual discussion with each potential co-researcher. What was deemed the appropriate level of information (determined by the collaborator who was aware of the individuals' cognitive ability) was emailed before these discussions (and would have been posted if requested), along with a sketched out plan for the first discussion group session and a list of topics for discussion (Appendix 4.6). During the initial introductory discussions, I was focused on beginning to establish a working relationship with potential co-researchers. These conversations were congenial, and I had a sense of starting to build a connection on which to base the research. But I also had in mind the question of how much is personality a factor in recruitment – is it more important for everyone to get along and have rapport for investigating the problem, or to ensure we have voices who will challenge and question – those who wouldn't necessarily agree with each other? I am not sure these are mutually exclusive, but I felt it would be interesting to see whether we could create an environment of friendly challenge.

The initial conversations with potential co-researchers were held via Zoom and also offered the opportunity to build trust, enabled co-researchers to understand what and who to expect in the group, enabled testing of functionality, to establish any access requirements and to iron out any issues with using the technology ahead of group meetings (Collard and Teijlingen, 2016; Matthews, Baird and Duchesne, 2018; Daniels *et al.*, 2019). I also opened the group session 10-15 minutes early to enable any further troubleshooting.

Potential co-researchers were able to feed back on the written information sheet and first session plan during this call, to make any changes and suggestions. Both were working documents that offered initial opportunities for involvement in co-production and shaping the direction of the project, with the intention for future sessions to be increasingly co-created as the process developed.

Methodological reflection on co-researcher recruitment discussion

Discussing the project with one co-researcher highlighted how the topic of this research is difficult to explain in the concrete terms and concepts that he would prefer. Also, because the research approach lacks a set structure, everything feels quite woolly. I was concerned about explaining the project well enough for him to be fully informed. The collaborator facilitated our discussion by asking me questions about the project and I had to explain the vital points clearly and succinctly. The involvement of this co-researcher will ensure the process as much the product of this research are accessible and inclusive.

4.7.4 Issues during co-researcher recruitment

During one conversation, I was talking to a potential co-researcher about how we would discuss different elements of the research within the discussion groups, and she joked “and then you’ll go away and do the work”, highlighting issues around distribution of power, roles and responsibilities that will be revisited in section 7.5.4. One person declined to take part after the collaborator’s initial conversation, and from viewing the recruitment video. They expressed concerns about the ‘academicness’ of the project in relation to their own interests and abilities. I did not have a chance to have an initial conversation with them, and felt I wanted to talk and reassure them but, on reflection, I must respect this decision and ensure that everyone joins on a voluntary and uncoerced basis. This is a commitment and if someone feels it is not for them, I cannot try to persuade them otherwise. It was inappropriate to press further, and this decision was respected. I reflected on this instance within my field diary:

Methodological reflection on rejection of involvement

It’s tempting to suggest a further conversation and I wonder whether I could have done something different with the recruitment information, but this is not about persuading people who do not think the project is for them.

Another concern during co-researcher recruitment was the potential for bias in who the collaborator selected. While they were aware of the need to ensure a diverse range of perspectives and characteristics in those approached about the research, they also had insight into who may be interested in the research and who may be willing to engage in the project.

We resolved this by openly discussing and reflecting on these various factors to ensure as diverse a group as possible, in the knowledge that it would be discussed together what the group thought of the representation and whether anyone else should be included. This approach reflects how bias and subjectivity are acknowledged and critically addressed within PAR, with recognition that attempts to erase it are futile (Wimpenny, 2013).

4.7.5 Co-researcher identities

Five people agreed to become co-researchers and to attend the first meeting: four disabled people and one family carer (supporting the involvement of the person with a learning disability). By making time to reflect together on the multiple intersections of our identities as co-researchers over time, we would consider how this could influence the process of the research (Brighton and Williams, 2019). As will be explored within the section on co-researcher discussion groups, a further co-researcher was recruited in December 2020. A table of co-researcher identities can be found in Appendix 4.7.

4.8 Timeline of co-researcher involvement

Figure 4.1 demonstrates the process undertaken from recruitment through to initial discussion groups up to the point of data collection.

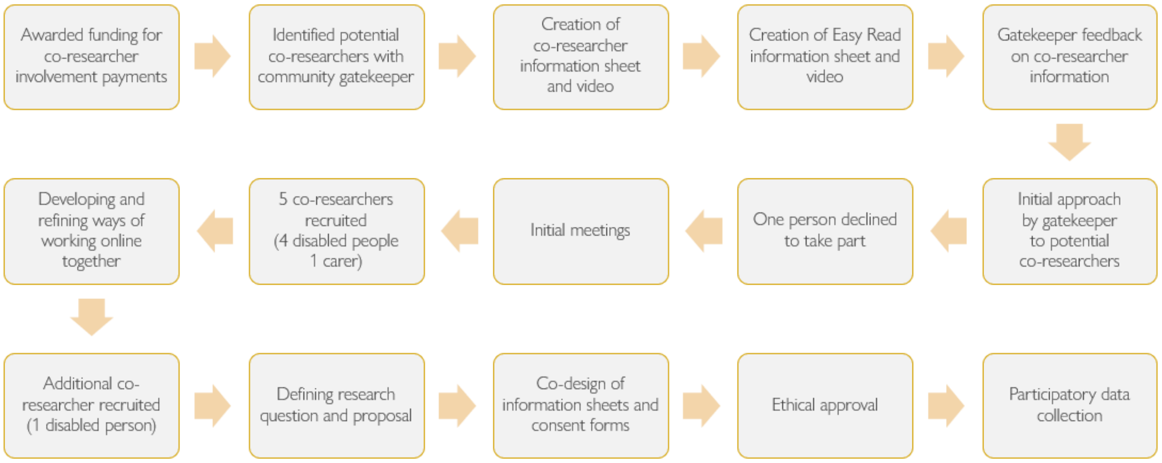


Figure 4.1: Initial process undertaken during co-researcher discussion groups

The GANTT chart in Appendix 4.8 provides an overview of the phases of the research process, while Appendix 4.9 outlines in more detail the activities undertaken.

4.9 Co-researcher discussion groups

For PAR projects, Koch and Kralik (2006) recommend up to 10 meetings per group, lasting 2-3 hours, including time allocated for relationship building (Koch and Kralik, 2006). While I had originally hoped to be able to use creative, practical and participatory methods to facilitate co-researcher engagement, we were limited by being online to a format involving talk, hence the description ‘discussion group’, which was intended to be a friendly and accessible term for co-researchers. Additionally, discussion is the mode of communication most used within PAR that also aligns with Freire’s demand for dialogue within the process of conscientisation (Freire, 1972). Referring back to Habermas’s (1996) theory of communicative action, deliberate, democratic dialogue is the most common mode of collaboration in action research, with three features: orientation towards mutual understanding, a goal of achieving unforced consensus on action, and creating a communicative space to bring people together (Habermas, 1987; Mertens, 2009).

In the first meeting we negotiated the conditions for future discussion groups. Sunday was the best day for all, with mornings (10am-12noon) preferred by those who experience fatigue. The first meeting was one hour but subsequent meetings were two hours. Co-researchers suggested that an hour was not enough to discuss everything that we needed to, and all agreed that two hours would be acceptable with adequate breaks (2 x 10 minutes), maintaining the frequency of one meeting per month at the beginning. The involvement payment provided was adjusted to take account of the longer meeting duration. We also discussed mechanisms for sharing and saving information between us, and co-researchers agreed to trial using the secure file sharing service provided by the University of Essex, Box. We had our own folder that only co-researchers could access.

Agendas for each discussion group can be found in Appendix 5.1-5.9 and an outline of topics discussed within each discussion group can be found in Appendix 5.10. Each discussion group plan featured the practical details at the top and started with time to review what we talked about previously. In the first group we had a section to talk about confidentiality and how what was discussed stayed in the group. After that we had the main tasks for the meeting. We always concluded with a reflection on how the session had gone, with each person having time to respond to two questions: How did the session go? What could we do differently? This helped us co-create the agenda for the following meeting; the date of the next session was then mutually agreed, according to everyone’s other commitments.

After each meeting I would do the practical facilitation task of recording what had been discussed (example in Appendix 5.11), sending a follow-up email to thank co-researchers for their participation, to arrange their co-researcher involvement payments but also to seek feedback on how they thought the group went. Co-researchers were also invited to input ideas for the next meeting. This often resulted in the opportunity to make further tweaks to the process or future agendas. For example, after the first meeting, one co-researcher suggested someone else who they thought may want to be involved in the research, so this was added as a point of discussion under the agenda item ‘who else should be involved?’. Another asked whether they could share details of the research with a service user group; ‘talking to other people about our research’ was added under the agenda point of confidentiality. As we progressed, this section also included more about sharing our research and who we had been talking to about the project and what collaborative dissemination opportunities had occurred since the last meeting. I would also set up and send the Zoom link for the next meeting.

4.9.1 Overview of co-researcher discussion groups

I mostly planned the first meeting as we had not yet met together, but overestimated how much we would be able to achieve in the time we had. We only had an hour together on this first session, but we managed to complete the planned activities of getting to know each other, introducing the project, and thinking about our group agreement. Koch and Kralik (2006) noted how when beginning to work with PAR participants (or co-researchers, within this study), outcomes can be technical and practical but, over time, action and reflection move towards more emancipatory outcomes (Koch and Kralik, 2006). This was initially the case, as we negotiated practical aspects for each meeting, as I reflected within my research journal:

Methodological reflection on first discussion group

We did not get through the whole schedule for the first session, but some key decisions were made, and we tried out some of the features on Zoom to see what might suit us best. We also had our first example of collaborative problem solving of a technical issue.

We began a cycle of discussing and collecting ideas that could then be revisited, reviewed and confirmed in the following meeting. As such, in our second discussion group, we reviewed and agreed our group agreement (Appendix 5.12) and undertook an exercise to explore and map our existing skills and experiences, and what we thought we would be bringing to the research, using the word cloud generating tool Mentimeter (Appendix 5.13). This discussion was rooted in the intention of taking an asset-based approach and making the most of existing co-researcher skills and experiences from within the group. Kramer-Roy *et al*. (2020) describe a process of building mutual respect with co-researchers who come together with a range of different experiences, some of whom may have felt uneasy or threatened by the differing skill levels. This reminds me particularly of the collaborator, who jokingly asked for more brevity in emails, was at pains to describe themself as a practical rather than academic person and was very open about their differing skill set. Also the family carer involved in our project, who was concerned whether they would be able to follow the discussions. It was therefore necessary to explore how a range of skills were beneficial for research; some co-researchers felt they had nothing to bring as they weren't 'academic', or hadn't done research before. We discussed what roles people might look to take in the sessions, for example facilitator or note taker (Rifkin and Pridmore, 2001), but despite this discussion, the sharing of responsibilities isn't something that happened straight away, it developed through the process as people's strengths and skills became apparent in the work.

The exercise also helped to reveal what connections and networks people had that would be useful to the work. This moved quickly into a discussion about who the potential audiences for this project were, who this research was for and what we were trying to find out, beginning the task of working towards our research question. Fernandez *et al*. (2021) noted how sensitivity to ethical questions are critical at the stages of formulating research questions (i.e. determining what is important to study and how to approach it) and when interpreting and disseminating data (what knowledge is constructed and how it is shared) (Fernandez *et al.*, 2021); it was therefore vital to ensure co-researcher involvement at these points in the process.

Also in discussion group 2, one co-researcher shared their own experience of conducting an evaluation of disabled people's participation at a particular venue, which offered co-researchers understanding of the issue in a real-life context. We concluded the main body of the meeting with a discussion considering who else needed to be involved. Co-researchers felt we needed another person, and we discussed who we might be missing from the group in terms of representation;

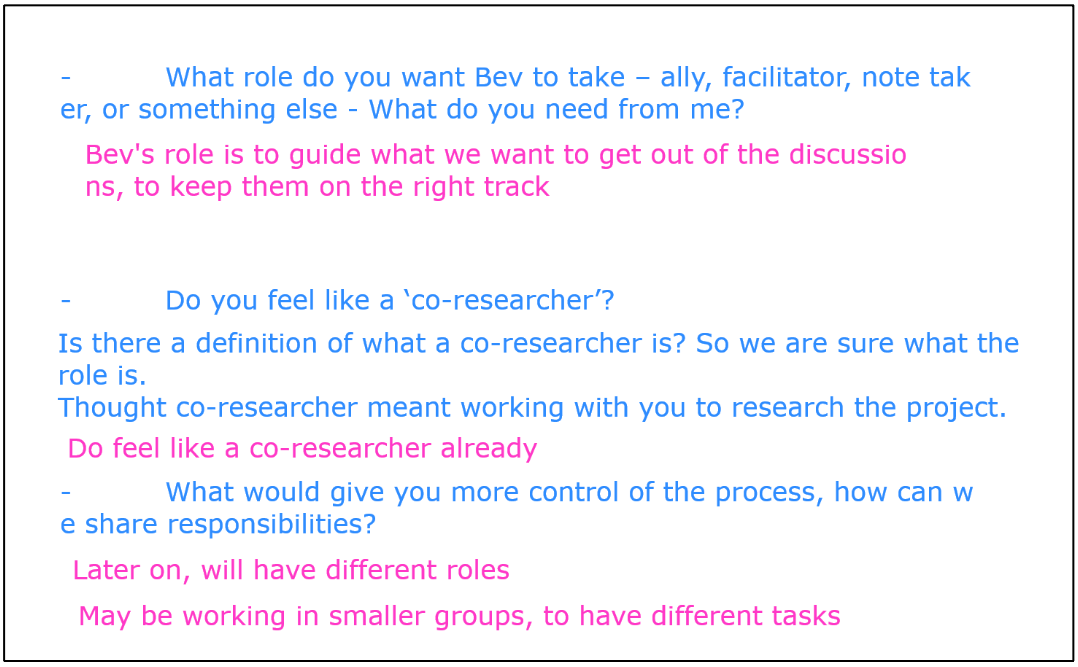
critical attention is needed within transformative research approaches to what voices might be missing or excluded (Mertens, 2009). Co-researchers felt we needed another male to even up the gender balance and I took their suggestions to the collaborator to see whether there was anyone they could approach. They had two people in mind and after initial discussions, one agreed in principle, and I met with them individually. They consented to take part and were given an overview of what we had done so far.

In discussion group 3, we met our new co-researcher and continued to build our understanding of the issue being explored by discussing some questions around the key concepts and terminology. Small group discussions in Zoom breakout rooms were focused around three separate questions:

- What does participation/taking part mean to you?
- What does evaluation mean to you?
- What are we trying to find out and how are we going to do it?

We came back together to collate our thoughts.

After discussion group 3, I actively reflected on my own position and role within the research, whether I was taking the right approach, and how this was changing as group relationships formed, and co-researchers began to take on responsibilities within the process. So, within discussion group 4, co-researchers had the opportunity to discuss within breakout rooms and decide what role they wanted me to take in the project. The consensus was that co-researchers were keen for me to act as facilitator, handling the administrative tasks and providing a steer in response to what was being said, enabling space in groups for co-researchers to discuss and make decisions. Co-researchers were also invited to discuss whether they felt like a co-researcher, and what would give them more control of the process and enable them to share responsibilities in the research. The outcome of this discussion is shown in Figure 4.2.



- What role do you want Bev to take – ally, facilitator, note taker, or something else - What do you need from me?

Bev's role is to guide what we want to get out of the discussions, to keep them on the right track

- Do you feel like a 'co-researcher'?

Is there a definition of what a co-researcher is? So we are sure what the role is.
Thought co-researcher meant working with you to research the project.
Do feel like a co-researcher already

- What would give you more control of the process, how can we share responsibilities?

Later on, will have different roles
May be working in smaller groups, to have different tasks

Figure 4.2: Whiteboard record of co-researcher discussion about our roles in the research

We also discussed our research question and what we wanted to ask the people involved; the development of our research question was an iterative process as co-researchers sought to define the issue and refine the question (See section 5.3.1). This is a common approach within PAR, at contrast with a traditional research approach where a research problem is defined directly from a review of existing literature (Cornish *et al*., 2023). I reflected on this process within my fieldwork journal:

Methodological reflection on building our research proposal

As we talked about potential research questions, one co-researcher said they wanted to know more about how the situation is now: I prompted whether it could be part of our research to directly ask funders about the current situation. I am attempting to take a facilitative approach in responding to such suggestions without being directive. The review of our discussion will be shaped into the research proposal template for co-researchers to review – this will help us make the most of our time together.

From the co-researcher discussion illustrated in Figure 4.2, at this point, we split into two groups of co-researchers; two were more interested and connected in the funders side of the project, while the remaining four co-researchers worked on the side focused on users and non-users of disability sport and physical activity.

Co-researchers wanted to be involved in the process of data collection, and we continued to plan the project in a way that ensured this could happen practically. Involvement in this stage, but also in data interpretation and analysis, intended to mitigate the danger of research mispresenting or lacking sensitivity to voices of disabled people, potentially perpetuating misinformation (Fernandez *et al*., 2021).

In discussion group 5, the group split into their two research teams, with a breakout group for each, where co-researchers worked together on deciding who they would want to be involved and what they would want to ask them. Together co-researchers developed a schedule of questions and decided what format they wanted to use. At this point we were still restricted from carrying out in-person research due to Covid-

19 infection prevention measures. While Zoom interviews were considered an accessible method for funders and related organisations, it was unclear how we would proceed with recruiting and exploring the issue with disabled people.

After this discussion group, I reflected on the progress that was being made and how individuals were finding their own ways of contributing, and on the plans of two co-researchers to meet together before the next session to refine their interview schedule for funders, providers and related organisations:

Methodological reflection on building momentum

Everyone is really getting into this session, working together on a specified task, refining the research question and simplifying the language. It seemed to make such a difference to have defined tasks to work on. One co-researcher has offered to go away and work on the final wording of the questions and to start adding pictures. Others have offered to support her by email. The other group of co-researchers are going to meet up this week to finalise their own set of questions. They also came up with a long list of grassroots, mid-level and high-level funders to approach. We are meeting up sooner – 3 weeks – as we can continue the momentum of working on our information sheets and consent forms. One outcome of this meeting is that others have taken on tasks. Another great thing that happened was that all were checking in with one co-researcher on whether he could understand the questions, so he was really involved in the process.

By this point, there was a collective reflection on a clear direction being established and progress being made, as co-researchers commented individually after the session:

Co-researcher reflections after discussion group 5

"The chance to consider and contribute questions before helped enormously. Helped structure the task and keep discussions focused. Was positive and not what I feared. It felt like progress."

"Funny how it suddenly comes together – I couldn't see how it could in previous sessions!"

"Had a great time today, couldn't believe how fast time disappeared, working in the small group really allowed for a good amount of focused work to happen. Getting excited to see it all come together."

"Thank you for another fab discussion group. I think now we've got a clear direction I can really see the project taking shape. Very happy to be working with you all."

With co-researcher agreement, I had prepared a skeleton template of the kind of questions that would need to be in our research information sheet and template, based on the requirements of the University of Essex ethical approval process. In discussion group 6, the majority of the session involved co-researchers in their separate groups, writing their consent form and research information sheet, tweaking and adding points where they felt the need to elaborate. Towards the end of the session, we reviewed the research proposal that I had pulled together from their discussions. This was an example of the benefit of my facilitative role, as it enabled the document to be built from an overview of their discussions and decisions. I also gave an overview of what would happen in the process of obtaining ethical approval from the University for our research.

Methodological reflection after discussion group 6

I was nervous about how today would go with the first (expected) absence. After the meeting, first thought is – fantastic. Why? It felt relaxed rather than rushed, with time for social chat. Everyone was happy with one break. One issue – I spoke over two co-researchers again; this was politely called out as another co-researcher couldn’t hear. We completed work on the consent forms in the allocated time. I said it would be difficult to set a next group due to timescales of ethical approval, but one co-researcher suggested setting a date and everyone was keen (in 7 weeks’ time). I raised my concern about having to do more than 8 groups to cover everything, but everyone expressed their continued commitment.

The application for ethical approval for our research was submitted after discussion group 6 but was not yet approved when we met together for discussion group 7. It was felt necessary to meet so as not to lose momentum. Co-researchers spent time exploring and confirming our definitions of disability and physical activity and completing our data collection plan.

By discussion group 8 we had received confirmation of ethical approval, so we discussed some practical tips for data collection; co-researcher Karen shared her tips from experience (Appendix 7.13), and we talked through our data collection process (Appendix 7.1). Within my reflective journal I had noted how the co-researcher with learning disabilities was better supported to participate by this session, being actively invited to help with the accessibility of participant questions, trying out and tweaking the wording and selecting accompanying Easy Read images.

Within discussion group 8 we also discussed the possibility of recording a podcast of our experiences of conducting our research; co-researchers were keen to do this but also suggested to have a video version too, with captions for accessibility. Data collection commenced after this meeting, and we were in contact individually and as a group by email to make arrangements.

In December 2021 we met together for a Christmas ‘catch up’, to check in with each other. While suggested dates were discussed and a compromise was found, only three co-researchers, including myself, were able to attend the meeting on Zoom. We discussed the progress of data collection and any further actions that could be taken. We discussed whether we should name our project, to give a more accessible description for us to refer to with people outside of the project in our dissemination activities and used the whiteboard function to generate ideas. One co-researcher had recently come across a project using the word ‘voices’ and liked this concept. Other ideas felt to be important included inclusion/inclusivity as well as activity, although ‘physical’ was not felt necessary to include, with the implication that our work could have implications for evaluation further than just sport and physical activity. Figure 4.3 demonstrates the Zoom whiteboard record of this conversation:

Voices for activity
Voices for inclusive activity
Inclusive activity project
Inclusive voices
Inclusive activity voices
Collaborative activity project
AIE project
Collaborative
Voice
Collective
Interpret
Explore
Peruse
Examine
Scrutinise
Investigate
Review
Determine
Measuring
Comparing
Collation

Figure 4.3: Working together using Zoom whiteboard to name our project

After various iterations, the co-researchers combined ideas into the Voices for Inclusive Activity project.

As data collection continued, we did not meet all together again until September 2022, when we met to talk about our approach to analysing and interpreting our data. We then later met to plan and record our podcasts and came together for our in-person analysis and findings day. The details of these later meetings will be further explored in the following chapter, which will explain how the VIA project was carried out.

4.10 Co-researcher relationships

Active collaboration and the building of relationships are foundational aspects within the PAR process, where issues are studied and action is taken in partnership (Grimwood, 2016; Cornish *et al.*, 2023). Equally in co-production approaches, attention, time and energy must be paid to forming equitable relationships as early as possible in problem definition and agenda setting, with accommodations made to ensure everyone is able to contribute (Williams *et al*., 2021a, 2021b).

The scoping exercise provided a route to establishing relationships, earning mutual trust with an organisation where the topic was of interest, a means of earning community ‘buy-in’, and enabled a trusted link between the project and potential co-researchers (Fernandez *et al*., 2021; Cornish *et al*., 2023). After initial co-researcher recruitment discussions, I reflected on my own status in this process within my journal:

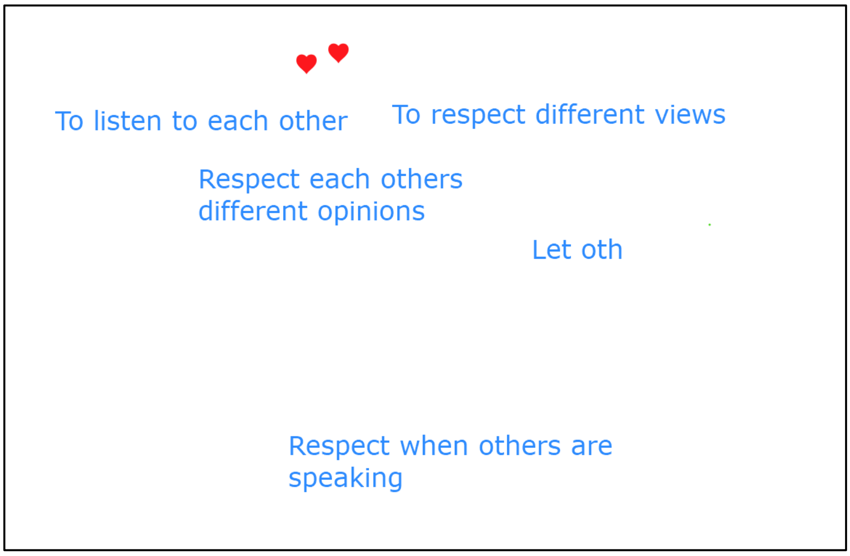
Methodological reflection on relationship building

At a conference, a fellow PhD student reflected on the forming of friendships with the participants in his research, which involved playing football together. My first discussions with co-researchers have been very relaxed and reciprocal conversations. Co-researchers have been keen to hear about my own interest in the project and sporting experience. I have started considering how much I give of myself; how much do I share of my own life?

An established relationship with the collaborator meant they built trust in the project with potential co-researchers, introducing the project, providing the project information and introducing us to each other. This relationship was enhanced by the collaborator’s vested interest in the project, resulting from the issues experienced evaluating their own activities, so they were keen to ensure its success. This approach then translated into the recruitment of research participants for the VIA project. The collaborator approached and recruited participants on our behalf, scheduled times and ensured we had a space in which to conduct interviews; all mechanisms described as building trusting research relationships by Fernandez *et al*. (2021).

When we met together, transparency about my position, intentions and motivations with this research was a vital basis for building a trusting relationship with co-researchers and this required acknowledgement from the outset that this project was connected to my PhD (Fernandez *et al*., 2021). However, I emphasised how I wanted to work together to find ways that co-researchers could benefit from the undertaking of this research. I explained in accessible terms how I was taking a critical stance to this issue, questioning existing practice, aligned with Fernandez *et al.*'s (2021) recommendation on how a collaborative relationship is built on a critical epistemological approach with a shared intention to tackle issues of oppression (Fernandez *et al*., 2021). However, it was also important to be realistic about what we might achieve during the project; as we progressed, I also had to manage expectations (Cornish *et al*., 2023).

The PAR research process has been described as a series of deliberate decisions affecting all involved and deliberate actions were put in place to begin the process of building connections between co-researchers (Fernandez *et al*., 2021). The first discussion group was an opportunity to get to know each other and to start thinking about our ways of working together. Everyone took part in introductions, and an icebreaker activity was used, although one person refrained from doing this. We then started developing together our 'ways of working', with everyone contributing to the discussion. The whiteboard shared on screen was used to record people's thoughts on how we should work together, with everyone adding to this (Figure 4.4), but some preferred to verbalise rather than type. The resulting ‘Ways of working’, negotiated during the session, can be found in Appendix 5.12.



To listen to each other

To respect different views

Respect each others
different opinions

Let oth

Respect when others are
speaking

Figure 4.4: Whiteboard from discussion group 1

As Cornish *et al*. (2023) note, working practices cannot always be completely determined from the start and are negotiated over time, as long as a foundation of trust is established through relationship building.

I included protected time at the beginning of each session for catching up and getting to know each other. We also had a scheduled bingo evening organised with the collaborator, who had been running popular online bingo sessions during the Covid-19 pandemic, along with a Christmas catch-up during our period of data collection in 2021. Although this may sound forced, it aligns with Fernandez *et al.*’s (2021) recommendation to be deliberate and transparent when looking to build trusting, collaborative relationships. Being online meant we did not have the natural social time at physical meetings that occurs during set up, breaks and after a session. Co-researchers also felt able to contact me individually if they wanted to discuss anything from the session; one co-researcher had practical concerns that we addressed outside of discussion groups:

Methodological reflection on co-researcher adjustments to process

A co-researcher contacted me with concerns about whether our participant questions would answer our research question. We talked it through, and the co-researcher suggested some changes that were well received by other co-researchers.

Despite the measures taken, we did lose involvement of the co-researcher who joined with their family carer, during the time of data collection. This was experienced through a long period of no response to messages. As a team, we sought different ways to maintain their involvement; other co-researchers were keen not to lose their input or unique voices in the project. However, there came a time when we needed to respect their decision to leave the process. I will explore more about this situation in *Chapter 7: Methodological Learning.*

4.11 Adapting the process

Within this project, my focus was on enabling meaningful participation within the research process and how we conducted ourselves within the group to ensure everyone was able to contribute. At this time, I was seeking learning from existing projects to inform the accessibility of the project, although was often having to further adapt the process for online working. I reflected within my journal on attending a PAR training session learning about the process taken in the Productive Margins programme, and many of these suggestions were adopted in our project (Barke *et al*., 2020):

Methodological reflection on suggestions for accessibility

We explored ways of making the research process more accessible – and how understanding specific needs and making it more accessible for one should make it more accessible for all. We talked about using symbols for ‘time out’ or inaccessible language, e.g. Zoom reactions, using the private chat box or having something physical to hold up. Other ideas included creating a decision log to have a record of progress, to hold people to account and help those unable to attend some sessions. To establish whether individuals are following the conversation, it was suggested to use gentle questioning and to offer one-to-one time as well as group time. Other ideas included asset mapping to share what experiences and skills everyone brings, asking simple questions to establish a research aim and question, and introducing methods by asking – what ways have you learned more about something? Also giving opportunities for training within the group, to share skills and interview each other.

Occupational therapists enable participation in meaningful activities according to individual needs, which might involve adaptations to the activity or the environment (Duncan and Hagedorn, 2021). Within occupational therapy training, skills for working with groups are developed, including working with group dynamics, considering the role of the facilitator and the needs of both individuals and groups (Cole, 2018). Operating with a critical, Social Model-inspired perspective on disability, the aim within this project was to ensure the environment for participation was as accessible as possible for co-researchers to participate fully within the research process. Some of these adaptations began from the point of recruitment, in ensuring a range of materials were available for co-researchers to make an informed decision about their participation. Working with a collaborator provided a trusted person to discuss their potential involvement before our initial meeting.

However, I did not want to dictate the approach and was cautious to suggest solutions when issues arose; co-researchers were encouraged through careful facilitation to find their own solutions, promoting a sense of shared belonging and ownership of the research process. For example, to begin with, some people found it difficult to follow the flow of conversation, so suggestions were made by the group to recap key points at the beginning of each group and to record our discussions on screen as we went along. We used the Zoom whiteboard function to record our discussions, although this was appreciated by some, it was not entirely successful for all; one person was unable to reach the keyboard and participate in the discussion simultaneously, so their suggestions were added to the whiteboard by another co-researcher. The suggestion was made to use communication tools to allow people to disrupt the flow of conversation for questions and clarifications. Two group members suggested resources, which were discussed and decided on during a subsequent discussion group (Appendix 5.14). The carer for the person with learning disabilities mentioned that they would find it useful to have a visual agenda to talk about before the meeting, so the agenda for the second meeting included

Easy Read images (Appendix 5.2).

4.12 Summary

This chapter has introduced the overarching methodological approach of PAR and its congruence with co-production techniques. Some of the ethical considerations have been detailed around the ethics of PAR, relational aspects and institutional ethics. Reflexivity has been explored, and initial reflections have been included relating to conducting research in the context of a PhD and as a non-disabled person. The formation of the co-researcher group has been discussed, including issues around recruitment, the practicalities of discussion groups, building relationships and ensuring accessibility. The following chapter will provide more detail of the research project created and carried out by co-researchers.

Chapter 5 The Voices for Inclusive Activity research project

5.1 Introduction

This chapter introduces the Voices for Inclusive Activity (VIA) research project developed by co-researchers and describes how it was carried out. The specific research processes are discussed, covering the practicalities of moving through the PAR phases of *Planning, Action and Reflection* to enact the VIA project together. Hereafter is described the *Planning* of our research proposal, which first involved defining key terms to underpin our investigation before we defined who should be involved and what we wanted to find out, the *Action* of engaging in participant recruitment and data collection, and *Reflection* as we took steps to discuss and interpret what we had heard from participants. The chapter will explore and explain the involvement of co-researchers within all stages of this process.

Some of my own methodological reflections feature within this chapter, demonstrating the process of reflexivity undertaken during the project.

5.2 Planning: Defining key terms

As we started to explore how to approach our investigation, exploring our key concepts was the first step in defining our issue, with co-researchers providing their own perspectives on concepts I had earlier defined for my own approach to the project (Section 3.2).

The final definitions adopted can be found in Appendix 5.15, however, discussions around the definition of disability were particularly challenging, so these will be further explored.

In discussing disability, one co-researcher suggested that some people with learning disabilities and experience of mental health issues may read our project title and not think the term ‘disabled people’ applies to them. As group members worked through how they would define disability, the focus was on compiling a list of impairments; a group member later emailed the definition of disability from the Equality Act 2010, suggesting this as the preferred definition in use by other Disabled People’s User-Led Organisations in their locality (UK Government, 2010).

Such a definition would serve the purpose of showing that people with learning disabilities or mental health issues were included within our conceptualisation of disability, however, I was surprised by this preference for a definition so rooted in a Medical Model perspective. I was aware of the possibility that community-based knowledge could reflect dominant discourse rather than challenging it (Mertens, 2009), but from the critical disability studies literature I had engaged with, I had assumed, without my own lived experience of disability, that I should frame my thinking within a Social or Social Relational Model perspective of disability (Brighton *et al.*, 2021).

I was concerned that a definition focused purely on personal impairment could be divisive if we included it in our information. From my position and perspective as an occupational therapist, I adhere to a professional philosophy where people are seen and responded to holistically, considering the whole person rather than simply what their impairment, condition or issue is, despite critique of the ableist tendencies within our profession (Patrick Gamboa Yao *et al.*, 2022). However, it seemed from co-researchers that, in the everyday reality of being a disabled person, the experience of individual impairment was too important a part of identity to be ignored. Some theorists have accused disabled people of ‘false consciousness’ for failing to identify with the Social Model of Disability, while recognising that some may not identify with this approach (Marks, 1999). This was reflected within co-researchers’ discussions. One co-researcher noted that, while they are conscious of the Social Model and acknowledge that social barriers can compound difficulties, a disability makes it more difficult to do day-to-day things that do not necessarily involve society. They identified with critique that the Social Model ignores the presence and impact of symptoms such as pain (Shakespeare, 2017). The same co-researcher also suggested that the individual and personal experience of disability was a more tangible concept to grasp for people with more complex and profound disabilities. There was subtle discord as we searched for an acceptable way of describing disability. Identifying with a Social Model approach, another co-researcher described themselves as not disabled in their own environment but disabled when in an environment that was not set up for them.

As we continued to exchange examples of existing definitions, I shared an adapted version of the Government Statistical Service (GSS) harmonised “core” definition, used by the Office for National Statistics, for consideration:

> *“Within this project we use the term ‘disabled person’ to refer to anyone who has a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities. This includes, but is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear.” (Office for National Statistics, 2021)*

Co-researchers decided to use this definition, although we expected this to evolve with feedback from research participants.

5.3 Planning: Our Research Proposal

The previous chapter outlined the structure and processes through which co-researchers worked together. Over the series of online discussion groups, the elements that would form the basis of our research proposal (Appendix 6) were discussed and agreed, through iterations of planning, acting and reflecting. At times there was a fine line in avoiding coaching and enabling co-researchers to drive the research, particularly at times of misunderstanding – I was keen to avoid directing how research ‘should be’ carried out, or to suggest any approach decided was ‘wrong’. For example, there was some misunderstanding about the difference between overarching research questions and data collection questions, requiring further discussion to tease out the difference, and how the research questions should follow logically from the overarching research question (White, 2017).

Within my reflexive diary, I wrote about the iterative process through which we developed ideas for our research question, and how we endeavoured to make this a collaborative experience. I also reflected that, at times, the research question seemed to be a 'holy grail' that we were searching for, but perhaps it was not as complex as it appeared:

Methodological reflection on developing our research question

One co-researcher suggested that we all think about potential research questions, to discuss and decide on in the next group. I had avoided providing any examples of research questions, but co-researchers wanted to have a starting point. Some of the questions co-researchers were asking about the project could actually be research questions and the people they thought should be involved were all potential participants, so I collated and shared suggestions already discussed by the group. We realised that the research question doesn't need to be anything mystical or complicated, it could be one of those questions we were already asking about the research.

Co-researchers stated the need for a sense of direction to discussions, so as the facilitator, I posed open questions for small groups to discuss, such as 'Who is our research for?'. This particular discussion led co-researchers to identify two distinct groups that may be key to consider: funders, providers and related organisations, and users and non-users of disability sport and physical activity, although, as the following methodological reflection highlights, there was no immediate agreement on whose knowledge and experience should be sought.

Methodological reflection on whose perspective is most valued

There is some discord in discussion about whose perspective should be valued in this research. Some co-researchers keep coming back to question what information funders want to find out, what do they want to measure? One co-researcher stated they couldn't imagine doing this research without understanding the current picture and practice, what funders are currently asking for and what is working and what isn't. Other co-researchers are commenting that their perspective is not the important one, that we need to turn it on its head – what is important for disabled people to measure? Co-researchers are talking about 'flipping the script' on evaluation: evaluating in a way that's person-focused, meaningful to disabled people, as that's when they're going to get better results.

5.3.1 Our research question

A research question not only provides direction and defines the course of the research, but it also helps to set boundaries on what will and won't be considered; for this reason it must be specific and the parameters clear (O'Leary, 2013). The process undertaken to define our research question echoed Green and Stoneman's (2016) suggestion to think of all possible research questions, before narrowing the list and then refining, questioning and critiquing wording and meaning, considering the questions' objectives, terminology and assumptions (Green and Stoneman, 2016). All co-researchers engaged in this activity through mini cycles of planning, action and reflection. It is recognised that transformative aims towards change don't translate easily into research questions and that questions can evolve or change as necessary (Creswell, 2014; Watson, 2020), which is something we found as we engaged with the process and felt it necessary to include more than just funders of disability sport and physical activity. However, through our iterative and collaborative process of discussion and refinement, we arrived at an articulation of our research question. It was split into three sub-sections, reflecting two different participant groups and suggesting the possibility of seeking a solution from good examples in current practice:

How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders?

> *a) What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part?*
>
> *b) What do funders want to know about disabled people's participation in sport and physical activities?*
>
> *c) How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?*

We discussed the individual elements required of the research proposal and as facilitator I pulled it all together into a cohesive document, which we then reviewed and discussed together (Appendix 6):

Methodological reflection on agreeing our research proposal

There was little feedback on the proposal aside from some wording, but the initial response was an audible 'wow' – everyone was pleased to see our progress written down and happy in how it was pulled together.

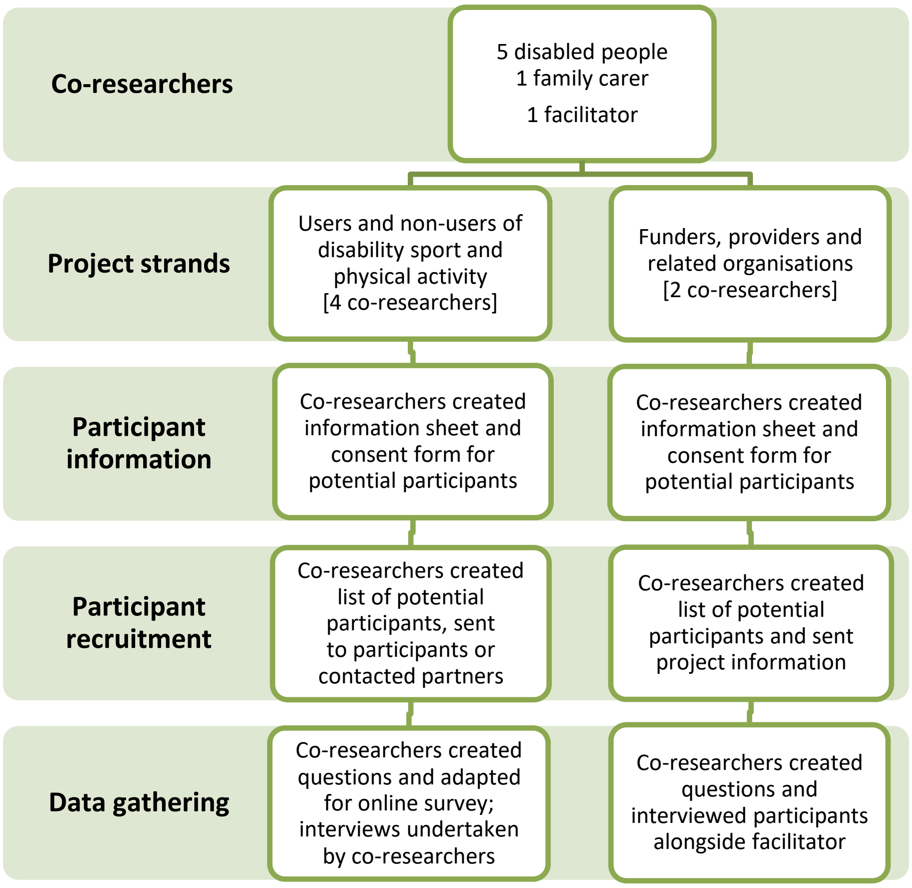


Figure 5.1: The two strands of the VIA project research proposal

The development of the two strands of the research proposal ran concurrently but separately (Figure 5.1). The process will be examined in more detail within the subsequent sections of this chapter.

Our original application for ethical approval was granted on 21st June 2021 (Reference ETH2021-1151) (Appendix 8.1), with an amendment for face-to-face data collection approved on 25th October 2021 (Reference ETH2122-0130) (Appendix 8.2).

Participant recruitment and data collection took place over a period of nine months from September 2021 to May 2022 (Figure 5.2). This protracted period enabled co-researchers to be involved in all episodes of data collection, accounting for their availability, and allowed processes to evolve, for example, adjustments to interview schedules and the addition of a survey version for carers and supporters to complete on behalf of a disabled person (where this was the preference). For reasons of availability, some co-researchers were more involved at this stage than others.

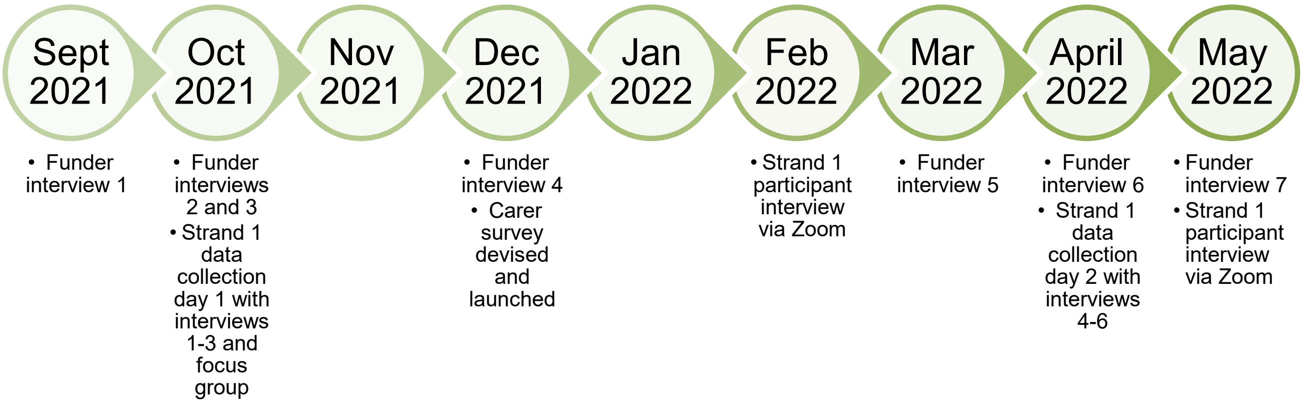


Figure 5.2: Timeline of data collection

5.4 Action: Data collection strand 1 – Users and non-users of disability sport and physical activity

The four co-researchers working on this side of the project met together within breakout room sessions across three discussion groups to plan their approach and create information to support this side of the project. First, they determined who they wanted to invite to take part in the research. The group decided how this group of participants would be described, users and non-users, the latter reflecting co-researchers’ desire to hear from people who do not currently participate in sport and physical activity, alongside those who do. The overarching aim within this data collection strand was to reflect the need for accessibility and inclusivity within the research methods selected, as a range of methods of data collection and analysis are required in response to the varying needs of disabled people (Watson, 2020).

5.4.1 Data collection strand 1: Participant information and consent

The four co-researchers worked together to design an information sheet (Appendix 7.2), a consent form (Appendix 7.3), an email to potential participants (Appendix 7.4) and an interview guide with questions that could be adapted for different modes of delivery (Appendix 7.5). This offered respondents the opportunity for choice according to what suited their own accessibility needs and reflects a qualitative approach where multiple forms of data are collected from different sources and reviewed together (Creswell, 2014). Co-researchers worked together to ensure the accessibility of all resources, and this was praised by the participants in the process of data collection:

Methodological reflection on accessibility of resources

In the course of talking about the need for accessible resources for visual impairment, one interviewee praised us for providing documents in Word rather than PDF, enabling them to magnify text as needed.

5.4.2 Data collection strand 1: Recruitment of participants

A total of 21 disabled people were recruited to this strand of the project, with 10 of these recruited with support of the collaborator for 6 face-to-face interviews and 1 focus group with 4 participants; the remaining 11 were recruited via distribution of the consent form, with 9 completing the online survey and 2 consenting to Zoom interviews. However, it took us some time to get started with data collection and I reflected on whether this was because I needed to take action, with concern whether I was holding back from taking the next steps:

Methodological reflection on starting data collection

I seem to hold the power to get data collection started; I've encouraged people to start making contact but I am concerned whether people have the time or inclination for this stage of the process, or whether they have been waiting for me to 'give permission'.

Co-researchers were involved in recruitment of participants, sending the project invitation email out to their networks, which included a link to the consent form, which was formatted for completion using Qualtrics. A co-researcher and I also attended an online meeting of a user involvement group of a disability sport and physical activity organisation to share details of the project. As I was the only co-researcher with access to the Qualtrics account (determined by the limits of university software licensing) I would check regularly for responses and note the method of data collection requested by participants who had consented to take part. Whenever an online consent form was completed on Qualtrics, the participant’s preferred method of data collection would trigger next steps. If they had selected online survey, they would be sent an automatic link. If they had requested an interview or focus group, I would manually check and email to check their availability, as well as emailing co-researchers whether they would be available to be involved. There was only one occasion where a person selected a focus group. As we did not have any other participants opting for this means of data gathering, I emailed to see whether they would like to instead complete an email or survey but received no further response.

We had planned our project in respect of Covid-19 restrictions, which necessitated us to recruit participants at a distance and plan for data collection online, with the option for use of telephone. However, there had always been concern about who we would not reach using these methods of recruitment and data collection. In September 2021, Covid-19 restrictions were lifting and there was potential for institutional ethical approval of restricted face-to-face data collection. This would be granted for a single site, subject to further Covid-19 risk assessment (Appendix 8.4). The collaborator was approached and agreed to support with participant recruitment and a case was made on the importance of being able to speak to people face-to-face, to collect data at a site contextually relevant to the inquiry (Creswell, 2014). The amendment for ethical approval was approved on 25th October 2021 (Reference ETH2122-0130) (Appendix 8.2). I reflected on the sense of progress at this point:

Methodological reflection on arranging face-to-face data collection

It feels like in this process the smallest of actions can enable snowballing of progress; from contacting the collaborator we now have a face-to-face data collection day during the half-term holiday. Not only would the timing help one co-researcher's involvement, but another co-researcher also attends the sessions on this day, so this could be a positive way to get them involved in data collection. While a detailed risk-assessment process is now required, being able to do data collection in person is so vital to capturing a greater range of perspectives and it will be a bonus to be able to see some co-researchers too – a final in-person meeting at last!

Collaborator access

In the process of planning, the collaborator and I discussed what we would be asking participants on the day. The collaborator used their knowledge of each participant to suggest who might be suitable to be involved and gained initial interest. While this relationship is an advantage in providing access to participants, with relationships brokered by a source they trust, there was potential for accusations of bias in selection. However, the collaborator's aims were to recruit people with appropriate capacity to consent and be actively involved in the interview process. The provider reassured they were offering a 'cross-section' of participants with different levels of capacity to respond and was best placed to have knowledge of people's ability to contribute to the research. Respondents of value may have been excluded by the nature of this selection process, but with the collaborator's understanding of the aims and purpose of the project and the full support they had for these, there was no intentional malice intended within their selection. On this first day of face-to-face data collection in October 2021, we spoke with a total of 7 participants. I reflected on the positive outcome from the day:

Methodological reflection on face-to-face data collection

Such good reflections on the day and the process. I have wondered whether we need to engage with face-to-face data collection outside of this one organisation. Pragmatically, it would be easier for us to stay where we are, because the site-specific risk assessment and ethics has been approved and we have potential to work with a range of different people across the different groups. Any other limitations are outweighed by the ability to involve co-researchers in the data collection at a site they know and can easily access.

As we had spoken to a range of participants with varied impairments on the first face-to-face data collection day, we did not feel we needed to approach and complete the process of ethical amendment to perform data collection at another organisation, with the risk of co-researchers not being able to attend. However, after this positive experience, data collection stalled. While treading a delicate balance between general reminders and directing action, I prompted co-researchers to continue recruitment efforts. One co-researcher invited members of their own sports club to be involved. Another co-researcher used their extensive network to distribute the study invitation to local and national disabled people’s organisations and disability sport and physical activity groups. This action enabled recruitment of a participant from Wales; although location of survey respondents is unknown, all other people involved in interviews and focus groups were based in the East of England. I reflected in my journal on the advantage of involving co-researchers in this process, with their valuable connections:

Methodological reflection on participant recruitment by co-researchers

One co-researcher is sending out to lots of contacts – a particular advantage of working in this way is having access to more people but particularly because they can judge who is well-placed to answer our questions. Also, they are hesitating until the time is right – they are aware of the priorities and preferred timings of these organisations, and the best window for approach. We would not have known this if not working in this way.

Co-researchers were keen to undertake a second day of face-to-face data collection, so I approached the collaborator, and this was arranged for April 2022. Although recruitment was not otherwise driven by impairment type, the collaborator was keen to ensure we received a variety of perspectives and experiences of disability. Whereas on the first data collection day in October 2021 we had mostly spoken with people with learning disabilities and issues with mental health, on the second data collection day we spoke with 3 participants with predominantly physical impairments.

5.4.3 Data collection strand 1: Participatory data collection

Appropriate to research under the Transformative Paradigm, decisions about data collection were made with co-researchers and time was taken to consider appropriate methods (Mertens, 2009). Co-researchers were involved in all aspects of data collection, supporting the notion that interviews need to be conducted in a way that builds trust with participants (Mertens, 2009). Co-researchers selected to use very traditional methods of data collection, which I reflected in my research journal:

Methodological reflection on selecting methods

Can co-researchers make informed decisions on the best research methods if they don't know the potential for more creative approaches? Should I have presented a list of possible methods to encourage thinking about more creative opportunities to capture information from people with the most severe impairments?

Perhaps this was more a product of the time, with Covid-19 restrictions and uncertainty whether we could collect data in person.

Online survey

A total of 9 qualitative survey responses were received, including 3 pilot responses. Co-researchers had worked to create a series of questions that could be applied in a range of formats (see Appendix 7.5). One of the co-researchers was particularly keen for the questions to be sent out as a survey, noting the lack of contact (due to the Covid-19 pandemic) with the service users she usually worked with. Using my university subscription I formatted the survey within Qualtrics, retaining the wording and accompanying images selected by co-researchers within discussion group 8. I created PDFs of the draft survey so that co-researchers could review and suggest any changes, and a version was also created for carers:

Methodological reflection on Introducing an online survey

From their own experiences of working with people with profound impairment, one co-researcher has insisted on an online survey, including a version for completion by carers and family members.

To pilot the surveys, the co-researcher sent them to a group of disabled people that they had worked with as advisors on different projects. We added a box for feedback on the survey itself and implemented a number of suggested changes before distributing the final version. Online survey software has advantages in supporting with formatting, including images, automating routing between questions and forcing certain responses, but it also requires access to the internet (Leddy-Owen, 2016). Hence the online survey was only one of a number of means for participation (Appendix 7.6).

Face-to-face interviews

A total of 10 face-to-face interviews took place on two occasions at the collaborator's disability sport and physical activity organisation, with participants attending cycling and keep-fit activities at an outdoor park surrounding a lake. Both occurred within school holidays so that the co-researcher who is a primary school teacher could be involved in data collection.

Face-to-face data collection day 1 – October 2021

On the first occasion of face-to-face data collection, two other co-researchers joined me. Before we began the process of data collection, we all joined in with a cycling activity, each selecting an adapted bicycle and joining a group cycling on a track around the lake. After our return, we began the process of interviewing. Our locations for data collection varied between sitting on adapted bicycles while interviewees sat on the tail bed of a lorry or on fold-up chairs, to a field shelter between the activity area and the café, where participants often had their lunch (Figure 5.3). We had good access to participants by conducting the data collection at the site of their sport and physical activity participation, but it was difficult to ensure a private and comfortable space for data collection. The first two interviews took place at the back of the organisation’s lorry, one of the participants had a parent alongside offering a small amount of support. A focus group of four participants had two parents nearby although they did not intervene; this focus group was held in their lunch venue by a noisy roadside.

Figure 5.3: Locations for face-to-face data collection (day 1)

Despite recommendations for consistency (Creswell, 2014), an interview protocol was not developed for ensuring standard procedures, as each interview required adaptation according to the needs of the participant, using the loose semi-structured question guide (Appendix 7.5). Questions were often approached in a different sequence and additional probing varied within each interview, according to whether later questions had been addressed earlier on (Fielding and Thomas, 2016). Together, the two co-researchers carried out interviews together, while I remained present to deal with technical aspects such as recording interviews. In most cases at least one co-researcher knew the participant, which encouraged their ease with the situation. While it is recognised that interviewees can share their own perspective and potentially introduce bias with misdirected prompting, probing or wording (Fielding and Thomas, 2016), co-researcher contribution to the co-creation of knowledge was prioritised.

The co-researchers undertook consenting procedures. To gain fully informed consent, it needs to be considered from the participant's perspective what they need to know and understand, without overwhelming them; co-researcher involvement aided this process (Boddy, 2016). It was not expected that all participants would be able to read or understand the participant information, so verbal explanations were given with time and space for participants to ask questions and discuss as needed (Boddy, 2016). In preparation for this, I had printed participant information sheets and consent forms in standard and large print, and copies of the questions. I had brought audio recorders and iPads loaded with the consent forms and surveys. I wanted to ensure a range of different options for people but it turned out the best approach, initiated by the co-researchers, was to give the participant a copy of the information sheet and for co-researchers to talk it through verbally, simplifying where needed and checking understanding throughout. Each participant was then offered to complete the consent form via paper or iPad.

The preferred format was for questions to be asked verbally, with co-researchers taking it in turns to ask the questions, adapting and prompting where necessary. The discussion was audio recorded. Co-researchers were acutely aware of the potential for our data collection to replicate difficulties experienced during evaluation with participants. The co-researchers interviewed one participant on their own, another with support of their father and a group of four friends together as a form of focus group. The third interview was conducted with a third co-researcher who was attending their keep-fit activity on this day. Despite the process of consent being successfully completed for this interview, responses to questions suggested that the participant’s level of cognitive understanding was limited. While the approach was adapted as far as possible to aid understanding, responses did not relate to questions, and it was necessary to disregard the data from the final analysis. On this day, one focus group with 4 participants and 2 individual interviews were successfully completed.

Face-to-face data collection day 2 – April 2022

On the second episode of face-to-face data collection our location was static (Figure 5.4). We used a bench near to the site of activity but far enough away to ensure a degree of privacy.

Figure 5.4: Location for face-to-face data collection (day 2)

The collaborator was leading a cycling group on my arrival but the first participant was present, so we started building rapport. The co-researcher was arriving later, so I introduced the project and proceeded with the process of informed consent and interview. As the interview proceeded it was clear that the interviewee was experiencing some mental health issues, so I raised a concern (without specific details) with the collaborator afterwards. The researcher has a duty of care to consider how it might be escalated or handled if a participant reveals any difficulties (Boddy, 2016).

The co-researcher was known to the second participant and the collaborator suggested the participant may feel more comfortable if the co-researcher took the lead in introducing the project, undertaking the process of informed consent and subsequently the interview. The co-researcher and participant drew on each other's experiences of having the same type of impairment and how it reflected their own experience. The collaborator then briefed the co-researcher and I on the third and final interviewee for the day. The collaborator suggested the co-researcher might find it easier to understand the participant's speech, so the co-researcher led the process of informed consent and conducted the interview, but there were no communication challenges and we both provided prompts and requests for further information.

On both the first and second face-to-face data collection days, following the completion of all interviews, we gathered together and each co-researcher shared a verbal reflection on the progress of the day using the process outlined in Section 5.5.4, which was audio recorded to be appended to the transcripts.

Zoom interviews

Two participants expressed a preference for an interview using Zoom, so these were arranged with co-researcher involvement. The first participant shared a perspective so far unheard, as a partially sighted person heavily involved in Goalball. The benefits of co-researcher involvement came to the fore within this interview, as the co-researcher and interviewee shared mutual experiences:

Methodological reflection on the benefits of co-researcher involvement

The interviewee and co-researcher shared their experiences of disability sport with one another. The co-researcher also identified with the interviewee's frustrations about inaccessible documents. It was also positive for the co-researcher to share their perspective on the project and what they thought would come of it.

The participant later emailed some additional comments, which were appended to the transcript. Both Zoom interviews took place with participants who were also involved in organising sport and physical activity opportunities for other disabled people, so there were some additional provider perspectives gained. After each interview, the co-researcher involved and I used the process outlined in Section 5.5.4 to capture initial analytical thoughts.

5.5 Action: Data collection strand 2 – Funders, providers and related organisations

Two co-researchers met together within breakout room sessions across three discussion groups to plan their approach and create information to support this side of the project. They first determined who they wanted to invite to take part in the research and what they would like to ask them. While the focus was initially funders, they expressed a desire to speak to organisations at three levels: large overarching funding bodies, intermediary organisations who distribute funding and grassroots providers who receive funding.

5.5.1 Data collection strand 2: Participant information and consent

The two co-researchers worked together to design an information sheet (Appendix 7.8), consent form (Appendix 7.9) and invitation email (Appendix 7.10). All interviewees but one (who was interviewed face to face) received the participant information sheet and link to the consent form on Qualtrics and completed the consent form via this route.

5.5.2 Data collection strand 2: Recruitment of participants

The two co-researchers on this project strand created lists of their own contacts and potential participants across the three categories, known through work or volunteering. Recruitment occurred organically via these existing contacts, and interviewees also shared project information with their networks.

A total of 7 representatives from a range of organisations were recruited to this strand of the project (Appendix 7.12), with the aim of representing varied perspectives across the categories of funder, which incorporated both large national funding bodies and smaller, regional bodies that often distributed funding on behalf of these larger funding bodies, and providers of disability sport and physical activity. Related organisations included those with alternative perspectives that did not fit within these two defined categories.

While co-researchers were actively involved in inviting people to participate in the project, the first and second interviews came from my own contact with two different organisations. During the scoping exercise, these contacts expressed interest in our next steps. I sent the project information, and the participants completed the consent form. The third and fourth participants were recruited to the project by co-researchers, who sent project invitations and arranged the date and time of the interview. In the cases where co-researchers arranged interviews with participants, I supported with the facilitation, for example, monitoring the completion of consent forms and setting up Zoom links. For the fifth interview, a co-researcher attempted to arrange the involvement of a participant within this specific organisation, but they were unavailable, so I approached my own contact at the same organisation, which was successful. As a result of this interview, where the use of evaluation companies was mentioned, the co-researcher suggested that it would be useful to hear from that perspective. We discussed a potential contact, and this led to our final interview. The sixth interview had been completed with the community collaborator, as their perspective was deemed invaluable by co-researchers.

There were other organisations approached by the co-researchers who did not proceed to complete the consent form. While in some cases co-researchers checked back to see they had received the information, they had an awareness of the ethics of coercion and did not push any further for their participation.

During this process, co-researchers identified a number of actors involved in the evaluation of disability sport and physical activity and were keen to illustrate the relationships between them. Figure 5.5 demonstrates the potential connections between data subjects and other organisations mentioned in the course of interviews. It should be noted that while a National Governing Body was consulted within the initial scoping exercise for this project, there was no representation from this level within the data collection. Additionally, while co-researchers were keen to speak to a representative from the UK Government Department of Culture, Media and Sport, describing it as ‘the missing link in the chain’, contact was made but did not lead to confirmed arrangements within the timescale allocated for data collection.

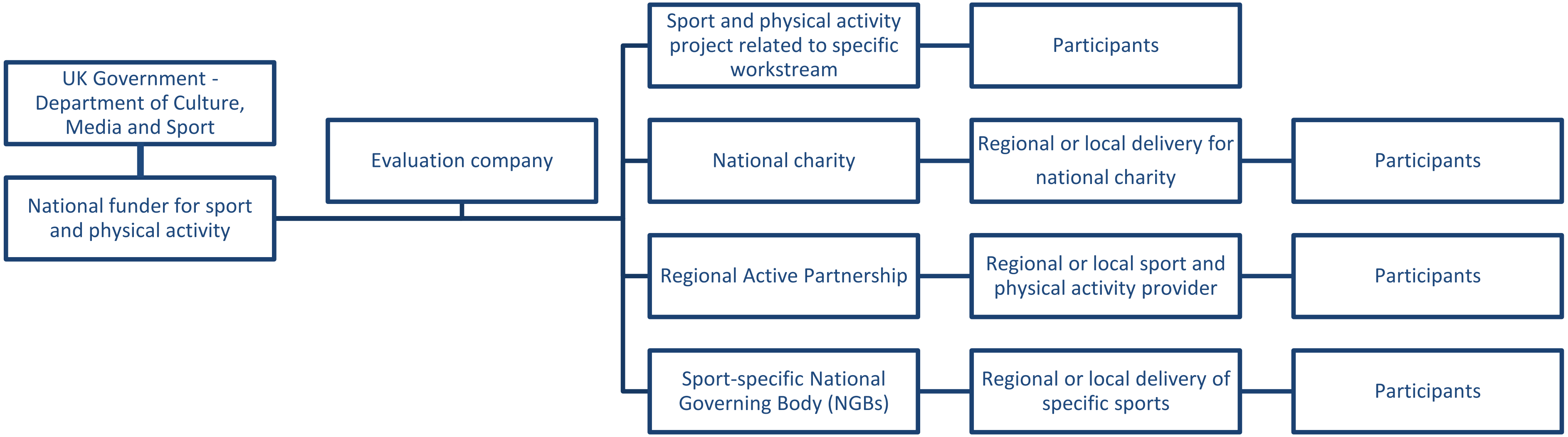


Figure 5.5: The potential relationships between participants in the Voices for Inclusive Activity research project

5.5.3 Data collection strand 2: Participatory data collection

Interviews on Zoom were felt to be the most accessible way to engage in data collection with participants on this side of the project. Two sets of questions (related but slightly differently worded) were composed for 1) funders and the intermediary organisations and 2) disability sport and physical activity providers who receive funding. The co-researchers were also proactive in meeting at a separate time outside of discussion groups to work on finalising their interview schedule (Appendix 7.11).

Co-researchers were involved in conducting all seven interviews. Six were completed online using Zoom and one was completed face-to-face, with audio recordings completed for all. After I had noted completed consent forms were received in Qualtrics, I either contacted both co-researchers working on this strand of the project, or the one who had sent the initial invite to the participant. Together, we negotiated our availability with the participant to find a mutually suitable time.

Co-researchers involved in this strand of the project undertook two and three interviews respectively, while the remaining two were conducted by co-researchers who had been involved with Strand 1. In one of these cases, the co-researcher had sent the invitation and project information as they were known to the participant, and the other two co-researchers were happy for them to conduct the interview because of this. The face-to-face interview with the collaborator happened opportunistically while a co-researcher and I were on site for Strand 1 participant data collection. The co-researcher was less familiar with the questions on this side of the project but was keen to be involved and the interview proceeded well due to their existing relationship with the collaborator.

For the Zoom interviews, the co-researcher and I would meet online 10-15 minutes before the start time to discuss and agree our plan, which involved taking turns to ask questions and to prompt for further clarification. In most cases I introduced the interview and consent process, where we checked they had read the project information, whether they had any questions and whether they were happy to proceed and be audio recorded. I reflected how this changed as co-researchers grew confidence in the process:

Methodological reflection on interviewing with co-researchers

In some interviews, the co-researcher took the lead, prompting and asking useful and insightful extra questions, especially when they knew more about what was being discussed. This was particularly present in one interview when the co-researcher knew the interviewee, but I did not, which represented a power shift in the process. I offered that the co-researcher would be welcome to work on transcription if they wanted to, but they were quick to respond that I was welcome to that task. This is a good reflection on maximising use of co-researcher skills and experience where they are most valued.

5.5.4 Post-data collection reflections

I was present alongside co-researchers for all episodes of data collection within both strands of the project. At the end of each interview (or data collection day) the co-researcher and I would share observations on the episode of data collection, using Rolfe *et al.*'s (2001) model of reflection as a loose structure for this conversation (see Figure 5.6) (Rolfe, Freshwater and Jasper, 2001). These conversations were recorded on the transcript alongside the data that had been collected and provided an initial stage of analysis from a co-researcher perspective.

What? What did you see, hear and feel?
So what? What do you think this means? What was important? What answers our research questions?

- How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders?
- What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part?
- What do funders want to know about disabled people's participation in sport and physical activities?
- How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?

Now what? What else do we need to know? Do we need to do anything differently next time?

Figure 5.6: The structure of post-data collection reflections with co-researchers

5.5.5 Data transcription

At the request of co-researchers, I took on the task of transcription of interviews. Face-to-face interviews were transcribed verbatim using the audio recordings from the digital recording device. Zoom interviews were audio recorded (video recordings were destroyed as per our requirements for ethical approval) and an automatic transcript was created. However, the precision of this method was unreliable depending on clarity of speech and each transcript had to be checked in detail for accuracy. All transcripts were saved in Microsoft Word in our shared secure area on file sharing platform Box and then transferred to NVivo. Due to institutional access restrictions, only I had access to survey data on Qualtrics, but I downloaded responses into Microsoft Word and saved this on Box for co-researcher access and simultaneously transferred this data on to NVivo.

After data collection and transcription was complete, we negotiated another co-researcher discussion group (five months after our last group catch-up) and discussed what data we had collected and our approach the next stage within the research process. Our previous discussion groups had been focused on planning the practicalities of data collection. However, in this process, one co-researcher had expressed particular concerns about the volume of data, how overwhelming this might be and how it might be handled:

Methodological reflection on our next steps

After our interview the co-researcher asked what we do with all this information – where do we see it going? They enquired about the process, showing an interest in how it might proceed.

It felt necessary to ensure co-researchers were fully informed about the stage of making sense of data. This was achieved through a process of negotiation about ongoing and continual involvement, which will now be described.

5.6 Reflection: Participatory data analysis

Within PAR there is no set approach to analysis, and it is a process present throughout the iterative cycles of planning, action and reflection (Cahill, 2007). However, this section will concentrate specifically on the analysis of data collected from participants; I will discuss our specific approach and how it has been located, theoretically and pragmatically, within the context of PAR.

At its essence, data analysis is about deciding what matters in the data in relation to the research questions being asked. The analysis of qualitative data often involves a series of steps that need to be well documented to demonstrate the validity of the approach; information is often organised inductively through a process of categorisation, but deductive thinking is also employed to see how data can be used to support those categories, with search for participant meaning paramount to the process (Creswell, 2014). Who is making the decisions about what matters, why and how, is of vital significance, because power relations are at play in terms of who is able to access data and who interprets it, and what is and is not significant (Mertens, 2009; Denzin and Lincoln, 2018). Not only is participation in data analysis essential for an inclusive approach, but insider ability to reflect on meaning within data can enhance validity and authenticity of the findings, grounding them in experience (Kramer *et al.*, 2011; Nind, 2011). By reducing the importance of the academic researcher's perspective, collaborative analysis gives potential to challenge academic approaches and raise new insights, and ensures co-researchers' views are central to the findings (Gillard *et al.*, 2012; Liebenberg, Jamal and Ikeda, 2020). Excluding disabled people from the process of data analysis is problematic in any attempt to observe the disability rights movement call for "Nothing about us without us" (Nind, 2011). It also denies the opportunity for people to draw connections between the data and any actions that result (Kramer *et al.*, 2011).

It was the intention to continue the collaborative nature of our project into this stage, aiming to involve co-researchers in as many aspects of the analytical process as possible, while respecting the rights of co-researchers to be involved as much or as little as their other commitments and interest allowed. While involvement in shaping and creating knowledge is embraced within PAR, it is recognised within the literature that this is a challenging and conceptually abstract stage in which to retain collaborative engagement (Nind, 2011). This may be for various reasons, including the complexity of each task and the time required (Frisby *et al.*, 2005; Nind, 2011; Liebenberg, Jamal and Ikeda, 2020). Consequentially, there is a danger of involvement being less rigorous and light touch, which risks compromising a research stage that is key to the production of new knowledge and insight

(Liebenberg, Jamal and Ikeda, 2020).

Deliberate decisions were required to shape a pragmatic approach that enabled contribution where it was most valued and the best use of our time together, maximising the strengths of co-researchers as people with lived experience. We discussed and negotiated the different levels for potential involvement, from analysis being completed by me alone, to involvement of some co-researchers in the process, to findings being verified by co-researchers or having co-researchers fully involved at all stages, including coding and re-coding (Cahill, 2007). Mindful of the time-intensive nature of data coding and theme development, we discussed and agreed for me to complete initial work to organise the data for accessibility. This did not sit entirely comfortably, as I did not want to take the data ‘away’ from the group of co-researchers, only to bring back a ‘polished up’ version. However, Tuffrey-Wijne and Butler (2010) and Liebenberg *et al*. (2020) describe a similar approach, where a certain level of analysis was undertaken before initial ideas were shared with co-researchers, which enabled meaningful contribution where skills, experiences and interests were best employed (Tuffrey-Wijne and Butler, 2010; Liebenberg, Jamal and Ikeda, 2020). Cornish *et al*. (2023) also describe how it may be appropriate for scholars to create an initial draft of messages for discussion, grounded in data, to provide something for co-researchers to react to, discuss, examine and contribute interpretations and recommendations (Cornish *et al.*, 2023). Co-researchers agreed in consensus that it was more practical for initial data interpretation to be undertaken by one person and appreciated the opportunity to contribute at a time that enabled them to make the best (and most efficient) use of their own lived experiences – to discuss and make sense of interpretations and determine next steps.

Our negotiations resulted in the analytical process outlined in Figure 5.7, which aligns with Cornish *et al.*'s (2023) description of collaborative analysis involving an iterative series of individual/pair/group discussions (Cornish *et al.*, 2023). While I later discuss the rationale behind my reticence in providing formalised co-researcher training in Section 7.5.6, the process of analysis is somewhat abstract; to ensure co-researchers could make well-informed choices about whether and/or how they wished to be involved, it felt pertinent to explore their understanding of analysis and to share an overview of what it entails. To further enable accessibility, our approach was oriented to processes of discussion and reflection on data in light of lived experience (Nind *et al.*, 2016); this relates back to Freire's (1972) emphasis on the value of group dialogue for exploring meaning (Freire, 1972).

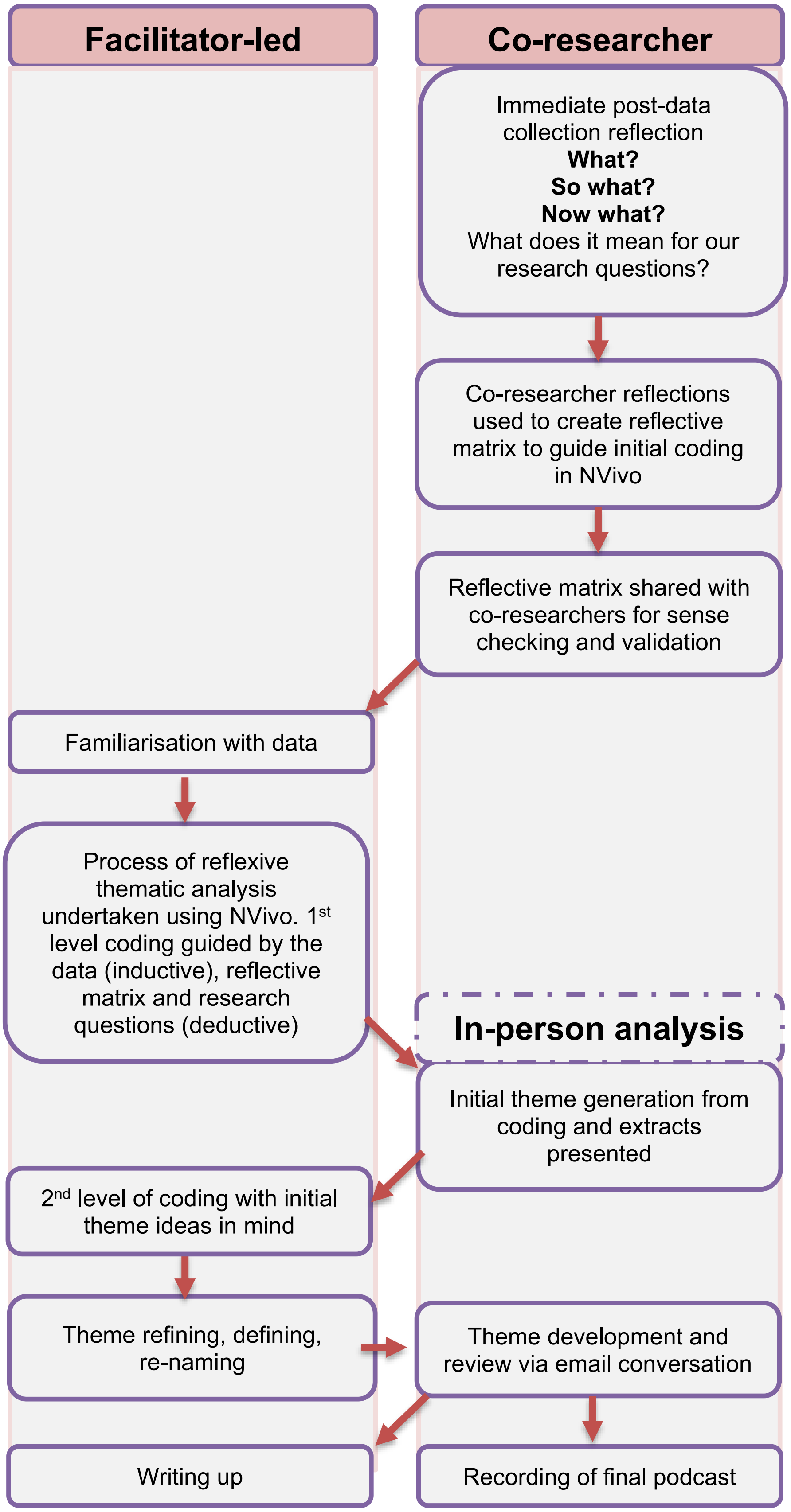


Figure 5.7: Our analytical process: a visual representation

As noted in the reflection below, I was hesitant in selecting to use Computer-assisted qualitative data analysis software (CAQDAS) as this would require me to take the data into a programme (NVivo) that only I had access to due to University licensing. However, use of analytical software enables transparent strategies, can demonstrate procedures and help with tracking and tracing developing interpretations (Silver, 2016). I reflected on this within my journal:

Methodological reflection on manual or computer-assisted analysis

Before we began collecting data, I was sure that I would undertake analysis manually, using printed transcripts, highlighters and pens to make notes, before transferring these online to be accessible for co-researchers. However, these efforts will not necessarily make the analytical process more accessible to co-researchers – the addition of many notes and tracked comments to Word documents that are many pages long, or scans of highlighted and annotated transcripts, are not necessarily more accessible. I was wary of hiding the data away within a programme inaccessible to co-researchers, both due to licensing and lack of software training, but using NVivo will not only help me to manage a large quantity of data, but it will automate an audit trail. The challenge is to convert this work into a more accessible format for co-researchers.

5.6.1 Reflexive thematic analysis

While I have endeavoured to ensure collaborative decision-making throughout this project, I did make the selection of reflexive thematic analysis as the analytical approach (Braun and Clarke, 2019). However, this is not entirely without founding in the thoughts of co-researchers, who were keen to know ‘what’ we found out.

While thematic analysis is a broad descriptor of a range of approaches to data analysis that explore patterns of meaning, the particular appeal of reflexive thematic analysis was the emphasis on reflexivity, with the researcher making active decisions about how they work with the data and why these decisions have been made; a concept that has been critical throughout this project (Braun and Clarke, 2022). This approach enabled continued centring of co-researcher knowledge and experience, and critical analysis of how and why decisions were made and actions taken. Additionally, with no attached theory or theoretical framework for analysis, it was appropriate for a project where multiple theoretical positions have been explored and combined (Trainor and Bundon, 2021).

Practically, we adopted a number of reflexive strategies within our analytical process. First and foremost, the reflective conversations at the end of interviews enabled co-researchers to respond to the episode of data collection and enabled me to centre their thoughts on the data and the process of collecting it. During the times when I was interpreting data away from co-researcher involvement, I took into account the reflective journal entry related to the episode of data collection as I was coding, following the approach taken by Trainor and Bundon (Trainor and Bundon, 2021). I created an audit trail in a physical journal that was purely for recording reflections on the process of analysis and used the NVivo annotation function to record my responses to the data with potential reasons, to ensure I was prioritising co-researcher responses.

As a novice researcher, the task of analysing data was a necessary but daunting task ahead. However, Braun and Clarke's (2022) six steps of reflexive thematic analysis provide a loose but useful aide memoire, as opposed to a fixed structure, and I took influence from Trainor and Bundon's (2021) thorough reflexive description of the approach taken in their own project (Trainor and Bundon, 2021; Braun and Clarke, 2022).

1. Familiarisation with the data – getting to know the information we've collected

After transcription was complete and transcripts were saved within an NVivo project, I continued the process of familiarisation by reading each transcript and using the annotation function to pick out anything that struck me as interesting or relevant to the research questions, reflecting on overall meaning and general ideas (Creswell, 2014). As co-researchers had been involved in the recruitment and data collection process, with each interview, at least one co-researcher was already familiar with content and had provided their initial reflections at the end of the interview. One co-researcher took the time to listen to all interviews to remain familiar with the progress of the project.

The data from the two strands of the project were treated as distinct data sets. As co-researchers planned our project together and considered who to involve (as described in Section 5.3) representation of the diversity of disability and disabled people's experiences was considered essential. Braun and Clarke (2022) reflect how ethical considerations around power, representation, consideration of difference and inclusion are present within the process of conducting reflexive thematic analysis

(Braun and Clarke, 2022). Thus, a question arose at this stage of how difference should be acknowledged within the analysis, and whether it was necessary to treat data separately according to the nature of the participant's impairment. Some difference was also notable in the reduced quantity of data provided by respondents identifying as having a learning disability, for example. Although all data was analysed together, this was a point held in mind throughout the process.

Reflective matrices guided by co-researcher reflections

At this point I diverted slightly from the process of reflexive thematic analysis to include an additional step. As previously noted, following each episode of data collection, co-researchers shared their observations through a loosely structured reflective process (Figure 5.6). These reflections included insight of both the content of the data and the practicalities and challenges of the process, with potential learning for evaluative practice. I began by working through each of the transcripts from these conversations, highlighting and adding familiarisation notes.

Starting with these co-researcher reflections, I produced three reflective matrices aligned with the three aspects of the research question (Appendix 9.1), which highlighted elements co-researchers had found interesting and significant during data collection. The name 'reflective matrix' is deliberate to enforce that this was not a framework guiding the coding process (as with a framework analysis approach) but a loose guide of ideas to use alongside my own response to the data. This distinction is important, as Braun and Clarke (2020) emphasise use of frameworks as the antithesis of reflexive thematic analysis, restricting deep engagement with data interpretation and creating potential for a topic summary rather than meaningful analysis (Braun and Clarke, 2020). As such, our reflective matrices were tools for enabling deeper collaboration rather than a tendency towards a formulaic approach. It was some comfort to be able to start with the reflections, thoughts and observations from co-researchers as the first stage of analysis, which signalled our intention to incorporate collaborative elements wherever possible within the analytical process. Once complete, the matrices were discussed and agreed with co-researchers ahead of the next step in the process.

2. Data coding

The next stage of the analysis involved beginning to apply codes to the data. I began with the funder and related organisation interviews, working systematically through from Interview A to G. I worked top down through the data, coding sentences and longer passages to look for both semantic (surface level, descriptive) and latent (conceptual, analytical) meaning (Trainor and Bundon, 2021). The ideas within the reflective matrix were summarised as codes within NVivo but were not fixed. I coded data to these codes but also created new codes, tweaking coding descriptions as I went along. This involved approaching the data more inductively, looking for ideas of interest within the data not related to research questions or ideas within the reflective matrices. I created a lot of codes to capture the nuance of ideas, not seeking to refine them but seeking connections where appropriate. As I progressed through the interviews I sometimes worked back and forwards between them, but tried to maintain the logical, top-down approach at this stage.

I did not want to exclude anything significant, but this perhaps led to over-coding. By Interview F I was applying a lighter touch in coding as I realised it was not necessary to code everything, such as contextual information unrelated to research questions that could be used to form case files. The user and non-user data was much lighter on codes, with some responses much shorter in length and complexity. While the survey format enabled accessibility to the research for some, the limited breadth of detail provided (in comparison with interview data) led to the application of fewer codes. In two cases, the Zoom interviews, the disabled people interviewed were also involved in the provision of disability sport and physical activity, so elements of their interviews were also coded to the funder code set.

I had initially decided to do a second run of coding at this point but instead made the decision to start a process of merging, collapsing and organising codes into hierarchies, approaching them now with both the research questions and reflective matrices in mind. After the first round of coding there were 225 codes related to research question A, 97 for question B and 25 for question C. I was concerned that the codes at this stage were predominantly descriptive and as I began to work with codes and bring them together, I started to consider theoretical and analytical ideas that might tie these together. However, I did not want to make too many decisions or narrow too far at this point.

3. Initial theme generation

I then proceeded to organise theme ideas in response to each of the three research questions. After some time spent combining, collapsing and redefining ideas, initial themes were ready for sharing with co-researchers for their perspective on what appeared to be within the data. At this stage, 4 themes and 12 sub-themes were presented for Research Question A, 4 themes and 2 sub-themes for Research Question B and 4 themes and 10 sub-themes for Research Question C. Each theme and sub-theme included a description capturing ideas from the data (Appendix 9.3).

4. Theme development and review: analysis and findings day

Co-researcher collaboration was paramount to this stage, with four co-researchers and me attending our co-researcher analysis and findings day , held at a mutually negotiated location on 14th April 2024. The venue was chosen to meet travel and accessibility requirements and was arranged by one of the co-researchers. In-person workshops (or ‘research parties’ as in (Frisby *et al.*, 2005)) have been reported elsewhere as offering good potential for engagement in participatory analysis (Pettican, 2018a; Liebenberg, Jamal and Ikeda, 2020). This group discussion approach to data analysis provides opportunity for deeper engagement as it enables each person to bring their own perspective to the data (Liebenberg, Jamal and Ikeda, 2020).

As with our other sessions, a loosely structured session plan was created and distributed to co-researchers ahead of the day, with allowance for flexibility (Appendix 9.2). As before, we began with gathering and social time; there was a shared consensus that it was a positive experience to finally meet together in person. I gave a brief review of the analytical process undertaken thus far and distributed copies of the research questions around the table, to provide a visual reminder during our discussion. Each of the theme and sub-theme ideas were presented with their initial descriptions on A3 sheets (Appendix 9.3). I gave a brief verbal summary of the themes generated before discussion of each question. Co-researchers were encouraged to discuss and question the interpretation of themes from the data, enabling a critical approach to reviewing, questioning and checking the ‘accuracy’ of interpretations, enabling a form of qualitative validity (Figure 5.8, 5.9, 5.10) (Creswell, 2014).

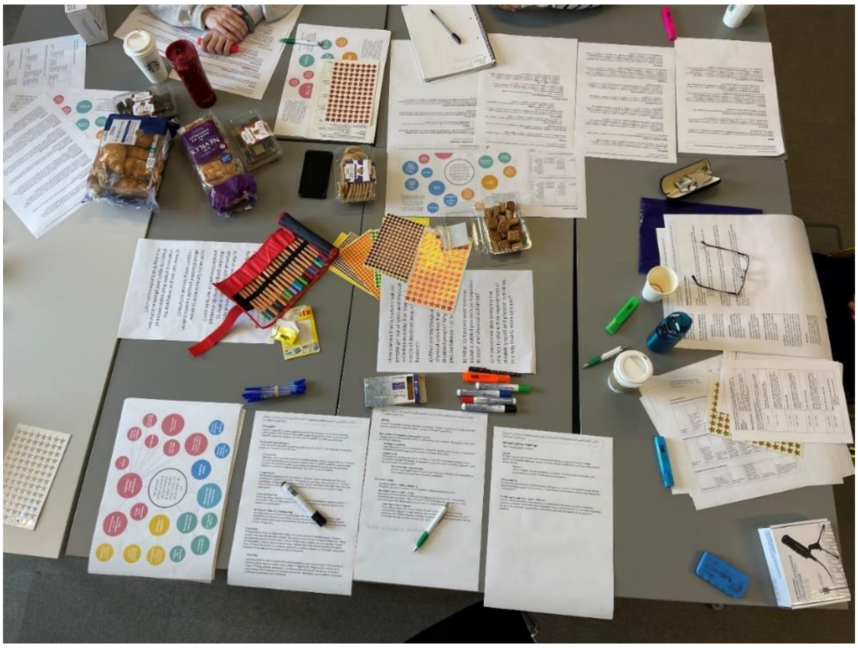


Figure 5.8: A space for discussion at our co-researcher analysis and findings day

Figure 5.9: Co-researcher Vanessa with findings documentation

Figure 5.10: Co-researchers discussed each research question in turn

We had a hesitant start as co-researchers appeared to defer to me to direct the process, as I reflected within my journal:

Methodological reflection on disrupting conventional power dynamics

Once co-researchers had read through the documentation for Question A, co-researchers asked me what I wanted them to do, and I reflected back for them to consider how they wanted to proceed. This situation, reminiscent of our earlier co-researcher discussion groups where we were searching for a way ahead with little direction, reflected the continual need to disrupt conventional power dynamics of the researcher as expert to sustain a participatory approach.

However, co-researchers soon rediscovered the medium that had suited us during our time on Zoom, group discussion. I provided stickers, sticky stars, highlighters and pens for co-researchers to annotate the sheets, to encourage an individual means of response seen in other studies where people contribute thoughts on findings in a way that suits them. In reality, there were few notes made by co-researchers during the session, as talk and the recording of talk once again became our mechanism for exploring our research questions. Conversation flowed as points were made, responded to and expanded. Co-researchers read the findings documentation and proceeded to pick out what appeared most resonant and important, providing personal experiences and reflections in relation to the points – far more than had been evident during the online discussion groups. There was also a more political angle to discussions that had not arisen previously. Perhaps this was a response to the shift in the UK political and socioeconomic landscape since our last discussion group in 2022, but it appeared that co-researchers felt more able to provide these contributions within this space, as I reflected in my journal:

Methodological reflection on the benefit of meeting in person

The dynamic of conversation was more natural in this context than it was on Zoom – conversation cues and body language were more accessible to all. A comment was made on how we achieved so much in this day, far more than had been possible on Zoom – how it would have been more productive to have met in person. But there was also reflection on the practical difficulties of meeting regularly.

We trialled use of the Dragan Dictate app, which a co-researcher had on their phone, to audio record our discussion. However, this had limited success, so I took on the role of notetaker, something that had been considered useful during our online discussion groups, where we made use of the virtual whiteboard function on Zoom:

Methodological reflection on my role as notetaker

I mostly stood back and took the role of scribe. The large whiteboard enabled us to capture the essence of our discussion. I aimed to be true to the words spoken – a co-researcher also highlighted the need to emphasise the words of participants.

I used the long whiteboard that spanned the length of the room to record all points made by co-researchers, aiming to record discussion verbatim as much as possible (Figure 5.11). I contributed little to the discussion, except to clarify and reflect on points at infrequent intervals. This enabled co-researchers to visualise outcomes from discussion and refer back to points as the day progressed.

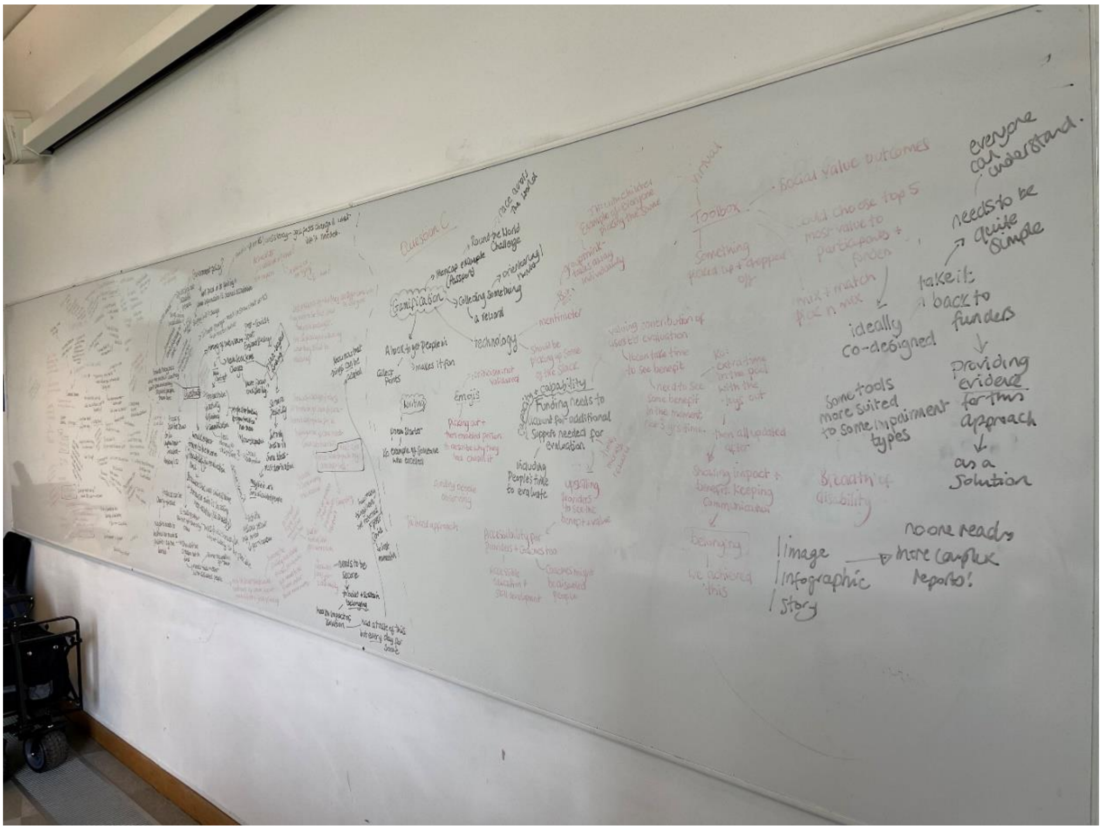


Figure 5.11: A full record of the discussion was made along a wide whiteboard

5. Theme refining, defining and naming

Following the meeting with co-researchers I returned to the data with their ideas fresh in mind, to complete a second level of coding. The approach this time was less top-down and more lateral, starting in the middle of the dataset and approaching transcripts in a different order, working between and among them to find anything else related to co-researchers' interpretations. The final themes and sub-themes are presented within *Chapter 6: Research Findings from Data Collection.*

6. Writing up

The final stage of the process of reflective thematic analysis, writing up, is the subject of *Chapter 6: Research Findings from Data Collection* and subsequent chapters. However, in our desire for collaborative dissemination, co-researchers came together to plan and record a podcast episode exploring our findings and recommendations (Appendix 10.3 and Section 8.4.1).

Figure 5.12: Co-researchers together at the end of our analysis and findings day

5.7 Rigor and quality in PAR

Any judgement of the quality of this study needs to consider the specific nature of PAR and how existing quality criteria based upon positivist values are unlikely to apply to community approaches that can appear ‘messy’, without a set structure and can offer a challenge to what research looks like (Hammersley, 2008; Warren *et al*., 2018). Previous critique of PAR as being ‘unscientific’ and ‘too specific to population’ could be reversed as a hallmark of quality (Silver, 2016). By its nature, PAR must be context specific and challenge traditional processes of knowledge production. The specificity of context means that findings cannot be generalised but there may be learning or elements of process that are applicable and transferable to other situations (Koch and Kralik, 2006; Silver, 2016). This is evident within Chapter 7: *Methodological Learning*, where a reflection on process offers recommendations for others undertaking collaborative research.

Sharma and Bansal (2020) offer useful reflections on the challenges within knowledge co-creation approaches that span two knowledge systems of research and practice, noting that research communities favour rigour, whereas relevance is more important to those in practice (Sharma and Bansal, 2020). The placement of practical or political goals above knowledge production has been a critique of participatory forms of inquiry, but any judgment of this type of research depends on a perspective that values additional criteria, such as whether findings are useful and whether they have made a difference that will sustain into the future (Koch and Kralik, 2006; Hammersley, 2008). Warren *et al*. (2018) argue against critique that advocacy-oriented research approaches cannot meet standards of quality and rigour because of inherent bias, proposing that such approaches must in fact be highly rigorous in order to support an aim towards social justice and accountability to the people involved and affected by the inquiry, rather than a scholarly community (Warren *et al*., 2018). As co-researchers within the VIA project argued, we needed evidence to demonstrate the need for change.

Quality within participatory research may be judged by the quality of relationships, trust, cooperation and accountability developed between co-researchers over time, with the involvement of the community from the outset and at all stages, with maximisation of their skills and expertise to solve a problem they've identified, with the researcher taking a facilitative rather than investigative role and conceding any power over the process (Koch and Kralik, 2006; Schinke, McGannon and Smith, 2015; Warren *et al*., 2018). Throughout this process I have sought to reflect on and ensure the presence of all of these elements; rigor is also present within reflexive processes, including the recording of reflections on the process, which require personal position, values and interests to be made explicit, (Koch and Kralik, 2006; Hammersley, 2008).

Attention to inclusive practice and process also ensures increased accountability to meeting needs, with a perceived positive impact on the quality of the research undertaken (Hickey *et al.*, 2021). Accessibility of the work is another question asked by Koch and Kralik (2006) in terms of judging quality; while this might not be the case with the construction and requirements of this thesis, efforts have been made in producing accessible summaries of chapters (Appendix 1) and in ensuring additional collaborative dissemination activities (Appendix 10) (Koch and Kralik, 2006).

As principles of co-production were adopted within this project, benefit would also be gained from mapping to the principles for judging the quality of co-produced research outlined within Smith *et al*. (2022). Co-researchers reflected how working on Zoom enabled their access to the research more easily than an in-person approach would have done. Focus was placed on the development of genuine relationships, with consideration throughout of power dynamics and capacity building for co-researchers. Co-researcher and participant knowledge was foregrounded and valued. Diversity was encouraged through a process of ensuring and revisiting accessibility from the point of recruitment and throughout the research process.

Opportunities for reciprocity were continually sought (Smith *et al.*, 2023).

Values of quality from the tradition of qualitative enquiry may be applied to the research undertaken within the VIA project. For example, *credibility* is seen within Chapter 6 in adequate representation of multiple people's voices and how these are traceable to the data through the examples included (Koch and Kralik, 2006). *Dependability* is present in the clarity of the research process, demonstrating an audit trail of decisions and choices made, which have been explicitly described within this thesis (Koch and Kralik, 2006). *Validity* could be judged by the level of ownership co-researchers have over the process (Silver, 2016). Various mechanisms for involving co-researchers in analysis of data has enabled an iterative process of member checking in order to build transactional validity, including reflections on episodes of data collection, our analysis and findings day, and the preparation of recommendations and scripts for podcasts and other dissemination activities (Caretta and Pérez, 2019).

5.8 Summary

This chapter has outlined the design of the VIA project and how co-researchers were involved at all stages of the process in enactment of the PAR approach, from discussing and formalising ideas for the research questions and research proposal, to designing and carrying out data collection. It has also detailed how data analysis was undertaken and how co-researchers were included as far as possible in this process. In the next chapter, the findings from this research project will be presented and discussed. The subsequent chapter will explore methodological learnings and what co-researchers learned and reflected on about conducting research together.

Chapter 6 Research Findings from Data Collection

6.1 Introduction

This chapter details the research findings from data collection undertaken with co-researchers, covering both strands of the Voices for Inclusive Activity (VIA) project. Figure 6.1 is included again as a reminder of project structure.

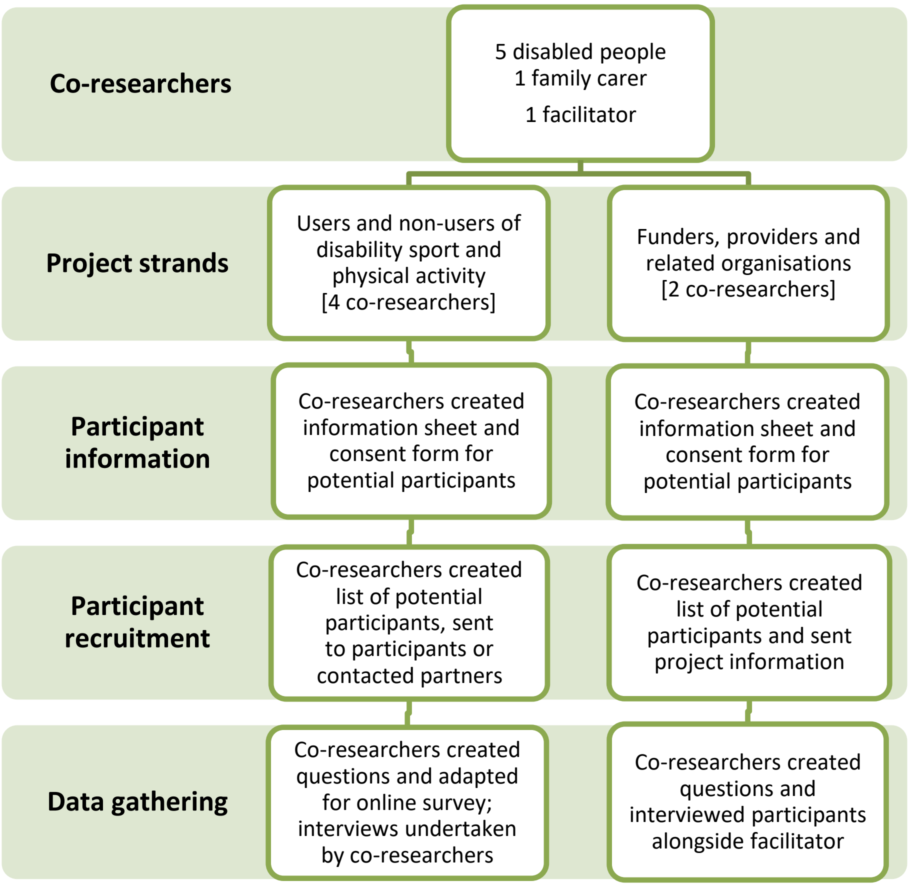


Figure 6.1: The two strands of the VIA project research proposal

The first strand explored disabled people’s perspectives and experiences of disability sport and physical activity and evaluation processes through an online questionnaire, in-person and Zoom interviews. The second strand explored the perspectives of funders, disability sport and physical activity providers and evaluators through Zoom and in-person interviews. These data sets were analysed separately, as co-researchers wanted to ensure the voices of disabled people were not lost and remained distinct. However, the findings are presented in response to the three research questions, as there was some crossover in responses and some disabled people interviewed were both participants and involved in the provision of sport and physical activity. The key arguments are drawn together in a discussion of themes, which draws connections across and between the responses to all three questions, along with the thoughts of co-researchers. This approach also offers a rounded response for the development of recommendations from significant findings.

Again, my own methodological reflections feature at points within this chapter, demonstrating the process of reflexivity undertaken during the course of the project.

6.2 Summary of themes

Research questions A: What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part?

A1 Doing

- A1.1 Doing in a way that works for me
- A1.2 Doing a range of different activities
- A1.3 Doing as a gateway

A2 Being

- A2.1: Being me
- A2.2: Being supported to participate
- A2.3: Being free
- A2.4: Being happy, finding enjoyment and wellbeing in participation

A3 Becoming

- A3.1: Becoming stronger
- A3.2: Becoming accomplished

A4 Belonging

- A4.1: People to take part with
- A4.2: Feeling at home
- A4.3: Feeling you don't belong

Research question B: What do funders want to know about disabled people's participation in sport and physical activity?

B1 Accountability

- B1.1: Control

B2 Sustainability

B3 Tackling inequalities and inactivity

B4 Funder distance/awareness

- B4.1 Flexible or no prescribed approach

Research question C: How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?

C1 Recognising the issues

- C1.1 Complexity
- C1.2 Issues with standardisation
- C1.3 Burden of evaluation

C2 Enabling access

- C2.1: Cognitive understanding
- C2.2: Access through creative approaches

C3 A collaborative voice for change

- C3.1: Enabling providers to prove
- C3.2: People supporting evaluation
- C3.3: To view evaluation as learning
- C3.4: Participatory and co-produced evaluation

6.3 Themes in response to research question A

This section provides an overview of themes developed from findings that relate to the first research questions:

> *What are the things about sport and physical activities that matter to disabled people?*
>
> *Why do disabled people take part or not take part?*

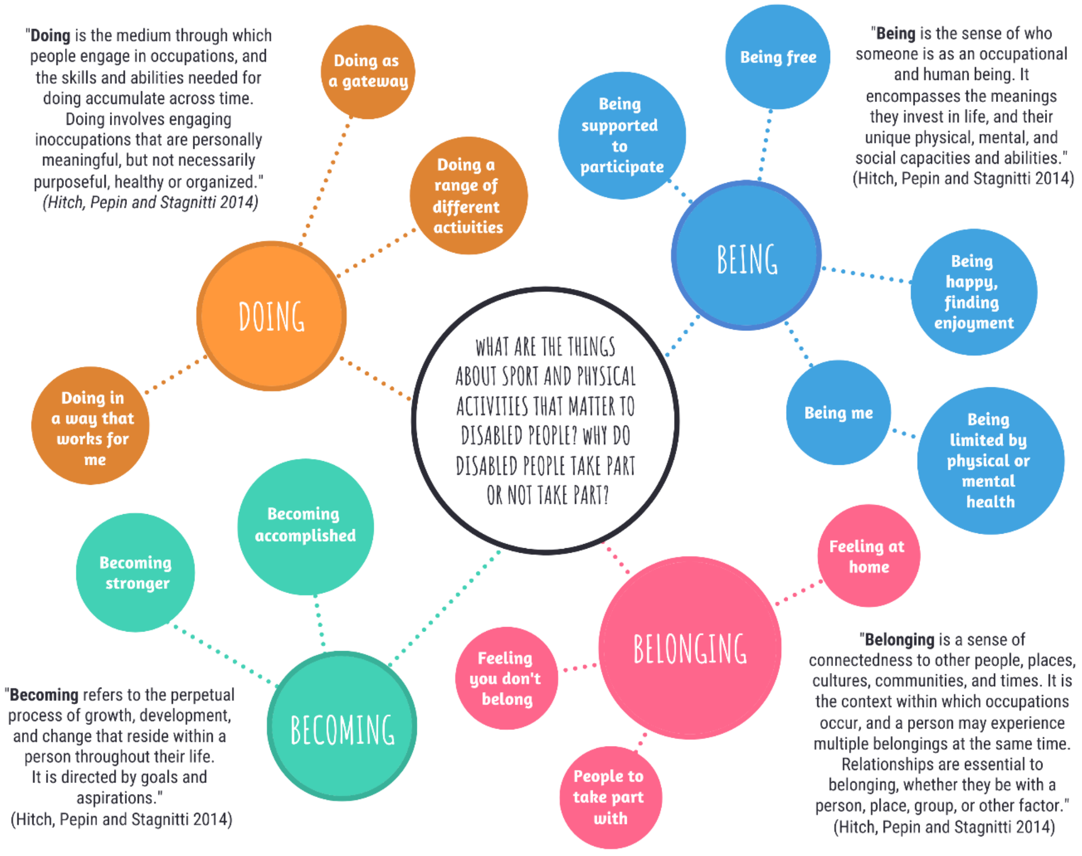
There are four key themes in response to this question:

- Theme A1: Doing
- Theme A2: Being
- Theme A3: Becoming
- Theme A4: Belonging

Doing, being, becoming and belonging

As previously explained in Chapter 5: *The Voices for Inclusive Activity project*, a reflective matrix was developed to ensure the key reflections of co-researchers after interviews could be used to guide data analysis. In our post-data collection reflections, co-researchers had particularly picked up on both participants' and providers' reflections on the non-fitness outcomes that are often most important and are not always measured, for example, social contact, reduced isolation and loneliness, and improved mental health.

The four terms attached to these findings, Doing, Being, Becoming and Belonging, come together within a key framework in occupational science literature, which provides a theoretical understanding of how people engage in occupations. As I began work to interpret the data, connections became apparent between responses and these four dimensions of occupation first described by Wilcock (Figure 6.2) (Wilcock, 1999; Wilcock and Hocking, 2015). Doing concerns the act of engaging in occupation, being describes a state of existence, but also relates to needs, roles and interests of a person (e.g. being a Boccia player), becoming is linked with ideas of change, transformation and development, and belonging relates to social aspects of occupation (Wilcock and Hocking, 2015).



"**Doing** is the medium through which people engage in occupations, and the skills and abilities needed for doing accumulate across time. Doing involves engaging inoccupations that are personally meaningful, but not necessarily purposeful, healthy or organized." *(Hitch, Pepin and Stagnitti 2014)*

"**Being** is the sense of who someone is as an occupational and human being. It encompasses the meanings they invest in life, and their unique physical, mental, and social capacities and abilities." (Hitch, Pepin and Stagnitti 2014)

"**Becoming** refers to the perpetual process of growth, development, and change that reside within a person throughout their life. It is directed by goals and aspirations." (Hitch, Pepin and Stagnitti 2014)

"**Belonging** is a sense of connectedness to other people, places, cultures, communities, and times. It is the context within which occupations occur, and a person may experience multiple belongings at the same time. Relationships are essential to belonging, whether they be with a person, place, group, or other factor." (Hitch, Pepin and Stagnitti 2014)

Figure 6.2: Visual representation of themes related to Question A

During our in-person analysis and findings day, I shared with co-researchers how researchers often apply theory to draw conclusions about the data, but how I was hesitant to apply an external theory from occupational science. However, co-researchers welcomed this understanding, especially presented visually, as it is relatively straightforward as a concept to explain how people engage in occupations. Co-researchers expressed how the concepts appeared to “flow and fit”, with personal examples added, as the provisional themes were discussed and agreed by co-researchers (Figure 6.3).

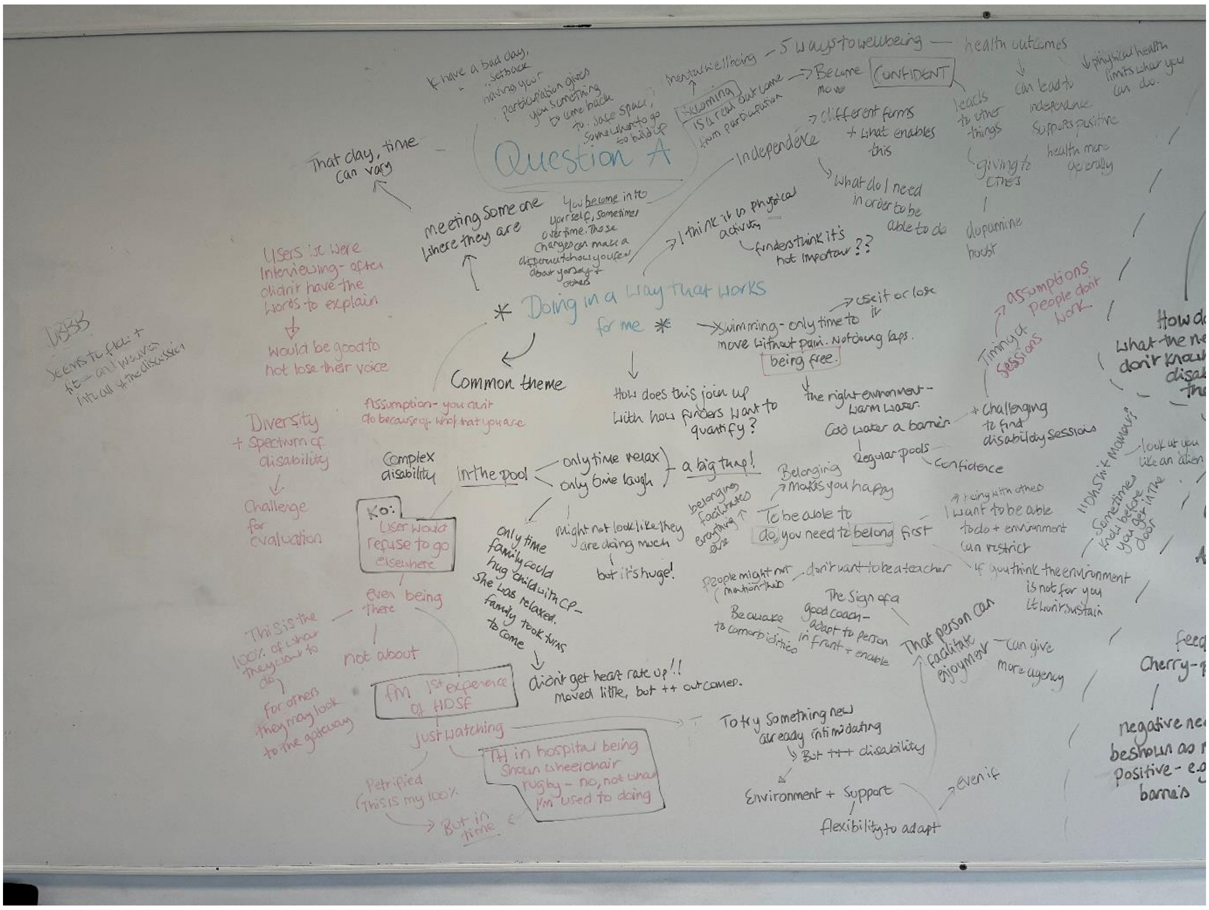


Figure 6.3: Whiteboard record of co-researcher discussion around Question A findings

Recalling the interviews undertaken, one co-researcher noted that some of the participants being interviewed often did not have the words to explain the issues, but how it would be good not to lose their voice and the specific words they had used to explain. However, there is a need to balance this with interpretations of the underlying meanings that were not always articulated explicitly. I have attempted to maintain the verbatim nature of comments as far as possible within this narrative.

6.3.1 Theme A1: Doing

This overarching theme relates to *doing* as the medium for engagement: how people participate in activities that are meaningful or necessary. There are three related sub-themes:

- A1.1 *Doing* a range of different activities
- A1.2 *Doing* in a way that works for me
- A1.3 *Doing* as a gateway

Sub-theme A1.1: Doing a range of different activities

This sub-theme recognises how disabled people shared their participation in a range of different activities. All survey respondents named at least three activities each that they take part in. While some disabled people will take part in non-adaptive or ‘mainstream’ sports and physical activities, some activities have been designed specifically for disabled people (e.g. Boccia, Goalball), while others are traditional sports that have been adapted for participation (e.g. VI football, wheelchair basketball or wheelchair rugby). Providers also described the range of different activities offered in their services, some designed specifically for disabled people, while others were un-adapted offerings. Interviewee B, from an organisation supporting people with complex disabilities, talked about the adapted activities they offer, for example:

> *"Sensory sport, where it's a bit more immersive and far less traditional. Sensory football, for example, is not on the football pitch or with a five-a-side or whatever side team. And it's more about the principles of football broken down into sensory activities."*

Sub-theme A1.2: Doing in a way that works for me

This sub-theme concerns how disabled people take part in sport and physical activity as individuals with individual needs. Adaptations that support participation and enable inclusivity are considered here, whereas support from others comes under a related theme of *Being supported to participate*. Participants mentioned conditions that enable their participation, including facilities and timings, but also for their need for adaptations to the activity, such as provision of rest breaks. Within her interview, Amy noted it was challenging for her to participate without opportunities for rest, and how she also prefers being prepared with appropriate instruction:

> *"Well, not having a break in between. And […] I struggle doing things without knowing what to do."*

Joanna noted how it had always been difficult to participate in mainstream activities, because she needs extra time:

> *"I just need to go slower and yeah, take more time to do things."*

Facilities and equipment were mentioned by a number of survey respondents, including Maggie, who discussed the need for adaptations:

> *"I would love to do archery but need to use a jellybow and not be on rough ground. I need to use a lower basketball net. I can do curling using a pushing pole. [I need] a hoist to get in the pool."*

Sub-theme A1.3: Doing as a gateway

This sub-theme relates to how being involved in one activity can lead to another. It considers how participation might build confidence to take part in other activities or subsidiary activities alongside the main activity, such as social or other physical activities with teammates. In their discussions, co-researchers considered participation as a gateway towards productive activity and employment and two co-researchers shared their own experiences of moving into the sport and physical activity sector as a result of their own participation experiences. Kate, who had progressed to being the Chairperson of her Goalball club, noted how participation in one activity had led to others:

> *"Once I found Goalball, a sport I could fully access and that was so inclusive, I was catapulted into the sport world. That's what motivated me to start going to the gym (and actually enjoying it!), be more active, find I enjoyed walking, etc."*

Interviewee Mark also talked about his love of Boccia, about refereeing, being on the ‘other side of the court’ and how he was about to start his coaching course:

> *“I enjoy Boccia. I'm doing level 1 course on Sunday.”*

6.3.2 Theme A2: Being

There are four sub-themes under this theme:

- A2.1: *Being* me
- A2.2: *Being* free
- A2.3: *Being* supported to participate
- A2.4: *Being* happy, finding enjoyment and wellbeing in participation

This top-level theme relates to the sense of who someone is (physically, mentally, socially), as a human being. Within occupational science it is considered who they are as an occupational being – someone who participates in a range of occupations that they need or want to do (Wilcock and Hocking, 2015).

Sub-theme A2.1: Being me

This sub-theme reflects participant responses around the individual experience of disability, and how the understanding and experience of disability can be self-determined. It considers different views on what disability means and reflects experiences of being classified in a group with others with very different experiences and impairments. For example, Joanna notes how she is defined as a person with cerebral palsy, but her experience is not the same as other people with the same condition:

> *“I've never actually met anyone like myself, they've always been in a wheelchair or not able to do anything at all. Um, so yeah, I think that's one of the main reasons I don't really fit in anywhere like cognitively or yeah.”*

Joanna reflects that this made it difficult to find sport and physical activity experiences that were relevant to her, and where she felt she belonged. The sub-theme explores being accepted as an individual and enabled to participate regardless. For Charlie, this is also about self-acceptance:

> *“I think to start with, it's going to be within me. Like wanting to do it. Because [PROVIDER] has been there through thick and thin for me, but it's ultimately up to me to get back into it. The chair is there if I want it, the bicycle is there if I want it, I just need to do it.”*

Overall, this sub-theme reflects how disability sport and physical activity – and its evaluation – has to cater to and consider a wide range of individual needs, reasons, goals and motivations for taking part, or limitations for not taking part.

Being limited by physical or mental health

Under this sub-theme of *Being me* was a further sub-theme; responses recognised that aspects of physical or mental health can make it more difficult to participate. For example, with Amy:

> *"Well let's just say, sometimes, unlike dad, he doesn't really have the physical disabilities, so he's all right with it, me, it makes my legs sort of go shaky and the same with my hands and that, when I get tired, and I feel like I'm getting overheated sometimes."*

While there was a recognition that participation could also lead to an improvement in mental health, Charlie also notes how mental health can affect the motivation to participate:

> *"I don't think I'm giving myself enough credit. I think I might be fitter than I think I am, but my mind is telling me otherwise because I've been out of it so long I know I am quite strong for my age, I brought my age up Um, but yeah, it's a mental thing."*

Sub-theme A2.2: Being free

This sub-theme concerns feelings of freedom and independence in participation, including freedom in the environment, being outdoors, such as these words shared by Oliver:

> *"I like being outside because I hate just sitting inside and being contained and not knowing what to do with myself. I love being outside and being free."*

Survey respondent Duncan noted water-based activities to be pivotal to feelings of freedom:

> *"Sailing - feel free and can go fast when windy.*

> *Swimming - free in the water, fun, I can build up stamina*
>
> *Hydrotherapy - warmer so helps muscles relax, feel free."*

A similar sentiment was expressed by survey respondent Maggie, in relation to swimming:

> *"When it comes to swimming that is freedom as I cannot stand, so it means a lot to me."*

Also contained within this theme are comments on freedom from reality and an escape, freedom from physical constraints or mobility devices. Also, freedom from fear and being judged by self and others, as noted by Charlie:

> *"I think because I've gone down so far in my fitness, I've got a thing in my head that people are going to look at me, judge me but, ultimately, I'm judging myself for thinking that. Um, yeah, I just got a fear of people judging me and that's always been there."*

Sub-theme A2.3: Being supported to participate

This sub-theme relates to having the right conditions in place for participation and reflects sentiments around the importance of support and encouragement to participate and the difference it makes to experience. Comments about how support from a particular provider or person who understands individual needs could encourage participation, have contributed to this sub-theme, along with considerations of transportation to get there. Knowing what activities are out there was also a key mechanism of support. The need for activities to happen at the right time, in a convenient and accessible location, was shared by survey respondent Jane:

> *"The time of day and time of the week that they are held. Disability sports are often given the least social times. Having sports held close to where I live, rather than driving for over an hour each way to access them."*

Accessibility of venues, including facilities, equipment and cost, was an issue experienced by survey respondent Duncan:

> *"There may be some hoists or equipment, but it may not be suitable for my circumstances. Cost - quite often I have to pay for myself and 2 PAs to attend and it's not fair to ask them to pay, however, it is not fair that to access somewhere I have to pay for 3 people either, which I cannot afford. For instance, there was one place where I could have had hydrotherapy, however, it was £80 an hour! A local swimming pool also wanted to charge monthly subscriptions; however, the only thing I could use was the pool and I also would have had to pay for my PAs to attend with me and this made it impossible to do."*

Sub-theme A2.4: Being happy, finding enjoyment and wellbeing

Quite simply, this sub-theme reflects the resounding response that people take part in sport and physical activity because they enjoy it and it makes them happy;

participation is for the enjoyment of it, for having fun. As noted by Charlie:

> *"It got the chemicals flowing, so the depression wasn't really there. Although it was there when I was at home or at school. But once I was doing sport, I was happy, it was my happy place."*

While Charlie's enjoyment related to the physical experience of activity, in response to whether physical fitness is an important outcome, Joanna noted that it was not a priority over enjoyment of the activity of cycling:

> *"I mean, that is important, but it's not the main reason why I go out, like, I like to ride my bike, I always have."*

6.3.3 Theme A3: Becoming

There are two sub themes under this theme:

- A3.1: *Becoming* stronger
- A3.2: *Becoming* accomplished

The domain of becoming relates to outcomes and what the activity leads to for the individual, including the potential for self-transformation. Becoming fitter was highlighted as important to some people, but only one part of what people get out of taking part. The notion of 'becoming' appeared to be very individual, with different outcomes of significance for different people, which might relate to mental health, social contact or being challenged.

Sub-theme A3.1: Becoming stronger

This sub-theme relates to becoming physically fitter and stronger from sport and physical activity participation. For some, fitness was a bonus of taking part, and not always the main driver, but it was an important aspect for Charlie:

> *"Just made me feel good. Um, blood flow, oxygen levels, all physical stuff, medical stuff improved."*

Some respondents also described the outcome of being able to maintain ability, to become stronger and more capable for everyday functional activities, for example Joanna:

> *"I think being physically active, probably helps your muscles and staying in less pain […] I had an operation last year, so I stopped and since then, I've been really struggling to get my strength back, so it was important for me to keep doing those things. So I don't lose my strength."*

Some providers described how they work with participants on functional movement, such as 'sit-to-stand'. For survey respondent James, maintenance of function was the most vital aspect:

> *"Keeping what little mobility I have."*

For survey respondent Duncan, the opportunity to become fitter and increase stamina led to feelings of achievement, which leads on to the next sub-theme related to accomplishment:

> *"As I am a wheelchair user, being in the water, swimming, is the only place I can raise my heart rate to increase my stamina, which is important to keep myself as healthy as I can. Also, I feel better mentally, as it helps to clear my head and gives me a sense of achievement."*

Sub-theme A3.2: Becoming accomplished

This sub-theme reflects experiences of building skills, being challenged, getting to be good at something and feeling a sense of achievement, sometimes involving trying something new. Experiences of becoming an expert, developing capacity and skills to coach or officiate were shared by participants. While Kate reflected on her role as the chair of her local Goalball club, through which she was able to share her passion and skills with others, Joanna described supporting the participation of others through volunteering:

> *"I love helping other people and watching them do their best on the bike."*

6.3.4 Theme A4: Belonging

There are three sub themes under this theme:

- A4.1: Feeling at home
- A4.2: People to take part with
- A4.3: Feeling you don't belong

This theme is all about connection and relationships, with people, places, cultures, communities and times, and the situations in which activities take place (Wilcock and

Hocking, 2015). A sense of belonging was a permeating theme within the responses of participants in disability sport and physical activity – and among co-researchers. Highlighted here was the importance of the social aspect of sport and physical activity and a socially welcoming space for participation. Co-researchers suggested this might be the most important aspect of participation for some disabled people, due to experiences and feelings of not belonging in other spaces.

Sub-theme A4.1: Feeling at home

The notion of finding a place to belong, somewhere to feel at home, was notable within the data, through sentiments such as feeling at home when participating, having friends and a team that feel like family, as shared by Kate:

> *“Added into that social aspect that I mentioned, you know, because it's all like being a family.”*

Contributing to this was being familiar and knowing how things work and knowing the rules (of an activity or environment). For survey respondent Maggie, the environment in which she participates is somewhere she feels comfortable to seek support if needed:

> *“I feel confident that the coaches will adapt things to enable me to join in everything. If there is a problem I can say.”*

Sub-theme A4.2: People to take part with

This sub-theme concentrates on the other people simultaneously engaged in an activity and recognises participation alongside others as one of the most enjoyable aspects, for example from focus group participant Jessica:

> *"I like going to see my friends."*

After the co-researcher probed further, Jessica identified this as the best part, for her, of taking part in rugby. Making and seeing friends are part of the process of participation and being part of the social side can support confidence and motivation, especially when working and bonding as a team. This was also recognised by providers, including Interviewee F, as important for participants:

> *"People feeling connected, coming out and enjoying themselves with friends. And if they don't have friends, if they're feeling socially isolated, feeling more connected to a group of people, and making those, making those friendships."*

Sub-theme A4.3: Feeling you don't belong

Countering the previous sub-theme were some reflections on feelings of not belonging, for example from Oliver, who found it challenging to participate in mainstream football:

> *"I used to get super angry because I would take things very, very seriously and not, I'm very kind of black and white with rules and stuff, so like, if I felt like if the ref made the wrong decision or someone was cheating, then I would really struggle to control my anger and I would get in trouble and get in fights and stuff like that. And in my mainstream team, quite often, they just don't know how to help calm me down. And they don't know how to manage my like meltdowns and stuff."*

This sub-theme describes the challenge in ensuring everyone feels included. Participants described examples of not feeling a sense of belonging alongside non-disabled children in school or not belonging alongside people with different types of impairment. Examples were shared of how groups that are labelled as ‘inclusive’ are not always experienced as inclusive for all. For example, people living with mental health issues may not realise they can access some opportunities in disability sport or physical activity. Also relating to mental health, Charlie reflected on past experiences and how his present social anxiety had changed how able he feels to participate alongside others:

> *“The part of being scared of people, wasn't there, so that social anxiety, because when I did sport, I was a lot more confident I could talk to anyone. Now, if someone doesn't talk to me, I wouldn't talk.”*

6.4 Themes in response to research question B

This section provides an overview of themes developed from findings that relate to the second research question:

> *What do funders want to know about disabled people’s participation in sport and physical activity?*

There are four key themes in response to this question:

- Theme B1: Accountability
- Theme B2: Sustainability
- Theme B3: Tackling inequalities and inactivity

- Theme B4: Funder distance/awareness

Within post-interview reflections with funders and related organisations, co-researchers had identified two significant themes in response to the research question, accountability and sustainability. Perhaps due to the timing of the interviews, towards the end of the Covid-19 pandemic and shortly after the publication of Sport England’s new organisational strategy (Sport England, 2021), there was a sense of change being discussed, along with a focus on tackling inequalities, a key component of Sport England’s new strategic focus, and therefore a prescient theme. There was variability in whether those interviewed were even aware of the issues with evaluating disability sport and physical activity and hadn’t even considered the problem, so funder awareness was therefore interpreted as a theme.

When overviewing the themes in person with co-researchers (Figure 6.4), I discussed with hesitance my concern that recognised themes were not necessarily answering the research question we posed. One co-researcher reflected that we may not have answered the question, but this perhaps reflects a lack of clarity and consistency on the expected outcomes for this population, and how to measure them successfully.

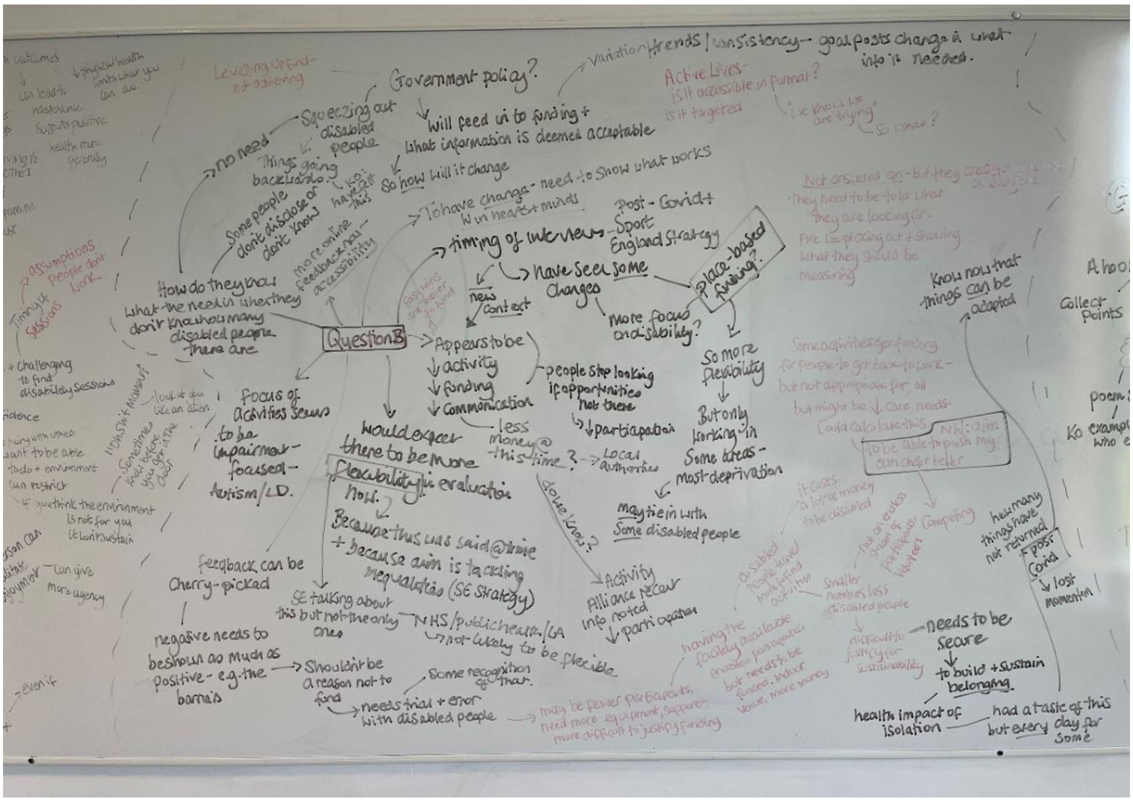


Figure 6.4: Whiteboard record of co-researcher discussion around Question B findings

6.4.1 Theme B1: Accountability

This theme recognises accountability as being a frequent purpose of evaluation. From this perspective, evaluation is less focused on learning and more concerned with ensuring return on investment. Funders ultimately want evidence of effectiveness, to focus on outputs, to know the funding has been used successfully and offers value for money, as suggested by provider Interviewee A:

> *"I think they need to quality assure that providers are doing what they're saying they're doing. That governing of one's specifications to make sure that, actually, are we supporting people to be more physically active?"*

Noted by Interviewee F, providers want to be able to show this too; to prove they are using money well and for the benefit of disabled people:

> *"Why it's important is so that then they know that the money's been well-spent. 100% agree with that. 100% agree with that, because I know a lot of organisations that put in disability and they tick the box and then just, yeah, they've just spent the money, they've had the money. Yeah, and not done anything."*

Participants mentioned tools they were recommended or had been asked to use, such as those for measuring health outcomes or wellbeing using the Office for National Statistics standardised questions, or Return on Investment (ROI) approaches for assessing value for money.

There is one sub-theme under this theme:

Sub-theme B1.1: Control

This sub-theme reflects the ultimate control of top-level funders and their strategies, it considers accountability to public health funders of physical activity and how the UK Government (DCMS) has ultimate control over most sport and physical activity funding via Sport England. There is a tension between the aim of tackling inequalities and being more accessible, with accountability to funders. As Interviewee D notes, funder strategy tends to determine the evaluation approach undertaken:

> *“They do trust us a lot more than they did, but they've been pulled back in their trust and saying actually we do, we do need numbers, we do need you to actually submit the case studies, cause before they were like, “Just don’t worry, we know you've got them, we know you'll collect stuff” […] They've even gone back on their word and said they're going to do surveys to beneficiaries online.”*

6.4.2 Theme B2: Sustainability

Funders want evidence of, and providers want to ensure sustainability; Interviewee C, a local funder, notes a desire to support further activity for providers and beneficiaries:

> *“As the funder, I think, a good outcome would be if that group then applies for funding again or is successful getting funding again. If the funding leads to continued activity or work in an area.”*

However, there was also recognition that money goes where things are going well and working, and proving sustainability can be challenging in disability sport and physical activity because it can be more difficult to build and maintain numbers.

Disability sport and physical activity may need more funding and support to ensure long-term opportunities and sustainability, as Interviewee D reflected:

> *“It's not just around giving them the money and leaving them to go, it's a case of right, well actually, let's plug them into the*

> *system, let's plug them into the network, but who can help them promote, who can help them with different things, so that they can have the best chance to sustain and even then, a year isn't long enough."*

Following on from the final point, ongoing participation can be limited by short-term solutions and time-limited investments. Projects with an end date do not offer reassurance for longer-term engagement. A sustainable approach is needed to support meaningful change, as noted by Interviewee E:

> *"We know from a lot of insight and evaluation that, like some communities they can be very put off by a six-week project that comes along, and is all singing all dancing and then disappears, and it's like there was no trace of it."*

6.4.3 Theme B3: Tackling inequalities and inactivity

This theme describes a sense of change that started with the Covid-19 pandemic and continued from the Sport England new strategy launch in January 2021. The focus is targeting less active groups, where funding had not previously been targeted, as seen in this example from Interviewee D:

> *"Two […] non-sporty organisations that we've given funding to […] had embedded that physical activity into what they do, so yeah, it's made a complete change to how the organisation now views physical activity, how it views movement and views*

> *being healthy etc, and the fact that they've actually been able to, you know, have that impact on their beneficiaries."*

This sub-theme, which involves looking at the actual needs of the group to help people become and stay active, draws from other themes. It also encompasses the progression from a narrow definition of sport to a broader view of physical activity, a focus on working together on the challenges and barriers to physical activity, and a connection with longer-term sustainability to support change.

6.4.4 Theme B4: Funder distance/awareness

There is one sub-theme under this theme:

- B4.1 Flexible or no prescribed approach

Flexibility with our approach to data collection and interpretation enabled issues that arose to be explored and discussed, including this unforeseen theme that was present in response to some of our questions to funders. The theme reflects the differing levels of awareness of the issues in evaluation of disability sport and physical activity, seen in the responses given by funders. What funders want to know and how achievable this is appears to be affected by their distance from beneficiaries and awareness of the issues, a point raised by Interviewee A:

> *"I've always challenged funders to come and see our model and I don't think necessarily that it [always happens]. I then fear that there's a risk that they're out of touch with actually what happens on a local level."*

Funders may not have the same awareness as providers of the complex needs of participants, as their evaluation might involve providers but not end users, an issue noted by Interviewee D:

> *“The problems with the surveys, was that we are one, if not two, steps removed from the beneficiaries, so trying to get organisations to then do stuff that they don't fully understand or that they don't really want to do is really difficult and that's why we made the decision actually, we don't want to make people's lives more difficult at this point, we'll just get what we can.”*

The theme represents the disconnect between the desire and the possibilities for measuring outcomes. Providers have tried to highlight the issues, but no action has been taken in the past. This might be changing as funders are starting to ask for feedback on what isn't working, and looking to alternative approaches, which is recognised in this response from Interviewee G:

> *“I think a lot of funders are recognising the benefits of the ‘why’ and the ‘how’, and that kind of erm, active learning approach, and increasingly, I see kind of government department commissioned evaluations going down that route, but we still have a little bit of a way to go, in terms of being comfortable leaving the ‘what’ behind.”*

Sub-theme B4.1 Flexible or no prescribed approach

As a sub-section of this theme, providers noted how, in some cases, funders haven't directed the required approach for evaluation, which can be beneficial if it supports accessibility for participants. Interviewee B suggests this has been enabled by providers feeding back to funders what has not worked and what will not work for them:

> *"I think there's more flexibility, I think it feels like it's more led by organisations that have got experience, where it's worked or hasn't worked and that's really good and funders are kind of listening to that."*

This sub-theme also potentially reflects the timing of interviews; it is suggested by some participants that the Covid-19 pandemic required a more flexible approach to be taken with evaluation. Interviewee A shared this experience:

> *"Some funders have gone, here is a blank page, you tell me what you're going to evaluate and that's good for us."*

However, as Interviewee A continues, such flexibility is not always useful, and direction would be useful for providers:

> *"Flexibility is good sometimes but sometimes, I suppose, if I was to look at it from a personal point of view, I'd like the direction, as long as it was an appropriate evaluation tool or mechanism that actually was suitable for our client group. It would probably make our lives easier because I'd go, oh that's quite straightforward because we're going to use that, this is what we're going to present, and this is what we're going to show."*

Providers have had to use a combination of approaches or find a solution that might work; some discussed having to make guesses at the level of impact. This is a challenge noted by Interviewee B:

> *"I don't, I can't tell you what those tools could be, sorry, we use things like, you know, at the moment we kind of scratch around using what we can."*

This is also dependent on who is funding the activity; as Interviewee D notes, with some funders there are no opportunities for flexibility:

> *"The commissioned project we've got with public health there is no flexibility, so you know they've got KPIs to reach, they've got data to gather, you know, they've got things to do, there isn't that flexibility."*

6.5 Themes in response to research question C

This section provides an overview of themes developed from findings that relate to the third research question:

> *How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?*

There are four key themes in response to this question:

- Theme C1: Recognising the issues
- Theme C2: Enabling access
- Theme C3: A collaborative voice for change

Foremost was the need to highlight issues with the existing approach and use of standardised tools, along with recognition that a more accessible and inclusive approach to evaluation was needed, as seen during co-researchers' discussion of the initial themes (Figure 6.5). Some innovative approaches were explored and picked out by co-researchers, including creative responses such as gamification, visual methods and a toolkit of solutions. The burden of evaluation to providers and disabled people was also highlighted in discussion, including the practical considerations of any evaluation solution. The themes within this section developed significantly from those presented at the co-researcher analysis and findings day (Figure 6.6) as I re-coded in response to the discussions and points raised. These responses required clarification for the formation of co-researcher recommendations for next steps.

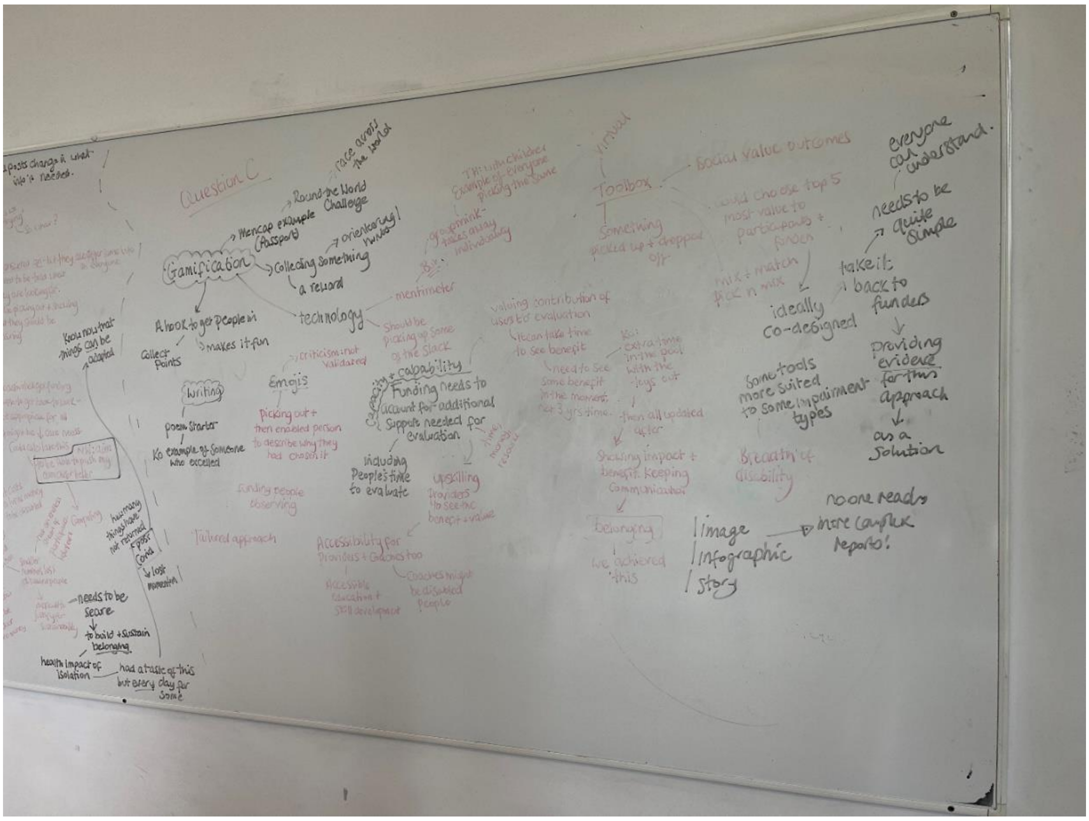


Figure 6.5: Whiteboard record of co-researcher discussion around Question C findings

Figure 6.6: Visual representation of themes related to Question C

6.5.1 Theme C1: Recognising the issues

There are three sub-themes under this theme:

- C1.1 Issues with standardisation
- C1.2 Complexity
- C1.3 Burden of evaluation

The first step for change is for issues to be recognised, that current approaches don’t quite fit. People have tried to find solutions by adapting what exists, but this has not been good enough. Regional funder Interviewee C recognised issues with expecting some groups to respond to burdensome evaluation approaches:

> *“Knowing the groups that we were trying to target, we didn't want to put lots of things over their head in terms of numbers and the data that they were gathering. We didn't want to put people off with that.”*

Sub-theme C1.1: Issues with standardisation

There are issues with using standardised tools that are common to all audiences, but there are particular challenges for disabled people in tools that are inaccessible, as noted by Interviewee B who works with people with complex disabilities:

> *“Through learning [we] failed to be able to provide that information because it wasn't accessible or appropriate for the people we were trying to get that information from, essentially, so there wasn't an alternative for this project. So we try and do most of our impact evaluation monitoring through stories and case studies, as well as the raw data.”*

If evaluation is not in accessible formats for disabled people, this can lead to skewed data, as only those who can use the tools can participate. There is some recognition of this from a national funding perspective, from Interviewee E, who notes the difficulty with providing data that is requested at a governmental level:

> *"The central difficulty is, we are required sometimes to provide evidence at a national government level, they want simple numbers about, show us the change, from this to this, and they want to see that that uses sort of reliable, credible measures. But the challenge we face, of course, is if you follow the funding all the way down to community level, you can't always collect that data in a meaningful and accessible way when you've got individual challenges, community challenges around, you know, accessibility needs, different disabilities, different languages, different audiences, so we're trying to balance that now, and I'm not sure we've got a solution to it at the minute, other than continuing to talk to audiences and the partners we fund to really understand how we can design evaluation that, that is co-designed and works for everybody."*

Another issue identified is that questioning can be inappropriate for the audience and providers described their hesitance at asking questions about concepts they might not associate with their sport and physical activity participation such as loneliness or suicide, or asking wheelchair users how much time they spend sitting or walking.

Sub-theme C1.2: Complexity

This sub-theme relates to both complexity of the issue and of disability, taking account of variability in conditions, individual needs and the range of activities available. It is challenging – perhaps impossible – to aggregate or standardise data for comparison when inclusive activities cater to people with varying conditions and needs, and people participate in diverse and inconsistent ways. For Interviewee B, approaches are not currently appropriate or sensitive enough to reflect the experiences of people with severe impairment or to demonstrate change in this picture of complexity:

> *“Even with insight that exists around disability […] for us it doesn't drill down to complex disabilities enough.”*

As noted by evaluator Interviewee G, disabled people’s lives are more complex than can be accounted for in a measurement tool, and standardised tools do not reflect the realities of disabled people’s experiences:

> *“I think part of it is because of the inadequacies of validated instruments and standardised data collection tools, if you come back to this evaluation question of what works for whom, why, and in what circumstances. When you're working with different disabled people, I have a sense, and I say this with no lived experience whatsoever, as a caveat, that their realities are infinitely more diverse and complex and changing, both in terms of themselves and their conditions, but also the communities and services that they engage with, the organisations that support them, the stigma they may or may not face in those communities.”*

This response hints at the additional barriers to participation that can be experienced by disabled people; how availability of an activity in the first place can be a big step, and the impact of external variables on enjoyment of an activity and subsequent evaluation.

Providers also discussed how they access a range of different funding streams, which are sometimes allocated to different impairment groups. This adds to the complexity of evaluation, as requirements and outcomes can vary according to the priorities of different funding organisations. This adds to the burden for providers.

Sub-theme C1.3: Burden of evaluation

Evaluation can become a burden for both providers and for participants. It can be particularly challenging for smaller organisations that have limited experience of the funding process and cannot afford external evaluation support. Evaluator Interviewee G recognised the potential administrative burden to organisations within the following comment:

> *"I would love to go down a route of more […] real time data collection and embedding data collection within the different processes that organisations go through to support people, so it's kind of collected there and then. But you're up against this challenge that in doing so, you create like this administrative burden that these organisations then have to go through to actually do that data collection."*

It was also noted within the data that employing evaluation companies can further remove funders from beneficiaries and their needs, and they may also not have disability-specific experience for an accessible and inclusive evaluation. Sensitivity to the needs and preferences of participants is also required to avoid placing burden on completing evaluation when their priority is to participate; Interviewee D shared an experience related to this:

> *“They literally had to fill in like 5 surveys on week one, so you've got this – the whole point of the project was that families were active with their kids together – so you've got a parent, maybe two, but normally a parent and with 1,2,3 plus kids running around being mad ((laughs)) and the deliverer trying to sort of like be, "You need to fill this survey in for each of your kids and you,” and you’re like...No!"*

Interviewee D also commented on the additional challenges in relation to the lack of evaluation skills of the coach involved in delivering this particular programme. Coaches and providers are experts in the delivery of activity but may not have the knowledge, skills, experience or capacity to plan, collect and interpret rigorous evaluation data.

6.5.2 Theme C2: Enabling access

There are three sub-themes under this theme:

- C2.1: Cognitive understanding
- C2.2: Access through creative approaches

There is a recognised need to ensure evaluation formats and phrasing are appropriate for all users, considering needs related to level and complexity of cognitive understanding, physical ability and sensory impairment, such as visual impairment. As an example from the data, Deaf people who use British Sign Language may have English as a second language and may find it difficult to interpret written text, as BSL has a unique syntax. Without accessible formats, feedback is not gathered consistently or from all participants and, as Interviewee B notes, an inclusive approach may have wider benefits:

> *"The more adaptive and inclusive they are, they will work with a wider population of non-disabled people too. I think that sometimes we assume that, you know, this is maybe a challenge specifically to disabled people, but actually, people with maybe mental health, or for other reasons, may not want to complete something that feels a bit more intrusive or is not accessible to them."*

Ideally, people will be able to engage in tools themselves, although having a proxy report may be favoured by an individual. Funders are starting to see the need for accessibility in adapting formats and approaches, as reflected by Interviewee E:

> *"You can design the best methodology and have the most rigorously valid validated tools on the planet, but if it doesn't work for a particular audience, then you've fallen at the first hurdle and you're not gonna get valuable data."*

Sub-theme C2.1: Cognitive understanding

Level of cognitive impairment can potentially affect a person's ability to understand evaluation questions and to respond appropriately. There is a need to consider the person's mental capacity to understand and respond, how this is assessed for the provision of valid data and how the process of data collection is adapted. Practical reflections from undertaking this research contributed to the development of this sub-theme, including our own reflections within data collection of needing to prompt, to reword and further explain some questions. At times, even those adaptations did not aid understanding of some of the more abstract concepts (such as understanding what we mean by evaluation). Anyone facilitating evaluation may need to adapt questions to support and enable meaning, or to provide alternative formats, such as Easy Read, as mentioned by Interviewee A:

> *"As an organisation, we need to understand cognitive ability of the individual that we're going to be perhaps using the tool on. Obviously, their physical needs if there's those type of questions in the tool. Easy Read formats, I guess, would be a great example, or devices, using the tablet that can be perhaps auditory, or I suppose there's loads of different ideas and opportunities to make an evaluation tool as inclusive as it possibly would."*

However, Interviewee F offered caution regarding their experience with using an adapted emoji-based format, and how evaluation in this case was affected by additional factors:

> *"We used to have the smiley face things, but you knew that the winning football team would come in with the smiley faces and the losing football team would come in with the sad faces, but on a non-competitive thing, that would work."*

Sub-theme C2.2: Access through creative approaches

This sub-theme represents suggestions to look outside of traditional approaches, including standardised tools and tick-box approaches, to enable the accessibility and inclusivity of evaluation. As stated by Interviewee D, approaches that help people with communication difficulties or other access issues to share their experiences can enable people to have a voice and for their experiences to be heard:

> *"The more and more we get creative with how we're collecting that evaluation to get the voice of the person or, you know, the group or whatever, then that will help, because actually that just shows, you know, that they can, you know, they do have a voice, they can tell us what they're doing."*

Interviewee D shared one specific example of a poem created for evaluation:

> *"It's the essence of what we've been doing, obviously through the eyes of that project and it's not disability, but actually it gives you a really good idea and it's creative evaluation. That's one of the things we shared with Sport England and they were like, "Oh my God, this is amazing," so yeah, we've had some really good feedback, but it just shows, if you've got someone that can do that for two minutes, it's just like, that impact is amazing."*

Provider Interviewee B also commented on how creativity has manifested in their evaluation practice:

> *"[The funder has] been quite receptive about a mixed methods approach, so that's data along with storytelling, has been something that's more recently been, I guess, recognised by [the funder] and in terms of the more, I suppose, traditional research that we did on our previous project."*

These responses suggest an increasing openness of funders to more creative approaches, which is also seen within this response from funder Interviewee E:

> *"I think we need to apply that same spirit to how we conduct the evaluation, looking at more novel and creative ways and, again, I think we've been, we've been certainly guilty of using quite standardised and traditional forms of evaluation for surveys, case studies, interviews, registers, you know, things like that. And that's just, just the way things have been, I think, for our sector, and again, it's recognising that we're changing and learning and evolving as a sector as well, and starting to open ourselves up, to how can we do this in a different way, in a more creative way."*

6.5.3 Theme C3: A collaborative voice for change

There are two sub-themes under this theme:

- C3.1: Enabling providers to prove
- C3.2: People supporting evaluation
- C3.3: To view evaluation as learning

- C3.4: Participatory and co-produced evaluation

This theme reflects a need expressed by both providers and funders to bring interest holders together collectively, to discuss and share learning about approaches to evaluation, to work together towards a solution, to build a consensus for the need for change and push towards policy change through strength in numbers. The involvement of disabled people in this partnership process was mentioned by participants and emphasised by co-researchers. Partnership and collaborative approaches were discussed by Interviewee E:

> *"I think we've talked about so many different ways, about starting with the individual, about being more adaptable and flexible with measures, about designing it with audiences, about working with senior stakeholders and decision makers to show the value."*

However, this comment from a national funder contrasts with the need expressed by providers for those funding sport and physical activity to be less distant from providers and beneficiaries.

Sub-theme C3.1: Enabling providers to prove

This sub-theme reflects a persistent desire by providers to have something available that enables them to demonstrate what they set out to achieve, that they are meeting needs, as reflected in this response from Interviewee A:

> *“I think it's important to demonstrate our, what we set out to achieve, it should be at the forefront of any funding application or funding bid, so that we can provide evidence to show what we set out to achieve, has been achieved or not.”*

Providers described trying various tools and approaches but there was nothing that perfectly enabled them to demonstrate their value and prove their worth. Interviewee F knows their potential to demonstrate value, as this was achieved when enabled to present their case face-to-face:

> *“Everybody knows the need, anybody that we can get in front of, we've never failed if we’re put in front of somebody […] We've never not got a grant that we've presented to people, but unless you can get in front of some of the bigger funders, it's hard.”*

However, Interviewee F was particularly keen for an approach that would provide ‘academic’ back-up for what they see anecdotally, “to help us be good enough”:

> *“And not just our stuff, putting it against other data, other proper medical research and things that public health will look at and go: “Yep. Okay. They know what they're talking about.””*

This reflected a desire for an approach that is held in esteem, not just anything because traditional methods don’t work. It would need to be an approach that worked for the organisation and its beneficiaries above all else.

While there was some realisation from participants of the need for a new approach, there was also recognition of how the UK Government still has ultimate control over the distribution of funding to disability sport and physical activity. Participants expressed a need to report ‘back up’ what works, to show the need for flexibility and that you don’t just need quantitative data. An alternative approach needs evidence and justification of its value. As shared by Interviewee E, this requires work at a national level to persuade, influence and negotiate around why we need to evaluate differently:

> *“I think there's a bit of persuasion and influencing and negotiation to be done to set out why we need to evaluate in a different way and why it is so difficult to get simple figures.”*

Sub-theme C3.2: People supporting evaluation

This sub-theme reflects commentary on the importance of people who administer or support people to respond to evaluation, and how building relationships and being close to beneficiaries or participants supports the evaluation process. The facilitator might support progress throughout, using techniques such as clarifying points, or using their knowledge of the local context to help explain difficult concepts. Ideally this person will have an understanding of the communication style or needs of the person they are supporting and can be flexible to adapt or rephrase questions as needed. They might provide practical support with the use of visual, verbal, physical or gestural prompts or cues, as was required within our own data collection. This sub-theme also considers how some people need the presence of a known and trusted person to respond on their behalf (proxy report), perhaps due to physical impairment or level of cognitive understanding. This was noted by survey respondent

Daniel, who needed support with responding to our survey:

> *"As my PA is supporting me to fill this out maybe this needs thinking about. For instance, people who have a learning disability and/or dexterity issues. It may be a good idea to note what participation they contribute to the survey."*

Sub-theme C3.3: To view evaluation as learning

This sub-theme concerns an approach to evaluation that enables learning about the programme or activity being evaluated. As noted by evaluation professional Interviewee G, evaluation should enable organisations to put the best conditions in place for success:

> *"At an organisational level, successful evaluation is helping, and this is going to sound very crudely phrased, but it's helping organisations do good better, in a way, it's about what I've spoken about in terms of that formative learning, in terms of helping them to adapt, in terms of giving them, giving their project the best possible chance to succeed and make a difference in whatever they're supporting."*

This response also reflects a focus on the need to learn about conditions – including the audience and the context – that enable sustainability rather than short-term interventions. Providers commented on the desire to learn from other organisations with experience of successful ways of working that have enabled participation, contributing to the evidence base to ultimately reduce inequalities. As exemplified by Interviewee A, providers reflected a desire for evaluation to be useful and meaningful, an approach that enables them to learn, adapt and improve as required for the ultimate benefit of participants' needs:

> *"We can see where the need is, because we might have got it wrong and then, if that's the case, then we need to adapt our service accordingly to make sure that we do then hit that, whatever that service need is."*

Two interviewees, a provider and a local funder, recognised a shift in approach they had noticed from Sport England, suggesting a move towards an insight and learning-led approach to evaluation with a focus on drawing out learning. Interviewee B:

> *"I think it's also a shift in the culture of Sport England as a funder and their leadership and their change of direction and strategy […] there's been much less of a focus on participation in numbers, the kind of bums on seats type of things that were being requested of people years ago and it seems to be much more quality insight, learning driven now, which is great."*

Although as noted by Interviewee D, this isn't an easy shift and there are potential limitations relating to ultimate accountability, which still haven't been overcome:

> *"I think the people at, the workforce at Sport England, get it, they really do get monitoring and evaluation and learning, it's very much, monitoring, evaluation and learning now, so they get it […] but then you've still got a lot of history to unpick to then get it across the whole organisation, 'cause it's big, in*

> *terms of all the other funds, but then they've got the battle, obviously with DCMS [UK Government Department for Culture, Media and Sport], their board and, you know, lottery money, whatever, so I don't know where it's gonna land."*

Sub-theme C3.4: Participatory and co-produced evaluation

This sub-theme confirmed co-researchers' own reflections on the need to work collaboratively with end users using peer research approaches to co-design inclusive evaluation. Participants discussed being open to alternative approaches and methods, and shared perspectives on how evaluation doesn't currently meet the principle of 'nothing about us without us'. However, Interviewee G also recognised that such approaches can create additional administrative, financial and time burden for organisations and participants, and need to be allowed the space for success:

> *"I think organisations or researchers need to have the space created to be given a bit of freedom to, through genuine co-production with disabled people, just like try different things out, you know. The disability sector, I would argue, is kind of chronically underfunded, and so I think funders that are working within that sector are also up against it in terms of trying to get the most for their money and that doesn't lend itself to a creative space, to an exploratory space, or to, you know, changing the way that we do things […] If someone could create that space for disabled people working alongside, you know, researchers, allies, to just try some different things out, that could potentially, you know, lay the foundations for thinking differently about how we do things in the longer term."*

This approach recognises individuals as experts in their own contexts, supports the building of capacity and elevates voice. As noted by Interviewee B, approaches created in partnership with disabled people may support principles of inclusion, control and independence for people who are currently unable to share their views and feedback by conventional methods:

> *“Something that people can self-use to self-report would be really, really, really crucial, I think, for us, because we can't really get that full feedback or co-production or anything from individuals themselves if those tools aren't accessible for them to be able to use themselves. So whether it's something immersive or tactile or whatever works for them, because of their, you know, whatever their needs might be. I think it's important that it's created with the people in mind, the individual people in mind, not just something that, well we'll ask a support worker to fill that out on behalf of that person, because that person is non-verbal.”*

6.6 Discussion of themes

I will now explore the aforementioned themes in more detail, drawing connections and bringing examples from the data as illustration; this section also brings in some of the points made by co-researchers during the discussion and development of our themes.

Most of the disabled people interviewed and surveyed shared little experience of evaluation, or acknowledgement of whether they had been involved in evaluation in the past. However, all spoke of their individual experiences of sport and physical activity and what helped and hindered their participation and engagement. The outcomes of sport and physical activity for disabled people are broad: five survey respondents mentioned the word fun as an outcome. As Interviewee Kate noted, “If I’ve enjoyed it, then I’m happy.” On the flip side, not enjoying an activity is reason enough to cease involvement; Joanna discussed stopping doing all of her activities: “I just didn't enjoy it anymore.” There are also challenges in measuring enjoyment noted by providers, such as Interviewee B:

> *“How you quantify that in terms of evaluating is really difficult isn't it, and they can enjoy it one week and hate it the next, for reasons outside of the activity that they're doing, so I think it, it's really down to the individual isn't it, and what they want to get from the session.”*

For some participants, fitness was identified as an important outcome, for example by Oliver:

> *“It's important for my fitness. I've always done sports, I've always been relatively fit, but I, like I mentioned earlier, I have a condition that affects my breathing. So, it's really extra important for me to try and stay fit and healthy.”*

However, the social benefits of participation in sport and physical activities featured regularly within responses. As shared by Amy, whose primary outcome of participation was making friends, having fun, chatting and laughing with others:

> *“Well, I like making new friends and I like having fun, a lot of chats. And I just like having a lot of good laughs.”*

All survey respondents mentioned getting together, socialising, being with others; Maggie included further detail:

> *"The group support is really important to me. I wouldn't go to a sports centre on my own. It took me some time to be confident enough to stay for a whole session, now I love going."*

As one co-researcher shared during our discussion of findings, a sense of belonging facilitates the ability to do and take part. Drawing a connection between *Doing* and *Belonging*, co-researchers highlighted the importance of the social environment, in particular, how: "To be able to do, you need to belong first," and how belonging facilitates everything else, "belonging makes you happy". Interviewee Kate discussed how people participate in their sport of choice, Goalball, for a multitude of reasons, and all are looking to get something different out of their participation:

> *"People join for different reasons, there's some people want to do it because they want to improve fitness, some people want to do it because they're competitive or want to go to tournaments, some people want to do it because it's just fun. You know, it's a hobby."*

The theme of *belonging* also considers how friends and family can support an individual's participation. All co-researchers identified with the point around being and doing with others, and how a supportive person can facilitate enjoyment and give more agency. Co-researchers discussed how isolation can be an everyday reality for some, and referred to research evidence relating to the health impact of isolation (Fawaz and Mira, 2023). Oliver is one of the participants who described feelings of being at home, of participating within a ‘family’:

> *“With football particularly, ’cause I've always played since I was like six years old. I feel kind of at home when I'm on a football pitch, because I know exactly what's expected of me and how to play and stuff. So I feel like I can just be myself and I also, although I find it really hard being part of a team because I really struggle with the social side when I'm on the pitch I, really like it, because, kind of, you feel a bit like a family.”*

Co-researchers also discussed the concept of independence and how this is often misunderstood, as it can take different forms and there are different enablers. Interviewee David emphasised the feeling of independence and freedom he experiences from participation (A2.3 *Being free*):

> *“Anything I do for me personally, like going skiing, sailing, ballooning, it's about the independence, it's about the freedom, it's about, it's about leaving my wheelchair behind and going, I’m not a wheelchair user, I'm now a sailor, or I'm now a skier, add your pronoun; and that's more about independence and challenging myself.”*

Co-researchers identified with the notion of ‘being free’, and how swimming offered the opportunity to ‘use it or lose it’. One co-researcher mentioned how swimming offered the only opportunity to move without pain rather than notching up laps. However, they noted how the right environment was required for this – warm water was an enabler, whereas cold water was a barrier and regular pools could affect confidence. It could also be challenging to find disability specific sessions, as there is an assumption that disabled people do not work, so sessions are often planned during weekdays. There are additional challenges in ensuring an appropriate environment for disabled people: an indoor venue may be more appropriate but costs more. Smaller group numbers, because there are fewer disabled people as participants, and a limited stream of participants and volunteers, makes it more difficult to justify for sustainability. Often, disabled people travel more to find available activities: co-researchers reflected that it costs a lot of money to be disabled.

One co-researcher noted how the concept of being, the opportunity to ‘be’, relates to the understanding of individual needs. Another described how they would need certain things in place in order to be able to do, but these needs can be misinterpreted by others as dependence rather than independence. One co-researcher who had worked with people with severe impairment felt it vital to enable proxy report to evaluation, whereas this was something Interviewee B wanted to avoid from their own work experiences with a similar population. Referring back to the literature review and the multiple perspectives on whether proxy report is reliable, this is something that would need to be considered at a local level according to the population being evaluated.

Appropriate support to participate may lead to other opportunities (A1.3 *Doing as a gateway*), as was noted by interviewee Kate, who recognised that, for her, participating in Goalball has led to other forms of sport and physical activity participation. As a provider, Interviewee A also noted this gateway to a range of outcomes often experienced by participants in their organisation’s activities:

> *“There isn't much more powerful than someone with learning disabilities [who is] perhaps isolated and wants to get into sport and physical activity, and we've supported that person on their journey, and it's led to a number of opportunities, increasing social circle, etc.”*

In co-researcher discussion on this theme, it was noted how, for some, just turning up to participate in the principal activity would be the limit of what they had energy and ability to complete, and there wouldn’t be a gateway to other activities. This reflects the work and effort needed just to get to the point of participation, as interviewee David notes in reflection on finding opportunities to sail:

> *“When you talk about going sailing as a paralysed person, there's a lot of issues and a lot of boundaries getting in and out, there's a lot of health and safety, there's a lot of stuff you have to go through to get actually on the water and kind of do that, so that you can go through all the, if you can kind of go through all of that, and then talk about the actual end goal of being sailing independently.”*

Two co-researchers shared their own experiences of what they described as being at the nexus before engagement: one shared their first experience of attending a disability sport and physical activity organisation, just watching, petrified, being at their limit just by being present. But in time, this changed. Likewise, the co-researcher who is now heavily involved in wheelchair rugby recalls being shown the sport while in hospital following his spinal cord injury and how he didn’t want to be involved as it wasn’t what he was used to doing (mainstream rugby). But both emphasised how this changed with time, with the right support from people and the environment.

Co-researchers also noted how participation opens a gateway to *Becoming accomplished* (A3.2) with opportunities including competing, coaching and volunteering. One co-researcher used a highlighter to select a number of terms within this sub-theme, highlighting the terms ‘confidence’, ‘sense of achievement’, and ‘learning something new’. They also discussed supporting others, making a connection between the notions of learning new skills and giving to others. One co-researcher noted the connection with physical and mental wellbeing and linked this with the *5 ways to wellbeing* (Aked *et al.*, 2008). During his interview, Mark, a wheelchair user with cerebral palsy and communication difficulties, talked with pride about winning a gold medal in Boccia, and how he wanted to achieve his coaching qualifications:

> ***Mark:*** *Um, I want to know about Boccia a bit more.*
>
> ***Fiona (co-researcher):*** *You want to do Boccia a bit more?*
>
> **Mark:** Yeah. Loads of games. And do all my [coaching] levels.

In discussion of the theme of *Becoming accomplished*, co-researchers identified with an experience of coming into yourself, sometimes over time, and how those changes can make a difference to how you feel about yourself and others. The notion of ‘Gaining confidence’ arose at various points in discussion, along with the suggestion that confidence can lead to other things, including opportunities to give to others and also the receipt of a dopamine boost. Co-researchers discussed how reduced physical health can limit participation, but how the health outcomes from taking part can lead to increased independence, supporting positive health more generally. The four focus group participants, Kelly, Carly, Jessica and Florence, commented on their breathing making participation difficult, and one participant noted that their heart: “All the time it hurts”.

Co-researchers discussed how if you have a bad day or a setback, having your participation and the resulting confidence gave a new starting point or new baseline, somewhere to build from again. Co-researchers also discussed different outcomes for some activities. One co-researcher shared how her aim for accessing physical activity was to be able to push her own wheelchair more easily, but this led to competing and eventually towards international competitions. Other outcomes might be reduced care needs, which could potentially be calculated. Under the heading of ‘Becoming stronger’, one co-researcher highlighted the phrase ‘more capable for everyday functional activities’; functional activities feature within the remit of provider Interviewee F’s work:

> *“People with learning disabilities will often come square on and step up to a pavement, because their range of movement is not great. So, we also work on functional skills as well, like sit-to-stands and being able to step up at an angle.”*

Participant David noted how development of functional skills and confidence is also an outcome from his provision of activity for children and young people with a range of needs:

> *“Even though we're kind of building skills up from a sporting perspective, we know that we're working on the hand eye coordination, we know we're trying to do this particular activity, because it's going to build the legs and dribbling. Dribbling, for example, dribbling a hockey stick around markers, we know it's about coordination, it's hand eye coordination, it's using your brain, and the skills that they get from that you can tell that the skills improve. And when the confidence, I think, a big thing is confidence, because you say an activity, and they're like, "Oh we can't do that, I can't do that," then, give it a go. And then you coach them through it, they have a go, and then they're, ah right, by the end of it, they're chuffed and stoked that, that they've done it and they've had a go.”*

The theme of *Being me* (A2.1) included examples from the data of how disabled people are individuals, with individual needs and may need particular support to take part. Joanna noted her dissatisfaction with being grouped with other disabled people when their abilities varied:

> *“I think if I wanted to do more, I think finding groups that are meant for physical disabilities rather than learning disabilities […] Because I feel like I, whenever I've gone to find a group or a club, it's always been about learning disabilities and that's why I've never been really, because you talk to them and you're on a much, and they're on a much lower cognitive level than you are.”*

This example informs the sub-theme of *Feeling you don’t belong* (A4.3). In relation to this theme, co-researchers discussed how they might want to be able to ‘do’, but the environment can restrict them: if you think the environment is not for you, participation will not sustain. Co-researchers discussed how they could sometimes know before they got in the door. One co-researcher described it as an “Oh shit moment”, where an instructor or coach would “Look at you like an alien”. This led discussion towards the concept of *Being*. Kate also shared some examples of such moments, experienced as a visually impaired person:

> *“The biggest thing for me I'd say is having and feeling like you have the support of somebody who is who is running it. For example, I'm really flexible, so I would love to do yoga. I really enjoy yoga, but I went to a couple of sessions with a friend, in my local leisure centre. But I didn't really want to continue, because unfortunately I couldn't really have a proper conversation with the teacher […] she didn't have time to stop and talk. So, even though you could tell she wanted to help me, she just, I didn't feel she had the time to actually properly support me in the way I needed.”*

Related to this, co-researchers noted in their discussion an assumption sometimes (or often) made that: “You can’t do, because of what you are”, bringing a connection with the theme of *Being*, specifically, ‘being a disabled person’. They shared their own experiences of situations, such as gyms where incorrect assumptions were made about their level of strength or cognitive function. The sign of a good coach was noted to be the ability to adapt to the person in front of them and to enable their participation. Co-researchers also discussed how this person should be awake to comorbidities, which may be more prevalent in disabled people. They recounted how they did not want to be a teacher about disability. Related to this theme is A1.1 *Doing in a way that works for me*. In our discussions, co-researchers highlighted how this involves meeting someone where they are (in terms of mood, mental, physical and cognitive ability), on that day and time, which can vary.

Disability sport or physical activity cannot be grouped as a single category for data comparison (A1.2 *Doing a range of different activities*), but the individuals themselves also cannot be grouped together for measurement or statistical purposes – this notion was already problematised with Chapter 2: *Literature Review*, but was also reflected within our data collection. Co-researchers questioned how this could connect with how funders wanted to evaluate, when the diversity and spectrum of disability offers specific challenges. One co-researcher stated, “What I think as physical activity, funders think is not important”; here we can refer back to points within the literature review regarding the prevalent use of the IPAQ tool, which requires physical activity to be at least 10 minutes duration to count, or other tools and devices that are only concerned with the frequency, intensity, duration and sometimes the type of activity, but without concern for the meaning of participation. Evaluator Interviewee G commented on efforts to move away from this form of evaluation that values quantity over quality and doesn’t reflect experiences of physical activity:

> *“One of the things that we've kind of pushed over the years is a movement away from kind of standardised, you know, validated tools, because I think in those tools, you see measures that don't actually reflect the realities of physical activity for people with different types of impairments, and it comes back to what I was saying, in terms of how physical activity is defined.”*

On the final point of how physical activity is categorised and defined, potential progress was shared by national funder Interviewee E, in their reflection on broader conceptualisation of what counts as physical activity:

> *"We've kind of moved from a fairly narrow definition of sport to looking at physical activity and movement in its widest forms […] we'll support any form of movement that helps people to be active in the way that works for them."*

The overriding sense is that standard and comparative approaches to evaluation do not work: any comparison needs to be more subtle, if it is possible at all. However, it is still felt by providers that funders want this ability to compare across disability sport programmes and activities, as discussed by Interviewee B:

> *"They want to show the impact of working with us and their investment in us and, I guess, they want to be able to do that consistently across all of the partners that they're investing in, so they want to be able to […] to showcase their investments. So without that impact it's quite hard to do, it's quite difficult to raise the profile of certain parts of different organisations if there isn't a consistent way of measuring impact or a way that's not appropriate, because you'll just end up with nothing, and then it looks like there wasn't anything, when really there is."*

Disability sport and physical activity providers had the keenest sense of an issue with the current approach to the evaluation of disability sport and physical activity. They shared examples from their experience of issues with standardisation (C1.2) in relation to the complexity of disability (C1.1). Providers discussed how numbers and quotes can be easier to capture, but questions on attitudinal changes can be particularly difficult to understand by some participants. Standardised tools most often cannot be adapted, and tools may not be sensitive enough to show change or improvement in disabled people’s participation or be too simple to capture the complexities of participation. They may not take account of the complexity of external variables, barriers and enablers to participation. One co-researcher raised how feedback can be cherry picked, but how the negative aspects of programmes and activities, e.g. the barriers need to be shown as much as the positive and shouldn’t be a reason not to fund. Although some recognition of this was noted, a trial-and-error approach is required when working with disabled people. It can be more difficult to justify funding, as there may be fewer participants, they may need more equipment and support.

Providers shared their discomfort about having had to pose standard questions about difficult topics, such as depression, suicide and loneliness, as illustrated by Interviewee F who felt uncomfortable about how these questions could raise awareness of situations that participants may not have even considered:

> *“Those guys would probably class themselves as lonely a lot of the time. Because they basically have their PA. And, [participant] is the most social guy ever, and he's out doing lots of things, but when he's at home in his flat, all he's got is his PA, thankfully he's got amazing PAs and therefore that's not a negative thing, but it could be a massively negative thing. [Participant] is isolated quite a lot. Cause she only has her dad at home now. So, when she's not at [Day centre], she's just at home and that's, so she would be lonely and isolated potentially. So, it’s a real triggering thing for people in a*

> *different, different way. And if they haven't thought of that, brilliant.”*

How questions or prompts are phrased can affect the answer given; again, Interviewee F provided insight on how it would be possible to encourage certain answers from people with lower levels of cognitive function:

> *“The problem with asking a question is I know with 80% of the people that I work with, if I even intimated a tiny bit, I can get them to say whatever I want them to […] So it has to be really, really carefully done to make sure that you don't end up, led down a path of getting the answers that you want. Cause that's also no use whatsoever.”*

We experienced practical insights into this during our research, with some of the answers given by participants. As co-researchers found, sometimes people will respond by repeating ideas from the question or prompt. This limits the potential for further exploration of a topic if such answers are accepted without further probing.

Providers, including Interviewee F, had an acute awareness of the need to enable access (C2) for the people they work with, and how appropriate accessibility was often not considered by funders:

> *“They haven't considered the end-users and quite often funders that we apply for are not just disability specific […] you could be doing it for a wide range of different participants, for*

> *activities, but IF they fund somebody that is doing a disability specific project […] they need to be adapting the questions and the evaluation appropriately.”*

However, this is also reflective of the lack of inclusion of people with the most profound forms of impairment in the development and validation of evaluation tools, as recognised with Chapter 2: *Literature Review*, particularly from the systematic review conducted by Dairo *et al.* (2016) exploring physical activity levels of people with learning disabilities. Again, Interviewee F argues for an inclusive approach:

> *“It's trying to make sure […] that everybody feels like they've been included and listened to, within that.”*

Where it was noted within the literature review that the perspectives of people with severe impairment can be absent, so can their preferred activity levels. What is defined as physical activity may vary for people with different impairment levels, for example, the sensory sport examples provided earlier by Interviewee B.

Regarding the burden of evaluation felt by providers (C1.3), the capability and capacity of providers to conduct evaluation was a key topic of discussion for co-researchers, with the recognition that funding needs to account for the additional support needed for evaluation, including the time, money and resources people have to evaluate alongside delivering sessions. Interviewee F, for example, was aware of the limitations of their capabilities:

> *“We knew that, from the start of the project to the end of the project, they were an awful lot more active, not just in our sessions, but you need somebody that can properly turn that into a research piece. An evidence-based research piece that we don't have that skill set for. And most small organisations that are doing our sort of work don’t have that skillset for.”*

Co-researchers felt that some providers might need upskilling to see the benefits and value of evaluation, also connecting with the sub-theme of recognising the importance of the people who support evaluation (C3.2). As a regional funder, Interviewee D would not ordinarily be present for the provision of an activity, but they noted how their attendance during a particular project and building relationships was useful, as it encouraged participants to complete the evaluation at the end:

> *“I ended up attending every session, the accountability helped because then the deliverers could get on with doing the delivery and […] I was part of the sessions, so the beneficiaries got to know me and got to know who I was […] Because I was closer to the beneficiaries I think that helped to finally get some really good follow-up data.”*

There was a sense that some funders, particularly those at a national level, are distant from the issue and have little or no awareness of what does and doesn’t work on the ground (B4). For example, Active Lives data is considered representative by some funders, which suggests not all funders are aware of the challenges with data collection for disabled people. Interviewee E, from a large national funder, suggested the reliability of this survey:

> *“We've become very data rich as a sector, we have fantastic national surveys like Active Lives, we have data sets that show us with absolute, you know, clarity, which groups are less active.”*

As demonstrated within Chapter 2: *Literature Review*, there are limitations to the inclusion of disabled people in population-level surveillance of physical activity in multiple countries (de Hollander and Proper, 2018; Hassett *et al.*, 2021). From a provider perspective, flexibility with evaluation approaches (B4.1) had been offered in some cases but it was not always useful. Having no prescribed approach was limiting, as providers want to be able to prove the good they can see happening (C3.1). Interviewee A emphasised how providers are trying to find a solution to proving their value – they want a tool to give evidence of what they know they are doing anecdotally:

> *“I don't know the answer as to what is perhaps the best evaluation method that we can really demonstrate our value to support disabled people to take part in sport and physical activity. We're striving to find that answer or striving to find something that will help us be good enough.”*

Interviewee A further discussed how any tool needs to work for their organisation and participants above all else:

> *“As an organisation we're trying to find. The best evaluation tools that I can go to the funders and say, no no no, this is*

> *what we do, this is what works for us as an organisation, this is what we'll provide."*

Again, Interviewee A suggested a desire for academic "back-up" for what they see happening anecdotally, a notion that was also present in other responses, including from Interviewee B:

> *"We've got so much anecdotal information about the outcomes that are achieved through sport and physical activity and it's really difficult to be able to hold those up against more academic measures, they don't seem to necessarily be recognised in the same way."*

Interviewee B suggested dissatisfaction with having to use an approach outside of recognised measures, as a less stringent approach, simply because the people they worked with couldn't use what was available.

There was discussion of how the Covid-19 pandemic had enabled more flexibility in evaluation (C2.2 *Flexibility*). Co-researchers noted how the pandemic showed us that things can be adapted, but there was reflection on how many activities may not have returned post-pandemic, as momentum was lost. However, the need for accountability was still there (B1 Accountability), as regional funder Interviewee C noted, there is desire to prove value for money, through 'checks':

> *"It's always good to show the impact and be able to share the impact of what's been funded and it's a bit of accountability on*

> *those that are receiving money that what they've said, is going to be delivered is delivered […] it's not just money and then nothing, no one knows what's happened in that sense, so the key thing there is that, but showing the impact […] so that's key, so for us it's accountability and just doing all the checks we need to."*

However, an idea explored from evaluator Interviewee G is that this approach creates a resulting power imbalance that favours the needs of funders at the potential expense of providers and participants:

> *"There's a lot of potential benefits there, elevating voice, for example, that we're not necessarily seeing yet. And I think one of the reasons we're not seeing it is actually because of […] the top tier in terms of funders, I think funders dictate the landscape of what they expect from organisations and from projects, and exert a lot of influence over approaches that organisations take because they want to, because of that inherent power dynamic in terms of receiving further funding."*

There were some examples given of providers being asked retrospectively to satisfy the ultimate providers of the money (B1.1 *Control*), for example from regional funder Interviewee D:

> *"They're now being pulled back as well, so where, where we will land, we don't know but I think there's a will to have that flexibility and actually be realists, but there's also that pull to have good data, as well as, you know, the nice stories."*

Interviewee E, from a national funder, highlighted how the requirements from the ultimate controllers of finance can restrict flexibility or new approaches:

> *“Or there's been a new directive from government, which means that the funding stops and we look at a different way of doing it, so sometimes it's, it's kind of out of our hands.”*

A sense of push-back from the top also came through in answers given by Interviewee C. Referring back to the answers given previously in the interview, they reflected that there may be a need to still demand quantitative outcomes, but suggested the existing evaluation framework would be used to facilitate this move to collect other forms of data:

> *“That's something we're working through at the moment to try and keep it as light touch as possible, you know, put qualitative at the front of everything, that's still the main thing, but in the background, just a couple of extra questions maybe or an extra bit of information that we need to gather outcomes and data like that.”*

One aspect of accountability was potential sustainability of an activity. Sustainability was identified as the lynchpin of approaches to tackle inequalities and inactivity, as noted by Interviewee A:

> *“I sometimes find it challenging that a lot of people expect people to come to [ORGANISATION A] for six weeks, and then to the exit, this ‘exit strategy’, I hear this all the time, or: “What's the discharge strategy?”. Well, actually, this is just potentially*

> *offering up a new way of life, with the individual, to take part in an activity that is meaningful to them. And there is no end date and actually, if we can support someone to grow independence and to empower them to be part of something else, then of course we will."*

Sustainability (B2) is a key aspect to disabled people as much as to funders and providers of disability sport and physical activity. Co-researchers highlighted in discussion that the need to sustain relates to the need to 'belong' (A4 *Belonging*) to be able to 'do'. Sustainable approaches can enable access: new approaches in partnership working may create sustainable, long-term interventions that enable access and tackle inequalities in access to sport and physical activity participation. Regional funder Interviewee D recognised that short-term approaches do not work for disabled people:

> *"We know that we used to run projects of like six weeks, we'll get someone active and that's it […] That doesn't work with disability at all."*

There is some connection with sustainability and the challenges in building and sustaining participation numbers within Mark's comments, as he discussed the difficulties in not having enough members of a similar level to compete against:

> ***Bev (co-researcher):*** *So, would you like to be able to go to Boccia more often?*
>
> ***Mark:*** *I only, I'm the only ramper*

> ***Fiona (co-researcher):*** *You're the only member of your club?*
>
> ***Mark:*** *No, ramper*
>
> ***Fiona (co-researcher):*** *The only ramper, sorry,*
>
> ***Mark:*** *I need to be against more*
>
> ***Fiona (co-researcher):*** *So, you need to be against more ramp- more BC3s?*
>
> ***Mark:*** *Yeah*

Disabled people may need extra support to be able to do (A1.1 *Doing in a way that works for me*) (A2.2 *Being supported to participate*). One co-researcher highlighted that this is particularly pertinent to the experiences of people with complex disabilities. From her experience of working with users in a hydrotherapy pool, she recalled how within the pool this could be the only time a person would truly relax their muscles, or the only time they would laugh – and this was a big outcome – it might not look like they were doing much in terms of physical activity, but the impact was profound. For another user, a child with cerebral palsy, being in the pool was the only time their muscles relaxed enough to be able to hug their family, so family members would take turns to go along to sessions. The heart rate was not raised as a result of this activity, the person moved little, but the positive outcomes were immeasurable. Another hydrotherapy pool user would refuse to go anywhere else but the pool – even just being there, before participation and engagement, was a big hurdle overcome.

Interviewee Kate provided an example of how disability sport and physical activity loses out when success is based on participant numbers, which can be more challenging to build and sustain and may not be comparable with mainstream activities:

> *"We sadly don't get much help or support from [FUNDER] because we're not seen as a club that 'gets the numbers'. Their funding goes to the 'bigger sports'. The more popular/well known sports - such as wheelchair basketball, swimming, athletics etc. Because these are seen to 'have the numbers'. So smaller clubs, like ourselves, don't get much help because they don't see that [FUNDER] will get much out of their investment. Sadly, that then negatively impacts us, because they don't see that with more help with funding, we can then run more sessions, which in turn will mean we can promote more, which then means we will get more numbers."*

Funders want proof of sustainability, but disabled people need reassurance that an activity will be there, with the appropriate conditions and support in place, and it needs to be viable to continue, for disabled people to be able to 'do'.

There was a political edge to the research findings and co-researcher interpretation of the findings, that was not necessarily surprising but unexpected. Perhaps a result of the times we are in, or the comfort developed between co-researchers to express and share such issues, but the politics of being a disabled person was more prevalent in co-researcher responses to research findings.

On the analysis and findings day, a broader discussion of government policy around disability emerged between co-researchers, in relation to funding. Overarching disability policy will feed into funding and what information is deemed acceptable, so this offers a potential restriction to how much change is possible. With reference to schemes such as the UK Government’s ‘levelling up’ policy not appearing to be achieving its aims, some co-researchers reflected their concern around the ‘squeezing out of disabled people’ and how they had felt personally that things were going backwards.

A political strand was also evident within the data, with interviewees suggesting the need for a collective response to call for change (C4). This theme brings together some of the key issues that providers identified in the evaluation of disability sport and physical activity. From providers, who work directly with beneficiaries, there is an acute awareness of the issues and what isn’t working. Some talked of a collective voice, others talked about a keenness to compare with other, similar organisations, but the challenges inherent in this related to the complexity and variety in disability and disability sport. There is a sense that while organisations have been raising awareness of these issues on an individual basis, there is a need for collective action, a collaborative voice for change, the need for strength in numbers. Interviewee F exemplifies this:

> *“’Cause I think all of us are looking at the same. Ultimately, we all want evidence, don't we?”*

Interviewee D, from a regional funder, discussed the need to influence upwards to national funders:

> *“I do believe that if we all keep pushing in the same direction in terms of that flexibility but also being able to report back up […]*

> *If we can prove what we're doing is working with different techniques and different things and, yeah okay, you can't aggregate it or you can't show a bigger picture and whatever else like this, but you could show a really good flavour of what's happening.”*

Elsewhere, Interviewee D emphasised their belief that there is a journey towards change:

> *“It is a change to everybody, so I think if we keep going on that journey, it will eventually filter through the whole system.”*

Interviewee E, from a national funder, discussed the need for evidence and justification of a different approach to the evaluation of disability sport and physical activity, in order to influence top-level funders:

> *“We're kind of working on the narrative to support why we evaluate in this way, why we don't have clear impact data drawing on academic literature and the latest thinking and why it's, you know, why it's important to evaluate in this way and that gives us that sort of justification to say, well we don't have that figure, but here's why, because it's more important to do it this way. So I think they'll [laughs] they'll always have to provide some sort of top level data but we're, I think, finally starting to build that narrative and that articulation for why that's not the only thing that counts.”*

Interviewee G noted the potential for policy change from showing that things can be done differently, with success:

> *"For funders, or at a slightly bigger level, I think successful evaluation is, can be kind of connected to policy change, it's about building a consensus and a narrative that some things work best in some circumstances, done in certain ways, and informing that overarching conversation, so it's about elevating that learning from evaluations."*

Related to this concern, funders talked about wanting to tackle inequalities in access to sport and physical activity (B3 *Tackling inequalities and inactivity*) and how more sustainable solutions were vital within this. As Interviewee E noted, systemic change is required to address inequalities that are not new and where past approaches have failed:

> *"So we sort of realised, we had to work in a different way if we were really going to provide more opportunities to be active, it was going to be sort of systemic change, change in the sort of language and the partnerships and the way we work and the strategies, the policies that we put in place."*

Interviewee E expanded in more detail about the relationship between this change in approach and how it might feed into evaluation, looking at the learnings around the conditions for success in promoting physical activity, rather than a tick-box approach of participant numbers:

> *"In the past, the traditional delivery model, you'd be looking at, you know, participation, attendance, recruitment, whether people are being retained in the activity, the sort of reasons that they were enjoying it, the sort of feedback they were*

> *providing about their experience, how you might sustain the activity. Recently it's become a bit more abstract, almost in thought, about what are the right conditions for promoting physical activity in this place, how do you support the best ways of working across the system or with different partners, how do you work together in collaboration and what is the added value of doing that, rather than working in individual silos."*

'Change' was initially, before the co-researcher analysis and findings day, highlighted as a potential theme, but this was reconsidered after the discussion that took place between co-researchers. They suggested the change-related focus may be over-influenced by the timing of interviews in the aftermath of the Covid-19 pandemic, concurrent with the period of the Sport England new strategy release. It was inconclusive how much had filtered into action, when co-researchers reflected on their own lives and work, and with Activity Alliance reporting a further reduction in disabled people's participation in sport and physical activity (Activity Alliance, 2024).

Referring back to discussions within Chapter 2: *Literature Review* regarding evaluation approaches that enable providers to consider the best conditions for participation (Willis *et al.*, 2018), there was recognition of the need to consider evaluation for active learning rather than monitoring and accountability (C3.3). Evaluation should be used to make improvements to activities, to make them more available to disabled people, to get more disabled people involved, as evaluation professional Interviewee G attested:

> *"In a happy world, I think, for organisations, evaluation would be exactly what I talked about before in terms of, being able to explore and adapt the way that your intervention is being delivered in order that it is the best possible intervention for the people that you're supporting, within the context that you're working, and with the money that you have."*

Evaluation should also enable providers to do things better and to prove that they are doing a good job, when they know this is the case from experience. It was acknowledged that this is not an easy issue to resolve, but this approach may be underpinned by the need and desire to work more closely together (C3), to work in partnership. Some of this work is already happening at a national level, as noted by Interviewee E:

> *"We've started talking more about learning and evaluation partnerships, rather than evaluators or evaluation contracts, reflecting a much more collaborative way of working where we design things together, rather than designing it first and then going out, and not being able to respond to the challenges."*

Accessibility of evaluation solutions can be better explored through partnership with participants through co-production with disabled people. There is also suggestion that evaluation solutions should be developed for each project in partnership with end users to consider individual needs at the specific site, to ensure they are accessible, appropriate and meaningful to disabled people.

In discussions, co-researchers emphasised the need to value the involvement of disabled people in any form of partnership working or co-production, with reward and recognition for their participation and contribution of experiential knowledge. There was discussion of how it can take time to see the benefit of evaluation and how, for some, it is necessary to see a benefit in the moment, rather than in 3 years' time. One co-researcher described how they gave evaluation participants extra time in the hydrotherapy pool after completing their evaluation, with the pool toys available, but then also made sure to update participants afterwards about any outcomes. This co-researcher shared how sharing the impact and benefits of evaluation through maintained communication contributed to pool users feeling a sense of belonging.

In contrast, Interviewee G, from an evaluation company, did note the additional burden that participatory approaches can create:

> *"We come up against the challenge, though, those multi-level challenges in terms of the money that is available to do that research, the administrative burden it can place on organisations to be involved in that research and to engage in more participatory approaches, the funding that is required for participatory approaches to be meaningful, the timeline that is required for that to be meaningful, versus the timeline of organisations or funders."*

Some suggestions were offered for what could be done using co-productive approaches, particularly more creative approaches to enable access, including use of visual methods such as photography and video. Co-researchers discussed ideas raised in the data, including use of gamification approaches, how collecting something and working towards a reward could be appealing to some, and a hook to encourage participation. Discussion of tech-based approaches were balanced with the need to consider accessibility, for example, for people with visual impairment or in relation to digital exclusion. However, the most commonly suggested approach was for a toolbox or toolkit, bringing together a combination of accessible approaches catering to a range of impairment types and desired outcomes, enabling a tailored and context-specific approach. Interviewee F mentioned this concept, as a potentially pragmatic and less burdensome approach:

> *“It would help organisations, especially little ones that don’t have the capability of doing all their own research, a box of tools that would enable us to collect easy and relevant information to make these guys feel like that they’ve had an input.”*

Interviewee F noted such an approach to include a range of administration methods, including use of simple visuals for people with learning disabilities and proxy report or fitness tracking for those who are unable to respond themselves. However, they emphasised, that even if tools are different, with a range of administration methods, they must all contribute to the big picture of collated data:

> *“I think it's really important for, from a research point of view, that the questions can all feed into the same place and the same analysis, but they need to be asked or worded in a different way. Now I know that can affect how […] there's a posh word, isn't there, about how it's received.”*

This was also reflected by Interviewee B, who emphasised the need to ensure the measures offer a recognisable quality of data:

> *“I think that's the key for me […] there needs to be a range that's going to be something that is suitable for lots of different people […] but somehow you can, they can all equate to something that you can consistently measure and be able to report back on, which is crucial for all of us and for the work that we do.”*

This is an approach that some evaluation companies have been advocating for, as noted by Interviewee G:

> *“We were accounting for such a broad range of health conditions, we've been trying to design questionnaire templates where there are like core questions and kind of optional questions, and organisations can kind of flex what they ask, based on what they think's appropriate, working with organisations to build their own questions into them as well.”*

National funder Interviewee E, from their working role in insight and evaluation, concedes that they currently do not have the answer, and that there is unlikely to be a single solution to the issue:

> *“I'm struggling, it's the big question, isn't it, that I don't have a, there's no single solution, there's lots of different measures together.”*

6.7 Summary

This chapter has detailed the findings from data collection across all three research questions, considering the sport and physical activity outcomes of importance for disabled people, and the evaluation priorities of funders and disability sport and physical activity providers. Key points were identified by co-researchers in the discussion of these findings, which resulted in a series of recommendations for future action, which will be outlined in further detail within the discussion chapter, where plans for dissemination will also be explored. Having reviewed findings from data collection, the next chapter will focus on methodological learning from the process we have undertaken.

Chapter 7 Methodological Learning

7.1 Introduction

Following on from research findings, this chapter explores the learning obtained from the process of planning and undertaking the Voices for Inclusive Activity (VIA) project with a group of co-researchers. It has been observed elsewhere that data analysis within a PAR project takes place throughout its lifetime, with information gathering and analysis happening concurrently to inform future action and research decisions (Rifkin and Pridmore 2001; Taylor and Francis 2013; DePoy and Gitlin 2016). However, within the VIA project, the project had a distinct period of data analysis in relation to the information gathered by co-researchers from participants. The information gathered within the process of planning and enacting the project is not regarded as 'data'. Instead, this process-related information forms the basis for this chapter on Methodological Learning. There is a connection here to what has been reported from the data, in the theme related to seeing evaluation as learning.

Some of the methodological learning from the VIA project have already been shared within a co-authored journal article (Pettican *et al.*, 2023). Within this chapter, some of the ideas from this article will be explored and further developed.

7.2 Cycles of Planning, Action and Reflection within the Voices for Inclusive Activity project

Participatory Action Research (PAR) is experienced through cycles (Dania and Griffin, 2020); Figure 7.1 illustrates how the phases of planning, action and reflection were experienced within the VIA project at an overarching level, but also cycled within the different stages of the project. At the top level, planning the project took place within discussion groups, where we co-created our research proposal. Action took place in the process of collaborative data collection. Reflection occurred as we reviewed our process and interpreted our data. Under this top level, the cycles occurred.

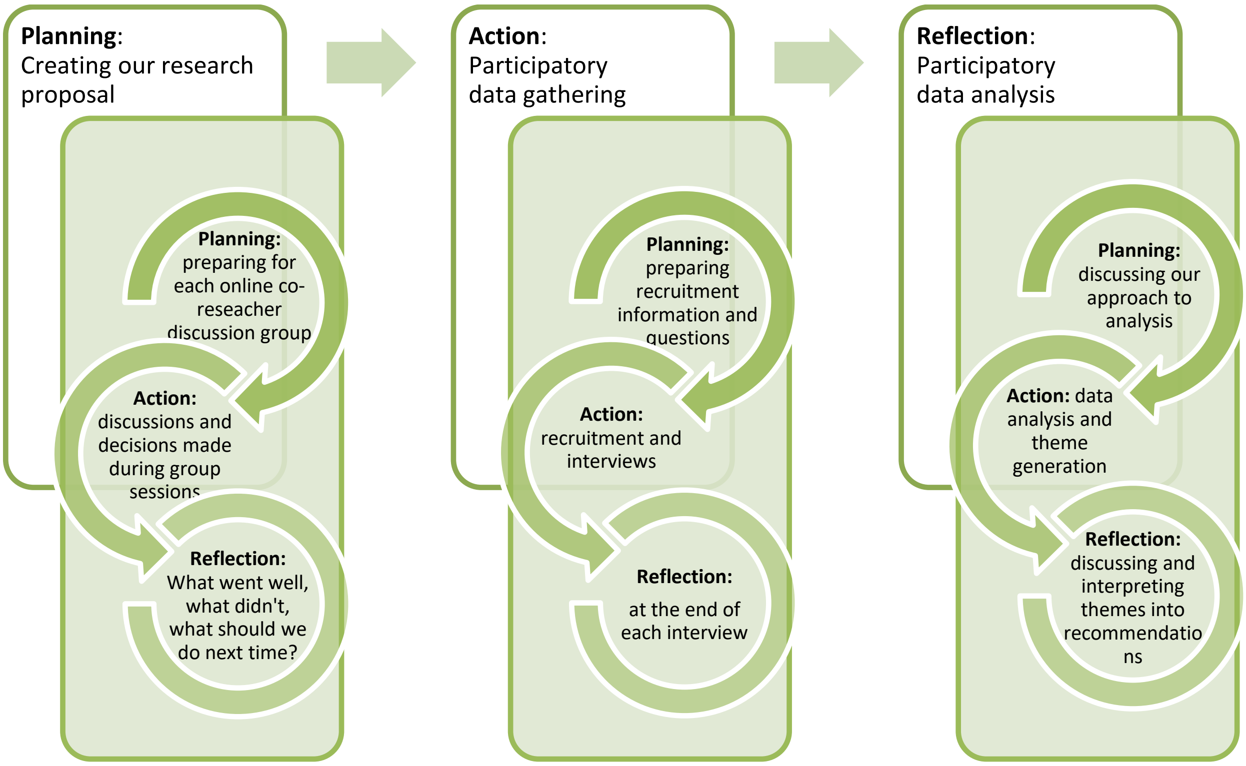


Figure 7.1: PAR cycles of planning, action and reflection within the VIA Project

While the stage of creating our research proposal fits within the Planning part of the PAR cycle, within this were additional cycles of Planning in preparation for each co-researcher discussion group, Action in the discussions and decisions made during group sessions, and the reflections at the end of each session on what went well, what did not, and what we should do next time. Hereafter came the main Action phase of our PAR approach in data gathering, although nested within this were additional cycles of Planning in preparing recruitment information, interview schedules and questions, Action in planning recruitment, recruiting and interviewing participants, and Reflection undertaken at the end of each episode of data collection. Participatory analysis is where the Reflection element of the PAR cycle was most evident, but within this stage we also experienced cycles of Planning in discussing our approach to analysis, Action in the process of data analysis and theme generation and Reflection in our discussion and interpretation of themes into recommendations.

Analysis of both data and process was present in the ongoing feedback loops that occurred as a result of reflective practice; interpretations were discussed, sense checked and clarified, and new questions emerged to drive the participatory cycle forward (Cahill, 2007). We were continually trying to find new ways to carry out activities, spread responsibility among the group of co-researchers and challenge assumptions about who has valuable knowledge, expertise, insight and skills (Cornish *et al.*, 2023). Together we reflected on the content and the process of interviewing, partly to help plan for the next episode of data collection, or for the next phase of data analysis. In preparation for data analysis, we discussed our approach and understanding of this phase. The process of reflexive thematic analysis and theme generation, but also our discussion of initial themes, involved an iterative process of reflection and refinement. When we met together for our analysis and findings day, we discussed and interpreted themes into recommendations, but these were further refined as we planned and enacted the creation of our collaborative podcast.

Of course, the diagram in Figure 7.1 somewhat neatens the iterative and uncertain process experienced by co-researchers. This was not planned, and it is only on reflection that we can apply such a model to what took place. It would also be possible to apply such a model to our learning from the process, in terms of the planning of the PAR process, the action in how it was carried out, and the reflections outlined within this chapter.

7.3 Co-researcher reflections on process

The co-researchers working on the VIA project were not subject to ethical approval as they were not providing data for the project, but they did engage in a series of reflective activities during the process of the project where their reflections contained learning for others, which they consented to share. This is not data that we set out to collect but concerns the reflective practices undertaken within the project.

Daniels *et al*. (2019) had made a recommendation for any future studies involving online steering groups to add an evaluative component to consider the process of working together online; the learnings shared here may contribute to this knowledge base. While I followed their lead on use of a reflexive journal to chart the planning, progress and effectiveness of groups, an additional mechanism of reflective group feedback on our process at the end of each co-researcher discussion group enabled us to clarify what went well, what did not, what could be done either the same or differently in future meetings, and specifically what the next group would entail. This helped to inform future iterations and to find ways of working that were best for all involved, including the ability to meet at a time amenable to all (Lember, Brandsen and Tõnurist, 2019). As an example, one co-researcher prompted tasks to be assigned between each meeting to maintain continuum and progress. The reflective discussions at the end of each episode of data collection allowed co-researchers to react to and highlight content within interviews but also to reflect on the process of undertaking them. The latter was particularly significant for this project for dual reasons: it allowed reflection and improvements to our process ‘in the moment’ but also enabled practical experience and learning for improvement around the process of undertaking evaluation in practice. Indeed, these practical reflections on the collection of data, and the inherent challenges experienced, might be seen as significant as the content of discussion in interviews. Learning about the process of engaging in participatory and collaborative research informed learning about the methods and conditions of undertaking evaluation of sport and physical activity in practice.

Preparation for collaborative dissemination activities also encouraged reflective discussions about our process. There were five occasions where co-researchers were able to disseminate their learning on the process of undertaking this research, as outlined in Appendix 10.

These opportunities promoted inclusion and enabled co-researchers to share and consolidate learning as it occurred. Before each of these activities, the co-researchers involved gathered to discuss and co-author their reflections on the process of undertaking the research. Some of the individual points raised by co-researchers can be seen within Appendix 10.3, but these have also been used to inform the reflections within this chapter. The challenges of lack of certainty of where the project was going, along with concerns about previous experiences of group work are covered within the sections of this chapter on *Trusting the process* and *Building and sustaining positive partnerships*. Concerns about meeting virtually, the challenges in working collaboratively and being able to access documentation feature within *Sustaining accessibility and making space for collaboration*. The aforementioned sections also include reference to the positive aspects raised, including working collaboratively with a diverse range of co-researchers and negotiating practical arrangements to suit everyone’s needs.

7.4 Reflection on practice: use of reflective tools

The notion of learning from activity is embedded into the practice of occupational therapy from pre-qualification onwards, often referred to as reflective practice (Andrews, 2000). Reflection is encouraged as a tool to think about and analyse situations and consider what approach may be taken in the future as a result. Reflective models, many drawn from other fields, such as education, help to structure our responses to these situations. In acknowledgement of this, a reflective model has been used to structure this chapter. Rolfe, Freshwater and Jasper’s (2001) reflective model, based on three questions, offers a simple framework to discuss what happened (What?), the significance and meaning of this (So what?) and the outcomes and learning from this (Now what?) (Rolfe, Freshwater and Jasper, 2001). I have selected this model as I use it regularly within my clinical practice; it is quick to administer and gives freedom to concentrate on the incident or occurrence itself, removing any concern over whether I am using the model accurately. It was also used with co-researchers for this reason; it is a straightforward model for those unfamiliar with the process of reflective practice.

There is a tendency within reflection to focus on the mechanics of an incident or activity and neglect deeper analysis, which is often where most learning can be obtained. As such, the focus here is on that learning and the resulting recommendations for the future, therefore, a brief description of ‘What’ will be followed by discussions of ‘So what’. The ‘Now what?’ section offers implications for the project but also learning and recommendations for others seeking to undertake PAR or co-production activities in the future, whether the co-production activity is related to research or not.

7.5 Methodological reflections: building on Doing together

During the course of this research, an article was co-written with the supervisory team and published in the journal *Qualitative Research in Sport, Exercise and Health*, entitled: *Doing together: reflections on facilitating the co-production of PAR with marginalised populations* (Pettican *et al.*, 2023). The article presented critical reflections on facilitating PAR, with three themes identified as points of learning from the VIA project:

- 7.5.1 *Building partnerships*, which focuses on the need to build trusting relationships with collaborators
- 7.5.2 *Sustaining accessibility*, which describes the processes of ensuring co-researchers were able to engage at all points of the research process
- 7.5.3 *Trusting the process*, which explores the messiness of the participatory research process and how this can be both expected and embraced by all involved.

All three of these aspects will be discussed and updated within this chapter. For example, building partnerships has been adjusted to consider the sustainability and long-term future of those partnerships, and what happens when the project ends. Sustaining accessibility has been expanded to consider how we made space for collaboration across different remote platforms. They have been joined by the addition of five specific aspects of learning, identified by co-researchers throughout the process, which will be discussed here:

- 7.5.4 Sharing power through distributed roles and responsibilities
- 7.5.5 Control and formulation of PAR
- 7.5.6 Training co-researchers
- 7.5.7 Time required for PAR
- 7.5.8 Co-researcher involvement in co-creation of knowledge

7.5.1 Building and sustaining positive, productive partnerships

What?

The initial mechanisms put in place within the VIA project to encourage relationship development were initially very organised and inorganic: initial individual project discussions, allocated time for social interaction and an icebreaker activity on our first meeting, along with co-creation of a document on our ‘ways of working’. Although four of the co-researchers had a loose connection through the collaborating organisation, they were not well known to each other. Working online reduced any opportunities for informal gathering before or after the meeting, although it did enable more regular meetings for co-researchers who otherwise worked or studied full time, who had other responsibilities, or may have had issues with travel due to cost or mobility. Over time, there were opportunities to meet with co-researchers in person, locally to them, both socially and for the undertaking of data collection. As we got to know each other over the five years we have been working together, people began to share other parts of their lives as we checked in with each other:

Methodological reflection on developing meaningful relationships

In communications, I added individual messages about things people share, about things going on in their lives. Co-researchers always ask about me and my experiences, too.

So what?

The development of positive working relationships is prevalent in literature relating to all forms of collaborative research, with attention paid to the power relationships that permeate research partnerships and the actions needed to address these (Egid *et al.*, 2021). This was further challenged by our need to meet online during pandemic restrictions; as was noted by Beresford *et al*. (2021) about this time; having to establish connections and work together at a distance contradicted the relational imperative of this type of work (Beresford, Farr, Hickey, Kaur, Ocloo, *et al.*, 2021).

It was therefore necessary to pay extra attention to the conditions of how we would work together, with limited examples in the literature of how to do this, because of the unusual pandemic situation we found ourselves within. Establishing working practices is described by Cornish *et al*. (2023) as one of the building blocks of PAR, along with establishing a common understanding of the issue in question (Cornish *et al.*, 2023). The ‘ways of working’ co-produced within our first session, considering our behaviours, practices, the environment and the language we use, were designed to ensure parity of participation and counter the informal conditions that can marginalise contributions and threaten parity of participation for people from non-dominant groups, even if they have been legitimately included (Fraser, 1990). Co-production has been a buzzword, in some cases for poor practice; it is widely acknowledged that avoiding tokenism means ensuring the process is inclusive, participatory, and explicitly ensures all instances of power imbalance are recognised and tackled, for change to happen and inequalities to be redressed (Egid *et al.*, 2021; Williams *et al.*, 2021b, 2021a).

Reflexivity and analysis of positionality is vital, but it must not be a private endeavour of the researcher: it needs to be vocalised with co-researchers. Together we discussed our identities, motivations and interest in the research (Egid *et al.*, 2021). We talked about my role as a non-disabled person and PhD student, and this contributed to me becoming more of a facilitator for the process, where knowledge was shared and built between co-researchers with lived experience. We sought ways to democratise decision making and valued their knowledge above any of my own; they were also the primary spokespeople for the project (outside of the academic requirements).

Having worked with co-researchers for more than four years on this project, the development of positive relationships was most evident when we met in person for our analysis and findings day The trust had been built, and within my reflective journal I noted the openness of co-researchers with their experiences:

Methodological reflection on capturing thoughts in person

There was acknowledgement that it had been some time since we last met but we soon got into discussion, picked up where we left off, working together, relationships already built. People refamiliarised with the project and it did not feel like 2 years later! Discussion flowed more readily than online and co-researchers seemed to share more personal examples and experiences. We all felt a sense of achievement to look back at the notes at the end of the day.

The development of positive working partnerships was beneficial to the progress of the project, creating a trusted space for collaboration and progress to be achieved. This was most evidenced as we came to consider our outcomes and work on dissemination. The practicalities of a collaborative approach were evident:

Methodological reflection on creating our podcast and recommendations

We worked through a very collaborative process of discussion, talking through any disagreement, agreeing a way forward. As we began, without prompting, one co-researcher opened a Zoom whiteboard to record our responses. As we discussed and adapted our script for recording, the co-researcher made the changes on screen for all to see.

The development of connections across and between co-researchers also resulted in mutual sharing of experiences, as noted within the following reflection, which also demonstrates how challenges in the process became easier to deal with over time:

Methodological reflection on social time in sessions

Waiting for a co-researcher with technical difficulties; I would have panicked about this happening at the start of the process, but we found ways to make the most of the time, catching up and hearing each other's news. Two co-researchers shared mutual experiences about the challenges of teaching.

However, I also reflected at this time on the additional challenges throughout this process of maintaining and sustaining relationships:

Methodological reflection on responsibilities to co-researchers

The ups and downs of a PhD are one thing, but more challenging when you are beholden to other people. I am always thinking – have we been in contact lately, should I check in?

As a PhD student undertaking this project, there also remained a tension that I would be writing about the experience of working together, and the threat this might pose to co-researchers' views of our relationship as genuine; a tension explored by other doctoral researchers (Huisman, 2008). Despite my efforts to be open from the start about the place of this research project within my PhD, this is an explicit example of where the building of trust in participatory research can be challenged by underlying hierarchies of power (Egid *et al.*, 2021).

Methodological reflection on the tensions of writing about relationships

Even now it feels odd writing about this – I would hate to think co-researchers thought I'd only offered to meet up so I could write about it, or to show how good the project was! It would seem so false, simply for the purpose of the thesis. In some ways it feels odd, a breach of trust and privacy to be writing here, when I value the relationships we've built.

With most of the remaining co-researchers, text messaging, specifically WhatsApp, became and remains a more convenient means of being in contact alongside email and Zoom meetings, echoing Cameron's (2007) suggestion that remote options can be useful in maintaining regular communication and can help with the large quantity of time that is necessary to commit to the process (Cameron, 2007). As this is a tool commonly used for both personal and professional means and all were consenting to use it in this way, we continued.

Methodological reflection on the use of WhatsApp

One co-researcher suggested keeping in touch using messaging, as they do not check their emails often, and WhatsApp has become the communication tool of choice with the collaborator and co-researchers. Another co-researcher found it more accessible than booting up their unreliable laptop to *send follow-up recommendations as voice notes. It is convenient and gains a quick response from us all. There are ethical considerations in the use of our personal phone numbers but there is no imperative to use it. One co-researcher who cannot use WhatsApp for technical reasons is not left out as key project information is still communicated by email.*

Without face-to-face support, undertaking this kind of work online required collective creation of boundaries (how and when would we contact each other outside of the project space, from our own homes), but it was useful to have an accessible route to checking in with each other (Beresford, Farr, Hickey, Kaur, Tembo, *et al.*, 2021).

Within occupational therapy practice, as with other healthcare professionals, we are trained to maintain professional boundaries in our practice with clients. While we look to build a meaningful connection, this is in pursuit of a therapeutic relationship with boundaries that prepares the client for the closure of professional contact (Taylor, 2008). Within this form of research, where the aim is to build meaningful and genuine partnerships, there is still a boundary but it is challenged. This is, in part, by the need to challenge any power differential that is in place within a professional/client relationship. PAR is a personally demanding process for an academic researcher; this is reflected by Cornish *et al.*'s (2023) consideration of the soft skills required of a PAR researcher. Their list includes humility and genuine kindness, patience and comfort with discomfort, self-awareness and the ability to listen, be confronted, to take responsibility and the confidence to identify and challenge power relations (Cornish *et al.*, 2023).

Now what?

The development of respectful and trusting partnerships that prioritise ethics and reciprocity can enhance validity within transformative research (Mertens, 2009). Yet developing concern for co-researchers as people has personal implications for researchers aiming to build collaborative working partnerships, extending beyond the limits and constraints of a project. Working in this way with a community of researchers means that ending involvement is not straightforward or necessarily desirable. The remaining co-researchers have expressed a willingness to continue the work of the VIA project, although this will require additional funding obtained beyond the project.

Personally, I have built connections with co-researchers through our online meetings from my home, during weekends, we have met socially and are in contact outside of the project. It is recognised that relationships built over time in PAR can extend beyond the project (Cameron, 2007). I would encourage other researchers planning a PAR study to consider how this type of research goes beyond the academic or employment-based endeavour to a more personal domain of emotional connection and how to plan for an appropriate conclusion that is satisfactory to all.

7.5.2 Sustaining accessibility and making space for collaboration

What?

Attention was paid to enabling participation within the research at all opportunities. Adaptations to process began from the provision of multiple formats of co-researcher recruitment information (long format, short format and Easy Read text and subtitled videos) and simplifying the introductory email to the project. The initial discussion Zoom call with the co-researcher with learning disabilities also took a different format: it was facilitated by the collaborator, as a means of establishing trust (the co-researcher had told the collaborator they were nervous to meet a new person in this way). I was challenged to explain the project in its clearest terms, to ensure the co-researcher had all the information required to make an informed decision to take part.

We were restricted by the need to meet on Zoom due to the Covid 19 pandemic, but attention was paid to accessibility of the process, including creation of Easy Read agendas for each discussion group. Some adaptations encouraged accessibility for all co-researchers, including negotiating meeting times according to individual preferences, not only considering availability but also selecting the time of day and choosing and adjusting the session length and break times according to individual needs. For some people, working remotely made the project more accessible, but the aforementioned co-researcher, who was joining the session with the support of a family carer, found it difficult to follow along with the discussion. Collectively we sought ways to encourage his valuable involvement, but after two sessions, I received an email from the family carer stating they did not think they could continue. I reflected on this within my fieldwork journal:

Methodological reflection on co-researchers wanting to leave the process

It felt like discussion was progressing well around the project in our second discussion group today, decisions were being made around who is the audience for the project and what is the aim. Suggestions were made about how to better record what we talk about, so everyone can review this at the start of each meeting to ensure progress is made. But I was concerned that not everyone was being included as well as possible. Shortly after the meeting I received an email from two co-researchers wanting to leave the group, not feeling they have anything to contribute. I keep playing over what I could have done differently and how I could have brought them in more. Where the session sometimes went off on a tangent, it might have been difficult to follow, and it is harder to check in with people on Zoom than in person. I don't want them to feel corralled into staying part of the project if they really want to leave, but likewise I don't think they realise how much their experiences are needed and how much has already changed because of their involvement.

In response, I sought ideas from other co-researchers if there was anything we could do to maintain these co-researchers' valuable involvement. One co-researcher suggested we look at changing the format of our meetings to involve everyone more readily:

Methodological reflection on renegotiating co-researcher involvement

The co-researchers are going to join us for another session after another co-researcher suggested we break into smaller groups to help everyone follow *the conversation and join in more easily. The broken-down structure, directed discussions and chance for small group conversation was a real success and allowed group members to share their own comments and experiences more freely.*

The family carer had also found it difficult to engage in the sessions and despite co-researchers' collective efforts to include them, they decided to allow the other parent to be involved in the process instead, which enabled this co-researcher's further involvement:

Methodological reflection on a change in co-researcher support

The other family carer joined us for the first time for discussion group 4 and one of the best things today was when they said how they were all going to work with the co-researcher to be involved, as they loved coming online and being part of the project.

With these changes and continual attention to process, the co-researcher remained involved throughout the planning and creation of the research proposal and recruitment information. Akin to what has been reported by Tuffrey-Wijne and Butler (2010), the skills and interests of this co-researcher were well applied to aspects of the project, such as helping to design and ensure the accessibility of participant information materials, by sense-checking wording and selecting Easy Read images (Tuffrey-Wijne and Butler, 2010):

Methodological reflection on co-researcher inclusion

There were little things that made a difference to people feeling involved in this session. The co-researcher was asked by another to select the colour used to type up and share the discussion notes on screen. Another co-researcher simplified evaluation into 3 steps, talking more about 'what is the value' – helping people to understand evaluation and make it more accessible. The co-researcher emphasised how using pictures in evaluation helps to make it more accessible and was pivotal in selecting these.

The co-researcher was involved in undertaking an interview, as the collaborator was involved in ensuring it coincided with his attendance at his own physical activity session. However, despite the attempts to maintain involvement, involvement ended after discussion group 8, with no further response to email invitations following the point of data collection. Communication with this co-researcher was conducted via the family carer rather than with them directly. I was aware of the concerns of Powers (2017) about action research conducted with people with developmental disabilities, where a lack of ongoing connections between researchers and community members could make research relationships and trust problematic, also that that strengths, perspectives and needs might not be understood (Powers, 2017). Powers (2017) had also noted how researchers might be reluctant to involve people in more technical aspects of research. Co-researchers continued to look for small ways to maintain involvement of this member, having found great value in his insight and perspective, even if it did not involve us meeting online, but while I attempted to maintain contact for a while, it came to a point where I needed to respect their decision to cease involvement. Together, co-researchers discussed the situation and ways to keep this co-researcher's voice within the project going forward:

Methodological reflection on offering alternative forms of involvement

Co-researchers are keen to maintain this co-researcher's involvement. We continue to offer small ways for them to contribute that don't entail a full meeting, but no response at all, I think we may have lost them from the process. I need to accept that they have given what they feel then can and have moved on. Not everyone has the same motivation or feels compelled to remain involved. While this co-researcher is not present, all are keen to ensure they still have a voice in the process.

Alongside concerns for the accessibility of the group for this individual, I was concerned whether the format was limiting any potential for participatory processes and progress:

Methodological reflection on the limits of participatory research

I am coming to terms with the fact I cannot ensure every aspect of this research is fully participatory and co-designed. A lot relies on listening to what is said, taking action/writing up/creating drafts and reporting back for feedback. It would be so much easier if we could be in person, sitting down with the various documents and writing/scrawling down on flipchart paper our thoughts and actions. There is a balance between prompting full involvement and making progress. There is only so much we can do and progress in two-hour meetings.

However, over time, we built a space for collaboration where co-researchers felt able to contribute to all aspects of the research process. For example, I had expected the phase of data analysis to be particularly challenging for the maintenance of interest and accessibility; Cahill (2007) describes an example where involvement in analysing content felt like an unpleasant burden, at odds with the emancipatory approach present in other stages (Cahill, 2007). However, in our case, all expressed their desire to remain involved, and a pragmatic approach was taken to involve co-researchers at specific points to provide their reflections and interpretations on data, making best use of their time, knowledge and experience.

So what?

At the time of Covid-19 pandemic restrictions there was a rush by many to take co-production online and replicate face-to-face meetings, driven by the software access available to researchers but not necessarily to all. Langley *et al*. (2021) identified potential inhibitors to participation including stable internet access, connectivity and experience using technology, along with personal factors including lack of confidence, fear of mistakes or resistance to engaging in this way; they found it important to consider the experience outside of meetings, recommending that people should be able to contribute to an ongoing process rather than just specific scheduled activities (Langley *et al*., 2021). Within the VIA project, we also enabled opportunities to contribute after and between sessions but hesitated on distribution of physical materials, as this would have required knowing co-researchers' personal addresses. Just one co-researcher requested physical materials before sessions, as they did not have a printer at home. I offered this to others, but it was not felt necessary. All co-researchers were able to access Box outside of our discussion groups but rarely did; engagement within sessions and making the most of these times were key for our group.

Attention was needed to ensure everyone’s voice could be heard within the virtual room, which is recognised as more challenging than in person, but required careful facilitation and use of additional tools such as the chat function, breakout rooms and virtual whiteboards to enable creativity and contribution (Allam *et al.*, 2021; Hickey *et al.*, 2021).

At this time I was learning from the UCL-based *Co-production Collective*, attending their events including ‘Co-pro Cuppas’, taking influence from their relationships-based approach, with practical tips for being ‘human’ and creating a welcoming environment in online communications, including creating spaces for informal conversation, greeting people by name, enabling contributions in smaller breakout rooms and co-producing as one team without job titles or labels (Allam *et al.*, 2021). I aimed for a simple approach recommended by the *Co-production Collective*, starting with a platform with minimal tech barriers and simply asking what and how people needed to participate, doing my best to enable it, recognising the high level of concentration needed for virtual meetings, so keeping to a maximum of 2 hours, taking regular breaks and not expecting people to be on video (Allam *et al.*, 2021). However, everyone chose to be visible on screen. We did trial use of tools such as Mentimeter and polls, but these seemed to stifle discussion, as people had to use an additional platform separately to the meeting space. I had reflected within our first few meetings on the difficulties of facilitating a group online:

Methodological reflection on the complexities of online facilitation

The transcripts from discussion groups are not accurate when multiple voices speak at once – they don't capture everything. Is there a danger of comments or voices being lost? Online facilitation is difficult – do I too easily miss or ignore some of the comments that are not within the main flow of conversation? Do I need to do more to stop and listen to these?

Allam *et al*. (2021) emphasise that in any co-production work, it is not necessary to wait until the conditions are perfect, but to make a start together and be open to learning and refinement as you go along. As we learned together, we all increased our skills in the use of technology, the features of Zoom and what worked best for us as a group. It was necessary to pay attention to process and make adjustments in the way we worked to find a productive space for collaboration, including breaking into smaller groups, recording notes on screen as we talked and findings ways to ensure everyone had a chance to share their ideas. Farr *et al*. (2021) discuss the challenges of ensuring everyone has access to and can use technology and how everyone should be actively invited to contribute should they want to. In their experience of making space to listen to each other, results from participation included a growth in confidence, a sense of purpose, being heard and being part of something important (Farr *et al.*, 2021).

A space for collaboration also requires support for respectful critique and disagreement to support knowledge development (Chatterton, Fuller and Routledge, 2007). While we did not experience outright disagreement or argument per se, comments were noted of the dominance of some voices over others, and the move to smaller group work also helped to manage group relations more effectively. Annand *et al*. (2021) describe the need for an even more concerted effort towards reflexive practice when the need arises to adapt the process and find solutions in the moment, to reflect on decisions made, how they are made and who is involved (Annand *et al.*, 2021).

Despite the changes made, we continued to experience the challenge within collaborative research of sustaining participation of all co-researchers throughout the process (Strnadová *et al.*, 2016). In recruitment of co-researchers I had purposely taken an inclusive, no-label approach, recognising that framing disability as social oppression involves the pursuit of equity and justice regardless of individual impairment (Oliver and Barnes, 2012). In pursuit of an equitable approach, I encouraged people to share whatever support they needed to participate. However, the particular challenges faced by the person with learning disabilities involved in the process meant his impairment was highlighted, and he was not necessarily able to anticipate what support he might need to engage.

We experienced the tension highlighted by Tuffrey-Wijne *et al*. (2020) that while co-researching can make research more relevant and useful, exploration of a research issue requires high levels of abstract thought, which can be challenging for some people with learning disabilities. Issues with delayed cognitive processing can make it difficult to join a group conversation; identifying appropriate places for turn taking, listening and maintaining attention to others for a long time can be tiring, and can make it challenging to maintain a handle on the topic being discussed (Volkmer and Broomfield, 2022). Discussions around the research topic and its key concepts were challenging to simplify, and I reflected on my concerns on whether we were providing enough support to enable everyone to be involved in the process:

Methodological reflection on concerns about accessibility

From some of the research questions sent over to me I can see that we do not have a shared understanding of what a research question is and what the project is about. The whole point was to make the process accessible, but it is so difficult with a complex project and differing levels of understanding. Are we not doing enough to make this research simpler for everyone to be involved and to understand?

Toogood (2022) provides a service user perspective on issues that can occur when involving people in research who may experience challenges with contributing to a group discussion. Toogood discusses how conversation might be dominated by those who take advantage of low intelligibility or pace of speech to interrupt or get their own point across (Toogood, 2022). This was further challenged within our own project by the diminished social cues in the online meeting environment. Some of Toogood's strategies were adopted, including giving time to turn taking; other techniques, including accepting and respecting views, and enabling by demonstrative listening, were already being modelled by other co-researchers (Toogood, 2022).

Occupational therapists have skills in grading and adapting occupations and the environment to enable participation, which translates well to the facilitation of accessible and inclusive research. The accommodation of co-researcher needs into the research design, challenging disabling barriers, relates to the theoretical positioning of disability as a social construct (McFarlane and Hansen, 2007). Using occupational therapy skills to adapt the research environment to requirements enabled access. I was concerned for the potential in our approach to ‘other’ and single out this particular co-researcher for their specific needs in the process; researchers have a duty to ensure that research practices do not cause further ‘othering’; sensitivity was required to ensure an inclusive approach for all that also took mindful account of individual needs (Rifkin and Pridmore, 2001). Yet we experienced that interest and attention was best on discrete, concrete tasks. Ultimately, the changes made were not enough to sustain involvement of this co-researcher and their decision to leave the process was respected.

Now what?

Having experienced the emergent and iterative nature of the PAR process, I now recognise how it is necessary to continually adapt as you go along. Creating spaces to enable participation is a continual endeavour and, even then, researchers should expect participation to be variable and redefined throughout the process, according to co-researcher skills, energy, interests and availability (Kesby, Kindon and Pain, 2007; Fudge Schormans *et al.*, 2020).

Some of the techniques for facilitation I would use in the future for sustaining accessibility are echoed within John *et al*. (2022)’s article that sought service user perspectives on what worked well during their involvement in participatory research. They recommend bringing people with and without research experience together, creating an informal setting and atmosphere, avoiding technical language without patronising, using facilitation skills to avoid multiple conversations, and valuing all contributions equally (John *et al.*, 2022). To extend this, I would continue to seek solutions to issues that occur from within the community of co-researchers. Sustaining engagement is a challenge that depends on attention to the process and its continual review to ensure its accessibility for all who want to be involved.

I was disappointed that two co-researchers did not want to continue with the process, but it was necessary to respect people's decision to cease involvement in research, whatever the reason for this. I would like the opportunity in future to involve people with learning disabilities in research, although would reflect on what did and did not work in this process and would push to meet in person where possible. Our process echoed many of the measures put in place by Henderson, McLean and Kinnear (2022) to ensure accessible involvement for people with learning disabilities (Henderson, McLean and Kinnear, 2022). However, I would take more time for initial capacity building to build greater confidence to discuss complex issues, before diving into engagement with the topic, and use more physical engagement methods such as visual voting with coloured stickers to support understanding of the process of decision making (Henderson, McLean and Kinnear, 2022). I would also look to put in place a plan of support for discussion groups.

7.5.3 Trusting the process

What?

From the outset I emphasised with co-researchers (from what I had read and been told) that PAR is an uncertain process that can be ‘messy’, and that there was a need to let go of expectations. On reflection, I was perhaps trying to reassure myself. Within the initial process of planning the project, I reflected on my own discomfort with the uncertainty of the process ahead and my concern for it to go well:

Methodological reflection on my concern for doing ‘true PAR’

The more I find out about co-production the more uncomfortable I feel about going through this process. I want to do it all ‘right’, but I also have worries about how this project will progress, especially in the allocated time. Having spoken to two other PhD students undertaking PAR in existing organisations, I am aware how it sounds like they are doing ‘true’ PAR, which makes me think my approach of forming a group from scratch could seem potentially contrived.

Further along, as discussion groups progressed, my concerns were reflected in my diary:

Methodological reflection on concerns about progress

I have a number of concerns about how the project is going to progress, how much we can realistically achieve in the time we have – it’s already session 3 of 8. It feels like we have achieved so much but this is a complex issue, and we have SUCH a long way to go to get anywhere.

Co-researchers consistently reflected at the end of discussion groups about the uncertainty of the process and the unclear direction, with a desire to know what was coming:

> ***Co-researcher Fiona:*** *"It is going exactly as I expected it to, what you said. But what will we have at the end?"*

After looking at the research proposal together for the first time, co-researchers reflected back on the process taken to get to this point:

> ***Co-researcher Vanessa****: "We've done good! We have done – actually, looking at it, seeing it all put together and it's like, wow, we've actually done a thing!"*

> ***Co-researcher Fiona****: "And it was all done kind of without us knowing we were doing it – I remember those first early ones we did, and we were like, er – what is it we're doing again? [laughter] But now, because we've got it all written down, it feels like we've really achieved something, I feel like we should all be really proud."*

One co-researcher, Vanessa, was particularly skilled in using analogy to explain the uncertainty of the process, describing it in terms of baking. This quote was included within our research article:

> *"I told my friend; there's this lovely group and we are making something. It feels like we're making a cake, like we had loads*

> *of ingredients, we weren't too sure, we were in the cupboard. We had all this choice and now we've gone, well we'll have a bit of that and a bit of that and we're not necessarily going to use that one, even though it's there, and we've made the cake batter. That's what it feels like – now we're waiting for the oven to warm up, and we can cook the cake."* (Pettican *et al.*, 2023, p. 7)

Vanessa returned to this analogy when we were preparing our recommendations from data analysis: *"Feels like the cake is cooking!"*

So what?

As experienced within this study, the process of PAR is unlikely to be linear because it involves engaging with and responding to complex human systems; and the resulting lack of control and predictability can be challenging to researchers (Cornish *et al.*, 2023). Actively seeking to surrender control and being flexible in allowing co-researchers to direct the process, while accepting any disruption and surprise, gives space and potential for new learning to emerge from the process – but this requires faith that this will happen at some point (Cornish *et al.*, 2023). The uncertainty present within this project was also reflective of the emergent nature of qualitative research (Creswell, 2014). Although not entirely comfortable with the notion myself, I needed to reassure co-researchers that it was acceptable for us not to prescribe our plans in detail and to expect them not to change through the process as we began to collect data. The changes we needed to make after our research proposal was written: changes to the questions, the addition of new forms and locations for data collection; were to be expected and represented new learning about the issue

(Creswell, 2014), but was also a reflection on the cyclical nature of planning, action, and reflection present within PAR.

It was challenging to both co-researchers and myself to let go of any expectations, while addressing my own fears of what PAR ‘is supposed to be’ and maintaining the hope of reaching a satisfactory outcome that will create the change for which this project has potential (Klocker, 2012). As noted by one of Seymour and Garbutt’s (1998) participants, “The danger of participatory research is that we don’t come up with the answers you want!” (Seymour and Garbutt, 1998, p. 7). There is a need for tolerance of ambiguity and to be comfortable with the tension between sharing control of the research while wanting to have a clear idea of where the project is going (Northway, 1997).

I was advised by those who have undertaken participatory research to expect to feel discomfort and unease throughout the process and this was apparent from early on in investigating the approach (Luguetti and Oliver, 2018). Part of this comes from the need to be accountable for this work: the student researcher has an obligation to the community to ensure the knowledge generated is used to influence local policy and planning (Rifkin and Pridmore 2001). Opening work up to scrutiny is in equal parts necessary, daunting and exciting, and any change that results will outweigh such feelings (Zarb, 1992). I have reflected on feeling a pressure and concern to do things ‘the right way’. This form of research is appealing in its capacity for action and change, but with this comes responsibility. Having an aim to undertake this approach doesn’t instantly assure that the research is ethical and morally sound; it is vital to pay attention to power imbalances that may be reinforced throughout the process

(Klocker, 2012).

Learning to trust the process is recognised as one of the ways of countering the challenges of PAR (Cornish *et al.*, 2023), and surrendering to it enabled the pursuit of directions that I would not have expected. Firstly, I would never have anticipated the focus on funders and related organisations, but this was a sensible suggestion for the potential of the project to elicit transformative change. This could be viewed as an example of confirmability within the process, where co-researchers have been able to view and understand the issue in a way I have not. They have seen how it is necessary to understand the policy context and the funder perspective in order for it to be challenged; the data from this strand has informed us about current practice (Chatterton, Fuller and Routledge, 2007). I had also not anticipated creating a podcast as a form of dissemination, or all the opportunities we have had to share our work with key interest holders.

Now what?

In hindsight it is possible to see how the advice given to ‘trust the process’ and to prepare co-researchers with the expectation to have no expectations was well placed. I have attempted within this thesis to provide a detailed account of the process undertaken; Fudge Schormans *et al*. (2020) noted this to be essential for any research to be seen as inclusive (Fudge Schormans *et al.*, 2020). A reflexive diary allows record and interrogation of events as they occur. Engaging in reflective practice – for all co-researchers – enabled us to recognise the progress made, although this co-researcher did not necessarily find it positive at the time:

Co-researcher reflection on the benefit of seeing progress through reflection:

“Reflection sometimes seems arduous but is the best part to see how far we’ve come!”

It is a process I will continue to centre within any future research practice. Cornish *et al*. (2023) noted how it can be uncomfortable and challenging to develop reflexivity within a PAR project and how a supportive space is needed for co-researchers to work through their discomfort. The various reflective mechanisms adopted within this project have enabled progress through iterations of the PAR cycle and are approaches I would consider again for future inclusion. It is now possible to see that the outcomes from the process of undertaking PAR can be as important as those from the research itself, with the potential for co-researchers to develop skills, knowledge and capacity from their engagement (Kindon, Pain and Kesby, 2007b).

7.5.4 Sharing power through distributed roles and responsibilities

What?

Referring to Foucault’s theorisation of power, it is not possible to avoid power relations, they are always present, but there is potential for shift in how, what and whom they affect (Foucault and Gordon, 1980). An aim and strength of PAR is the recognition of power and how it appears, and sharing of power, roles and responsibilities between co-researchers, enabling a sense of control over research production and process. The resulting autonomy and sense of ownership has been identified as critical to developing useful and less alienating research and is vital for long-term sustainability (Rifkin and Pridmore, 2001; Koch and Kralik, 2006; Kesby, Kindon and Pain, 2007; Huisman, 2008).

PAR brings people together with different skills, experiences and positions (Chatterton, Fuller and Routledge, 2007), and a discussion of these helped to explore co-researchers’ existing strengths, with the intention of bringing these into the project. However, co-researcher strengths, roles and responsibilities emerged and developed through the course of the process. Early on, it was suggested that the group split into two distinct groups with responsibility for the channel of research that was most relevant to their skills and experience. One group worked on Strand 1, focused on enquiry with disabled people, and the other group worked on Strand 2, with funders, providers and related organisations. The latter group met independently to finalise the data collection questions for their participants; within sessions themselves, work was focused and progress swift as a result.

Methodological reflection on maximising co-researcher skills, knowledge and experience

I asked a co-researcher to share their local experience, expertise and skills, drawing on existing capacity within the team for the benefit of the project and the group. The co-researcher came back within minutes with ideas, using their knowledge for practical action.

As we met together for our analysis and findings day towards the end of the active research phase, each co-researcher took on specific roles that had developed during the course of the project, resulting in power sharing and collaboration. I reflected on this within my journal:

Methodological reflection on distribution of power and roles

Distribution of power and roles became evident in how the day progressed. One co-researcher had booked the room and was instrumental in practical arrangements for the day, and another who is a teacher was quick to search for a board pen and eraser when needed. Another co-researcher maintained the critical friend role they had previously played, bringing us back to points, keeping us on track and holding us to account, seeking clarity in what our recommendations would be. This co-researcher also provided political context to our discussions, providing evidence of potential policy changes being considered by the UK Government, which would have ramifications for disabled people.

Different roles have emerged throughout the project: one co-researcher consistently took on the role of taking and sharing notes on screen during discussions. They also used their skills in selecting images for communications and have offered to create a presentation document for dissemination. Another is our podcast host; they have also been sharing and discussing details of the project with the high-level contacts they have in disability sport. They have also provided creative ways of describing and talking about the project. Another co-researcher acted as a critical friend, really focusing on details. Through their job, another co-researcher provides a link to the sport and physical activity sector but also took responsibility for arranging the venue for our meet-up. My role was to scaffold our discussions: to field input from co-researchers and bring together items to be worked upon and discussed, but within the sessions themselves I step back to allow co-researchers to explore issues from their own perspectives. Our ways of working together have involved a process of continuous adjustment, making small changes from session to session.

The continual PAR cycles of Planning, Action and Reflection were evident from discussion groups, through to data collection, analysis and collaborative dissemination. As we reflected on what we could do differently next time, co-researchers were actively involved in amending the process. Co-researchers continued to question the direction of the project and to search for clarity on what would happen next. Reflecting on data collection, co-researchers reflected on their own interview technique, including where they had wanted to probe for more detail. Suggestions were made to amend questions for clarity, to adjust sequencing of questions, and to get more detail, which only became apparent in practice. These changes were checked with other co-researchers and adopted in future interviews. Within their interview, a funder mentioned working with an evaluation company. We made adjustments to the questions to suit an interviewee from an evaluation company, who was related but distinct from our other data subjects. Co-researchers verbalised concern that echoed my own, about whether we were proceeding in the right way, whether we had selected the best way of involving disabled people, and this led to further action and adjustments.

So what?

Disability research has tended to focus on highlighting impairment rather than finding solutions (Watson, 2020). By challenging methods that perpetuate the power imbalance between researchers and the researched, working alongside disabled people to give power and control over the process, disability is framed as a political issue and research can be used to challenge oppression and lead to more useful, meaningful and practical solutions (Watson, 2020). Oliver and Barnes (2012) noted that it’s not enough to ‘give voice’ to those who were previously denied this; it doesn’t change the situation. Both the concept of ‘voice’ and ‘participation’ have been critiqued for not being enough to bring action (Fudge Schormans *et al.*, 2020).

Active disruption of hierarchies and unequal power dynamics is required to avoid reinforcement of inequalities in both health and in knowledge production, where knowledge is created and owned by the researcher but is legitimised through the reported use of participatory processes (Kesby, Kindon and Pain, 2007; Ocloo, 2021). The way the knowledge is created, with attention to the accessibility of the process and the relationship between the researcher and the researched, is as important as what is revealed, and the researcher must make their skills available for those experiencing inequalities (Oliver and Barnes, 2012). Within both PAR and Co-production, the ‘social relations of research’ that Oliver and Barnes (2012) refer to are challenged through the different roles and responsibilities that co-researchers assume during the process. Especially in relation to academic research projects, attention is required to who leads, who is involved and who makes decisions (Ocloo, 2021). Transparency about the different roles and responsibilities taken on by co-researchers contributes to the credibility of the research (Nind *et al.*, 2016).

As the sessions progressed it became increasingly apparent that my role within the project was to facilitate our discussions and ensure continuation of project activities. As I reflected in my journal, I was concerned about this at first, whether it was a positive aspect:

Methodological reflection on my role as a facilitator

I definitely feel I'm taking more of a facilitator's role. I chose not to be part of the breakout discussion groups as it matters less what I think, and I don't want to stifle thought or pick one group over the other.

However, this was a positive development from the initial thoughts of one co-researcher:

Methodological reflection on expectations of roles and responsibilities

During an initial recruitment discussion with one of the co-researchers, one said as a passing joke: "After our meetings, then you'll do the work". It was a challenge to convey the intention of researching together.

Within the official role of facilitator, I did indeed do a lot of the administrative work between sessions, but this left space for co-researchers to use their time and expertise most wisely in sharing their knowledge, skills and experience to progress the project. As I found, the facilitative role requires the researcher to actively respond to co-researchers, forgetting any expertise of their own and ensuring knowledge comes from the community (Grimwood, 2016). Often, this required reflection in the moment, to actively avoid stepping in with solutions or suggestions. Cornish *et al*. (2023) describe the role of scholar-activist, where during the process of collaboration with community members, researchers use their scholarly knowledge and skills to address injustices and make changes. I reflected on the role within my reflective journal:

Methodological reflection on facilitating rather than leading

People took turns to write on the virtual whiteboard, and it was a process of learning together, how best to use technology. However, there were comments that it was more efficient when I took the notes. This could be viewed negatively as a critique of the skills of others, but on the flip side, it freed co-researchers to concentrate on sharing their ideas with each other when I was taking notes. I saw this as a facilitative rather than leadership role: while the idea was to share responsibility, there was a balance between this and ensuring everyone was happy and not frustrated by the process.

The facilitator is even more vital within the online environment to enable continued discussion and involvement of all parties (Collard and Teijlingen, 2016). With the need to facilitate an environment encouraging conversation and mutual expression of views, advice was also heeded on the need to attend to visual cues (bearing in mind that these were more limited and less readily visible than in person) and to keep to a small group size to aid easy and open conversation (Collard and Teijlingen, 2016; Matthews, Baird and Duchesne, 2018). Being able to see everyone on screen at once facilitated group feel (Collard and Teijlingen, 2016).

As we found within this process, enablement and facilitation was key, with continual attention to the accessibility of language, communication and all aspects of the research process (Mikulak *et al.*, 2022). With the bringing together of collective co-researcher experiences, expertise and skills within this approach, reflexive facilitation ensured these could be used most effectively where it mattered and had most value within the process (Annand *et al.*, 2021). Initially my facilitative role involved collating what was discussed into draft documents, always shared back with the team – for example, research questions and the research proposal. But later on, it became evident that confidence in the process had built, where co-researchers were able to respond readily to questioning around an issue and one co-researcher shared a document on screen without any prompting and began recording the outcome of our discussion.

On the opportunities where co-researchers were invited to share their experiences of collaborative learning with other organisations (see Appendix 10.1), co-researchers reflected on the value of having a facilitator. While this was positive, I was hesitant about this emphasis placed on my role in the process, as I was attempting to minimise my own voice and opinions wherever possible (Henderson, McLean and Kinnear, 2022). Another challenge that I also wrestled with, was not wanting to ‘present back’ information that had been taken away from co-researchers and ‘polished up’:

Methodological reflection on 'presenting findings' to co-researchers

I am cautious in how I describe this process, as it seems a power issue to be 'presenting back'. But it didn't feel like presenting results, more giving a starting point for discussion. Some points made by co-researchers related back to their experience in undertaking the interviews. There was resounding consensus that time would be better spent by me completing an initial interpretation of the data before co-researchers contribute most value in determining recommendations and next steps.

The sharing of research tasks is a collective effort at odds with the individual and original authorship required of a doctoral thesis (Seymour and Garbutt, 1998; Klocker, 2012). Hence the approach I took to separate the collective PAR project as being distinct from (although in many ways overlapping with) the individualised thesis writing process. The VIA project exists in its own right, with its own outcomes and associated actions. Co-researchers were involved in as many aspects as they wished to be, while this thesis was written separately and personally about the process of undertaking the project. There are certain actions that I believe contributed to the ability of co-researchers to take their own roles in the project, to feel responsible and accountable and to feel a level of ownership over the project. These included exploring existing skills and using these as strengths, spending time developing relationships and building a safe space to share and question ideas together.

Now what?

The practical insights mentioned here provide techniques that build on the call to ‘change the relations of social research’ and might be useful to other researchers faced with the challenge of ensuring power and responsibilities are distributed among co-researchers. I now recognise the importance of my professional training in group facilitation and recommend other PAR researchers to draw on or develop such skills, which are so important for encouraging everyone to contribute, participate and engage in dialogue, with attention and sensitivity to power relations within the group (Cornish *et al.*, 2023). I will also take this learning into any future groupwork in my practice.

It was important to establish the discrete nature of the VIA project, developed and named by co-researchers, separate to my PhD qualification and hopefully surviving beyond it. Being novice researchers together was another element; all of us not having undertaken a project of this type before. The latter will be more challenging to take forward, but I also have the confidence now that it is possible to get to this stage of project ownership. The control of research will be further explored within the next reflection.

7.5.5 Control and formulation of PAR

What?

Early in the process of formulating this project, I was questioned where the idea for this project arose from, citing the ideal for a PAR project to originate from the community that then goes on to investigate it, and for disability research to be initiated by disabled people (Zarb, 1992; Koch and Kralik, 2006). Klocker (2012), however, questions the notion that community-initiated projects are the ‘ideal’ model for initiation of a PAR project and how it would be a rarity for a PhD student to have the research included in their thesis to have begun in this manner (although this may partly be because Klocker’s own project was not conceived in this way). Likewise, I had concerns whether the issue I explored with co-researchers was something that would have concerned them personally before I raised it with them. However, while the initial concern for a lack of inclusive and accessible evaluation came from a Boccia England report (Pettican, 2018b), it was echoed by inclusive sport and physical activity organisations during the initial scoping exercise, who cited an awareness and some attempts to address it without satisfactory and consistent conclusion. As the project progressed, I asked co-researchers how they felt about the project and whether they felt like a co-researcher – which they did – but whether they were in ‘control’ of the project is to be debated.

So what?

As Klocker (2012) astutely notes, most non-researchers do not think about the world in terms of a research project, consider research a priority and rarely exist in groups able to initiate research. Unlike the experience reported by Seymour and Garbutt (1998), where the advisory group was not involved in the formulation of research questions and subsequently suggested major changes that redirected the focus of enquiry, my aim was for the earliest possible involvement in the research project by co-researchers. I had therefore avoided defining the issue too much further before their involvement. Developing a mutual understanding of the issue of concern is one of the first steps within PAR and is a political act, as co-researchers define and determine what action is worth taking, and which is not (Cornish *et al.*, 2023). While one co-researcher held a role in a physical activity programme that had required them to conduct a lengthy and comprehensive evaluation and therefore had distinct knowledge of this situation, and another had been involved in an activity group that had to fold due to lack of funding, when the issue was drawn to the attention of the other potential co-researchers, discussions were marked by a concern to be involved in addressing inequality.

To begin with, I wanted to avoid bringing in any suggestions of my own for how to proceed, but Cornish *et al*. (2023) noted that this is common with less experienced practitioners who may take a naïve approach to avoid any external ideas affecting co-researchers response or suggestions for action. Instead they note that more experienced practitioners will seek a collaborative process of skill and knowledge exchange that is more likely to result in an effective response (Cornish *et al.*, 2023).

Involving co-researchers in a tokenistic manner, without authentic and meaningful participation could be as oppressive and detrimental as not involving them at all; alongside developing a shared understanding of the issue, I was at pains to avoid this through active attempts to facilitate equal and collaborative relationships and control over processes (Kramer-Roy, 2015). As discussion groups progressed, there was a notable development in ownership of the group, as I reflected in my journal:

Methodological reflection on developing ownership of the group

During our check-in at the start of the group, everyone reported that they are starting to feel like a co-researcher and are keen for me to retain a facilitator *role. Group members stayed online again to chat during the break, there is a definite commitment being shown by everyone – no one has missed a session yet! One co-researcher was really excited that this project could create real change, and I received messages afterwards thanking me for a great session. The most interesting aspect is that people are starting to take responsibility for certain aspects of the project.*

As noted by Kramer-Roy (2015), cycling through the PAR process of planning, acting, observing and reflecting while ensuring a continued focus on practical outcomes can support the handing over of control of processes. As we progressed, the direction of the project developed through co-researcher reflections:

Methodological reflection on co-researchers directing progress

In our post-interview reflection, the co-researcher provided a detailed response and definitely picked up on some points that I had missed. The co-researcher thought aloud during our reflection, working through ideas they weren't sure about, and was particularly interested in the mention of evaluation companies. They suggested we get the perspective of one and had ideas of how questions could be reworked to be suitable for such an interviewee.

Co-researchers all said they identified as a co-researcher; having this identity and being recognised as a researcher and feeling part of a team contributed to a sense of responsibility to each other and to the project (Fudge Schormans *et al.*, 2020).

Now what?

I will take forward the experience we had on this project; I will no longer feel it an issue if co-researchers do not have the original idea. Through the process of undertaking this research, co-researchers have drawn connections between evaluation and the sustainability of participation and were able to draw on their own experiences in relation to the issue during our analysis and findings day. Co-researchers shaped their response to the issue considering their own experiences. We have come to a point where co-researchers identify personally with the issue and feel connected to the project and its outcomes and are inherently involved in steering its direction beyond the remit of my PhD study. All feel a sense of responsibility to make change to benefit disabled people’s participation in sport and physical activity.

7.5.6 Training co-researchers

What?

Before recruiting co-researchers, I spent time reviewing the literature on the advantages and disadvantages of training co-researchers in research, including processes and techniques. There were varying levels of skills and experience in the group, as we found from a discussion to explore what we were each bringing to the project. Our starting point was to explore existing skills with the intention of seeing what we could maximise within the process.

My concern was that giving training in research might bias ‘the way things should be done’ from my perspective, within an academic context, rather than encouraging new, democratic forms of knowledge production to take place. As noted by Nind *et* *al.,* (2016), there is the danger of ‘training away’ any difference:

> *“The conundrum is that if, as inclusive researchers, we value differences, then we should not inadvertently train them away and thereby lose the very sense of differences in dialogue that we were seeking. There is a danger that if unchecked and unproblematised, a drive toward training people with learning disabilities as researchers could be counterproductive. It could push an agenda in which academics are implicitly saying to people with learning disabilities that for this to work you need to be more like me – know what I know.” (Nind et al., 2016: 549)*

Any ‘training’ therefore was subtle and experiential rather than formalised and came as and when needed. As an example, training in data collection techniques seemed to emerge through the process of doing: we hadn’t applied any labels to the kind of interviews we were going to do, but as co-researchers took to prompting for further information around the questions they were asking, we discussed how this technique might be described as a semi-structured interview, where some questions were set but other information would be gleaned from additional prompts and follow-on questions.

One opportunity for training came from a co-researcher sharing their own experience and tips on interviewing from previously undertaking an evaluation with service users. These were made available as a document for co-researchers to refer back to before data collection (Appendix 7.13).

When it came to the process of data analysis, all co-researchers shared that this was an area with which they were less familiar. For our discussion group in September 2022, where we came together to discuss our plans for this stage, I included a section within the plan where we discussed existing understandings of data analysis and thought about different ways we could interpret and find meaning from the data (Figure 7.2).

Plan	**Data analysis: making sense of our data** What is data analysis and what do you know about it? What approach should we take? How would you like to be involved?

Figure 7.2: Excerpt from plan for discussion group 10: analysis

As a novice researcher myself, we were all covering new ground, discovering and developing through the process together. As we talked about co-creating a journal article, co-researchers asked me to explain what this would involve, and I was able to explain the process from my recent firsthand experience.

So what?

Within our research process, while our aim was for an inclusive process involving everyone equally, there was a notable difference between the accessibility requirements of co-researchers with physical and learning disabilities. This was also skewed by the educational experiences of the co-researchers with physical disabilities – one is an ex-teacher, one is a current teacher with a university degree and, at the point of recruitment, two were in the process of studying for an undergraduate degree.

I had elected to take an experiential, ‘learning by doing’ approach, advocated by co-researchers who, when asked, wanted to make the most of the time and get on with exploring the research issue. This approach is supported within the PAR cycles where reflection on learning from action supports planning for the subsequent cycle (Cornish *et al.*, 2023). Cornish *et al*. (2023) take an alternative view on research training that, rather than devalue co-researcher knowledge, experience or skills, it takes their role in knowledge production seriously. They also assert training that university-based researchers might benefit from, including training in facilitation, team development and the history and context of the community (Cornish *et al.*, 2023).

While there are examples in the literature of courses and training programmes designed to support development of understanding and skills in disabled people, particularly people with learning disabilities (Strnadová *et al.*, 2016; Tuffrey-Wijne *et al.*, 2020), there is also recognition that research skills can be gained not just through organised courses but also through discussion and reflection. The approach taken has much in common with that described by Bigby, Frawley and Ramcharan (2014), where research methods were adapted through a continual process of reflection and adjustment, and built on the strengths, skills and needs of group members (Bigby, Frawley and Ramcharan, 2014). As we found throughout our process, emergent processes enabled distinct contributions and perspectives (Bigby, Frawley and Ramcharan, 2014).

With no current coordinated approach or criteria for developing co-researcher research skills, there is critique in the literature of the expectation to ‘learn on the job’ to become a co-researcher and a call for more formalised approaches; training to enable understanding of what research entails and whether it is really of interest. There is a notion that, without support to develop appropriate skills, any resulting lack of confidence and knowledge might reinforce exclusion and lead to tokenistic contributions (Nind *et al.*, 2016; Fullana *et al.*, 2017; Tuffrey-Wijne *et al.*, 2020; Mikulak *et al.*, 2022). I noted the potential impact of this lack of confidence in my reflective diary:

Methodological reflection on the training dilemma

This is supposed to be a democratic form of involvement, but how can we ensure people feel that, if they feel discomfort about not being ‘good enough’, having the right experiences or not knowing enough? Did an exercise designed to show the strengths, capabilities and experiences within the group actually have the opposite effect, and make someone think that they didn’t have enough relevant skills and experience to give?

The reflection above may echo the experiences of Mikulak *et al*. (2022) where researchers were not confident that the existing skills and experience they had counted as ‘research skills’. It can be confidence rather than skills that are lacking and building confidence and capacity is linked to the addressing of power imbalances in co-research (Egid *et al.*, 2021). The perspective of Mikulak *et al*. (2022) is that training can help overcome the confidence gap that may prevent people with learning disabilities, but how it must be co-created to cover what people with learning disabilities want to know and learn, rather than what researchers think they should learn (Mikulak *et al.*, 2022).

However, training does not have to be by formal course and Nind *et al*. (2016) do present models of training that align with our approach; an ‘inclusive immersion model’ of training that involves learning by doing the research with other novice researchers, dealing with and working through problems and challenges as they arise. Secondly, a ‘dialogic’ model where learning occurs “Through engaging with and testing each other’s knowledge contributions” (Nind *et al.*, 2016: 548). An example of learning together is given in a team looking together at connotations of words used in their research; this is an approach we took to understand more about the research topic, exploring our definitions of the key concepts.

Any need for training must be preceded by an exploration of existing skills and experience and how they can be used in the research; this existing knowledge must be recognised, celebrated and valued over literature and theory from academia (Nind *et al.*, 2016). The aim must not be to instil a researcher’s perspective on what co-researchers need to know in order to do research, as this can further compound inequalities (Mikulak *et al.*, 2022). Nind *et al*. (2016) describe how training should not undermine the reciprocity of partnerships, with knowledge only coming from academic researchers. This was maintained in our approach with the training session in interviewing provided by a co-researcher, but also in how co-researchers were able to share with me their pre-existing knowledge of participants, their communication needs and potential requirements for interviews.

I was also learning myself as we went along; academic researchers are often self-taught when it comes to conducting inclusive research (Nind *et al.*, 2016), however, there is also potential for researchers to benefit from training in practical skills and knowledge, including facilitation, team development and the history and context of the community (Cornish *et al.*, 2023). Facilitation and team development is likely to feature within the occupational therapy training programme, hence demonstrating another advantage of occupational therapists undertaking this form of research.

Now what?

When we came together on the in-person analysis and findings day, I asked co-researchers whether they felt they would have benefited from training in research. They felt it was not necessary, that it would have taken valuable time away from the project itself. They felt the way the project had developed over time had made the research process accessible to them. As noted in this comment, that I recorded in my reflective diary:

Methodological reflection on enabling co-researchers through the process

A co-researcher commented how they didn't feel they had needed training, as they felt the way the sessions had been planned and our way of working together had made the research process accessible. For example, talking *together about collated themes made discussion of the data and their input to the analytical process more accessible.*

As we continue in our quest for collaborative dissemination, we will be undertaking tasks that all of us will be unfamiliar with. The remaining co-researchers are people with physical impairments, and our challenge was maintaining involvement of the co-researcher with learning disabilities who began the process with us. Despite our adaptations, we were not able to retain this co-researcher's involvement in the group.

Within future work, while I might take a more organic, experiential approach for co-researchers without learning disabilities, depending entirely on the existing skills, experience and needs of the co-researchers involved, for any future research with people with learning disabilities I would consider integrating research training into our process, if this was required by those involved.

7.5.7 Time required for PAR

What?

Participatory Action Research (PAR) requires time for the process to develop, particularly for setting the groundwork and building relationships with co-researchers (Koch and Kralik, 2006). In the case of this project, time was spent undertaking an initial scoping exercise (October 2019 – March 2020) and laying the groundwork for the project by building a thorough understanding of the nature and requirements of collaborative research projects. The uncertainty of the Covid 19 pandemic hit at the point of project planning. Co-researcher recruitment took longer than anticipated, with the first discussion group taking place in October 2020. I was honest with co-researchers from the outset and throughout about the uncertainty inherent in the process and the timescale of PAR and reassured that co-researchers could leave the process at any point. Two co-researchers did leave the process part-way through data collection and while I left it open for them to return, I also respected their decision to leave at this point. The other four co-researchers remained connected to the project, even four years later, to the protracted timescale the result of my change to part-time registration and period of maternity leave. Initial discussions with co-researchers involved discussing availability and groups were arranged at the end of each session according to everyone’s availability, recognising that everyone had other responsibilities elsewhere. This was an essential negotiation throughout.

So what?

The initial scoping exercise helped to build my own understanding of the context – physical, social, economic, political – for this research project and enabled me to establish trusted contacts for the recruitment of co-researchers. Activities to build understanding and access to the community as an outsider take time and energy and the process of relationship building is ongoing (Johnson and Parry, 2016). Another reason that participatory approaches take time is the focus on process; initial exploration is required on how best to work together in the first place, and further attention is given to the shaping and negotiation of working practices as the research progresses (Atkin, Thomson and Wood, 2020).

A PhD funding period may be seen as restrictive for such a project to develop. On the other hand, it also gives time and space to consider and develop a project in detail and perhaps less pressure to reach a defined outcome, in comparison with academics undertaking PAR who may be combining multiple research projects, teaching commitments and administrative responsibilities (Klocker, 2012). Seymour and Garbutt (1998) noted that while time can be on a PhD student's side, they haven't yet had time to build experience and skills in research methodology (Seymour and Garbutt, 1998). While I appreciate that research experience builds knowledge, I would question this with a type of research that is about collaborative exploration and potentially finding new ways of knowing. Some novice researchers will also bring previous transferable experience: personally, I had to employ my previous experience of creating accessible information resources for the co-researcher recruitment information, and the groupwork skills developed during occupational therapy training proved to be useful for facilitating co-researcher discussion groups.

The clash of a PAR approach with expected milestones is reflective of expected tensions around timings (Klocker, 2012). In comparison with PhDs based within existing projects or following a more traditional structure, a PAR project is 'messy' and less linear; expected milestones have been approached with more flexibility. The requirements to write a research proposal and apply for ethical approval within the first year, for example, were not met, as both were co-created with fellow co-researchers for the VIA project that we planned together. Applying for ethical approval before the recruitment of co-researchers would have required specification of the project and its proposed direction; it would have instantly created a power imbalance between the other co-researchers and myself, not only in the need to conceptualise the project before they were involved, but also because it separates between whose involvement as a co-researcher requires approval and whose doesn’t (i.e. mine).

The timescales of academic research can conflict with co-researcher desire to keep things moving and to maintain action; funding applications and publishing research articles can be long processes through which to maintain interest (Cornish *et al*., 2023). Cornish *et al*. (2023) note how academics can often work over a long period of time to complete a project and influence agendas, but involvement of community members and collaborators facing an immediate issue adds impetus for action and a solution to be achieved sooner.

Patrick Gamboa Yao *et al*. (2022) discuss the need for recognition of the concept of ‘crip time’, which has been developed by disabled people to demonstrate disabled people’s experience of time, where more time and effort may be needed to do something within an ableist world. Flexibility is required ahead of expectations for disabled people to fit the ableist social construction of time and timeliness (Patrick Gamboa Yao *et al*., 2022).

Now what?

There remain issues around the closure of the project and uncertainties around the funding of further dissemination activities; co-researchers have all expressed a wish to continue with the work of the project and, indeed, with the VIA project on other opportunities in the future. I had been advised to expect that tasks would vary in how interesting and engaging they were to co-researchers, but there was no part of our process where co-researchers were not present in some form. Although I can't be entirely sure how this 'buy in' to the group developed, it was essential to create this community with passion for the project, proactively monitoring members' thoughts and feelings about it throughout. This learning has shaped how I will apply for research funding in future, in that I will factor in funding for co-researcher involvement for as extended a period as possible, including allocated amounts for all potential dissemination activities beyond regular project involvement costs.

7.5.8 Co-researcher involvement in co-creation of knowledge

What?

Co-researchers have been involved in all aspects of the VIA project, but involvement in the process of data collection and interpretation was particularly valuable to the co-creation of knowledge. Co-researchers were involved in almost all interviews. Within the transcripts there are demonstrable examples of the influence of co-researchers on the data collection process. These five examples occurred with interviewees who were previously known to the co-researcher, but whom I had never met before:

- A co-researcher and an interviewee knew each other through work. This previously established working relationship enabled further prompting on responses, due to the co-researcher's prior knowledge of what was being discussed.
- Another co-researcher and participant had previously taken part in the same

activity. They have the same form of impairment and discussed some commonalities in their experience, identifying with how people's expectations of them had been low.

- In another example, the co-researcher knew the interviewee and could probe further on the evaluation work she knew about. She identified with the example of working with people to produce poetry to demonstrate impact.
- Another interview included a co-researcher reflecting on their own experiences of delivering a mentioned evaluation tool in practice, and the challenges inherent in this. Prompts, follow-on comments and questions reflected mutual awareness of the issues.
- In the final case, the co-researcher used their own sports-related knowledge and skills in the process of interviewing, and supported the interviewee in explaining to me the issue they experienced in their participation and supported them in what they were trying to say. The co-researcher recognised that the interviewee was talking about a survey distributed by an NGB, which they had also had to complete themselves.

The involvement of co-researchers in the research also has implications for findings around the administration of evaluation. Observations were made by co-researchers about the practice of the research being undertaken. On-site, co-researchers led much of the interviewing of participants. In some but not all cases they were familiar with the participants, due to their involvement in the sports provider organisation. We worked around the provision of activity during the day, so would speak with participants when they were available, before or after they had participated in their activity. As an outdoor venue with no indoor space, we interviewed participants from the back of the sports provider’s lorry, sitting on accessible bikes, or at picnic tables, where the odd gust of wind would send paperwork flying. The park was situated by a busy traffic intersection, so background noise and vehicle movement interspersed our conversation. We attempted to sit away in a private space, but other participants milled around, and the provider would pop along and see how we were progressing. Carers hovered waiting to take people home. Respondents were supported by carers or family members. Differing levels of literacy meant some could read the participant information and consent forms, while others had them read verbally. Others needed further rewording to simplify concepts.

As reflected within the introduction to this chapter, co-creation of knowledge was also present in the formulation of these methodological learnings as much as in the collection of data. This following reflection was written after a meeting with three co-researchers, during which they planned for an early dissemination activity, a workshop at a co-production event where they shared the positives and negatives from their experiences of being involved in a co-produced research project:

Methodological reflection on co-creating methodological learning

This could be seen as a first act of dissemination, to have this opportunity to share our experiences of working in this way. But also, for the co-researchers it might be a useful experience to learn the theory behind co-production? I immediately suggested that I should not be leading it. I actively stayed quiet as between the three of them planned together what they wanted to say. All three shared in different ways that they would have been unlikely to be involved had it not been online.

So what?

There is an argument that, while the building of rapport can support the quality of data, there is potential for respondents to give socially acceptable and therefore biased responses (Leddy-Owen, 2016). Some feel the validity of data can be affected by the closeness of relationships between co-researchers and participants, or the capacity levels or expertise of community members in undertaking research (Wilson, Kenny and Dickson-Swift, 2018). Inconsistent probing or prompting from different interviewers is also thought in traditional research approaches to be an issue for reliability and quality (Leddy-Owen, 2016). However, PAR challenges the epistemological expectations of traditional research (Kindon, Pain and Kesby, 2007b), and there is strength in the knowledge co-created within interactions between co-researchers and participants. The ontological position of PAR promotes that reality is socially constructed and multiple interpretations are possible, enabling different forms of knowledge generation with co-researchers actively involve in this process (Kindon, Pain and Kesby, 2007b).

When we interviewed people known to the co-researchers who I did not know (which occurred in the majority of cases), the power dynamic of the interview changed, as they had an advantage of prior knowledge and a previous relationship. In most cases this enabled further prompting for information that I would not have been aware of, with potential to add richness to the data. Co-researchers, as has been seen in other examples of participatory research, had belief in the power of their own knowledge and lived experiences, and brought their own reflections and experiences to discussions, data collection and interpretation (Fudge Schormans *et al.*, 2020). Rather than be discouraged and seen as a tangent, as it might in other forms of research, experiential knowledge and personal stories are welcome in the co-creation of knowledge (Beresford, Farr, Hickey, Kaur, Ocloo, *et al.*, 2021; Henderson, McLean and Kinnear, 2022).

There are examples in the literature of this co-construction of knowledge, where co-researchers built on what interviewees had said, adding their own knowledge and reflections to data and encouraging participants to be more comfortable in their responses (Bigby, Frawley and Ramcharan, 2014; Tuffrey-Wijne *et al.*, 2020; Mikulak *et al.*, 2022). As facilitator, my role was to bring together the results of co-researcher discussions, with sensitivity to suspend my own opinions and views and to centre their priorities rather than my own. Fudge Schormans *et al*. (2020) describe a similar approach of using the result of conversations to create drafts that were then discussed with co-researchers for feedback, before final drafts were created (Fudge Schormans *et al.*, 2020). Kindon, Pain and Kesby (2007b) describe this as a form of transformative reflexivity, where co-researchers collectively reflect on understandings and misunderstandings to negotiate meaning together (Kindon, Pain and Kesby, 2007b).

This also reflects on the importance of the person administering evaluation or gathering data, and how their knowledge of a person and their communication style can affect the process and the information gained. In addition, it enabled co-researchers to use their understanding of the communication needs of individuals to adapt their process of gaining consent, for example to read information sheets and consent forms to people, to slow speech, adapt or rephrase interview questions in the moment, in response to levels of understanding and what was relevant to the individual. If this had been a standardised assessment, there would not have been room to do this, as the inconsistency of translation may be thought to affect the outcome. However, this was a necessity when working with people with variable levels of cognitive function. In some cases, participants were supported by carers or family members. This was encouraged to enable participation, but there are acknowledged issues where questions were reworded, or answers were suggested on behalf of participants.

From a comment made within one interview, a co-researcher reiterated her previous assertion for a version of the online survey for carers to complete on behalf of disabled people, thus putting a positive case forward for proxy reporting, as noted in the methodological reflection below:

Methodological reflection on enabling co-researchers and participants to challenge my perspective

From their direct experience of working with non-verbal people, a different perspective on proxy reporting was put forward by a co-researcher. On reflection I hadn't previously taken this suggestion seriously – I did not think it could ever be good to disempower a person from responding for themselves.

The physical conditions of undertaking this research also highlighted some of the issues with undertaking evaluation in the field. People had come to participate in physical activity and had to be selected and prepared by the trusted provider to participate in something in addition to that. Environmental conditions – lack of shelter, seating, wind, rain, privacy, traffic noise – affected the process. Co-researchers were present with the specific purpose of undertaking this evaluation, but activity deliverers might otherwise have to fit in time to obtain feedback between activities in a back-to-back schedule that makes the most of the time the space is hired.

Now what?

This approach demonstrates the value of ‘insider’ researchers in putting participants at ease and identifying with thoughts shared (McFarlane and Hansen, 2007), but also facilitates a challenge to the politics of representation, away from discourse between academics – ‘us’ about ‘them’ – that can reinforce inequalities (Cahill and Torre, 2007). As co-researchers collaborated to collect data, the methods used revealed many of the challenges inherent in evaluation in practice. The practical nature of what we were doing often revealed more than the answers to the questions asked and also contributed to the knowledge co-created together, which has implications for our findings and recommendations for more accessible and inclusive evaluation practice. Involvement of co-researchers in data collection offered an opportunity for co-creation of knowledge that I would look to incorporate in any participatory research undertaken in future. Co-researchers have expressed a desire for continued involvement in the project through dissemination activities, signalling involvement at all stages negotiated according to their availability and wishes.

7.6 Summary

This chapter has considered some of the practical steps taken within the process of conducting the VIA project and the learning offered to future undertakings of PAR and co-production, whether in a research context or elsewhere. It has demonstrated the power and process of reflective practice and how this was experienced by co-researchers. Implications of this learning are explored further within the reflective discussion and conclusion in the next chapter, including in relation to my own learning and development as a PAR researcher.

Chapter 8 Reflection: Discussion and Conclusions

8.1 Introduction

This final chapter provides a reflective discussion on the outcomes from the Voices for Inclusive Activity (VIA) project, the significance and implication of findings and recommendations, and outlines where there is an original contribution to knowledge, while noting limitations of the project. Finally, there is consideration for future development and opportunities for further research.

My own final methodological reflections feature within this chapter as part of the process of reflexivity undertaken during the project.

8.2 Summary of recommendations

Within the final section of our in-person co-researcher analysis and findings day, where data interpretations were discussed and developed towards the themes outlined in Chapter 6: *Research Findings from Data Collection*, co-researchers took time to consider what we might do with this information. Co-researchers felt that, overall, our findings demonstrated a mismatch in current evaluation approaches between what funders request and the information that providers and disabled people are able to give.

There is an impetus within PAR to co-create accessible and understandable knowledge that can be used to bridge the gap between policy makers and those affected by policy, enabling these voices to be heard within public spheres and to influence the development of more useful solutions (Chatterton, Fuller and Routledge, 2007; Annand *et al.*, 2021). Co-researchers reflected that the purpose of our project could be to demonstrate and provide evidence of the problem to interest holders, and to provide recommendations for next steps; these will now be discussed in the context of existing literature and theory.

8.2.1 Disabled people cannot be standardised

The predominant theme within our data, but also from the very first scoping exercise conversations, was a sense of frustration from providers that they had been asked to use standardised and validated tools that were not applicable or accessible to their participants. This recommendation is therefore to funders to recognise and reconsider their demands for standardised approaches that are not applicable to all.

Self-report instruments such as the *International Physical Activity Questionnaire* (IPAQ) have little validity and reliability data when used with many disabled people (Martin Ginis *et al.*, 2021). Although it was uncovered in the literature review that attempts have been made to adapt the tool for administration to people with physical disabilities (Clina *et al.*, 2023) and the tool is reported to be valid for use with people with learning disabilities (Dairo *et al.*, 2016), there is no inclusive approach considering all disabled people and, in many cases, people with the most profound forms of impairment are excluded from research and validation studies (Dairo *et al.*, 2016). There are disabled people for whom the recommended 150 minutes of physical activity a week is simply unachievable, or the level of exertion required is not physically possible; thankfully there is recognition that even a small amount of physical activity is positive for those otherwise inactive (Martin Ginis *et al.*, 2021). However, these big steps for individuals from completely inactive to participation can be obscured by obsession with measuring in comparison to a ‘norm’ of what ‘should’ be achievable.

Carr *et al*. (2023) acknowledge the prevalence within physical activity research to take a Medical Model approach to defining disability by condition. Variability in how disability is defined and described has implications for comparability across studies. Yet, as Carr et al (2023) note, experiences of the same condition or diagnostic label are variable and not homogenous (Carr *et al.*, 2023). One particular challenge we encountered was in how disabled people define themselves, which can be variable and influenced by a range of factors. How to ask about disability was an ongoing conversation for co-researchers, in acknowledgement of the difficulty approaching participants and asking whether they identify with potentially stigmatising categories (Leddy-Owen, 2016). We found taking an impairment-based approach to be problematic, time-consuming and not overly effective.

There have been collective calls for global population data relating to disabled people’s participation in sport and physical activity, for consistent definitions of disability and of physical activity (Martin Ginis *et al.*, 2021); yet this call for consistent labelling is driven by policy requirement rather than an attempt to better understand facilitators of high quality participation. We believe the lack of global surveillance data is because standard and comparative approaches do not work. A theme within our discussions with disabled people, providers and with co-researchers was that disabled people are individuals with individual needs and cannot be grouped together for measurement or statistical purposes. Within our small group of co-researchers, we've discussed that the experience of being a disabled person is not universal, with different ways and means of participating in and describing both disability and participation in sport and physical activity. This relates to the problematic nature of defining and categorising disability as a homogenous population, or disability sport as a single category for comparison. This was first discussed within Section 3.2 of this thesis, along with recognition that measurement is problematic in relation to populations that do not fit the dominant 'norm' of what a body 'should be' (Davis, 2017a). Measures and classifications rarely reflect the complex experience of disability, including the degrees of variation within categories, and that conditions are rarely static and unchanging (Marks, 1999; Oliver and Barnes, 2012). There were reflections from disabled people within our interviews that people within categories of impairment are not homogenous in their experience of impairment.

This difficulty of synthesis is reflected within evaluation research literature, with acknowledgement that different interest holders, contexts and criteria for success can affect how evaluation is conducted and conclusions are made (McGuire, 2016). Further complexity is introduced in the variety of experiences of participation welcomed in disability sport and physical activity. As noted by Mansfield (2016):

> *"The authority of objective measurement of effectiveness and efficiency in public health has produced and reproduced a knowledge economy defined narrowly by the status and generation of predominantly quantitative data on which to base*

> *decisions about health. Debates abound regarding the proliferation of quantitative measures of effectiveness.”*
> *(Mansfield, 2016: 718)*

Revisiting arguments within the literature review on whether it is possible to take a fully inclusive approach, I refer to the limitation expressed by Gee *et al*. (2024) in their attempt to involve people with different impairments in the validation of the LTPAQ-D tool; they noted that people with different impairments may not respond in the same way to the same amount of physical activity. A number of providers suggested that a ‘toolkit’ of evaluation solutions would be useful, because it would allow them to pick the best strategies and formats to consider the individual needs of service users within their specific context.

8.2.2 Capacity and capability of providers to evaluate

The burden and logistics of evaluation and the capacity and capability of providers to evaluate needs recognition; this argument followed through from the scoping exercise to the literature review and through to our findings. Who conducts evaluation needs to be considered – what are their skills and how well do they understand the needs of participants? This needs to be built in, so it doesn’t feel like a chore or have a negative impact on the session length. As Wadsworth (2011) notes, there is a gap between the skill and practice of evaluation professionals and those who deliver activities, and a need for building of capacity and confidence, but also for evaluation to be built into daily practice rather than a time consuming, difficult and disempowering chore that needs to be completed afterwards (Wadsworth, 2011).

Another note of caution concerns the burden of evaluation to participants and how disabled people may experience evaluation in a particular way due to how they have been judged against standards to their disadvantage (Oliver and Barnes, 2012). How do we evaluate in a way that does not repeat the experiences of being judged against criteria that they haven't been able to meet? There is an ethical imperative to ensure that evaluation of an enjoyed activity does not echo the experience of questionnaires completed in medical and healthcare environments. The evaluation facilitator is vital within this process.

8.2.3 Evaluation for learning rather than accountability

This recommendation from our research questions the purpose of evaluation and who benefits from the process. Evaluation should be used to make improvements to activities, to make them more available to disabled people, to get more disabled people involved, to ensure their sustainability. It should also enable providers to prove that they are doing a good job, when they know this from experience.

In addition, co-researchers identified the need for evaluation to be a useful and meaningful process for participants. During the scoping study, a discussion between an activity leader and a participant/volunteer revealed how evaluation may be made useful for the person themselves. It was highlighted how, in many cases, evaluation is completed not for the benefit of the person themselves, but for the purposes of the organisation or, indeed more often, to satisfy requirements of funding investors. Perhaps learning can be taken from the application of evaluation within the occupational therapy process. Here, evaluation offers the person themselves to engage in feedback (preferably two-way), to see change, progress and to take satisfaction in accomplishment, which may help to sustain motivation and change (Hocking and Whalley Hammell, 2017).

Noting that current focus of evaluation within sport and physical activity is predominantly quantification of effectiveness, efficiency and achievement of public health outcomes, Mansfield (2016) demands more scrutiny of the processes through which knowledge is produced and deemed legitimate. They note that complexity of monitoring, assessment and measurement in sport and physical activity is tied to current political and policy viewpoints of its place as a simple and cheap response to public health issues that, in reality, are complex and resulting from social inequalities (Mansfield, 2016).

8.2.4 Recognising sport and physical activity outcomes valued by disabled people

This recommendation relates to the mismatch between outcomes that are currently recorded from participation and what disabled people truly value and recommends exploration of what is meaningful to record. As noted by Hammel *et al*. (2008):

> *"To adequately reflect and capture the meaning that participation holds for people with disabilities, participation instruments need to address the values and meanings of participation for people, as well as the interactive and transformative influence of the environment on participation choice, control and opportunity" (Hammel et al., 2008:1459).*

This recommendation also relates back to the literature review theme *Identifying and valuing participant outcomes,* which considered outcomes of participation beyond performance alone, for example from Shirazipour and Latimer-Cheung (2020):

> *"Knowledge of desirable program outcomes linked to quality experiences can allow for improved development and delivery of quality programs, as well as more optimal evaluation of whether we are achieving advancements in full and equitable participation for individuals with disabilities within the [physical activity] domain."* (Shirazipour and Latimer-Cheung, 2020, p. 575)

As noted by Martin Ginis *et al*. (2024), participation experiences – involvement and quality of experience of participation - can better explain relationships between subjective wellbeing and sport and physical activity than quantitative measurement of attendance or frequency, intensity or duration of performing an activity (Martin Ginis *et al.*, 2024). Some of the elements of a quality participation experience outlined in the *Quality Parasport Participation Framework*, highlighted within the literature review, align with the themes identified within our data: autonomy (being me, being free), belongingness (belonging), challenge, engagement, mastery (becoming accomplished) (Evans *et al.*, 2018). Understanding the quality of participation experiences can inform learning about design and conditions for interventions that, in turn, create more positive participation experiences with the potential to sustain (Martin Ginis *et al.*, 2024).

One point highlighted by co-researchers is the connection between belonging, availability and sustainability of opportunities to be active. Activities for disabled people need extra support to ensure sustainability. It can take time to build numbers – and participant numbers may not be comparable with mainstream activities. Co-researchers reflected how a sense of belonging facilitates the ability to do and take part; the importance of social aspects and belonging in disability sport and physical activity is not novel and reflected findings from other studies (Smith and Sparkes, 2020). The comments on feelings of 'home' and being among 'family' had also been reflected within the study by Ovenden, Dening and Beer (2019) within the earlier literature review, where people with dementia and their carers attributed these notions of belonging to their experiences within a Boccia group (Ovenden, Dening and Beer, 2019). Research in the general population has also demonstrated the quality of life and wellbeing benefits of physical activity within group settings (Gillison *et al.*, 2009; Farrance, Tsofliou and Clark, 2016). However, there has previously been no alignment between sport and physical activity participation and the occupational science concept of *Doing, Being, Becoming and Belonging*. Although Cornish *et al*. (2023) warn against the imposition of outside ideas when interpreting data, co-researchers felt the framework offered by Doing, Being, Becoming and Belonging was supportive of their own interpretations regarding the valued outcomes of sport and physical activity.

Some providers mentioned difficulties in asking certain questions to the people they work with, and some outcomes are notoriously challenging to measure within any population. The notion of 'quality of life', for example, has been adopted as a measure of welfare and life satisfaction, but is inherent with prejudice in terms of what is seen as quality and who is deemed to have a good quality of life by others (Marks, 1999). Another note of caution concerns how disabled people may experience evaluation in a particular way due to how they have previously been judged against standards to their disadvantage; as noted in section 8.2.2, there is an ethical imperative to ensure the evaluation experience does not echo such situations (Oliver and Barnes, 2012).

Considering disabled peoples' perspectives on their own valued outcomes are vital, in light of Engdahl-Høgåsen and Bentzen's (2023) observation that participation is most often measured as 'attendance', with little attention paid to subjective accounts of participation, which they term 'involvement'; although such information is acknowledged as challenging to collect and requires appropriate methods to enable people to provide their own perspective (Engdahl-Høgåsen and Bentzen, 2023). This leads on to our next recommendation, which is the enabling of access through creative approaches.

8.2.5 Creative solutions enable accessibility

In line with the call from occupational scientists to reject ableist measurement practices, the findings from this study do not suggest a complete rejection of the use of outcome measures where they can be used appropriately, but refocusing to consider the person's subjective view on their performance and participation (Patrick Gamboa Yao *et al.*, 2022). However, this requires creative approaches to enable all to contribute in a way appropriate for them. Some of the evaluation challenges identified in this study are not exclusive to working with disabled people. Responding to a question in an evaluation survey involves a series of cognitive processes with potential for error at each point, and may require a lot of cognitive effort and mental processes to answer, particularly with recalling past situations or feelings, even irrespective of any cognitive impairment or learning disability (Streiner, Norman and Cairney, 2015). Measuring attitudes and subjective responses are notoriously challenging even within a general population; any response is likely to be affected by other factors alongside what they actually feel about what is being asked, including question wording, who is asking and how, understanding of the question and why it is being asked (Scotto, 2016).

Although accuracy of self-report can be an issue in the wider population, it can be particularly problematic in people with learning disabilities and dementia (Warms, 2006). Known communication challenges can include difficulty understanding language, with abstract concepts and memory, and the potential to agree with the views of people they see as professionals (Henderson, McLean and Kinnear, 2022). While it is a common method of evaluation, there are noted methodological and construct challenges, particularly in people with issues with recall and where proxy report may be necessary (Cervantes and Porretta, 2010). As one provider mentioned within their interview, standardised approaches often resulted in inaccurate responses or could not be used at all. These were challenges that we also faced within our data collection.

As discussed within Chapter 2: *Literature Review*, proxy reporting for people with the most complex impairments is problematic for the enabling of rights of disabled people, including choice, dignity and control (Sallis and Saelens, 2000; Fujiura, 2012). Co-researchers were particularly concerned that all participants should have a chance to have their say and contribute to improvements to the activities they take part in; facilitating their involvement can support the validating experience of being listened to (Henderson, McLean and Kinnear, 2022). While the ideal is for people to respond themselves, in some cases despite every possible effort being made, someone may not have the mental capacity to receive, process, understand and respond; yet it is doubtful whether proxies could ever know the internal emotional state of the person to be able to give the same response, without introducing their own bias (Streiner, Norman and Cairney, 2015). Fujiura *et al.* (2012) note that much of the conversation around self-report concerns whether the person can use the existing tool, and ask: “Can the measurement tasks be re-evaluated and adapted to the capabilities of the interviewee by better understanding how responses are formulated?” (Fujiura, 2012:363). Therefore, we argue that more creative responses are required to enable accessibility. Suggestions were made that if the process of evaluation was more rewarding and fun, using gamification approaches, it may encourage more people to give their views freely. By making evaluation easier and user friendly, it would enable more participants to have their voices heard and have greater opportunities to make change.

8.2.6 Co-production with disabled people

With the preceding point in mind, as an alternative to a blanket application of standard approaches, our recommendation is that evaluation solutions should be developed for each project in partnership with end users to ensure they are accessible, appropriate and meaningful to disabled people. As we have found from co-researchers, disabled people can have knowledge, critiques and viewpoints that might not be accessible or available to outsiders (Cahill and Torre, 2007). However difficult it is to hear the voices of participants, this should be prioritised and these voices should be listened to through a variety of channels according to their needs, to ensure the voices of those who ultimately benefit can be heard and used to judge value, rather than the views of dominant others (Wadsworth, 2011).

This aligns with the recognition that, in current socioeconomic times, collaboration, collective advocacy and action is required more than ever to effectively tackle issues of inequality (Fudge Schormans *et al.*, 2020; Beresford, Farr, Hickey, Kaur, Tembo, *et al.*, 2021). Collaborative and partnership working has also been emphasised at strategic government level as a means towards achieving public health and social outcomes in sport and physical activity (Mansfield, 2016; Sport England, 2016), but there is a need for this to continue through to grassroots level in collaborative work on monitoring and evaluation with end users and participants.

Recommendations have also been seen within recent sport and physical activity research for the inclusion of disabled people within co-producing research, recommendations and policy (Martin Ginis *et al.*, 2021); this study is one step towards that, but an integrated knowledge translation research approach is advocated. Such an approach emphasises the importance of partnership working to engage the right research users and shared decision-making to ensure findings are relevant and useful. A similar approach was adopted by Bryant *et al*. (2012), who describe the requirement within collaborative working for an exchange (or transfer) of skills, understanding and knowledge in order to work together (Bryant *et al.*, 2012).

The approach involves a dynamic process of creating and using knowledge and requires researchers to relinquish power and control in order to embrace the experiences and expertise of the people they are working with.

A subsidiary recommendation of this point is the need to value the contribution of disabled people. When involved in the development of evaluation tools and resources, disabled people should be reimbursed for their contribution and experiential knowledge in line with other contractors. Funding for co-production of evaluation should be factored into any funding application and people should be renumerated in line with current policy (National Institute for Health and Care Research, 2022). This demand echoes calls from within co-production networks for specific funding to be allocated to co-production, with fair and adequate valuation, payment, support and reimbursement for involvement (Beresford, Farr, Hickey, Kaur, Tembo, *et al.*, 2021).

Within PAR and co-production, the practice of reciprocity is key, where everyone benefits from the process and product of working together, rather than relying on goodwill (Smith *et al.*, 2023). Attention to opportunities for meaningful reciprocity is an ethical essential throughout any collaborative project, but it was critical within the VIA project, with its potential to contribute to my own personal academic and career success. As the project progressed, I had opportunities to learn about co-researchers' motivations for taking part, but also to hear what they were gaining themselves. Our dissemination activities, where co-researchers talked freely with those outside of the project about what was happening within it, proved to be a useful opportunity to hear co-researchers discussing elements related to reciprocity and what they had gained through the process, including skills and research knowledge.

However, I was adamant that co-researchers should have some kind of financial recompense for their time, skills and experiences, in line with recommendations for co-production work (Williams *et al.*, 2021a), and obtained funding to provide co-researcher payments through vouchers or charity donation (dependent on co-researcher preference). While direct payment would have preferable, this was a solution in light of inflexible institutional practices recognised by other participatory researchers (Atkin, Thomson and Wood, 2020). Co-researchers have been clear in their recommendations to others that anyone contributing their lived experience to research should be paid for their contribution, at a level aligned with that of professional project consultants.

8.3 Discussion

Our recommendations relate to the impossibility of applying standard approaches to evaluating disability sport and physical activity that rely on the capacity and capabilities of activity deliverers to prove their accountability. Approaches developed in partnership with disabled people that consider meaningful outcomes, enable contribution of people whatever their accessibility needs, and support the creation of ideal conditions for taking part, are most valuable to tackling inequalities in participation and the resulting occupational injustice

Noting the current lack of consensus about how sport and physical activity should be measured with reliability and validity in disabled people, Heath and Levine (2022) argue how this is necessary to ensure that reduction of inequalities in participation can be tracked and achieved (Heath and Levine, 2022). Yet, I would maintain the argument that there is a reason this difficult issue has not been resolved; it is not possible to take a standard and consistent approach to measure physical activity levels in all disabled people in a way that is meaningful to those people.

We recommend reconsidering the purpose of evaluation and who it is serving. Evaluation is unlikely to be successful if it is completed for external bodies who are not familiar with the local context or service (Wadsworth, 2011). Although referring to a school sports programme, Smith and Leech (2010) offer interesting critique of the type of evidence that is relied upon for policy making, referring to an “essentially political exercise” where an outcome-based measurement approach was seen by providers as inadequate and merely demonstrated “‘hitting targets’ and ‘jumping through hoops’ to meet the government’s objectives,” rather than considering quality of experiences (Smith and Leech, 2010, p. 327).

Our research has echoed such tensions between the motivations for and meaning of evaluation across different stakeholders involved. While accountability and value for money were an important motivator for evaluation for funders and indeed some providers, the tools used to evaluate often aligned value with measuring frequency, intensity and duration of physical activity. However, within the data we collected, participants highlighted outcomes of value that could be mapped across the domains of Doing, Being, Becoming and Belonging, drawn from occupational science literature (Wilcock, 1999). For participants, their participation contributed not only to the doing (e.g. doing different activities, in different ways), but their sense of self (e.g.

being me, being supported, being free) and who they could become (becoming stronger, becoming accomplished), and their feelings of belonging (e.g. alongside other people and feeling at home in their activity). These aspects could not have been captured within a single standardised questionnaire but required a qualitative approach that captured the subtleties of their multi-faceted experience.

What is instead important is to consider the words of Martin Ginis *et al.* (2024) in their arguments for considering subjective experiential aspects and how these can contribute to improving conditions that encourage participation. This requires evaluation strategies that are creative, inclusive, context-specific and developed in partnership with disabled people. There is a connection here with the use of evaluation not for accountability, but for learning, for whole-system approaches that improve the conditions in which sport and physical activity occur – the conditions, people, support, equipment, funding and opportunities in place that enable disabled people to have positive experiences of sport and physical activity in a way that is meaningful to them. This approach relates to the suggestion made by some respondents within our data towards a realist approach to evaluation, which considers the underlying causal and contextual factors that support success, alongside the effectiveness of an activity or programme (Chen, 2018). Such an approach offers learning on ideal conditions for participation but is still potentially an approach to be delivered mechanistically by ‘experts’, without true involvement of disabled people in its creation, so I would caution this being the ultimate solution.

Instead, drawing on the identified call within our data and from co-researchers to seek solutions that involve working with participants to co-produce evaluation approaches, Participatory Evaluation could offer one way forward. Although discussing within the context of Sport for Development, Oatley and Harris (2020) note similar challenges in evaluation including the privileging of academic and other ‘official’ voices over those of providers and participants, which can limit the benefit of evaluation for delivery (Oatley and Harris, 2020). The authors label as ineffective accountability-driven, technocratic evaluation approaches influenced by funding and governance structures, which measure success through objective data (Oatley and Harris, 2020). Participatory forms of evaluation take account of people’s experiences to reconsider whose values and outcomes an activity should be judged against; taking account of people’s experiences in setting benchmarks can enable a better understanding of whether value for money is really being achieved (Wadsworth, 2011; Oatley and Harris, 2020). As an evaluation approach stemming from participatory research (like PAR), sharing of power and control is vital within a Participatory Evaluation process that gives local actors power and control in how they evaluate, enabling co-production of an evaluation framework relevant to context, and a form of epistemic justice in the sharing of local experience and knowledge, with potential for better learning, understanding and use of findings (Oatley and Harris, 2020).

However, it is also important to recognise the thread throughout this thesis of the need to consider capacity and capabilities of small grassroots providers to administer complex forms of evaluation. Providers highlighted the time cost, not having the skills required, or not knowing how to get accurate responses to certain questions, either due to the tool or the needs of the person in front of them. A pragmatic solution may come from the suggestion within the data of a collaborative approach to develop context-specific toolkits of evaluation approaches that are easily accessible to participants and providers alike; although given previous discussions, this comes with some caution of whether adequate tools already exist or whether they are possible to create. Our research demonstrated the need to consider accessibility from a broad perspective, as adaptations may be required for multiple reasons, related to sensory, physical or cognitive impairment. A creative response including a range of formats may help some – including large font, Easy Read, audio or video recordings, images, use alternative and augmentative communication – but some people will still require support of someone close to them to support as a proxy responder. The skill of the person delivering evaluation and their understanding of an individual's access and communication needs is essential to ensure voices and opinions are not excluded, with additional consideration for people with the most complex and profound forms of impairment. This is a further argument in support of context-specific solutions. While a standardised approach to evaluation may be seen as more cost-effective, site-specific responses may enable organisations to tailor their evaluation and prioritise learning to create the most valued participation conditions for the people they are working with, which, in turn, may be more beneficial for ensuring ongoing sustainability.

Specific recommendations from our findings are outlined within Section 8.7.5 *Implications for the sport and physical activity sector, evaluators and policy makers*.

8.4 Collaborative dissemination

Now our recommendations have been discussed, perhaps the most valuable aspect of a PAR project is that the co-constructed research findings can be used for immediate benefit, through accessible dissemination (Holloway and Galvin 2017 Koch and Kralik 2006). While I would not use the terminology of ‘giving voice’ to co-researchers as their voices were not mine to give, within this project, co-researchers’ voices were heard within podcasts and in dissemination discussions with large organisations, breaking the ‘culture of silence’ described by Freire (Freire, 1972). Co-researchers within this project had the choice of whether or not they wanted their contributions to be anonymised, but they chose to be recognised by their own names, faces and voices. As Pain, Kindon and Kesby (2007) note, PAR requires academics who engage in quieter processes of dissemination for change and are happy not to be the ‘public face’ of the project (Pain, Kindon and Kesby, 2007).

Mertens (2009) describes how the reporting and utilisation of findings from research within the Transformative Paradigm connects with the furtherance of social justice and how these choices relate to power (Mertens, 2009). For example, the writing of this thesis about the broader PAR project, which will (hopefully) result in an academic award, will likely only benefit myself. An activist approach also demands that co-researchers challenge the traditional routes of dissemination from the purely academic to other routes and audiences that are more likely to enact change (Fudge Schormans *et al.*, 2020). As a group we were challenged to consider how we disseminate our research outcomes in an accessible way and co-researcher involvement in co-constructed dissemination ensures both accuracy and accessibility to community members (Koch and Kralik 2006).

In many ways, dissemination efforts began from the outset of the project, when relationships were established directly with organisations and policy makers and throughout, as we shared our ways of working together. We have actively sought opportunities to disseminate to a range of audiences throughout the project, sharing our learning about working together, not simply the research project findings at the end (Appendix 10.1). In one example, three co-researchers designed and hosted an online co-production workshop for organisations with an interest in the evaluation of disability sport and physical activity (Appendix 10.2). The co-researchers shared their experiences of our ways of working, and such reflections were also shared in a second example, when co-researchers were invited to share experiences of co-production while being interviewed by a large funding body. The process of preparing for these activities enabled joint reflection on our process, its strengths and challenges. Co-researchers taking ownership of findings by presenting them to external organisations is a demonstration of control and ownership of the research; discussing and thinking through findings, what is important to convey and how to present the information can be considered a further stage of analysis (Kramer-Roy, 2015). Within my reflexive diary, I considered how these opportunities had demonstrated co-researchers' increased knowledge and reflexivity on the research process:

Methodological reflection on our interview about co-production

They wanted to find out from us what we have been doing around co-production and to learn from the practice of our project. This shows how important it has been to develop these working relationships. Co-researchers provided engaging insight and reflection on their experiences, demonstrating their increased knowledge of research and co-production in the process.

8.4.1 Podcast

During data collection, one interviewee described a range of evaluation methods they had been involved in, including recording a podcast. In our post-interview reflective discussion, the co-researcher suggested it as a good approach for us, so we explored podcasting as a form of accessible dissemination. As noted by Johnson and Parry (2016), there is an ethical dimension to employing creative forms of dissemination, which may be more engaging and accessible to a wider audience, potentially facilitating a higher propensity for social change and impact (Johnson and Parry, 2016). Podcasting is reported elsewhere in PAR as a useful and collaborative activity enabling co-researcher involvement in dissemination (Smith *et al.*, 2021). Four co-researchers worked together on Zoom to co-produce and record a series of four podcast episodes, introducing ourselves and our project, what happened within it, the process by which we have worked together, and to share our outcomes and recommendations (Appendix 10.3). One co-researcher designed a VIA project Zoom background that we could each display during recording (Figure 8.1). The podcasts are available as audio and subtitled video versions, with an accompanying transcript.

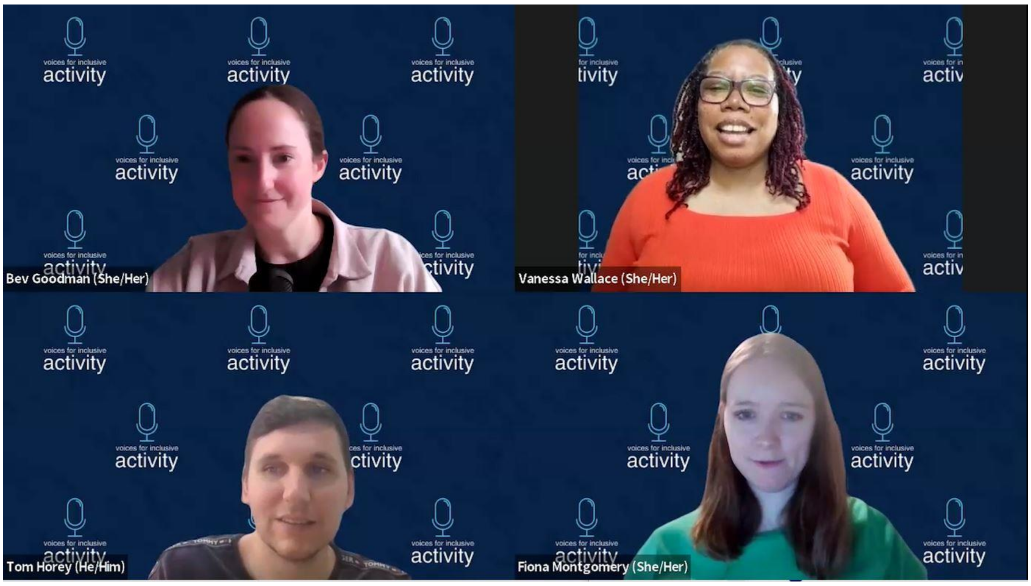


Figure 8.1: Co-researchers recording our audio/videocast on Zoom

While our podcast has been completed and shared on Podbean and YouTube, co-researchers discussed and agreed other opportunities for dissemination that will occur beyond the completion of this thesis, as funding is being sought to ensure ongoing co-researcher involvement for these tasks. An infographic was felt to be a digestible and accessible route for sharing information and one co-researcher offered skills in using a software package to visualise our recommendations, while mindful of the need for image description for people with visual impairment.

While co-researchers wanted to prioritise accessible routes, it was also felt that a research article may help to provide the evidence of the issue and support use of the infographic. Publishing an academic paper could suggest a privileging of a certain audience who might consume such texts that are written in exclusionary language (Mertens, 2009); the very idea that co-researchers believe this is an important way for our research to have credibility, is suggestive of the power assigned to certain avenues for dissemination. The project had previously been referred to within a research article; although methodological reflections were the basis for this article and it featured quotations with consent of co-researchers, it was written from an academic perspective and not from co-researchers (Pettican *et al.*, 2023). Having discussed the process for creating a journal article, co-researchers are keen to co-author an article about findings and recommendations, ideally one that is accessible to as many audiences as possible, following previously published exemplars (Garbutt *et al.*, 2010).

One recognised outcome of PAR is the development of strategies to reach out to audiences, including engaging those in power to motivate change (Cahill and Torre, 2007). We considered this as another source of dissemination and discussed other organisations who could support dissemination, exploiting co-researcher contacts with sport and physical activity governing bodies, funders and providers.

8.5 Limitations of the study

There are limitations enforced by the conduct of a PAR project within the context of PhD. Whatever measures I have attempted to put in place, I cannot escape the reality that this activity will contribute towards my own career and I cannot meet the expectation of ensuring that outcomes and benefits of this project are received and owned equally (Beresford, Farr, Hickey, Kaur, Tembo, *et al*., 2021).

Co-researchers planned the project within the context of the Covid-19 pandemic and research methods had to be appropriate to conduct during times of varying restrictions and uncertainty. This was a time that posed additional challenges to working in participatory ways, but also highlighted the presence of social inequalities and how co-production offered a way to work with, rather than for, people to generate knowledge and action towards potential improvements (Williams *et al*., 2021b).

Interviews were useful for gathering information from funders, providers and related organisations, and Zoom offered a useful medium to involve participants and co-researchers at a mutually convenient time. We used dialogic methods, which are most commonly employed within PAR (Kindon, Pain and Kesby, 2007b) but, on reflection, interviews offered limited value as a method with some physical activity participants. Interviews depend on the articulatory and perceptive skills of interviewees and have been critiqued as a method for the mismatch between what people say and what they feel, mean or do in practice (Hammersley, 2008). Co-researcher involvement in interviews may have countered some of these relational issues. While we could fortunately conduct interviews in person, if we were planning the project again, we would likely consider more creative methods to enable wider involvement. It is possible that we lost access to people who could not easily verbalise their opinion but could have collaborated in other ways. For example, we did not collect data from anyone using any form of Alternative or Augmentative Communication (AAC), who are often alienated from the process of research (Volkmer and Broomfield, 2022). While the collaborator had mentioned a potential participant who used AAC, they had judged it not to be practically feasible to include them within data collection. On reflection, I should have sought the opportunity to plan and prepare for this situation to ensure conditions and support were in place to enable their involvement.

This limitation relates to who was involved in our research and who was excluded, either as a co-researcher or as a participant. Sampling is an ethical issue because there is potential for stories, experiences and views to be excluded (Boddy, 2016). However, despite the need to attend more closely to situations such as the one aforementioned, it would not be possible to ensure a truly representative group of disabled people. Disabled people's experiences are not homogenous and many people do not identify as disabled (Oliver and Barnes, 2012), so it can be challenging, if not impossible, to ensure a representative group of either co-researchers or participants. Lived experience of their condition or disability might also make research participation more challenging for some (Cornish *et al.*, 2023).

Also recognising that people with learning disabilities are often excluded from research, it is a limitation that we lost involvement of one co-researcher and family carer during the process. While the stages of data analysis and reporting can be more challenging for maintaining involvement, it is recognised within PAR that participation levels can change at all stages, recognising that not everyone wants to or can be involved in all parts of the process and that co-researcher choice should be enabled (Kindon, Pain and Kesby, 2007b; Fudge Schormans *et al.*, 2020).

8.6 Original contribution

Within this thesis, original contribution is offered from both an epistemic and process perspective.

It was demonstrated within both the scoping exercise and data collection that disability sport and physical activity organisations are calling for more accessible and inclusive ways of evaluating participation in sport and physical activity. The VIA project offers new insight on the evaluation of participation in disability sport and physical activity from the perspective of participants and those involved in delivering activities with disabled people. It offers co-created recommendations that have practical applications and offer potential to influence change for disabled people and those who are dedicated to improving opportunities for participation in sport and physical activity.

In the call for participatory approaches to developing context-specific methods of evaluation that are focused on improving and promoting the conditions for participation, this thesis offers an extension to the work of occupational science theorists engaging with critical disability studies to critique the inappropriate use of outcome measurement that assesses for and looks to solve any deviation from a standardised ‘norm’ (Whalley Hammell, 2023). As a profession, occupational therapists have been reluctant to be overtly political but the tide is changing, and PAR offers an explicitly political vehicle for the promotion of social justice (Kesby, Kindon and Pain, 2007). I believe this work answers the call for occupational therapists to engage with a politicised form of practice to tackle systemic inequalities (Whalley Hammell, 2020).

Epistemological concerns have been prioritised throughout this study; critical disability scholars have called for a move from research as investigation to transformative and social justice approaches where lived experience is privileged in collaborative knowledge construction (Mertens, 2009; Oliver and Barnes, 2012; Johnson and Parry, 2016). Aligned with the lens of epistemic justice through which I am approaching this thesis, in their discussion of Participatory Evaluation approaches, Oatley and Harris (2020) recognise a need to challenge what knowledge is deemed legitimate (Oatley and Harris, 2020). In its collaborative approach to knowledge creation, this project has contributed to the discourse challenging perceptions of disabled people being unable to create knowledge, indeed, challenges perceptions of 'inability' more generally (Smith *et al*., 2010). As noted by Fudge Schormans *et al*. (2020), inclusive research:

> *"Challenge[s] discourses that silence and belittle labelled persons as non-knowers."* (Fudge Schormans *et al.*, 2020, p. 354).

The VIA project also demonstrates methodological findings that could contribute to the development of participatory evaluation approaches. There are specific points of learning about conducting PAR online with disabled people. As experienced by VIA project co-researchers, online research has the potential to be more accessible without transport, venues, or the 'othering' experience of having to ask for adjustments to attend (Hickey *et al*., 2021). Reflections on facilitating research online and how the principles of co-production can provide a practical approach to participatory forms of research have been explored and shared with the wider research community through the article *Doing together: reflections on facilitating the co-production of participatory action research with marginalised populations* (Pettican *et al*., 2023). Chapter 7: *Methodological Learning* and our approaches to collaborative dissemination have extended this knowledge and practical insight. This thesis also provides a new perspective on how PAR may be situated within the constraints and context of PhD study, hopefully offering some reassurance to others embarking on a similar, at times uncertain, path.

8.7 Implications

8.7.1 Implications for co-researchers

In sharing their own and enabling other disabled people to share their own experiences of participation in sport and physical activity, co-researchers have demonstrated a need to reconceptualise understanding of the value of participation. By embracing a broader conceptualisation of the meaning of participation in relation to the occupational science framework of Doing, Being, Becoming and Belonging, co-researchers have demonstrated that the value of participation is multi-faceted and goes beyond physical performance alone, which has implications for future approaches to evaluation.

As well as in the findings, there are implications for co-researchers in the research process undertaken. The outcomes of PAR can involve direct transformation of people's lives or indirect via institutional change (Cameron, 2007). The latter is what we are hopeful to achieve through our activist, participatory approach, which intends to cross the barrier between small-scale research and larger-scale legislation with an aim to influence policy (McFarlane and Hansen, 2007). The political angle that emerged during co-researcher discussion continued strongly into the discussion of recommendations. Co-researchers noted an assumption that disabled people will give their experience, knowledge and guidance for free, that people most put-upon will do the work for people who are not affected by issues. Co-researchers reflected how disabled people should receive financial reward for the value of their experience and this recommendation would be extended to anyone working in collaboration with disabled people, in line with current recommendations (National Institute for Health and Care Research, 2022).

The PAR approach undertaken has placed co-researchers not as objects of study but has emphasised their capability in analysing a relevant issue and finding solutions (Kesby, Kindon and Pain, 2007). Through their involvement within the VIA project, a potential outcome for co-researchers was the development of capacity, not only in the process of carrying out research, but through use of skills in planning, collaboration, decision-making, networking and public speaking (Trentham and Cockburn, 2005; Pain, Kindon and Kesby, 2007; Kramer-Roy, 2015; Kramer-Roy *et al.*, 2020; Cornish *et al.*, 2023).

8.7.2 Implications for theory and practice of collaborative research

One of the key aspects that all co-researchers have reflected upon is the need to trust the process, to accept the potential for uncertainty and to be attentive to opportunities to value alternative perspectives (Kesby, Kindon and Pain, 2007). This requires careful facilitation; I would recommend other researchers to see themselves as a facilitator rather than an expert within the process of working with co-researchers; an alternative would be ‘advocate’, for the role in bringing co-researchers together and supporting them to articulate issues (Johnson and Parry, 2016).

Co-researchers within this project have stated that they would not have been able to take part in this project if it had not been conducted on Zoom. Disabled people's participation in all aspects of social life was disproportionately affected – and continues to be affected – as a result of the Covid 19 pandemic, but if we are to take any positives, it is that it forced the exploration of new ways of working (Williams *et al.*, 2021b). While it should not be seen as the default option, where it is appropriate and support is available to source, access and use technology, remote access options enable some disabled people to participate in co-production and participatory research where they would not have been able to before (Hale and Allam, 2021; Williams *et al.*, 2021b).

The co-researchers involved in this project are not 'the usual suspects' who are most often engaged to participate in research (Beresford, 2013). All had other roles and responsibilities outside of the project that meant careful negotiation at every step on the conditions for involvement. Meeting times, frequencies, durations and conditions were always discussed and agreed. Time was spent building and nurturing relationships, within the group and individually. I was honest and reflexive from the start about my own position and what I would be getting out of the research. Opportunities for reciprocity were sought at every turn, from provision of involvement payments to provision of equipment such as printer ink and microphones for podcast recording, meeting up for coffee or lunch, or to provide refreshments and expenses for our in-person meeting. Accessibility was enabled through provision of information, to the conditions of meeting together online and in our experiences of dissemination. Strategies for power distribution have also been shared within this thesis for the benefit of other researchers and those wishing to take part in research that maximises and develops the skills, connections and experiences of everyone involved.

In particular, I would encourage other PAR researchers, where possible, to follow a similar model in relation to how and when ethical approval is sought within their studies. I am fortunate to be operating within an institution that recognises the argument for involving a co-researcher steering group akin to a form of PPI, which does not require ethical approval in itself (Volkmer and Broomfield, 2022). This requires the researcher to be bold, to fight against the tide of expectation that the conditions and direction of the research should be set early in the process, in order to apply for ethical approval. Our alternative approach enabled co-researchers to have control in driving the direction of the study, making key decisions and developing information about the project for participants.

8.7.3 Implications for occupational therapy research, practice and education

Two strands of occupational injustice have been addressed within this study, relating to the topic of the research and the conduct of the study. Firstly, the occupational injustice of existing evaluation practices that exclude disabled people and undermine their participation in health enhancing occupations. Secondly, the exclusion of disabled people from active involvement and control of processes of knowledge production, which also contribute to epistemic injustice.

Although it is less common for occupational therapists to tackle issues affecting collective health and wellbeing, this study has explored a structural and systemic issue in how sport and physical activity is evaluated (Whalley Hammell, 2020). This issue has theoretical and practical parallels with critique of the practice within occupational therapy of using standardised assessment and outcome measurement to satisfy a Medical Model approach to practice, that fails to challenge the socio-economic and political conditions that serve to disable people from participating in valued and meaningful occupations (Whalley Hammell, 2019, 2021a; Whiteford, 2020). Referring to Muller's (2018) text *The tyranny of metrics,* Whiteford (2020) notes that such inappropriate reliance has the potential to deepen the mistrust between disabled people and occupational therapists (Muller, 2018; Whiteford, 2020).

The critical approach and engagement with critical disability studies has heeded a call for occupational therapists to resist ableist practices and to collaborate with disabled people as experts in their own lives (Patrick Gamboa Yao *et al.*, 2022; Whalley Hammell, 2023). By working in 'radical solidarity' with co-researchers towards new modes of knowledge production, this study is an enactment of what Whiteford describes as 'Occupational Justice Plus', where pursuit of occupational justice and epistemic justice are aligned (Whiteford, 2020, 2023). A PAR approach challenges existing hierarchies in what and whose knowledge counts, and disrupts the traditional divide between abstract theory and its meaningful, practical application (Cornish *et al.*, 2023). As an additional point of reflection, current discussions within occupational science question the dominance of hegemonic forms of knowledge and knowledge creation within the discipline, and a need to incorporate alternative and multiple knowledge systems from outside of the Global North, including non-academic voices in knowledge creation (Ahmed-Landeryou, 2024; Veiga-Seijo *et al.*, 2024).

A particular reflection permeating the process, sitting alongside but intricately interwoven, is on research as a co-occupation, and particularly collective approaches to research (Pettican *et al.*, 2023). While not focusing on research, Fransen-Jaibi *et al*. (2020) explore how shared, community or collective forms of occupation, which could be termed co-occupation, can enable people to transform and transcend issues. The authors discuss approaches based in reciprocal recognition, sharing voices and doing together – all of which have been present throughout this research process (Fransen-Jaibi *et al*., 2020).

Also present throughout was the value of occupational therapy skills in adapting and enabling participation appropriate to each co-researcher's needs (Meriano and Latella, 2016). This extended to the recognition that not everyone has to do everything within a research project, and the negotiation of different levels of involvement. Throughout this process we have attempted to ensure accessibility of the process but have found this challenging at times, aware that it can be inaccessibility rather than lack of interest that can prevent participation and compound inequality (Fransen-Jaibi *et al*., 2020). There is an absence of literature considering how co-researchers might consider their participation in research as a meaningful occupation; I believe this worthy of further exploration.

8.7.4 Implications for myself, as a PAR researcher and an Occupational Therapist

As I found from this experience, the experience of undertaking PAR is not easy, my position has been constantly tested and it has been emotionally challenging (Cornish *et al*., 2023). Rather than a private endeavour of a single or team of academic researchers, the process of PAR is more public, so accountability to all interest holders is present from the start (Cornish *et al*., 2023). I found the expectation of change from this process personally challenging, especially combined with the need to have limited control over the process.

Although work on this thesis has been concluded, as I have reflected, I feel a deep ethical responsibility to pursue the transformative potential of PAR. It would be a disservice to the community – in this case the co-researchers, disability sport and physical activity participants and providers – for this project to make no difference in tackling this issue (Chatterton, Fuller and Routledge, 2007). This is intended to be research not for communicating with academic experts, but to inform collective grassroots action (Cornish *et al*., 2023). There is an imperative and expectation for something to come out of this project – quite rightly, co-researchers are maintaining pressure to keep moving along. Undertaking research with disabled people with the intention of change, underpinned by a Transformative Paradigm, through a social and occupational justice lens, is an intentionally political act that has developed my understanding and experience of how to take a politicised form of practice from theory into action. As we moved through the research process together, the issue was increasingly politicised by co-researchers:

Methodological reflection on political discussions

"More political slant to discussions today that we hadn't seen/heard before so strongly. Perhaps a sign of changed times? Acknowledgement of issues facing disabled people. Feeling more squeezed out. Feeling effects of economic downturn. Changes in Government policy for disabled people. How it could affect funding and future participation. Political feeling on how disabled people are expected to give up their time, their experience for free. Resistance to this idea – it has value, it is exhausting. Disabled people are not there to be a teacher. Relates to our next steps."

As I continue to reflect on whether we have done enough, I am reassured by Cornish *et al.*'s (2023) assertion that a single PAR project may be part of a longer collaboration and may only make one small action towards change (Cornish *et al*., 2023). I intend to find a way to make it possible to continue to work with the VIA project co-researchers, but am aware, although nevertheless frustrated, by the need for this to have some level of institutional backing for the essentials we need to continue – funding, email and Zoom access, insurance and so on – which means this project can never exist in the community without its ties to the university. I also reflect on the learning I have gained from this project to inform future participatory research, taking forward the reflections from Chapter 7: *Methodological Learning*, and how I cannot imagine undertaking research in any other way that doesn't acknowledge the vital influence of relationships, power, collaboration and reflexivity.

Akin to the skills gained by co-researchers through the process of undertaking this research, I have been challenged to work in innovative ways, to call on resources and develop skills in facilitation and collaborative working (Cahill and Torre, 2007). I have also been honing my research skills within this process and found the analysis and data interpretation stage particularly challenging, certainly in the difficulties experienced in whether interview questions had really enabled us to answer our research questions. There is much learning here for me in respect of any future research projects.

Critical reflexivity has been a vital tool throughout this research, to examine my own learning, but also my position and enable transparency about what I am gaining from this work (Marks, 1999). I must therefore acknowledge that another benefit I have gained from this process is clarity on the kind of role that I want to take as an occupational therapist. As I come towards the end of writing my thesis, I have begun a new role within an organisation where occupational therapists work within leisure centres to break down barriers and enable people’s access to sport and physical activity. I started my Occupational therapy career within a Medical Model-focused neurorehabilitation environment, but the opportunity to engage with critical disability studies literature and the work of Whalley Hammell regarding the ableist values inherent within some areas of occupational therapy practice has encouraged me to consider the values that underpin my work, and the environment in which I can work most productively with people to challenge existing health inequalities (Whalley Hammell, 2023).

8.7.5 Implications for the sport and physical activity sector, evaluators and policy makers

Participants’ reflections of the value they gain from participation in sport and physical activity, conceptually aligned with the occupational science framework of Doing, Being, Becoming and Belonging, demonstrates the need to determine the value of participation away from physical performance indicators of frequency, intensity, time and type alone. Within the period of data collection, some sport and physical activity funders and evaluators discussed a shift towards an alternative, realist approach to evaluation focused on nurturing conditions in consideration of who is and wants to take part, what they want to do and where participation is occurring, as reflected within the work of Chen (Chen, 2018).

However, it was evident within providers’ reflections on practice during interviews, and co-researchers’ more recent experiences in practice, that this epistemological shift and any resultant change in approach has not yet filtered down to grassroots delivery of disability sport and physical activity. This study offers further impetus that any attempt to address existing inequalities in access to sport and physical activity requires a rethink of evaluation practices, emphasising the need for disabled people to be involved within the process of developing evaluation solutions and offers practical guidance for meaningful collaboration. This may be through Participatory Evaluation approaches described by Oatley and Harris (Oatley and Harris, 2020), or the engagement of disabled people in developing a contextually specific toolkit of evaluation solutions that are accessible to both participants and providers of disability sport and physical activity.

Summary of key issues and recommendations for the sport and physical activity sector, evaluators and policy makers

Current evaluation methods in disability sport and physical activity often rely on standardised questionnaires and physical performance metrics. These approaches fail to account for the diversity of disabled people and overlook broader, more meaningful outcomes.

- Standardised methods do not work for diverse disability experiences.
- Evaluation tools often ignore the broader benefits of participation.
- Providers may lack capacity for complex or burdensome evaluation methods.

Recommendations

1. **Embed co-production**: Work collaboratively with disabled people in designing and evaluating programmes to ensure their experiences and priorities are central.
2. **Move beyond standardised questionnaires**: Traditional, one-size-fits-all evaluation methods are ineffective and insufficient for disabled populations and should be reconsidered. Evaluation methods must be flexible and tailored to individuals' needs and contexts.
3. **Develop context-specific, location and disability-sensitive solutions**: Evaluation methods should be tailored with sensitivity to the local setting and adapted creatively to ensure accessibility for all, including those with severe impairments, adapting to their personal communication requirements (e.g. Easy Read, imagery, audiovisual solutions).
4. **Minimise participant burden and match provider capability**: Evaluation

methods must account for both the capacity of service providers and the potential burden placed on participants, ensuring they are not overly demanding for either, and are realistic within the available resources.

5. **Emphasise learning over compliance**: Treat evaluation as a learning opportunity, not merely a tick-box exercise, so that participants see tangible benefits from the process.
6. **Promote Evaluation as Learning**
   Shift from a compliance-focused model to treat evaluation as a learning opportunity supporting reflection, learning and improvement, not just a tick box exercise, so that participations and organisations can see tangible benefits from the process.
7. **Broaden and redefine definitions of success**: Move beyond physical performance metrics and consider outcomes that matter most to disabled people, such as health, wellbeing, inclusion, and personal value derived from participation.

In conclusion, to ensure inclusive, effective, and meaningful evaluation in disability sport and physical activity, policies and funding must support flexible, co-produced, and context-sensitive approaches that reflect the true value of participation.

8.8 Next steps: influencing change and further research

For PAR to reach its potential as a form of disability activism, it is not enough to have had active involvement of co-researchers throughout the process, but change must have happened as a result (Fudge Schormans *et al.*, 2020). While providing definition of a problem, as our recommendations have done, can be a valid outcome for PAR (Cornish *et al*., 2023), a stated mission for transformative research is the use of findings for social action, to influence policy change or advocacy, pursued through the building of networks and connections with interest holders (Mertens, 2009).

Approached from a critical disability studies lens, we are providing the evidence of a need for policy change to remove structural barriers to effective, inclusive and accessible evaluation practices (Watson, 2020). While co-researchers intend to present our recommendations to those at the highest levels of funding policy to encourage action for change, these recommendations are simply a starting point for the discussion of how co-researchers could work with organisations and evaluation specialists to develop site-specific solutions for evaluation (Mertens, 2009). Providers want to be able to evidence the value of their activities and for disabled people to experience the resulting outcomes of improved and sustainable opportunities for participation, but minoritised groups cannot redress alone the institutional structures that perpetuate social injustice and a collaborative approach is essential (Fernandez *et al*., 2021). We now call on those with expertise in insight and evaluation to further explore the potential for participatory approaches to evaluation, and to work in partnership with disabled people and providers of disability sport and physical activity to develop of toolkit of accessible resources with the flexibility to be applied to specific contexts.

Current co-researchers have expressed an interest in remaining involved and to continue the work of the VIA project, beyond the limits of the PhD for which it was originally created. It is not surprising that it feels to co-researchers like unfinished business – as Cornish *et al.* (2023) note, collaborative relationships usually extend beyond a PAR project, as it is rare that one project will finalise a desired change (Cornish *et al*., 2023). However, as difficult as it is to reconcile, such ongoing partnerships need institutional backing and infrastructure (Cornish *et al*., 2023). We will continue to be constrained by the need for funding and other resources.

8.9 Summary

This chapter has overviewed the recommendations from the VIA project. Collaborative actions taken to disseminate findings and recommendations have been shared, along with the original contribution made by this study, in relation to knowledge production and research practice. The limitations of this study have been outlined. The implications of this study for co-researchers, collaborative research approaches, occupational therapy research, for myself as a researcher, and the sport and physical activity sector have been explored. The next steps involve further action to influence change in evaluation practices involving collaborative approaches to such as Participatory Evaluation. However, in recognition of the resource-intensive nature of such approaches, a second pragmatic solution may come from collaboration with disabled people to establish a toolkit of evaluation tools that are accessible to participants and providers alike.

Within the findings from the VIA project, co-researchers have provided evidence of the current issues in the evaluation of disability sport and physical activity and through dissemination have made them accessible to disabled people through audio/video podcasts, supporting Freire's notion of 'conscientisation' (Freire, 1972).

Co-researchers now call on those driving the evaluation agenda to work in collaboration and offer their expertise to develop inclusive, accessible and context-specific solutions that enable better conditions and increased opportunities for sustained participation for disabled people in sport and physical activity.

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Chapter 9 Appendices

Appendix 1: Accessible summary of this thesis

Appendix 1.1: A quick introduction

- Disabled people are less likely to take part in physical activity than non-disabled people.

- It is difficult to know how many disabled people take part in sport and physical activity because the tools used to measure this do not include all disabled people, they are not easy for people to use.

- Tools used to measure sport and physical activity usually don’t measure the activities that disabled people take part in.

- This project is about working with disabled people to look at ways to find out how disabled people take part in sport and physical activity, that are easier to use and include all the ways they like to take part.

Appendix 1.2: Literature review: a quick introduction

This chapter includes information that is already available about the evaluation of disability sport and physical activity.

First, I spoke to people who have an interest in disability sport and physical activity, including people who run activities and people who take part. They told me:

- They find it difficult to show how their activity is a success.
- Sometimes they know the people taking part enjoy their activity, but they can’t find ways to show this.
- Some of the people they work with find it difficult to use questionnaires or tools that would show this.
- They might not have time or know how to show the value of their activity.
- Sometimes people’s thinking and memory skills make it difficult to share what they get out of taking part in an activity.

Next, I looked at what researchers had written about this problem. This showed that:

- There is no one way of measuring physical activity for disabled people.
- Researchers use tools such as questionnaires and diaries, or measurement devices, to see whether disabled people do enough physical activity.
- People have tried to measure physical activity for all disabled people, but most researchers look at different groups, such as people with learning disabilities, people with physical disabilities, people with problems with their vision or hearing, or people who use wheelchairs.
- People with complex disabilities are often left out of research.
- Proxy report, where people answer questionnaires for other people who can't, might not give the right answers.
- What people get out of taking part in disability sport and physical activity might be different to what is currently measured.
- Evaluation can be too difficult or take too much time for disability sport and physical activity providers to complete.

Appendix 1.3: Conceptual framework: a quick introduction

- This chapter is all about the ideas that are connected to this work.

- The idea behind this research is that it should make change that is useful to disabled people.

- The aim for the research was to be controlled by disabled people, and to concentrate on their experience of being a disabled person.

- Disabled people’s knowledge and experience is prioritised and valuable.

- Disabled people have rights to take part in sport and physical activity.

Appendix 1.4: Methodology: a quick introduction

- This section is all about how the research was carried out.
- The research project was planned by a group of 6 disabled people and 1 family carer, working with Bev. This group were called ‘co-researchers’.
- The co-researchers were all involved in doing the research, but two co-researchers left the group after the project was planned.
- The co-researchers talked about who they wanted to be involved in the research and what they wanted to ask them.
- The co-researchers decided to talk to disabled people who do and don’t do sport and physical activity.
- The co-researchers all had different things to do in the research.
- Some co-researchers found people to take part in the research, called research participants.
- Some people were involved in asking the participants questions.

Appendix 1.5: The Voices for Inclusive Activity project: a quick introduction

- This chapter is all about how we carried out our research project together. Our project was called Voices for Inclusive Activity.

- We planned our research together and created a research question to answer. We created a research proposal that included all the information about how we would carry out our research.

- The university had to tell us whether we could do our research.

- We collected information from two groups of people: disabled people who take part in sport and physical activity and people who run or fund activities. Mostly we talked to people online or in person, but some people completed an online survey.

- We talked together about what we had found to try to make sense of the information and what it meant.

Appendix 1.6: Research findings: a quick introduction

- Disabled people shared that they like to do a range of different sports and physical activities. Disabled people want to do these things in a way that works for them. Sometimes taking part in sport and physical activity leads to other opportunities.

- Disabled people talked about being themselves and being free when taking part. They talked about the people and things that help them take part. They talked about being happy and enjoying taking part.

- Disabled people talked about being fitter and stronger, becoming better at their activity but also doing more such as volunteering or coaching.

- Disabled people talked about belonging when they take part, feeling at home and having people to take part with, but also times when they've felt like they don't belong.

- Funders want providers to show that their activities offer value for funding money. They also want to know that activities will last, but providers also want to support to keep going.

- Funders want to get more disabled people taking part.

- Sometimes funders are distant from what is happening on the ground and aren’t aware of the problems.

- Participants asked for the issues to be recognised and for ways to help people access evaluation. They talked about working together to find solutions and for disabled people and providers to get together to call for change.

Appendix 1.7: Methodological learning: a quick introduction

- This section is about what we learned about carrying out our research together.

- Co-researchers talked about what we learned after we did any part of our research. This is called reflection. Talking about what we have done helped us to think and learn about it.

- Finding the right people and groups to work with helped our research.
- We all tried to share our research, and all had different things to do.

- When co-researchers met together, everybody could share their ideas, thoughts and feelings.

- Co-researchers knew different things about research and used the skills they already had.

- We found different ways to help people be involved in the research.

- Sometimes we did not know what would happen in our research. We had to trust that it would all be okay.

- What we did helped us to see what it was like to ask people about their experiences of sport and physical activity.

- We told lots of different people and groups about how we were carrying out our research.

Appendix 1.8: Discussion and Conclusions: a quick introduction

- This part of the thesis is all about what we found and what comes next.

- Co-researchers recommend that evaluation should be co-produced with disabled people and disabled people should get something back for the contribution they make.

- Being creative can help some people to give their thoughts and ideas on activities.

- Evaluation should help organisations make their activities better for disabled people.

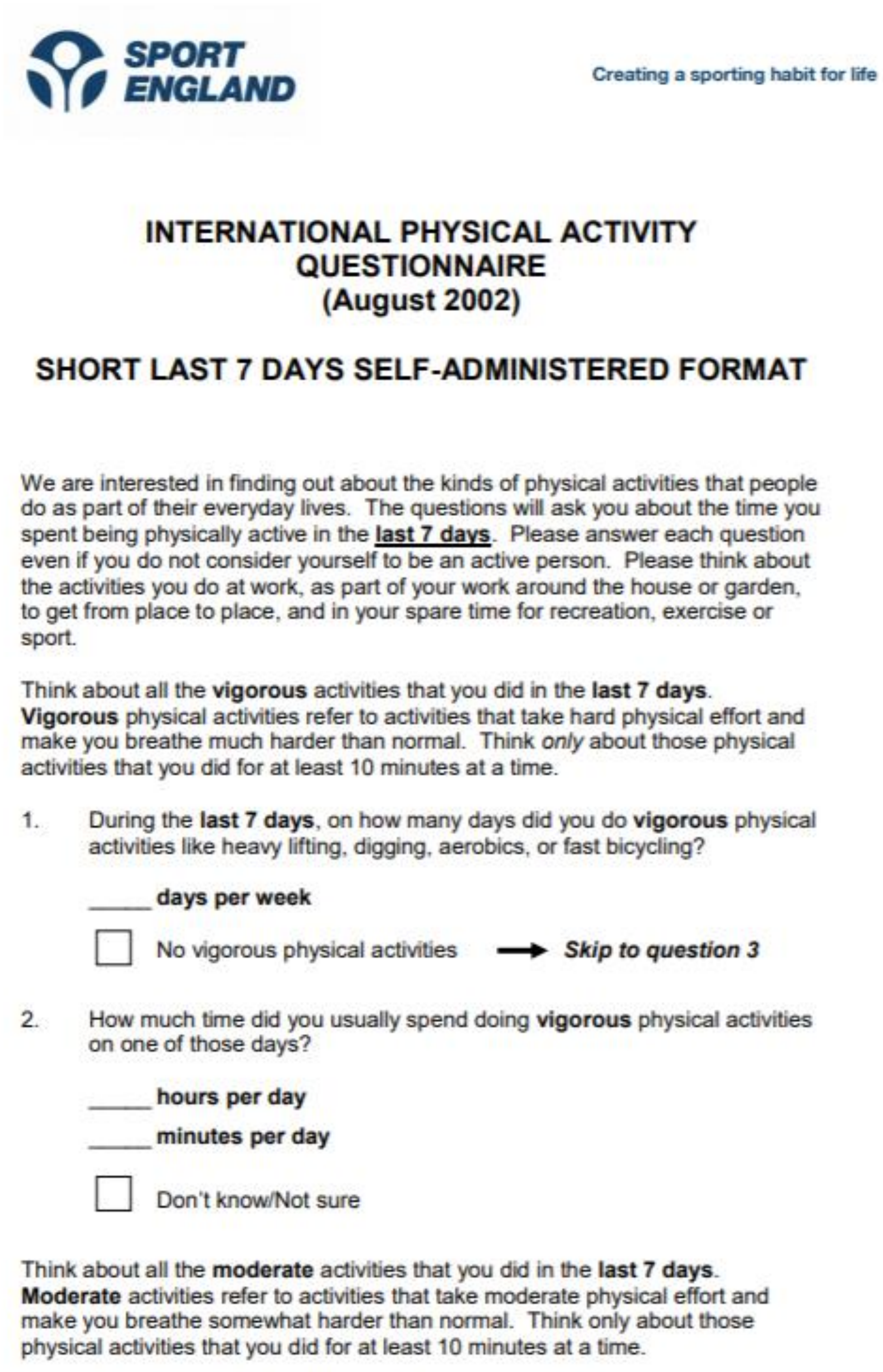
- Disabled people aren’t all the same and haven’t all got the same abilities, so it doesn’t make sense to measure them in the same way.

- We shared what we learned by making a podcast. We have plans for other ways to share with other groups about what we’ve done.

- This chapter talks about what this study means for different people, including co-researchers, disabled people and other researchers.

Appendix 2: Existing evaluation tools

Appendix 2.1 International Physical Activity Questionnaire (IPAQ, short form)



SPORT ENGLAND

Creating a sporting habit for life

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE (August 2002)

SHORT LAST 7 DAYS SELF-ADMINISTERED FORMAT

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your work around the house or garden, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

   _____ **days per week**

   ☐ No vigorous physical activities → ***Skip to question 3***

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

   _____ **hours per day**

   _____ **minutes per day**

   ☐ Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week**

☐ No moderate physical activities → ***Skip to question 5***

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ **days per week**

☐ No walking → ***Skip to question 7***

6. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

Finally, I'd like you to think about any **Sport** that you have done in the **last 7 days.** By **Sport** we mean any competitive or non-competitive sporting activity, including sessions of deliberate exercise such as running or jogging. Think only about those sports or exercises that you did for at least 10 minutes at a time.

8. During the last 7 days, on how many days did you take part in any **sport**?

_____ **days per week**

☐ No sport ***Skip to end*** →

9. How much time did you usually spend doing sport on one of those days?

_____ **hours per day**

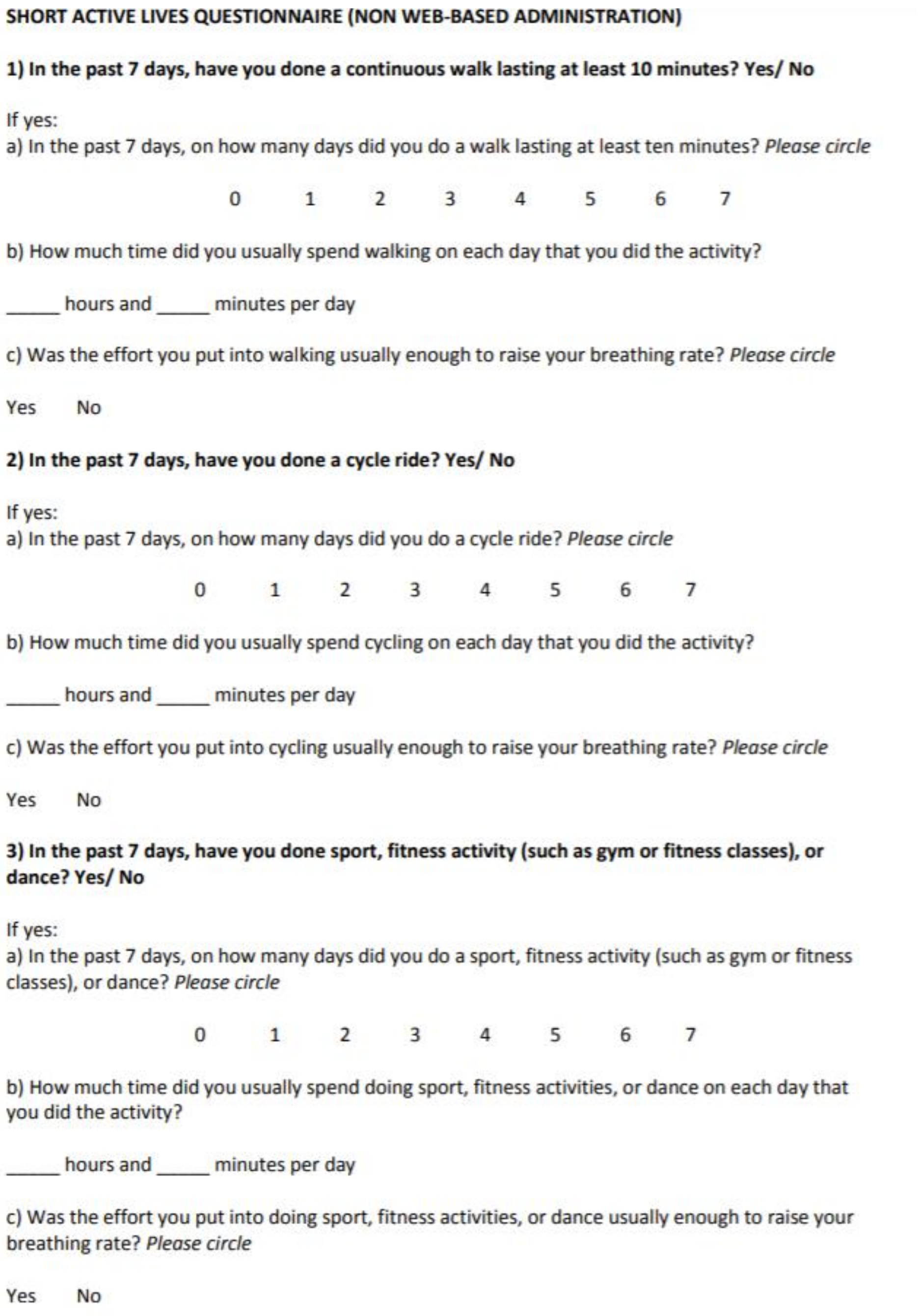
_____ **minutes per day**

☐ Don't know/Not sure

This is the end of the questionnaire, thank you for participating.

(Sport England, 2019)

Appendix 2.2 Short Active Lives Survey



SHORT ACTIVE LIVES QUESTIONNAIRE (NON WEB-BASED ADMINISTRATION)

1) In the past 7 days, have you done a continuous walk lasting at least 10 minutes? Yes/ No

If yes:
a) In the past 7 days, on how many days did you do a walk lasting at least ten minutes? *Please circle*

0 1 2 3 4 5 6 7

b) How much time did you usually spend walking on each day that you did the activity?

_____ hours and _____ minutes per day

c) Was the effort you put into walking usually enough to raise your breathing rate? *Please circle*

Yes No

2) In the past 7 days, have you done a cycle ride? Yes/ No

If yes:
a) In the past 7 days, on how many days did you do a cycle ride? *Please circle*

0 1 2 3 4 5 6 7

b) How much time did you usually spend cycling on each day that you did the activity?

_____ hours and _____ minutes per day

c) Was the effort you put into cycling usually enough to raise your breathing rate? *Please circle*

Yes No

3) In the past 7 days, have you done sport, fitness activity (such as gym or fitness classes), or dance? Yes/ No

If yes:
a) In the past 7 days, on how many days did you do a sport, fitness activity (such as gym or fitness classes), or dance? *Please circle*

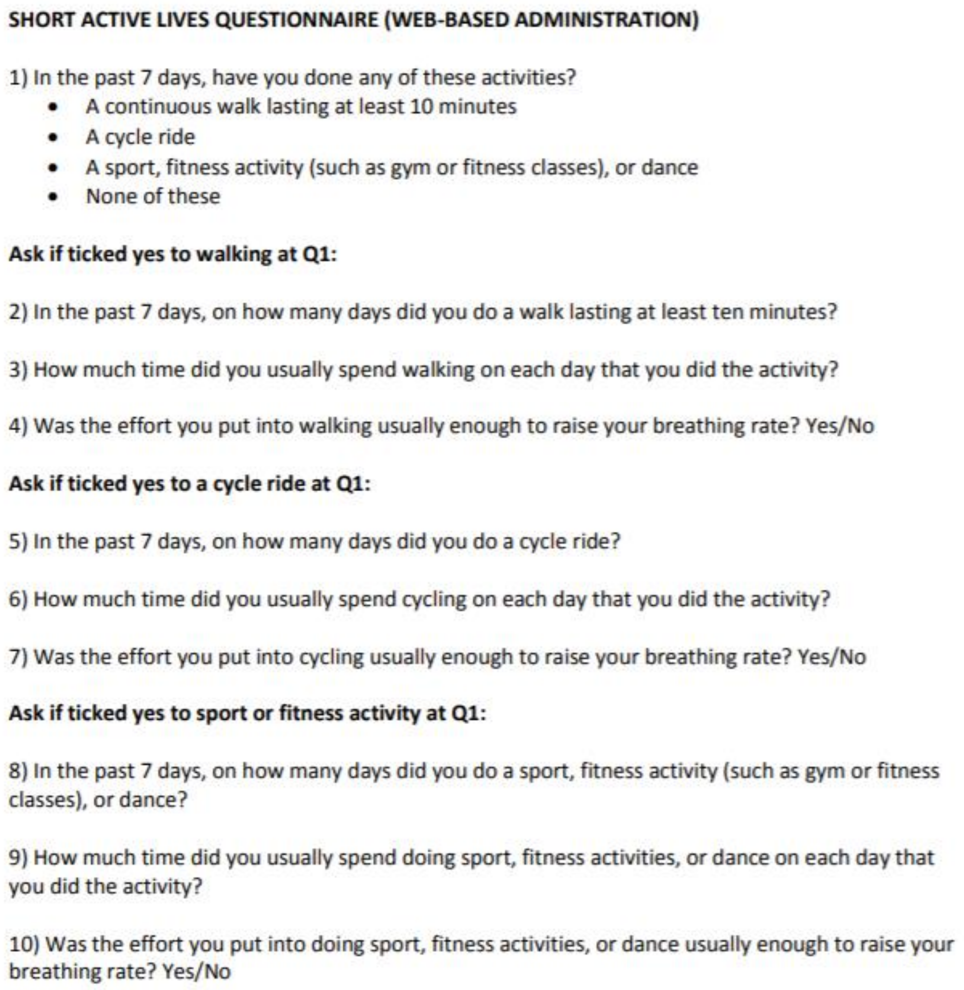
0 1 2 3 4 5 6 7

b) How much time did you usually spend doing sport, fitness activities, or dance on each day that you did the activity?

_____ hours and _____ minutes per day

c) Was the effort you put into doing sport, fitness activities, or dance usually enough to raise your breathing rate? *Please circle*

Yes No



SHORT ACTIVE LIVES QUESTIONNAIRE (WEB-BASED ADMINISTRATION)

1) In the past 7 days, have you done any of these activities?
- A continuous walk lasting at least 10 minutes
- A cycle ride
- A sport, fitness activity (such as gym or fitness classes), or dance
- None of these

Ask if ticked yes to walking at Q1:

2) In the past 7 days, on how many days did you do a walk lasting at least ten minutes?

3) How much time did you usually spend walking on each day that you did the activity?

4) Was the effort you put into walking usually enough to raise your breathing rate? Yes/No

Ask if ticked yes to a cycle ride at Q1:

5) In the past 7 days, on how many days did you do a cycle ride?

6) How much time did you usually spend cycling on each day that you did the activity?

7) Was the effort you put into cycling usually enough to raise your breathing rate? Yes/No

Ask if ticked yes to sport or fitness activity at Q1:

8) In the past 7 days, on how many days did you do a sport, fitness activity (such as gym or fitness classes), or dance?

9) How much time did you usually spend doing sport, fitness activities, or dance on each day that you did the activity?

10) Was the effort you put into doing sport, fitness activities, or dance usually enough to raise your breathing rate? Yes/No

(Sport England, 2019)

Appendix 2.3 Single Item Metric (SIM)

In the past week, on how many days have you done a total of 30 mins or more of physical activity, which was enough to raise your breathing rate? This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places but should not include housework or physical activity that is part of your job.

0 days; 1 day; 2 days; 3 days; 4 days; 5 days; 6 days; 7 days

(Sport England, 2019)

Appendix 3: Literature Review

Appendix 3.1: Literature search strategy

PICO		**Concept**	**Key words/alternative terms**	**Subject Heading terms (MeSH, CINAHL headings)**
Population		Disabled people	Disab*	Disabled persons/rehabilitation
Intervention		Sport or physical activity	Sport “Physical activity”	Exercise Leisure Activities
Comparison				
Outcome		Evaluation methods or outcome measures	Evaluation Outcome Survey Tool Questionnaire Instrument Measure Assessment	
Search strategy [Disab*] AND [Sport OR “Physical activity”] AND [Evaluation OR Outcome OR survey OR tool OR questionnaire OR instrument OR measure OR assessment]				
Limits: English language				

Appendix 3.2: Literature review inclusion and exclusion criteria

Inclusion criteria

- Articles about tools used to measure sport and physical activity in disabled people and/or people with long-term conditions.
- Articles about the evaluation of disability sport and physical activity programmes or schemes were included, whereas time limited interventions that were clinic based or in the context of treatment for or recovery from a specific health condition were not.
- The article had to concern disabled people and those with long-term conditions, as opposed to short-term conditions or recovery from treatment.
- Participants of any age (children and adults).
- Articles written in the English language.

Exclusion criteria

- Copies of tools that were not situated within explanatory literature.
- Conference presentation abstracts.
- Articles about evaluating participation in general, rather than specifically in sport and/or physical activity.
- Articles about measuring or assessing participation in non-disabled people.
- Articles not written in the English language.
- Studies concerned with the validation of measurement tools into different

languages.

- Articles specifically about measurement of physical activity in an older adult population.
- Articles concerned with para or competitive athletes and their participation.
- Tools concerned with measuring barriers or facilitators to participation (e.g. parental support) or measuring the behaviour of support professionals in physical activity support, or parental orientation to sport and physical activity.
- Articles where the term disability is used in reference to specific health conditions (e.g. back pain, femoral fracture, cancer, stroke) or older adults.
- Articles concerned with access to facilities.
- Tools specific to measuring motivation for participation.
- Programmes that were evaluated using purely academic methods, such as Randomised Control Trials.
- Articles that were focused on experiences of participation that were not primarily concerned with how this was evaluated.
- Articles purely focused on the evaluation of physical fitness.

Appendix 3.3: Literature review search results

What evidence is there to inform the evaluation of disabled people's participation in sport and physical activity?

Article	Aims of study	Participants	Tools used	Key findings	Type of evaluation
1. (White *et al.*, 2016)	1) to identify the self-report and objective instruments used to examine habitual physical activity behaviour within this population and 2) to determine the reliability and validity of these instruments.	Children and youth with physical disabilities.	Various self-report and objective instruments.	Lack of reporting of psychometric properties of self-report instruments means there is no ideal PA measure to use. Current self- report measures appear unacceptable for use in measuring PA behaviour within intervention trials. There was consistent evidence of acceptable reliability and validity for objective measures, such as accelerometers, and these are recommended for use in intervention trials.	Use of questionnaire tools
2. (Ross, Case and Leung, 2016)	To conceptualize childhood physical activity within the International Classification of Functioning, Disability and Health, and provide guidance on aligning measurement tools with physical activity dimensions, in order to support meaningful interpretations of physical activity behaviour measures among children with disabilities, away from concern about performance and activity levels.	Disabled children.	Various self-report and objective instruments.	There is an emerging need to align PA measurement selection with contemporary, multidimensional models of health and disability, with greater attention to participation as an important aspect of physical activity. More meaningful measurements and interpretations of physical activity for disabled children are necessary. This will enable the building of build detailed and comprehensive pictures of physical activity patterns and experiences to guide and support intervention strategies for increasing physical activity.	Use of questionnaire tools
3. (Lankhorst *et al.*, 2020)	To systematically review the evidence evaluating validity or reliability of self-reported and device-based instruments, to measure physical activity (PA) in individuals who use a wheelchair, and to make recommendations for the selection of PA outcomes tools.	People who use a wheelchair.	Various self-report and objective instruments.	The Physical Activity Scale for Individuals with Disabilities (PASIPD) and The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI) seem the most promising self-reported instruments for measuring the intensity of PA. Device-based instruments that can be used for measuring both the intensity and type of PA are the GENEActiv, Actigraph GT3Xþ, Actiheart, or the Physical Activity Monitor System (PAMS), showing moderate evidence for a	Use of questionnaire tools

				positive rating of criterion validity. For measuring the type of PA, the PAMS and VitaMove are suitable, showing both good evidence for a positive rating of criterion validity.	
4. (Jimenez-Pardo *et al.*, 2015)	To assess whether the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) is a reliable tool for assessing physical activity levels in people with Parkinson's.	People with Parkinson's	PASIPD	The PASIPD was demonstrated to be a reliable measure within this population, with three theoretically defensible factors: (1) housework and home-based outdoor activities; (2) recreational and fitness activities; and (3) occupational activities. These results suggest that the PASIPD may be useful for monitoring physical activity involvement among individuals with PD, particularly within large-scale questionnaire-based studies.	Use of questionnaire tools
5. (Soundy *et al.*, 2014)	To critically explore existing literature on the outcome measures used to assess physical activity in people with severe mental illness.	People with severe mental illness	Various self-report and objective instruments.	Identified significant limitations within the published literature in the choice and use of outcome measures of physical activity in studies of individuals with SMI, with limited consideration given to the use, value, purpose or shortcomings of the measure selected, and awareness needed of any previous validation processes that have been conducted to support the use of particular measure.	Use of questionnaire tools
6. (Farina *et al.*, 2019)	This scoping review aimed to identify and quantify the use of physical activity questionnaires within a dementia population.	People with dementia.	Various self-report physical activity questionnaires	There is no standard method of measuring physical activity using questionnaires in a dementia population. In addition, the majority of studies did make adaptions to the administration format of existing self-report questionnaires, affecting validity. Proxy report physical activity questionnaires could be useful for people with dementia to minimize the risk of inaccurate recall; however, before relying on these measures, rigorous validation studies comparing proxy-report to objective measures should be undertaken to improve confidence regarding the effectiveness of these measures.	Use of questionnaire tools
7. (Caron *et al.*, 2019)	To create a parsimonious, psychometrically sound measure of experiential aspects of	Disabled people	MeEAP	The MeEAP is the first measure to capture all 6 experiential aspects of participation for individuals with physical disabilities across 4 major life domains. The MeEAP can be used as an	Use of questionnaire tools

	participation (MeEAP) for people with physical disabilities.			outcome measure or as a mediator to help explain broader outcomes (e.g., life satisfaction). The MeEAP could also be used for program evaluation to provide insights about the types of interventions needed to promote full participation.	
8. (Rosenbaum *et al.*, 2020)	To assess the reliability and validity of the five-item Simple physical Activity Questionnaire (SIMPAQ) to assess physical activity and sedentary behaviour in people with mental illness.	People with mental illness	SIMPAQ	The SIMPAQ had good test-retest reliability and validity against accelerometer measures of physical activity. The SIMPAQ is a brief measure of physical activity and sedentary behaviour that can be reliably and validly administered by health professionals.	Use of questionnaire tools
9. (Clina *et al.*, 2024)	The objective of this study was to assess the reliability and validity of a version of the International Physical Activity Questionnaire (IPAQ) that has been adapted to be inclusive of disabled people.	Disabled adults	IPAQ	The adapted IPAQ demonstrated acceptable reliability and validity and is appropriate for use in people with and without disabilities.	Use of questionnaire tools
10. (Ross *et al.*, 2016)	A systematic review of literature critically examining the current conceptual and methodological approaches to evaluating physical activity participation in disabled children.	Disabled children.	Various self-report and objective instruments.	Physical activity engagement and participation are two different concepts and should be measured differently. No consistent definition of participation in the literature; the authors given their own and assert that physical activity participation can serve to represent a broader health experience associated with dynamic child-environment interaction. Differentiating physical activity engagement and participation consistently within health-related fields and approaching participation as a measurable construct are further required to support effective assessment of the health status among disabled children.	Use of questionnaire tools
11. (Murrock, Bekhet and Zauszniewski, 2016)	To examine enjoyment as an outcome of physical activity for people with functional limitations, through a secondary analysis reporting the reliability and validity of the Physical Activity Enjoyment Scale (PACES).	People with functional limitations.	PACES	Enjoyment for physical activity is an important construct for understanding physical activity participation in adults with functional limitations and this study supports the reliability and validity of the PACES in this population.	Use of questionnaire tools

12. (Clina *et al.*, 2023)	To demonstrate the methodology behind their adaptation of the IPAQ for disabled people.	Disabled people.	IPAQ	The framework used resulted in the successful adaptation of the IPAQ for people with physical disabilities.	Use of questionnaire tools
13. (Wrzesińska *et al.*, 2018)	The aims of the study were to assess the level of physical activity in students with visual impairment, with regard to their age, gender, level of visual impairment, body mass index and abdominal obesity, and to identify the percentage of study participants who did not meet the international recommendations for physical activity	Adolescents and young adults with visual impairment.	IPAQ	The elements of interest from this paper concern how the IPAQ was adapted from administration to visually impaired people. The physical activity level was measured by the self-reported International Physical Activity Questionnaire-Long Form (IPAQ-LF), Polish version. Documents were prepared in a larger font (Arial 18) for the poor-sighted students, while the blind people completed the questionnaire with the assistance of the interviewer.	Use of questionnaire tools
14. (Vancampfort *et al.*, 2016)	To examine the validity of the energy expenditure recorded in the IPAQ by people with bipolar disorder compared with an objective measure, the Sensewear Armband (SWA).	Outpatients with bipolar disorder.	IPAQ	The IPAQ overestimated active energy expenditure and underestimated total energy expenditure from physical activity by almost 40% compared with the SWA. Results demonstrate that the IPAQ should be used with caution as a measure for estimating energy expenditure from physical activity in outpatients with bipolar disorder.	Use of questionnaire tools
15. (Tyagi and Mattu, 2016)	To evaluate the association between physical activity and chronic disease and function outcomes, using the Physical Activity Questionnaire for Individuals with Physical Disabilities (PASIPD).	Disabled people.	PASIPD	There is a need for a reliable and valid measure of physical activity for research in this specific population, and this scale is useful for evaluating associations between physical activity and chronic disease and functional outcomes.	Use of questionnaire tools
16. (Pakravan, Ghazirad and Shaddel, 2022)	There is a need for a specific physical activity assessment tool for people with learning disabilities and this paper details how a multidisciplinary team	People with learning disabilities.	LDPAQ	The LDPAQ is an easy-read, picture-based, self-reported and concise questionnaire with options relevant to people with learning disabilities was developed. Feedback from the audit confirmed ease of use and high levels of respondent	Use of questionnaire tools

	devised the Learning Disability Physical Activity Questionnaire (LDPAQ) as a tool to measure physical activity and tested it within community and inpatient settings.			satisfaction. The LDPAQ is a novel questionnaire that aims to be a universally applicable tool for the assessment of physical activity status in people with learning disabilities. It is designed to be used by people with learning disabilities themselves, professionals and organisations. Further research is needed to explore the full potential of this tool.	
17. (Gee *et al.*, 2024)	There is an urgent need for valid and reliable measures of physical activity (PA) participation for use among people with physical and/or sensory disabilities. This study involved adapting the Leisure Time PA Questionnaire for People with Spinal Cord Injury for use in individuals with disabilities (i.e., the LTPAQ-D) and performing a preliminary evaluation of its content validity, construct validity, and same-day test–retest reliability in people with disabilities.	Disabled people	LTPAQ-SCI adapted into the LTPAQ-D	The development of the LTPAQ-D addresses the urgent need for an easy-to-administer, valid, and reliable measure of LTPA for people with disabilities. This study provides preliminary evidence of its construct validity and reliability among individuals living with physical and/or sensory disabilities. Collecting data on LTPA participation using a valid and reliable measure is essential to advance the knowledge regarding the influence of PA on health outcomes in people with disabilities, and to continue to develop and refine PA guidelines.	Use of questionnaire tools
18. (Duncan *et al.*, 2017)	To characterize the validity and reliability of the International Physical Activity Questionnaire (IPAQ) for assessing sitting (sedentary) time in people with schizophrenia.	People with schizophrenia	IPAQ	The “minutes” of sitting reported by the IPAQ do not reflect objective sedentary behaviour measurements and this current measure may be unsuitable for the population level assessment of sitting time among individuals with schizophrenia.	Use of questionnaire tools
19. (Shirazipour and Latimer-Cheung, 2020)	The aim of the current study was to fill remaining knowledge gaps by (a) exploring what outcomes military veterans with physical disabilities link to quality PA experiences, and (b) determining what contexts may foster these outcomes.	Military veterans with physical disabilities		Knowledge of desirable program outcomes linked to quality experiences can allow for improved development and delivery of quality programs, as well as more optimal evaluation of whether we are achieving advancements in full and equitable participation for individuals with disabilities within the PA domain	

20. (Seves *et al.*, 2021)	The study aimed to determine the test–retest reliability and concurrent validity of the Adapted Short QUestionnaire to ASsess Health-enhancing physical activity (Adapted-SQUASH) in adults with disabilities.	Disabled adults	Adapted Short QUestionnaire to ASsess Health-enhancing physical activity (Adapted-SQUASH)	The Adapted-SQUASH is an acceptable measure to assess self-reported physical activity in large populations of adults with disabilities but is not applicable at the individual level due to wide limits of agreement. Self-reported physical activity assessed with the Adapted-SQUASH does not accurately represent physical activity assessed with the Actiheart in adults with disabilities, as indicated with a systematic bias between both instruments in the Bland–Altman analysis.	Use of questionnaire tools
21. (Lynch *et al.*, 2024)	This study aimed to explore the self-reported inactivity of people with intellectual disabilities using the International Physical Activity Questionnaire – Short Form (IPAQ-SF) and Rapid Assessment of Physical Activity (RAPA) questionnaire.	People with learning disabilities	IPAQ-SF and RAPA	This study examining IPAQ-SF and RAPA questionnaire use in adults with ID showed low activity levels, irrespective of instrument. Weak inter-questionnaire correlations were observed. The IPAQ-SF may be too complex for this population, but further research on RAPA use is recommended. The accurate measurement of activity to inform practice is required.	Use of questionnaire tools
22. (Firkin, Obrusnikova and Koch, 2024)	Assessment methodologies for physical activity and sedentary behaviour have predominantly been developed for adults without intellectual disabilities, raising questions about the suitability, feasibility, validity, and reliability of these tools and techniques to obtain sufficient data among adults with intellectual disabilities. The purpose was to synthesize the current state of assessment methodologies for quantifying physical activity and sedentary behaviour volume in the free-living setting for adults with an intellectual disability.	Adults with learning disabilities	Various self-report and objective instruments.	This review underscores the need for greater consistency and accessibility in physical activity and sedentary behaviour assessment methodology for adults with intellectual disabilities. This review has identified significant gaps in the validity and reliability of assessment tools used with adults with intellectual disabilities, echoing findings from previous reviews. Tailored preparation, instruction, and behavioural strategies may enhance assessment viability and suitability for adults with intellectual disabilities, with or without caregiver or researcher involvement in the free-living setting.	Use of questionnaire tools
23. (Nightingale *et al.*, 2017)	To evaluate the currently available tools to measure physical activity and energy	People with physical impairments	PARA-SCI LTPAQ-SCI	Choosing a physical activity assessment tool for people who use wheelchairs remains challenging. The PARA-SCI has been extensively developed and is the most suitable self-report measure to	Use of questionnaire tools

	expenditure in people who use wheelchairs.	who use wheelchairs	PADS PASIPD Device-based measurement	predict time spent performing various intensity activities. Tri-axial accelerometers worn on the wrist or arm are a well-tolerated and relatively unobtrusive promising alternative to self-report methods, particularly when combined with devices attached to the wheelchair or by incorporating complex data analysis methodologies. Multi-sensor devices, with algorithms developed specifically for the individual or generally for persons who use wheelchairs, demonstrate considerably improved error in the prediction of PA/EE during controlled laboratory protocols.	
24. (Aubert *et al.,* 2023)	The objectives of this work were (a) to adopt the Active Healthy Kids Global Alliance Report Card methodology to evaluate the state of physical activity for French children and adolescents with disabilities and (b) to identify the strengths, weaknesses, opportunities, and threats perceived by French physical activity experts for promoting physical activity among children and adolescents with disabilities.	French children and adolescents with disabilities.	AHKGA Report Card methodology.	This work highlighted the urgent need for the inclusion of children and adolescents with disabilities in a comprehensive national PA surveillance system and for more efficient strategies promoting PA specifically targeting children and adolescents with disabilities in France.	Population level measurement
25. (Dairo *et al.,* 2016)	To produce a systematic review to establish physical activity levels, determine how they were measured, and what factors influenced physical activity in adults with intellectual disabilities.	Adults with intellectual disabilities.	Various self-report and objective instruments.	Only 9% of participants achieved minimum PA guidelines. PA levels were measured using objective and subjective methods. ID severity, living in care, gender, and age were independently significantly correlated with the number of participants achieving PA guidelines with the strongest predictor being ID severity (Beta 0.631, p b 0.001). Findings should be in the context that most of the participants were in the mild/moderate range of ID severity and none of the studies objectively measured PA in people with profound ID. To inform measurement and intervention de- sign for improved PA, we recommend that there is an urgent need for future	Population level measurement

				PA studies in adults with intellectual disabilities population to include all disability severity levels.	
26. (de Hollander and Proper, 2018)	To examine the physical activity levels of Dutch adults with disabilities, using existing healthcare registration data.	Adults with physical or sensory disabilities.	Short QUestionnaire to ASses Health enhancing physical activity (SQUASH) as part of the Public Health Monitor 2012 survey	Adults with physical or sensory disabilities were less physically active than people without a physical or sensory disability, but self-reported activity limitations had a major impact on the data, as did complications over how the category of disabled person was constituted.	Population level measurement
27. (Hassett *et al.*, 2021)	The objective of this study was to describe and compare the amount and type of leisure- time physical activity, and motivations and barriers to participation among adults with and without a disability	Australian adults with disabilities	The AusPlay survey conducted by telephone	Adults with a disability are less physically active and report different physical activity profiles and barriers to being active than adults without a disability. Adults with a disability who could not verbally communicate or who live in institutional settings were excluded, and type of disability was not specified. Results cannot be generalised to all adults with a disability.	Population level measurement
28. (Ng *et al.*, 2017)	The aim of this study was to compare PA levels among 15 European countries after disaggregating data by disability	Adolescents With Long-Term Illnesses or Disabilities	A single item assessed the number of days the pupil participated in moderate- to vigorous-intensity PA frequency of at least 60 min during the last 7 days.	Meeting the recommendations for physical activity was more common among boys, younger adolescents, and those from more affluent families and there were no significant differences in meeting the recommendations between boys or girls with LTID and those without long-term illnesses or disabilities at a national level, with two exceptions (Romania and Slovakia). The findings from this study were dependent on the way adolescents self- reported LTID and PA as well as how they responded to the questions unaided. As such, there are some study limitations to consider.	Population level measurement

29. (Dairo, Collett and Dawes, 2017)	Our understanding of low PA levels in people with intellectual disabilities is limited by a lack of information on how it can be measured effectively, particularly in those with severe/profound intellectual disabilities. This study aimed to explore the feasibility of measuring physical activity levels using the International Physical Activity Questionnaire- short version (IPAQ-s) and a wrist- worn 7-day accelerometer to inform effective measurement of physical activity across the disability spectrum of intellectual disabilities to include the most profound impairment.	Adults with intellectual disabilities	International Physical Activity Questionnaire- short version (IPAQ-s) and a wrist worn 7-day accelerometer	While both the IPAQ- s and accelerometers can be used to evaluate physical activity levels, the IPAQ- s was more acceptable and carer report was accurate, but it underestimated absolute moderate- vigorous physical activity levels. These findings indicate that IPAQ- s can be used to measure physical activity levels, including in those with profound intellectual disabilities.	Device-based evaluation
30. (Moss and Czyz, 2018)	The purpose of this study was to determine the level of agreement between objective physical activity (PA) (ActiHeartVR) and subjective proxy-respondent International Physical Activity Questionnaire- short version (IPAQ-S) data in adults with intellectual disabilities (IDs).	People with intellectual disabilities	ActiHeart and the IPAQ	IPAQ-S is inaccurate when determining physical activity in persons with intellectual disabilities as it significantly underestimates the true levels of physical activity in this cohort.	Device-based evaluation
31. (Leung, Siebert and Yun, 2017)	The purpose of this study was to synthesize the current practice of using accelerometers to measure physical activity levels among individuals with intellectual disabilities.	Individuals with intellectual disabilities	Systematic review related to accelerometer usage	There is a lack of consistent research protocols for measuring physical activity levels with accelerometers. Issues with the amount of time participants wore the accelerometer was a challenge for multiple studies. Studies that employed external strategies to maximize wear time had higher compliance rates. There is a need to establish and standardize specific accelerometer protocols for measuring physical activity levels of individuals with intellectual	Device-based evaluation

				disabilities for higher quality and more comparable data.	
32. (Ptomey *et al.*, 2017)	In order to determine the success of physical activity interventions, identification of feasible methods for assessment of physical activities is necessary. The purpose of this study was to assess the feasibility of adults with IDD to track daily steps and wear an accelerometer.	Adults with intellectual and developmental disabilities	Pedometers and accelerometers	Adults with IDD will adhere reasonably well to wearing a pedometer long term but may be unable to record the step data accurately. Furthermore, adults with IDD have poor compliance with accelerometer protocols, and future studies should determine if a shorter wear time protocol would produce valid data in this population.	Device-based evaluation
33. (Brandenbarg *et al.*, 2023)	This scoping review aimed 1) to provide a critical mapping of the existing literature and 2) directions for future research on measurement properties of device-based instruments assessing physical activity behaviour in ambulant adults with physical disabilities and/or chronic diseases.	Ambulatory adults with physical disabilities and/or chronic diseases:	A range of device-based instruments	This scoping review shows a large variability in research on measurement properties of device-based instruments in ambulatory adults with physical disabilities and/or chronic diseases. The variability highlights a need for standardization of and consensus on research in this field. The review provides directions for future research.	Device-based evaluation
34. (Lynch *et al.*, 2025)	To compare between activPAL objective measures and International Physical Activity Questionnaire short form (IPAQ-SF) self-reported activity levels in older adults with intellectual disability.	Older Adults with Intellectual Disability	ActivPAL and IPAQ-SF	Compared to the activPAL, the IPAQ- SF overestimated moderate and vigorous activity time and underestimated mild activity time. The results here suggest that the IPAQ- SF is not the most optimal tool for the determination of activity levels of older adults with intellectual disability. Future research should use objective measurements of activity.	Device-based evaluation
35. (Lankhorst *et al.*, 2019)	The objective was to investigate the criterion validity of the Activ8 for measuring static (sitting, standing) and dynamic (walking, bicycling, running) activities, and for separating postures and movements within basic and complex activities in children and adolescents (youths) with typical	Youths With Typical Development and Youths Who Are Ambulatory and Have Motor	Activ8	Activ8 is a valid tool when the merged categories static and dynamic are used to interpret physical activity in daily life in both youths with typical development and youths with not-typical development and mild motor impairment. To optimize the quantification of separate postures and movements, adjustment of the existing algorithm is required.	Device-based evaluation

	development and peers with motor disability (not typical development).	Disability			
36. (Johnson, Yun and McCubbin, 2014)	Self-reported physical activity behaviour with assistance from a secondary source has previously been used with adults with an intellectual disability. Limited evidence of reliability and validity have been provided for this approach. This study examined evidence of convergent (CV) and discriminant (DV) validity for self-report with assistance from a secondary source as a measure of physical activity in adults with intellectual disabilities.	Adults with an intellectual disability	The physical activity questionnaire section of the NHANESIII (National Center for Health Statistics, 1994) was used to assess regular PA habits.	Reliability and validity issues of the responses of people with intellectual disabilities to self-report measures of PA— whether completed independently, with assistance from a secondary source, or through proxy–have been identified as a pressing research need in the literature. Self-report with assistance from a secondary source as a measure of PA in adults with intellectual disabilities was highly reliable. Results also indicated that accelerometer and pedometer outcomes are reliable and that significant relationships exist among the outcomes as measures of physical activity in adults with intellectual disabilities. Further research is needed on the development of contextually specific self-report measures of physical activity for adults with intellectual disabilities, which could strengthen validity evidence.	Self-reporting
37. (Strongman *et al.*, 2023)	The aim of this study was to evaluate the use of mat-based group Pilates as a possible 'return to sport' intervention for adults with visual impairment	Adults with visual impairment	Measures of quality of life and balance confidence were collected at the start and end of the intervention. In addition, qualitative surveys and participant interviews were conducted pre- and post-intervention to gather data about the participants views and lived	There were no statistically significant changes to overall quality of life or balance confidence over the 10-month intervention period, but participants started with good scores with limited scope for improvement. Despite no quantifiable positive changes in balance confidence or quality of life, the qualitative analysis identified that the participants valued and benefitted from the intervention and found it helpful to their overall function as well as wellbeing and mental health.	Programme evaluations

			experiences of participating in the session.		
38. (Schmid, Short and Nigg, 2019)	The purpose of this study was to conduct qualitative process and pilot outcome evaluation of AccesSurf, a non-profit organization empowering people with disabilities to perform adaptive swimming and surfing	Disabled people	Focus groups	Qualitative methods are specifically appropriate for evaluation where program processes and outcomes are general or not defined. This is the case for AccesSurf, where overall goals are unspecific, and detailed goals need to be determined for future evaluation purposes. Conducting additional focus groups would have resulted in higher quality; however, personnel resources were limited. The results need to be treated with caution, and confirmed, especially for participants with recent onset of disability.	Programme evaluations
39. (Willis *et al.*, 2018)	This study aimed to describe the association between context, mechanisms and outcome(s) of a participation-focused physical activity intervention to understand what works, in what conditions, and how.	Children and youth with disabilities	A realist evaluation using ethnographic methods comprising participant observation, interviews, and focus groups.	This study provides new knowledge of mechanisms and contexts that may enable participation in physical activity for children and youth with disabilities. The ethnographic methodology was time consuming to complete.	Programme evaluations
40. (Dixon-Ibarra *et al.*, 2018)	The purpose of this study was to complete a process evaluation of Menu-Choice programme, which assists staff in creating physical activity goals alongside residents with intellectual disabilities and provides strategies to incorporate activity into the group home schedule.	People with intellectual disabilities in a group home setting	Face-to-face interviews	Changes in programme training and simplified programme materials are needed to accommodate identified barriers for implementation. The importance of obtaining increased agency support and policy change is highlighted. Limitations of the method included that residents were selected based on mild intellectual disability and their ability to communicate in an interview. One site did not have a resident representative, because their site had residents with severe intellectual disability.	Programme evaluations
41. (Carter *et al.*, 2014)	This appreciative, qualitative study explored the experiences of children, families and stakeholders at a wheelchair	Children who use wheelchairs.	A mixed qualitative methods approach was	The Cheetahs created opportunities for meaningful participation in wheelchair sports for children.	Programme evaluations

	sports club, their experiences and perceptions, and what benefits (if any) occur as a result of bringing children with disabilities and children without disability together.		adopted, employing participant observation, children's research activities, focus groups and interviews		
42. (Pochstein, 2022)	Children with intellectual disabilities (8–15 years) and their parents were given the opportunity to participate in an 8-week sports program in four mainstream clubs organized by a self-help organization for people with intellectual disabilities. Focus groups were conducted with all participants (parents, children, and club representatives) before and after the program and evaluated by means of a thematic analysis.	Children with intellectual disabilities	Focus groups	The children rated participation very positively and only very occasionally reported that they had been excluded. The parents confirmed this experience but were nevertheless more critical in their assessment. The use of questionnaires and scales to measure satisfaction with the program in a more structured way could add some more information. In the present study, the focus was on understanding the processes and the stakeholder's common experiences of inclusion. Specific outcomes or intra-group com- parisons were not the focus of interest. However, this could and should be a topic for future research. The sports clubs themselves received valuable information about what their failings were: sufficiently available and qualified staff, better access to sports facilities, and a wider range of inclusive groups are needed.	Programme evaluations
43. (Matthews, Seaman and Bremer, 2023)	In response to the pandemic, the Acadia University Sensory Motor Instructional Leadership Experience (S.M.I.L.E.) Program shifted its programming to a virtual platform; however, there was little research to guide its creation, implementation, or expected outcomes. Thus, this program evaluation explored program feasibility and impact on physical activity and physical literacy.	Disabled people	A mixed methods case study approach. Demographic data, physical literacy (PLAYself), and physical activity (IPAQ-A) data were collected using caregiver pre-and post-programming surveys.	Results from this program evaluation suggest that physical literacy and physical activity levels were generally maintained throughout programming and caregivers indicated several social and activity benefits. In-person assessments of physical literacy were not possible resulting in all data being collected through the perspective of the caregiver. Miscommunication or different interpretations in the understanding of questions in the surveys may have affected the validity of the responses. Furthermore, all assessments of motor improvements and physical activity levels were not able to be measured and assessed by researchers through objective measures, which	Programme evaluations

			Weekly check-in surveys, post-programme caregiver and leader interviews.	may have reduced the overall accuracy of the program's impact on the motor domain of physical literacy and physical activity. Additionally, the age range of participants within the study was large, yet overall, the sample size was small, preventing researchers from conducting age- specific analyses to better understand program effectiveness. Finally, as all assessment tools, check-ins, and activity delivery were online, the technological literacy of the caregivers and/or participants may have impacted participant numbers and overall program participation.	
44. (Ovenden, Dening and Beer, 2019)	This qualitative study explored the impact of a Boccia (modified indoor bowls) group on the lives of people with dementia and their carers.	People with dementia	Semi-structured interviews with people with dementia (N=6), carers (N=10) and the group organisers (N=6) analysed using thematic analysis	The study was only able to look at one group over a fairly short period of time; and the group may not be representative of the whole population so Boccia may not have these positive effects for everyone. It was not possible to measure clinical or other outcome measures in this group so we cannot provide quantifiable evidence of the benefits of Boccia. However, the qualitative data suggest this should be explored in a larger study.	Programme evaluations
45. (Berthiaume *et al.*, 2024)	This study aimed to describe individuals with disabilities' perceived quality of participation in an adapted paddleboard program, and to explore their suggestions of strategies to support meaningful engagement in the program	Adults with physical disabilities	Ethnographic mixed methods: participant observations, semi-structured interviews based on the Quality Parasport Participation Framework (QPPF), MeEAP	Participants expressed high-quality of participation in adapted paddleboarding. The study allows the development of knowledge about conditions that enhance the experience of participating in outdoor leisure time physical activity.	

Appendix 4: Co-researcher information

Appendix 4.1: Co-researcher information sheet

Project title: 'Nothing about us without us': Working with disabled people to explore accessible and inclusive ways of evaluating their participation in sport and physical activity.

Date: 5 August 2020

My name is Bev Goodman and I am a PhD student at the University of Essex. I am inviting you to take part as a co-researcher in a project to explore the accessible and inclusive evaluation of disabled people's participation in sport and physical activity. A co-researcher is a partner in research, and we will work together to explore this issue as a group.

Before you decide whether you want to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read this information, which we can then talk about. You can also let me know if this information needs to be changed: for example if you think anything is missing or difficult to understand.

What is this project about?

Disabled people and people with long-term health conditions are less likely than others to take part in sport and physical activity. This situation is made worse because there is no tool available that can be used to collect information from disabled people about their physical activity, including what they do, for how long, and why. There are already some surveys used to collect information about people’s sport and physical activity, but these are not easy for everyone to use, and they don’t include all the different things that people do to keep active. Some sports projects can’t use these surveys with the people they work with. Because the results of these surveys are often used to get funding, it can be hard for the projects that can’t use them to get money to do more or keep going.

This study is part of the work towards my PhD degree at the University of Essex. It is important for me to be clear that I will be the person to write up the final project and submit this for my degree, but the actual process of the research will be decided and directed by the co-researchers. There are lots of organisations interested in this project, so it might have a wider effect in the world of inclusive sport and physical activity.

What type of project is this and what does this mean for me?

This is a Participatory Action Research project. This is a type of project where people from a community come together as co-researchers to learn about an issue they want to change. You will have the opportunity to work in partnership as a co-researcher, and you can be involved in many parts of the research, from planning the research, to recruiting people to take part, to collecting research information, making sense of this information and deciding what to do with it. This type of research is all about making sure that all partners are equal. No-one is more important, more expert, or has more ‘power’ than anyone else. During our first discussion group we will talk about and create a ‘group agreement’ of ways of taking part, that will help to make sure everyone is heard and has the chance to have their say. Don’t worry if you don’t know anything about research, as we will work together to share our knowledge and have training if we need it.

Why have I been invited to take part?

I am looking for around five people to come and meet in partnership as co-researchers. The principles of participatory action research ensure that the people most affected by an issue are involved in investigating it, which fits with the disability activist statement: ‘Nothing about us without us’. I am not a disabled person, but I am inviting people who identify as being disabled to take part as co-researchers.

How long will this project last and how much time do I have to give?

First we will have a video or telephone call to talk about the project. The co-researchers will then come together for an online discussion group, using a video calling programme called Zoom. If you haven’t used this before and need help to set it up, we can do this before the first session, and we will support each other as we go along. We will decide as a group when, for how long and how often we will meet, but as a rough idea it will be no more than one hour per month, for up to eight sessions. During our discussion groups we will talk about and plan how to do the research. You can take part in many parts of the project, but what you do and the time you give is up to you. It’s understandable that everyone has different time available and that you might not be able to do everything.

Are there any risks involved?

I do not think there will be any risks to you, but as a team we will take care to keep each other safe throughout the project and respond quickly to any problems that come up.

Are there any possible benefits of taking part?

You will have a chance to work together with a team of co-researchers to help shape how sport and physical activity is evaluated. This may help to challenge some of the current inequalities in access to activities that are experienced by disabled people. Through this process you'll have the chance to connect with others interested in this research and may develop new skills. We will discuss as a group of co-researchers how your contribution is recognised, but you will be given the opportunity to claim an involvement payment of £20 for every discussion group you participate in. You can choose to receive this as a voucher or a donation to a user led organisation or a charity. People who receive welfare benefits will need to check whether they are able to accept a voucher, but we can talk about this.

Will you keep my information safe?

We will discuss and decide as a group what information is kept and how it is kept, and any personal information will be kept safe and secure in line with data protection law. We have the option to audio or video record our discussion groups but will only do this if all co-researchers agree.

What will happen after the project?

All co-researchers will share the progress and results of our research, and we will decide as a group how we would like to share these more widely. We may choose to share our results in a report, or write articles for academic journals, newspapers, blogs or elsewhere online, as examples. We may have the chance to share our results at events or conferences. I will also be writing up what we did and what we found to submit for my PhD at the University of Essex, and my final thesis will be shared online.

Who is funding the research?

I have been awarded a University of Essex scholarship to undertake this PhD research project, and the project has been given some other money from the university to fund initial research. The project has funding from the Elizabeth Casson Trust to cover involvement payments and any co-researcher expenses.

Do I have to take part in this project?

You do not have to take part if you do not want to. It is up to you to volunteer to take part once you have read the information and have had a chance to have your questions answered.

What if I no longer want to take part?

You have the right to leave the project at any time for any reason, without saying why and without any penalty. However, when you first agree to take part, you will be asked to agree for us to use any information or ideas (without your name or other details) after you have left the project. You can also rejoin the project after you have left, but you must be aware that the other co-researchers may have developed ideas and made decisions while you were gone.

What if I have questions, concerns or complaints about the research?

If you have any questions, problems or complaints about this study, please contact me directly on bg16905@essex.ac.uk The research will change as a result of feedback and ideas, so any concerns can be shared. If you are still concerned, please contact Dr Ewen Speed, Director of Research for the School of Health and Social Care on esspeed@essex.ac.uk

Appendix 4.2: Involvement payment request form

Co-researcher Involvement Payment Claim Form

Claiming an involvement payment

If you are receiving welfare benefits you must have permission to receive a voucher as an involvement payment.

Your welfare benefits could be stopped if you accept a voucher without permission. We recommend that you speak to your benefits agency before accepting any involvement payments. You may need to complete a PW1 form from your Jobcentre to get permission to work. Please let me know if you would like to read a guide about claiming involvement payments while receiving benefits.

Please choose one of these two options:

a) I would like to claim an involvement payment of a £20 voucher for taking part in a co-researcher discussion group

Yes / No (please delete)

Please confirm what type of voucher you would like to receive:

OR

b) If you do not want to claim a voucher you can donate £20 to a user-led group or charitable organisation for taking part in a co-researcher discussion group

Yes / No (please delete)

Please confirm which group or organisation you would like the donation to be made to:

I confirm that I took part in a co-researcher discussion group on:

I understand that it is my responsibility to ensure that receipt of this payment does not affect my entitlement to any welfare benefits.

Name: Signed: Date:

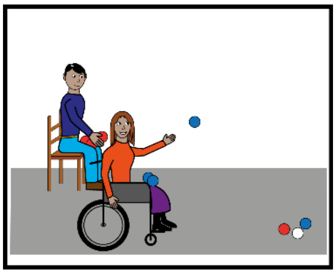
Return this form to Bev Goodman: bg16905@essex.ac.uk

Thank you to Shaping Our Lives, a National User Network of service users and disabled people, which has allowed their involvement payment form to be adapted for this project.

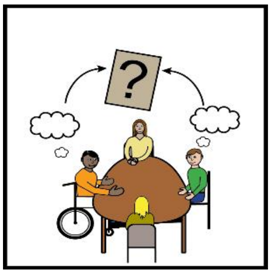
Appendix 4.3: Easy Read Information for co-researchers

My name is Bev and I am a student at the University of Essex.

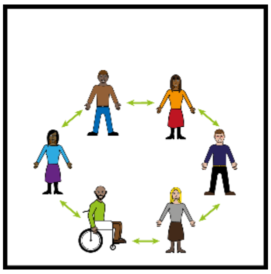
I would like to know if you would like to join a research project. You do not need to know anything about research to take part.



The research project is all about how we measure how disabled people take part in sport and physical activity.

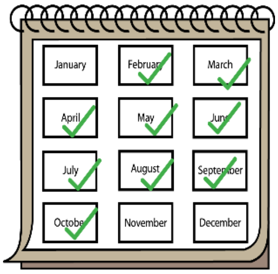


This is a type of research project where people in a group talk about a problem and work together to find things to do about it.

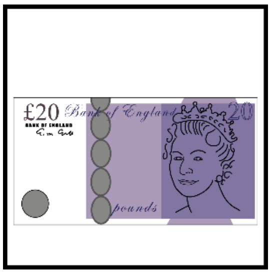


I am looking for 5 disabled people who would like to be a co-researcher. This means we will all work together as a research team.

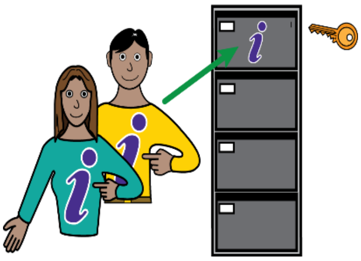
We will meet using a safe online place called Zoom.



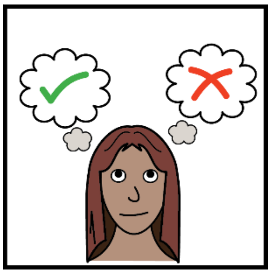
We will decide together when we will meet, how often and for how long.



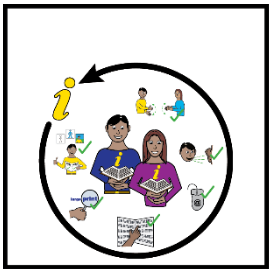
You may be able to claim a £20 voucher for each time we meet.



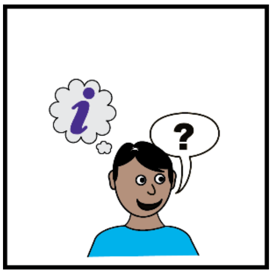
We will talk about and decide how to keep everyone's information safe.



You do not have to take part in this research if you do not want to. It is your choice. You can also leave the project at any time if you want to.



After the project I will write about it for my degree. But we will talk about how we want to share what we find out.



If you want to talk to me to find out more, please tell the person who gave you this information.

Appendix 4.4: Co-researcher videos

Full co-researcher information video:

https://tinyurl.com/coresearchers

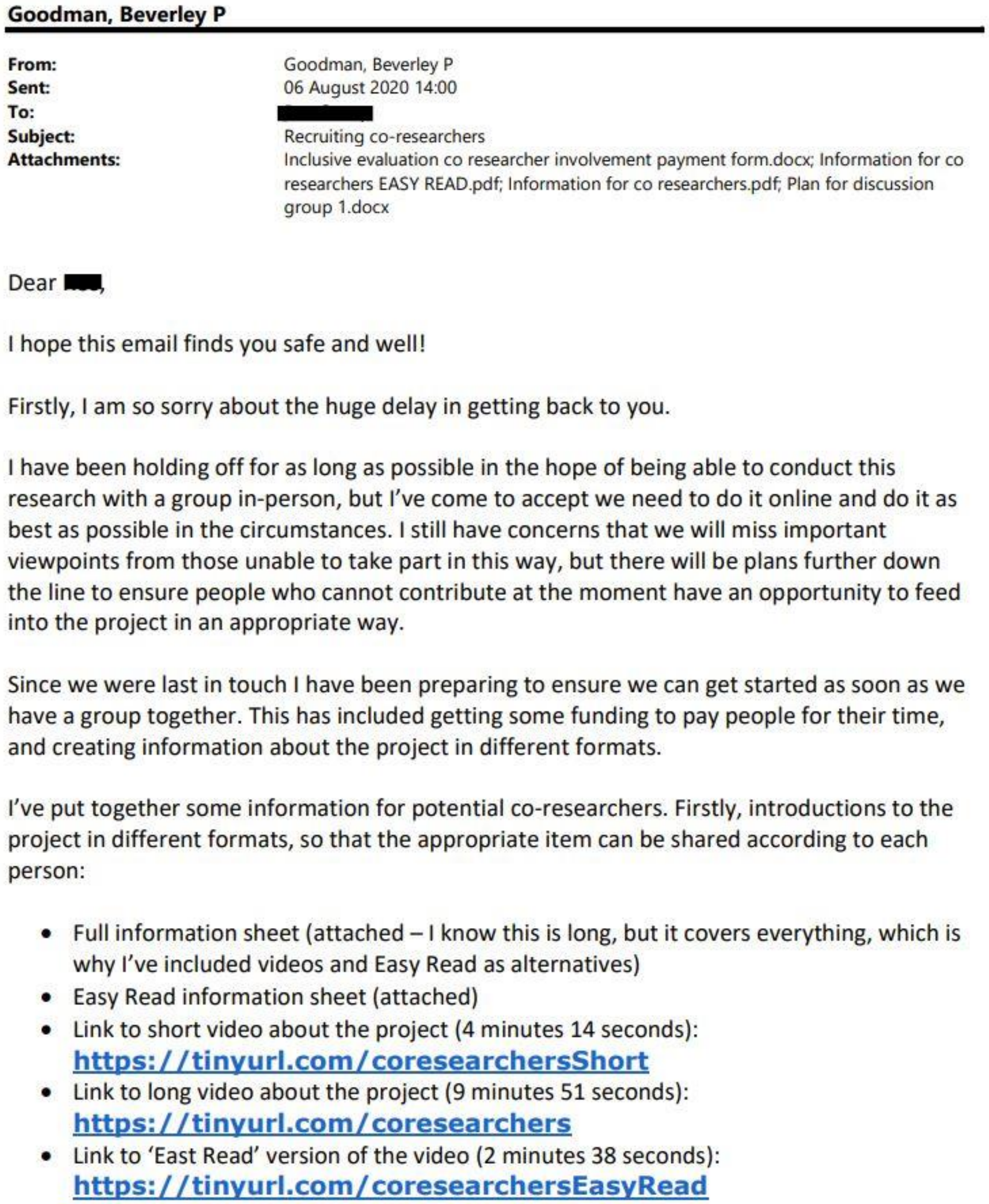
Short co-researcher information video:

https://tinyurl.com/coresearchersShort

Easy Read information for co-researchers:

https://tinyurl.com/EasyReadCoResearchers

Appendix 4.5: Email to gatekeeper



Goodman, Beverley P

From:	Goodman, Beverley P
Sent:	06 August 2020 14:00
To:	[redacted]
Subject:	Recruiting co-researchers
Attachments:	Inclusive evaluation co researcher involvement payment form.docx; Information for co researchers EASY READ.pdf; Information for co researchers.pdf; Plan for discussion group 1.docx

Dear [redacted],

I hope this email finds you safe and well!

Firstly, I am so sorry about the huge delay in getting back to you.

I have been holding off for as long as possible in the hope of being able to conduct this research with a group in-person, but I've come to accept we need to do it online and do it as best as possible in the circumstances. I still have concerns that we will miss important viewpoints from those unable to take part in this way, but there will be plans further down the line to ensure people who cannot contribute at the moment have an opportunity to feed into the project in an appropriate way.

Since we were last in touch I have been preparing to ensure we can get started as soon as we have a group together. This has included getting some funding to pay people for their time, and creating information about the project in different formats.

I've put together some information for potential co-researchers. Firstly, introductions to the project in different formats, so that the appropriate item can be shared according to each person:

- Full information sheet (attached – I know this is long, but it covers everything, which is why I've included videos and Easy Read as alternatives)
- Easy Read information sheet (attached)
- Link to short video about the project (4 minutes 14 seconds): **https://tinyurl.com/coresearchersShort**
- Link to long video about the project (9 minutes 51 seconds): **https://tinyurl.com/coresearchers**
- Link to 'East Read' version of the video (2 minutes 38 seconds): **https://tinyurl.com/coresearchersEasyRead**

(Please excuse my terrible presenting style on the videos, but I wanted people to know who they would be working with!)

Potential participants will also be sent:

- Involvement payment form (attached)
- Outline plan for the first discussion group (attached – potential co-researchers will be encouraged to help shape this session by suggesting changes)

Of course I can send the appropriate level of information to potential participants by email or by post, depending on what suits them.

As mentioned, these will be used to support an individual conversation, but I would really appreciate your thoughts on what I've included, and whether you think these could be shared with potential participants. These are NOT final versions and I would be very grateful for any feedback. I know you won't be afraid to be honest and I welcome this wholeheartedly, as I am keen to get this right rather than be precious about anything. It's all part of the research process! If you have anyone you work with who may also be interested in taking a look at these documents, please feel free to share.

I also wondered whether, once you have had the opportunity to find out more about the project, whether you have in mind anyone we could approach anyone who might be interested to join. I am only looking for 5 people to keep the group small so it will be difficult to ensure full diversity but it would be good to consider a range of characteristics, including gender, age (18+), impairment type. The main requirement would be that people have the ability and capacity to participate in a discussion via Zoom (with pre-meeting set up and support provided by me).

Look forward to hearing your thoughts (and not immediately, as I know you are an incredibly busy person!)

Bev

Beverley Goodman
PhD Student
Research title: '*Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity*

School of Health and Social Care / School of Sport, Rehabilitation and Exercise Sciences
University of Essex

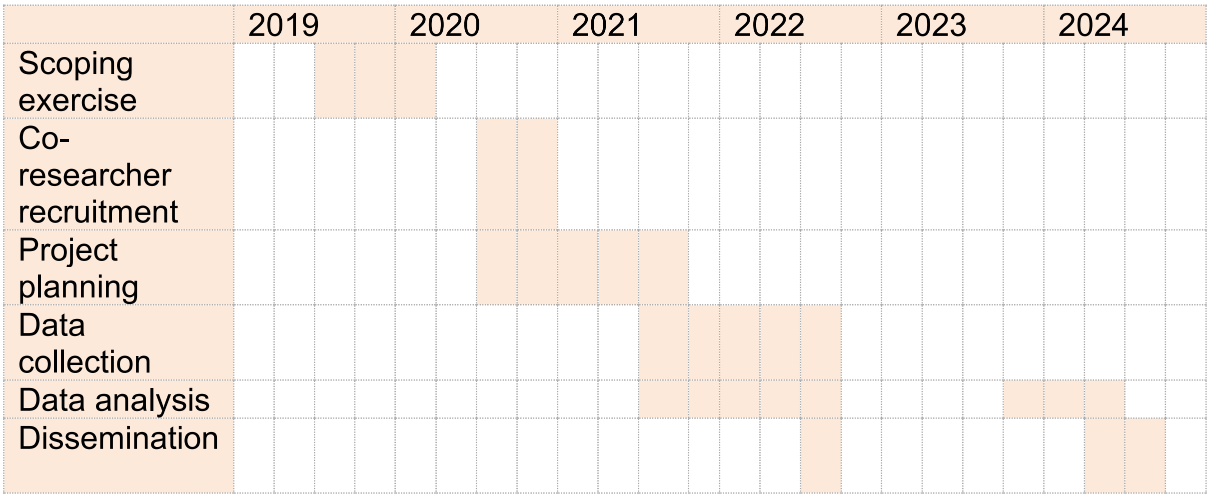
Appendix 4.6: Topics for the first individual discussion with potential co-researchers

- Introductions
- Are you happy for me to make notes while we talk?
- Do you have any questions about the information or the project in general?
- Was anything not clear? Does anything need to be changed?
- Would you like to take part?
- Thoughts on the first discussion group plan
- Do you have any access needs to consider?
- Have you used Zoom before, do you need help to set it up? Using chat, reactions, breakout groups and polls
- Confidentiality and recording our sessions (video recording and/or auto transcription)
- How would you want to keep in touch? Are you happy to share your details with me?
- Claiming involvement payments and expenses
- Communication and sharing information between groups
- Leaving the group
- Who else do you think we need to involve? Do you know anyone who may be interested?
- What is your availability for the first meeting?

Appendix 4.7: Co-researcher identities

	Gender	**Disability/Impairment category**	**Physical activity experience**
1	Female	Physical	Leading user group of hydrotherapy pool
2	Female	Physical, Neurological	Paralympic athlete
3	Female	Physical	Former youth track athlete, gym user
4	Male	Learning disabilities and Autism	Regular participant in various disability sports
5	Male	NA - Family carer	
6	Male	Physical	Wheelchair rugby player; club Chairperson
7	Female	NA – PhD researcher	Various recreational activities

Appendix 4.8 GANTT Chart of phases of the research process



	2019				2020				2021				2022				2023				2024			
Scoping exercise			▨	▨	▨																			
Co-researcher recruitment							▨	▨																
Project planning							▨	▨	▨	▨	▨													
Data collection											▨	▨	▨	▨	▨									
Data analysis											▨	▨	▨	▨	▨					▨	▨	▨		
Dissemination															▨							▨	▨	

Appendix 4.9: Timeline of the research project

2019	
9th October 2019 – 4th March 2020	Scoping exercise
2020	
August – December 2020	Co-researcher recruitment
3rd October	Discussion group 1 (1 hour) – getting to know each other, introducing the project, thinking about our group agreement.
1st November	Discussion group 2 – reviewing and agreeing our group agreement, our skills and experiences, who this research is for, what are we trying to find out. Karen's experience of evaluation at St George's hydrotherapy pool, thinking about who else needs to be involved.
13th December	Discussion group 3 – what does participation/taking part mean to you?, what does evaluation mean to you, what are we trying to find out and how are we going to do it?
2021	
17th January	Discussion group 4 – what role do you want Bev to take? Do you feel like a co-researcher? What would give you more control of the process, how can we share responsibilities? Our research question. What do we want to ask the people involved?
28th February	Discussion group 5 – deciding on our interview questions; writing our consent form and research information sheet
21st March	Discussion group 6 – writing our consent form and research information sheet; reviewing our research proposal; the ethical approval process
9th May	Discussion group 7 – our definitions of disability and physical activity; completing our data collection plan
17th June	Disability Physical Activity Impact Collective Co-production workshop
21st June	Confirmation of ethical approval for application ETH2021-1151
4th July	Discussion group 8 – confirmation of ethical approval; practical tips for data collection and

	practice; our data collection process
2nd September	Interview A (Funders, providers, related organisations)
5th October	Interview B (Funders, providers, related organisations)
11th October	Interview C (Funders, providers, related organisations)
25th October	Confirmation of ethical approval for application ETH2122-0130 for in-person data collection
26th October	Face-to-face data collection day (Users and non-users)
5th December	Discussion group 9 - Christmas catch-up & naming our project
21st December	Interview D (Funders, providers, related organisations)
2022	
14th February	Zoom interview 1 (Users and non-users)
16th March	Interview E (Funders, providers, related organisations)
5th April	Face-to-face data collection day (Users and non-users)
5th April	Interview F (Funders, providers, related organisations)
6th May	Zoom interview 2 (Users and non-users)
19th May	Interview G (Funders, providers, related organisations)
4th September	Discussion group 10 - analysis
25th September	Discussion group 11 – podcast planning
17th October	Sport for confidence team meeting
26th October	Sport England interview on co-production and innovation
3rd November	Sport England co-production group session (follow-up from interview on 26/10/2022)
6th November	Podcast recording
6th December	Confirmation of extension of ethical approval for Application ETH2223-0362 to 30th September 2024
2023	
November 2022 – November 2023	Maternity leave
2024	
14 April	Co-researcher analysis and findings day
12th May	Podcast planning

23rd June	Podcast planning
7th July	Podcast recording

Appendix 5: Co-researcher discussion group plans

Appendix 5.1: Plan for discussion group 1

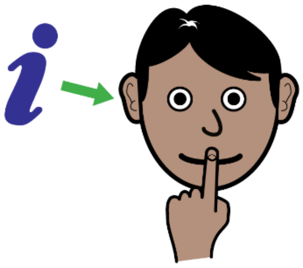
When?	Saturday 3rd October 2020
What time?	10 – 11am
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

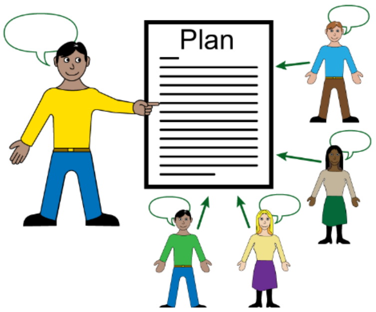
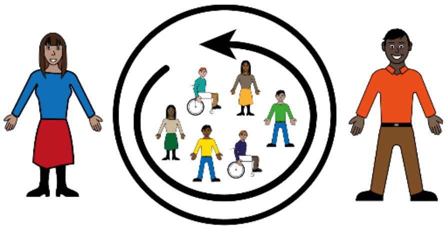
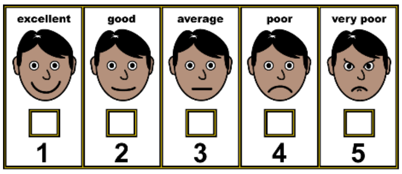
What are we going to talk about?
Recording our sessions and confidentiality
Saying hello - About us - What do we know about research? - Why were you interested in being involved? - Bring and share – something about us
What is this project about and what does this type of research involve?
Making our group agreement - Ways of being (rules for meetings) - Format of sessions – length, breaks, frequency - How do we make sure everyone has an equal say? - What should we call ourselves? - Our roles in the sessions - How do you want your contribution as a co-researcher to be recognised? - Do we want ways to keep in touch or share ideas between meetings? - Who do we talk to if we have a problem?

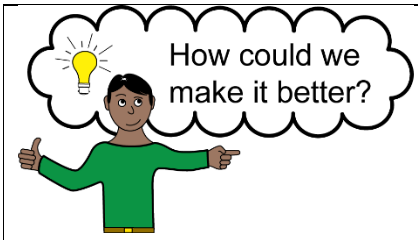
Short break
Exploring participation in sport and physical activity What does participation mean to you?
Reflections How did the session go? What could we do differently? Should anyone else be involved? How do we want to keep in touch and share ideas?
Planning our next discussion group What do we aim to do with this research?

Appendix 5.2: Plan for discussion group 2

When?	Sunday 1st November 2020
What time?	10 – 12am (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: review and pressing record** Talking about the project outside of this group
	**Our group agreement** Anything to change or add? Discussion cards – which do we want to use? • Mencap traffic light cards for virtual meetings • DIY option: Red - Stop/I don't agree Amber - Slow down Green - Yes I agree White with a question mark - I need to ask a question. Introducing the decision log

	**Our skills and experience (asset mapping)** What skills and experience does everyone bring?
	**Who else needs to be involved?**
	**Discussion:** What does **participation/taking part** in sport and physical activity mean to you?
	**Discussion:** What does **evaluation** mean to you?

	**Reflections** How did the session go? What could we do differently?
	**Planning our next discussion group** 4 weeks' time: Saturday 28th or Sunday 29th November? To think about for next time: • What would success look like? • What do we want to know? • What questions do we want to ask?

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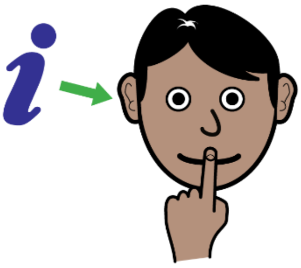
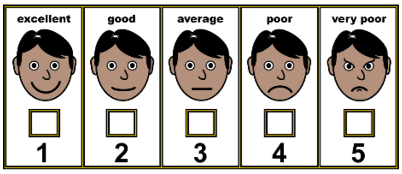
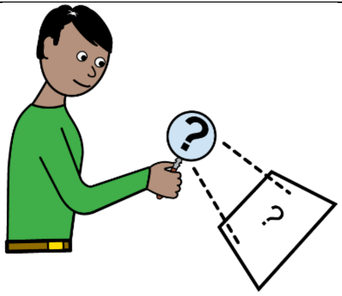
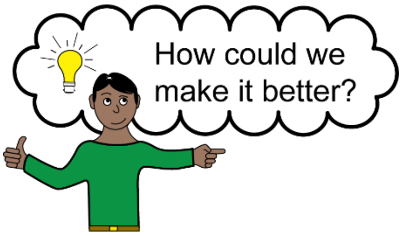
Appendix 5.3: Plan for discussion group 3

When?	Saturday 28th November 2020
What time?	10 – 12am (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: review and pressing record**
	**What did we talk about last time?**
	**Who else needs to be involved?**

	**Discussion:** What does **participation/taking part** in sport and physical activity mean to you?
	**Discussion:** What does **evaluation** mean to you?
	**What are we trying to find out?** - What would success look like? - Who are our audience? - What is our research question?
	**Reflections** How did the session go? What could we do differently?

	**Planning our next discussion group** 6 weeks' time (avoiding Christmas and New Year): Saturday 9th or Sunday 10th January What should we talk about?

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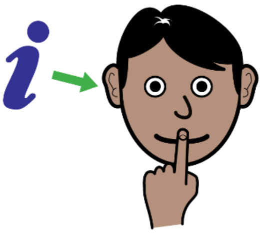
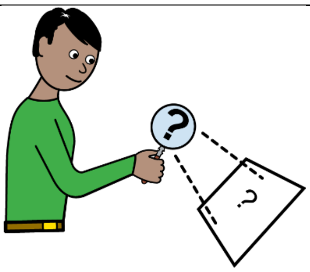
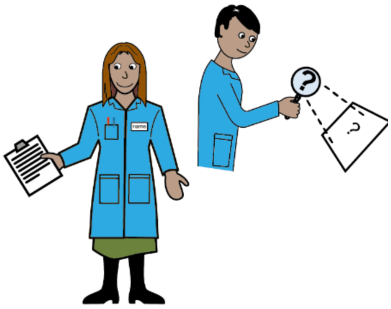
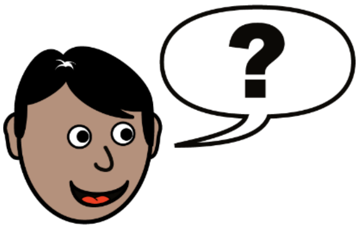
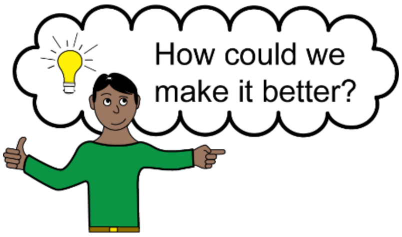
Appendix 5.4: Plan for discussion group 4

Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 4

When?	Sunday 17th January 2021
What time?	10 – 12am (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: pressing record** Should we put our feedback in the chat box rather than on the whiteboard? What would work best?
	**What did we talk about last time?** • What is participation? • What is evaluation? • What are we trying to find out?
	Small group discussion: 2 minutes! - What role do you want Bev to take – ally, facilitator, note taker, or something else - What do you need from me?

	- Do you feel like a ‘co-researcher’? - What would give you more control of the process, how can we share responsibilities? **2 minutes to feed back**
	**Our research question** 1) Sharing our question ideas 2) Small group discussion: What should our research question be? How should we decide? **10 minutes in breakout rooms** **5 minutes feedback from each group**
BREAK	
	**Planning our research** **Small group discussion:** How do we find this out? Who do we need to involve? **5 minutes in breakout rooms** **5 minutes feedback from each group**

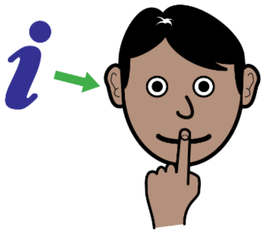
	**What do we need to ask the people involved?** **Small group discussion:** **10 minutes in breakout rooms** **5 minutes feedback from each group**
BREAK	
	**What do we need to do before the next meeting?** Ethical review application
	**Reflections** How did the session go? What could we do differently? One at a time, passing on to the next person

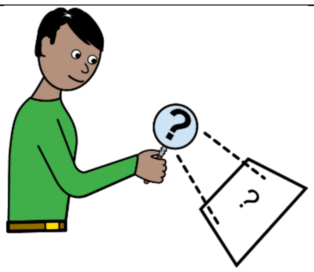
	**Planning our next discussion group** 4 weeks' time: Saturday 13th or Sunday 14th February 2021 What do we need to do for next time? What should we talk about?

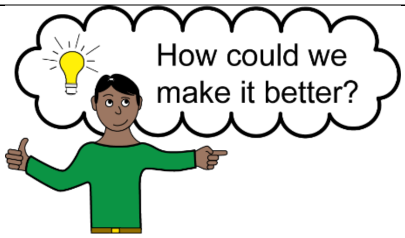
Appendix 5.5: Plan for discussion group 5

Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 5

When?	Sunday 28th February 2021
What time?	10am – 12noon (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: pressing record** Taking a screenshot picture of our research team in case we need it in the future – what do you think?
	**What did we talk about last time?** • We drafted our research question • We split into two groups: participants and funders • We talked about what we wanted to ask each group and who we wanted to involve

We will spend most of this session working in our two groups, Bev will hop between and make sure we have breaks!	
	**Task in our research groups:** Deciding what we want to ask participants and funders.
	**Task in our research groups:** Writing our research information sheet and consent form for each group.
	**Research proposal** If we have time, Bev will talk through our research proposal: the plan for our research project.
	**Our next discussion group** Before our next meeting we need to make sure we are happy with all of these documents:

	- Research proposal - Questions for funders - Questions for 'participant' group - Information sheet for funders - Information sheet for 'participant' group - Consent form for funders - Consent form for 'participant' group We might need to wait to get ethical approval to do our research before our next meeting.
	**Reflections** How did the session go? What could we do differently? One at a time, passing on to the next person

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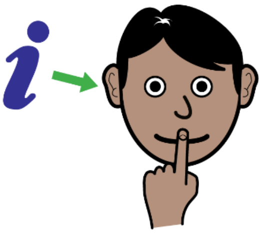
How can we evaluate sport and physical activity in a way that meets the needs and priorities of disabled people and funders? a) What outcomes in sport and physical activity are important (matter) to disabled people?	How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders? a) What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part?

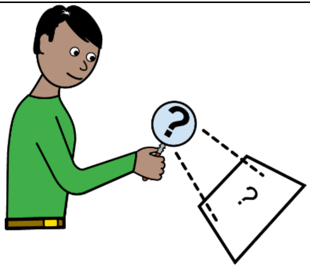
What do disabled people want to tell? b) What in disability sport and physical activity is important to funders? What do funders want to know? c) How can we make it possible for everybody to have the same opportunities to contribute their feedback or experience?	b) What do funders want to know about disabled people's participation in sport and physical activities? **c)** How can we give all disabled people the chance to share their experiences of sport and physical activities, in a way that funders can use?

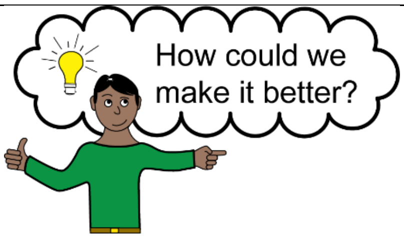
Appendix 5.6: Plan for discussion group 6

Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 6

When?	Sunday 21st March 2021
What time?	10am – 12noon (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: pressing record** Taking a screenshot picture of our research team – I will remember to do it this time!
	**What did we talk about last time?** • We split into our two groups to work on our questions for funders and participants.

We will spend most of this session working in our two groups, Bev will hop between and make sure we have breaks!	
	**Task in our research groups:** Writing our consent form and research information sheet for each group.
	**Research proposal** Bev will talk through our research proposal: the plan for our research project.
	**Our next discussion group** Our next job will be for Bev to use our documents to apply for ethical approval for our research, and then for us to carry it out. If this takes a long time, I might set up a 30-minute meeting to update on progress, if that's ok?
	Reflections

	How did the session go? What could we do differently? One at a time, passing on to the next person

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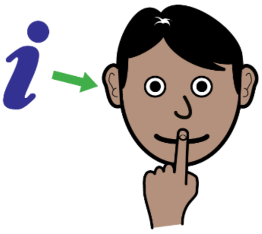
How can we evaluate sport and physical activity in a way that meets the needs and priorities of disabled people and funders?	How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders?
a) What outcomes in sport and physical activity are important (matter) to disabled people? What do disabled people want to tell? b) What in disability sport and physical activity is important to funders? What do funders want to know? c) How can we make it possible	d) What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part? e) What do funders want to know about disabled people's participation in sport and physical activities? **f)** How can we give all disabled people the chance to share their experiences of sport and physical activities, in a way that funders can use?

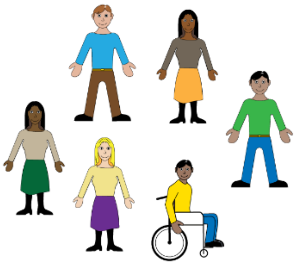
for everybody to have the same opportunities to contribute their feedback or experience?	

Appendix 5.7: Plan for discussion group 7

Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 7

When?	Sunday 9th May 2021
What time?	10am – 12noon (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: pressing record** Taking a screenshot picture of our research team – I will remember to do it this time!
	**What did we talk about last time?** Update on our ethical approval application
	Small group discussion – what do you think about the following? **Our definition of disability**



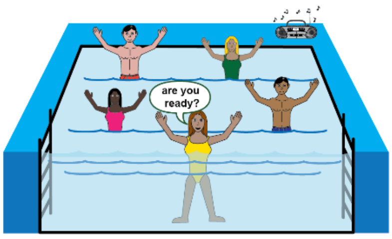
There are many ways of describing disability but within this project, co-researchers have decided to use the term ‘disabled person’ to refer to anyone who has a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities. This includes, but is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear. This definition might change throughout our work.

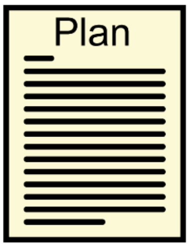
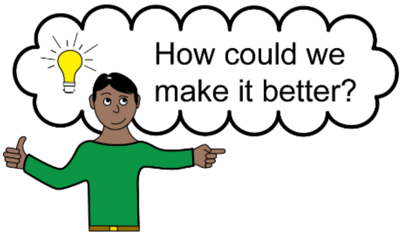
Disability ‘categories’ for our surveys

Do you have a disability or impairment?

If yes, please choose from this list:

- Vision (for example blindness or partial sight)
- Hearing (for example deafness or partial hearing)
- Mobility (for example walking short distances or climbing stairs)
- Dexterity (for example lifting and carrying objects, using a keyboard)
- Learning or understanding or concentrating
- Memory
- Mental health

	• Stamina or breathing or fatigue • Socially or behaviourally (for example associated with autism spectrum disorder (ASD) which includes Asperger's, or attention deficit hyperactivity disorder (ADHD)) • Other (please specify) **From:** https://gss.civilservice.gov.uk/policy-store/impairment/
	**Small group discussion:** **Our definition of physical activity** Some ideas: • Any bodily movement produced by skeletal muscles that results in energy expenditure • People moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships • Physical activity is an activity which makes you breathe faster while still being able to hold a conversation • Physical activity is an activity which makes you feel warmer and makes your heartbeat faster • Physical activity is an activity that raises your heart rate, makes you breathe faster

	and feel warmer • Physical activity is any body movement that expends energy and raises the heart rate • Physical activity is any body movement that works your muscles and requires more energy than resting. Walking, running, dancing, swimming, yoga and gardening are a few examples of physical activity
	**Task in our research groups** Completing our data collection plan
	**Co-production workshop** The Disability Physical Activity Impact Collective would like to invite you to be involved in a co-production workshop
	**Reflections** How did the session go? What could we do differently? One at a time, passing on to the next person

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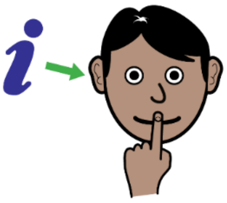
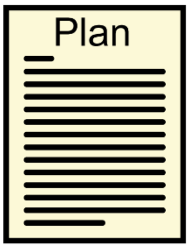
Appendix 5.8: Plan for discussion group 8

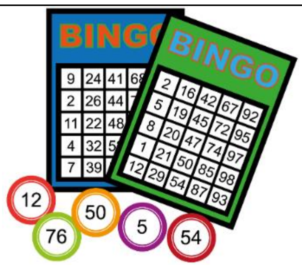
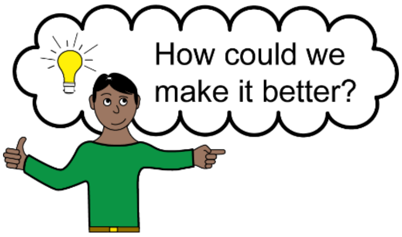
Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 8

When?	Sunday 4th July 2021
What time?	10am – 12noon (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Confidentiality: pressing record** Taking a screenshot picture of our research team – I will remember to do it this time!
	**What have we been doing?** • Co-Production workshop • Ethical approval – we can start our research!

	**What did we talk about last time?** **Our definition of physical activity:** Physical activity is any body movement that uses your muscles and needs more energy than resting. Walking, pushing in a wheelchair, running, dancing, swimming, yoga and gardening are a few examples of physical activity. **What do you think of this one?** “Physical activity involves people moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships” **If this is physical activity, what is physical inactivity?** **Our definition of disability:** Our co-researchers describe and experience disability and impairment in different ways. In this project, we use both person-first language

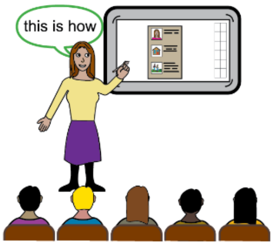
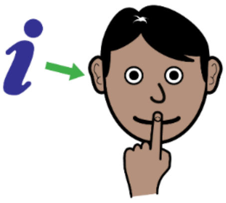
	‘person with disability’ and ‘disabled person’, which considers the social model of disability. We use these terms to mean anyone who has a physical, learning disability, sensory impairment or mental health condition or illness, that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities. This includes, but is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear.
	**Doing our research** **Are we happy with our questions?** • Let’s look at the ‘participant’ questions together as a group • Pictures need to be chosen **Karen’s tips on interviews and surveys** **Practising our questions with each other in small groups**

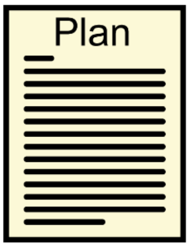
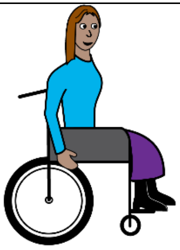
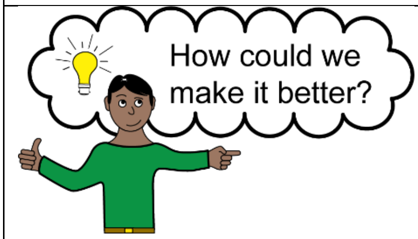
	How did you find that? • Is there anything you're not sure about? **Our data collection process** Look at the diagram in small groups.
	**Bingo** • When is everyone available for Bingo? • How will it work?
	**Reflections** • How are you feeling about the next stage of our research: what would you like to do? One at a time, passing on to the next person

Appendix 5.9: Plan for Discussion group 10

Exploring more inclusive and accessible evaluation of sport and physical activity: Plan for discussion group 10: Analysis next steps

When?	Sunday 4th September 2022
What time?	10am – 12noon (Zoom room open from 9:45am) 2 hours with 2 x 10-minute breaks
Where?	Zoom Meeting [REDACTED]
Who will be there?	[REDACTED]

What are we going to talk about?	
	**Time to catch up** How are you? Bev's conference presentation in Paris
	**Confidentiality: pressing record**

	**Data collection** What information have we collected?
	**Data analysis: making sense of our data** What is data analysis and what do you know about it? What approach should we take? How would you like to be involved?
	**The Washington Group questions: a different way of asking about disability**
	**Making a podcast/videocast** Is this something we would still like to do?
	**Reflections** • How do you think it went today? One at a time, passing on to the next person

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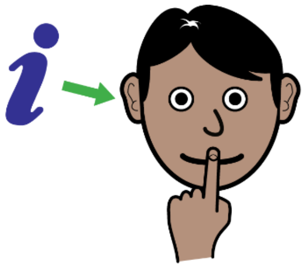
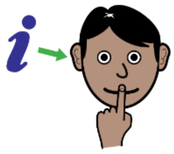
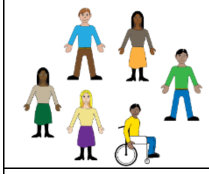
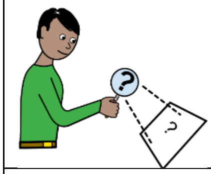
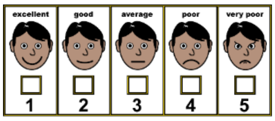
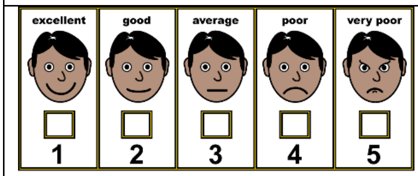
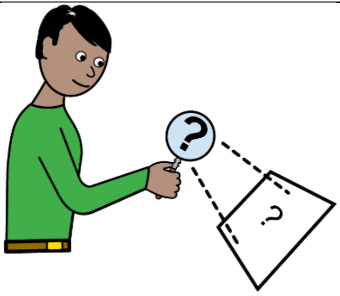
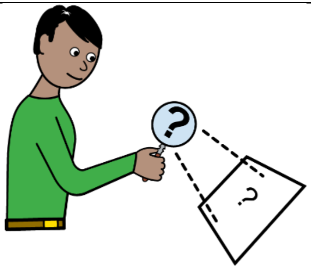
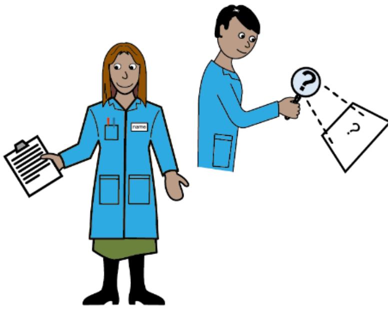
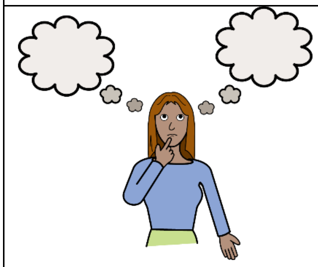
Appendix 5.10 Overview of topics covered within each discussion group

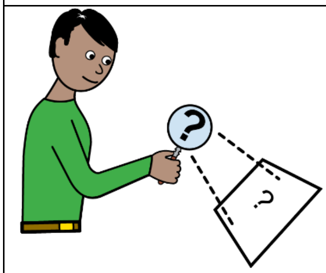
At the start of each session	
	How are you?
	**Confidentiality: pressing record**
	**What did we talk about last time?**
Discussion group 1 – Sunday 3rd October 2020	
	Recording our sessions and confidentiality – making decisions about this
	Saying hello: introducing and meeting each other, building rapport

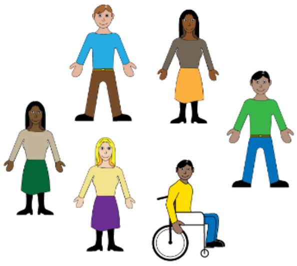
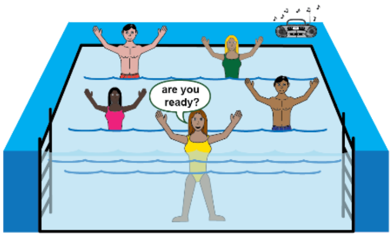
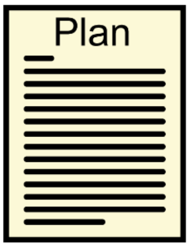
	Finding out people's motivations: why involved
	Hearing about people's experience and understanding of research
	Creating a draft of our group agreement
	Talking about the collaborative way of working
	Making our group agreement
	Deciding on our future schedule – frequency, duration of meetings, date of next meeting
	Thinking about roles we might take in the group
Discussion group 2 – Sunday 1st November 2020	
	**Sharing our research**
	**Group agreement and communication cards**
	**What skills and experience might we need for this research?**

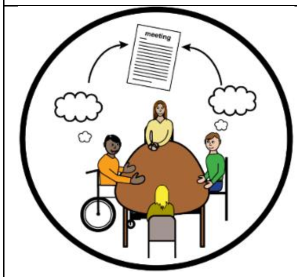
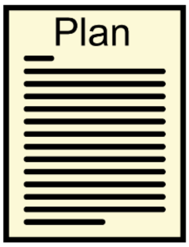
	**Who is this research for?**
	**What are we trying to find out?**
	**Evaluation of St George's Hydrotherapy Pool –** **Karen's experience**
	**Who else needs to be involved?**
Discussion group 3 – Sunday 13th December 2020	
	**Introductions – meeting our new co-researcher**
	**Discussion:** What does **participation/taking part** in sport and physical activity mean to you?

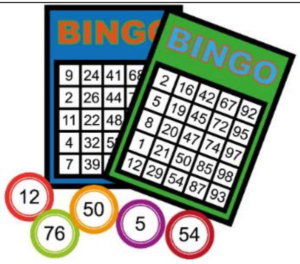
	**Discussion:** What does **evaluation** mean to you?
	**What are we trying to find out and how are we going to do it?** **Research questions**
Discussion group 4 – Sunday 17th January 2021	
	**Small group discussion: 2 minutes!** - What role do you want Bev to take – ally, facilitator, note taker, or something else - What do you need from me? - Do you feel like a ‘co-researcher’? - What would give you more control of the process, how can we share responsibilities?

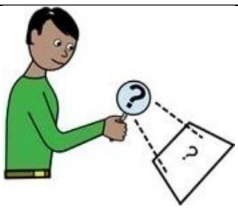
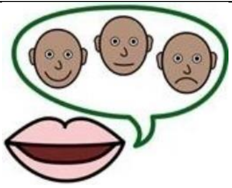
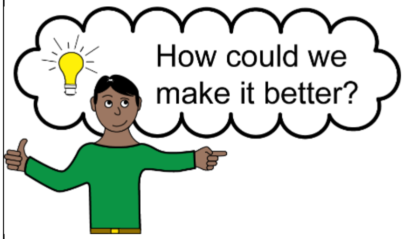
	**Our research question** 3) Sharing our question ideas Small group discussion: What should our research question be? How should we decide?
	**Planning our research** How do we find this out? Who do we need to involve? What do we need to ask the people involved?
	**Ethical review application**
Discussion group 5 – Sunday 28th February 2021	
	**Task in our research groups:**

	Deciding what we want to ask participants and funders.
Discussion group 6 – Sunday 21st March 2021	
	**Task in our research groups:** Writing our research information sheet and consent form for each group.
	**Research proposal** If we have time, Bev will talk through our research proposal: the plan for our research project.
	**Our next discussion group** Our next job will be for Bev to use our documents to apply for ethical approval for our research, and then for us to carry it out.

Discussion group 7 – Sunday 9th May 2021	
	**Small group discussion:** **Our definition of disability** **Disability ‘categories’ for our surveys**
	**Small group discussion:** **Our definition of physical activity**
	**Completing our data collection plan**
	**Co-production workshop** The Disability Physical Activity Impact Collective would like to invite you to be involved in a co-production workshop

Discussion group 8 – Sunday 4th July 2021	
	**What have we been doing?** - Co-Production workshop – Karen, Nessa and Tom - Ethical approval – we can start our research!
	**What did we talk about last time?** **Reviewing our definitions of physical activity and disability** **What is physical inactivity?**
	**Doing our research** **Are we happy with our questions?** - Let's look at the 'participant' questions together as a group - Pictures need to be chosen **Karen's tips on interviews and surveys**

	Practising our questions with each other in small groups **How did you find that?** • Is there anything you're not sure about? **Our data collection process**
	**Bingo** • When is everyone available for Bingo? • How will it work?
Christmas catch up – Sunday 5th December 2021	
	**How are you?**

	**How is our data collection going?**
	**Who else do we need to talk to for our data collection?**
	**What should we call our project?**
At the end of each session	
	**Reflections** How did the session go? What could we do differently?

	**Planning our next discussion group** When? What should we talk about?

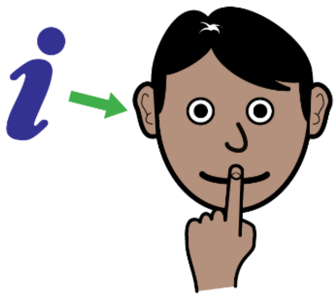
Appendix 5.11: Examples of discussion group records

Key points from discussion group 2

When?	10am-12noon Sunday 1st November 2020
Who was there?	[redacted]

What did we talk about

Sharing our research



Bev will be talking about her research to supervisors, in general terms about progress.

Karen is going to update her service user group about the project.

Nessa has links with a group of disabled people who are involved in strategy around the delivery of community sport services in her London Borough.

Group agreement

Everyone was happy with our agreement

We voted on which communication cards we will use in our meetings. They will include pictures and say:

- OK or I agree (green)
- Slow down (yellow)
- Stop or I do not agree (red)
- I would like to speak

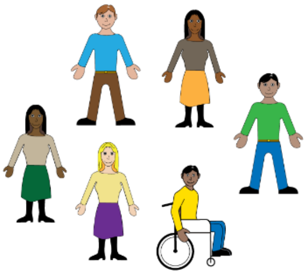
Karen is going to save a draft in the Box folder so we can try them in the next group.

What skills and experience might we need for this research?

We all have skills to bring – some have experience of evaluation, working with funders and organisations, others have experiences of talking to other people, other disabled people about their experiences.

- We might need computer skills such as spreadsheets, and PowerPoint to share our research.
- We talked about how we might have different ways to share our research in an accessible way.
- We talked about how we will need good communication and to use our networks to widen our research.
- Networking – people in the group have connections with other activity users, funders, coaches, governing bodies, football associations, Sport England, London Sport, Sporting Equals
- Interviewing or speaking to people with empathy from experience of living with a disability. The importance to speaking to people on their level rather than sending blanket questions.
- Asking questions in a way that’s kind and thinking about how other people may be thinking and in a way that’s not too difficult to understand.
- Our experience of being involved in activities.

Who is this research for?



We talked about who our audience might be:

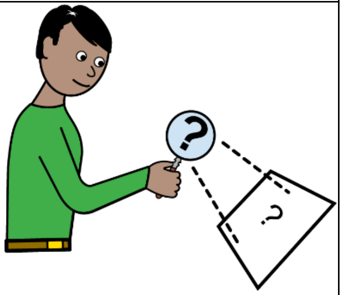
- People who fund things, like commissioners
- Trustees of organisations
- Organisations that deliver activities
- People taking part in activities, of all ages
- Organisations that support others to deliver activities (e.g. National governing bodies like Sport England, London Sport, Sporting Equals)
- Football clubs have foundations for specific impairment, age and inactive groups – service users are important, but these are the kind of organisations who have to capture the data.
- The gatekeepers of the money who don't always continue funding or recognise that something needs to be funded because it doesn't look the same as non-disability sport.

We might need to focus down to a smaller group.

Do we need to think about how funding is allocated to certain groups

(e.g. by age or type of impairment or disability)?

What are we trying to find out?



- Asking blanket questions in an email or questionnaire will get blanket answers. Yes no, maybe. But this is not what this research is about. It is about delving into the reasons why people take part in these sorts of activities and what the benefit is to them, and feeding that back into the best way for them to give us their reflections on that.
- Experiences of people collecting the data, can they? People have got to be able to complete it. It's got to be accessible and inclusive, but also for the people collecting the data.
- The impact can't be captured. We can't just tick boxes. We are not that way.

- Finding out lived experience of coaches delivering activities and their experience of capturing data. Is it fit for purpose, is there anything they would like or change, what would they like the experience to be for them?

- Finding out from funders, what kind of data do they need, how do they need it presented? (Do they need it presented in a certain way?) The people who need the data, what are they missing or what aren't they getting?

- What is the ultimate outcome of what we are trying to do?

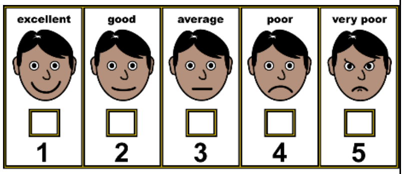
- I think, what we're trying to do is find out whether the way that they present data at the moment to do with disability activities is accessible for those that actually Influence that and actually need to see it.

- It doesn't matter if data is supposed to be presented in an official way if it doesn't work for most of the people that we are talking about and talking to. We are trying to find a different way of getting their input and presenting the data. We're thinking about how we can simplify the information and get responses from people who are most affected and it's most important that we get the responses from.

- Would it be worth getting some examples of how data collection is being done? How do different places ask about different things in different ways?

Evaluation of St George's Hydrotherapy Pool – Karen's experience

- Conducted a mixed evaluation. Did have some tick boxes as that was easy for people to fill in. But also had a part where people could put the value in their own words.



- Also, needed to include information that the funders valued (CCG, NHS, council), but also had to be an accessible report that any pool users could read and understand.

- There were little bits in the report that gave people a voice. Important to give people a voice that hadn't been heard before.

- Also had a form for carers to fill in on behalf of someone.

- Did the council and health authority get out of it what was needed? I got what I needed, which was funding. It was hard making this information fit the criteria of the funders. I was quite lucky. From contacts, knew there were certain things I had to do certain ways, but it was very much our words. People shared pages and pages, heartfelt, of how much they valued us.

- How did they measure that question, that extra information, the powers that be? It’s a beautiful collation of information and lived experiences, but how was it valued or used by those people?

- The information that came back to me was actually they were sometimes the most powerful rather than the stats they remember the story. The people in these jobs are human. It gave people an opportunity to say what mattered to them.

- I would be really interested to know once you'd handed it over with all of those impact statements. To the powers that be, what their thoughts on and what they were able to do with those impact statements because I want to know… What do we, what needs to happen or what format. Does it need to be in to have that value recognised in the ways that then …Result in funding or recognition of what you're doing, you know, I mean, it's that kind of, it's an amazing, wonderful, beautiful thing and … How can we get them to be able to use that as well, rather than it just being that someone's thankfully got a great heart. You might get someone who is so the opposite who wants numbers and wants this and wants that.

- Or is it finding that it doesn’t exist, and needs to? The thing that can suck up all the fabulousness from your impact statements and translate across into whatever

- How can we make it so that impact statements which are the most valuable thing and not just the box ticking exercise. How can we make it so that they have to use it in the valuable way in which it should be used and it’s not just down to someone’s thoughts about it.

- Example of someone doing exercise and as a result she could put her own bra on. And someone who is considering going to university because they did activity. These type of things aren’t necessarily measured in activity levels and who’s engaging.

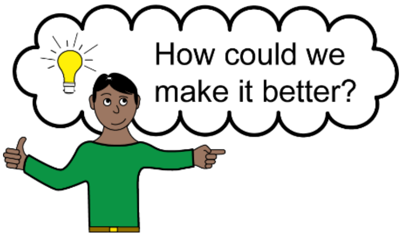
- Considering independence, falls, physical and mental wellbeing.

- St George’s evaluation looked at independence, reducing visits to the GP. Examples of people reducing number of carers

Plan for next session

- We want to make sure we use the time efficiently and make sure everyone has a say.

- We will recap the last session at the start.



- We will work towards our research question, but not too many questions as it will be difficult to get an answer.
- The discussions are great but it is hard to process what everyone has said and how it all fits together. From the next session we will write comments on screen as we go along.
- Fiona happy to take control of whiteboard, writing what people say in text boxes. The whiteboards can be saved as photos.
- We will talk about evaluation and participation. Bev will bring a definition that could start our discussions. We don't need to talk for long.

Who else needs to be involved?

- Do we have someone involved in delivering activity, someone who's experienced that the data collected doesn't fit into the boxes of the people who they're collecting the data for, who can feedback on that element of it? We identified that Karen has had this experience.
- [redacted] had someone who might be good to involve but she won't use Zoom (could be someone to consult in the future?)
- Would it benefit having someone who is not as sporty? Do we need to consider neurodiversity? (We already have people in the group)
- Another male participant.
- Sensory impairment - we talked about how online research may be difficult, but we need to be very mindful of these needs in our project.

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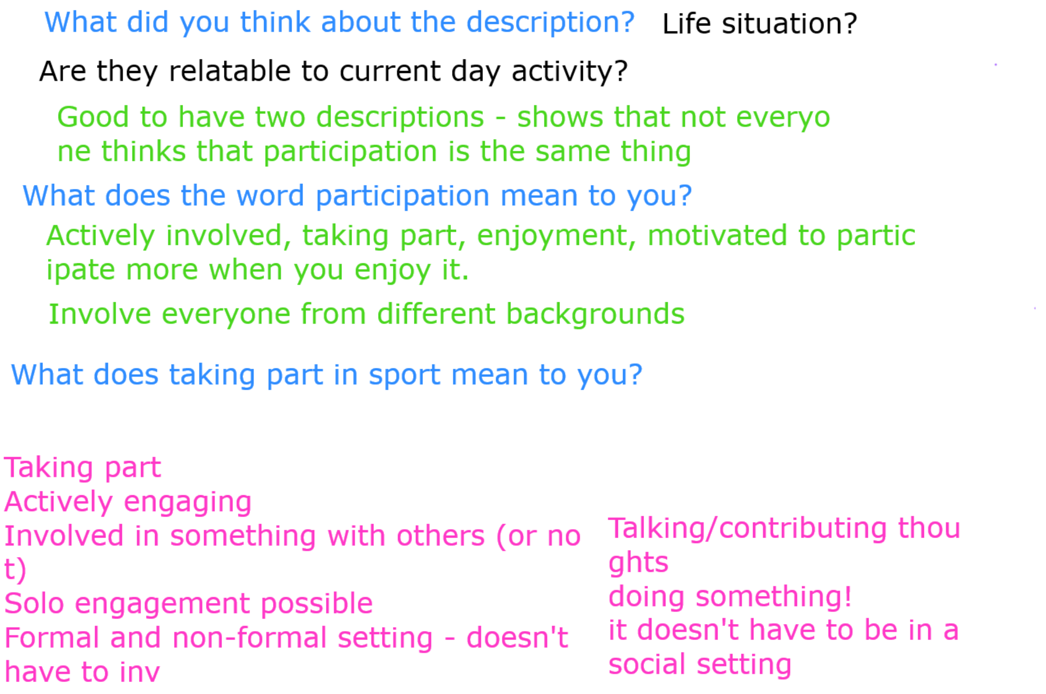
Key points from discussion group 3

When?	10am-12noon Sunday 13th December 2020
Who was there?	[redacted]
What did we talk about	

Introductions – meeting our new co-researcher

We all introduced ourselves to Tom.

Discussion: What does **participation/taking part** in sport and physical activity mean to you?



What did you think about the description? Life situation?

Are they relatable to current day activity?

Good to have two descriptions - shows that not everyone thinks that participation is the same thing

What does the word participation mean to you?

Actively involved, taking part, enjoyment, motivated to participate more when you enjoy it.

Involve everyone from different backgrounds

What does taking part in sport mean to you?

Taking part
Actively engaging
Involved in something with others (or not)
Solo engagement possible
Formal and non-formal setting - doesn't have to inv

Talking/contributing thoughts
doing something!
it doesn't have to be in a social setting

Discussion: What does **evaluation** mean to you?

EVALUATION

What do you think about the description?

Quite wordy, quite comprehensive, quite abstract. Needs to be simplified. Interesting that it mentions what can be improved, but no mention of what went well.

What does the word evaluation mean to you?

Means thinking about what went well and what we can improve, thinking about the result of something and the impact of it on a wider scale. It was assessing the value or the number of something.
Gathering the information that you particularly want to find out, and is it relevant to whoever is doing the evaluation.
Systematic - there can be different stages
1 - Starting position - nothing has happened
2 - Something happens - activity or intervention of some sort
3 - Outcome - is there a difference or a change - can it be measured, is it positive or negative?
Do you have any experiences of evaluation?

Questionnaires, Focus groups

Ryan, Lisa and Nessa

1.
The description was very wordy, not easy to get your head around. Needed to be smaller, more direct and broken down. It is not accessible to look at for everyone.

2/3.
Evaluation involves completing tickboxes to tell someone about your experinces.
Asked questions, responses, giving feedback. Having pictures and icons /writing can make it easier to understand and answer the questions.

What are we trying to find out and how are we going to do it?

Trying to find out what you get out of evaluating
What does Ryan enjoy doing, what matters to Ryan? What does he get out of it?
Ryan talked about: making new friends, enjoying time on Zoom, makes happy, looking forward to seeing them again, no bored any more, able to join in. Makes me feel better as well.
Carers - Lisa - it's nice to see the person enjoying themselves. You get to make new friends - a double whammy

If we were doing this research ourselves, what would we want to get out of it? We'd like to know what the overrall impact is on the service users of disability sport.

Make it possible for everybody to have the same opportunities to contribute their feedback and experiences

To use different tools, eg askin
g que
ing

Gather Gathering lived experiences of everyone

To

To use different tools, including asking questions verbally, using visual cues, pictures etc,

How challenging it is to extract the information shouldn't impact on people trying to do it. It shouldn't impact on service users. Just because it's difficult, doesn't mean it should be done. May need to use a different tool or have different points. Shouldn't make the service user think they can't give across their feedback or opinion in what ever way is best for them.

Not one size fits all!

Research questions

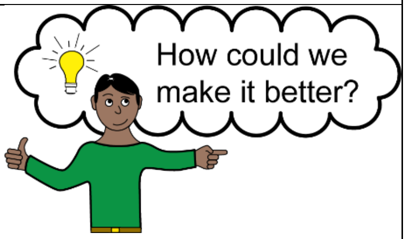
Plan for next time: For everyone to come up with question ideas then we can talk about these.

Co-researchers asked Bev to share two question examples (Bev was hesitant to lead ideas, but this was agreed important to give parameters).

- what do funders and sports organizations want to know about how disabled people take part in sports and physical activity.
- how can this be done in a way that is more accessible inclusive and meaningful for disabled people.

Nessa: The second example is more what I thought we were going for. Making it more centred to the individual's experience and not making it so catered for the powers that be. Flipping the script – how do we flip the script on evaluation in disability sport?

Fiona: It has to be person-focused. It's not about the big 'head honchos' – it's about us and the users. How they can evaluate things in a way that's meaningful, because that's when they're going to get better results.



Reflections

- Smaller groups, with specific things to think about and Bev sharing timings (e.g. halfway, 1 minute left) and questions in the chat box.
- Focused feedback on screen, colour coding it.
- Specific action points for next time, so we can move things forward.
- Pace of the session better.
- Everybody could be involved.
- It is ok for Bev to give a starting point for some things, so there are parameters (it is not leading!)
- Feels like we're moving towards the question, so more productive.
- Being able to print off copies beforehand is useful.
- Enjoyed it.
- Bev doesn't listen to breakout rooms.
- It was more efficient when Bev scribed the feedback.

How long is the window for this research? Bev expects us to have collected information by the summer, but it is dependent on how things go!

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Appendix 5.12: Our group agreement

Exploring inclusive and accessible evaluation of sport and physical activity

Our discussion group agreement	
Group members	[redacted]
Version 1 date	3rd October 2020
Agreed on	1st November 2020

- We will listen to each other and respect when others are speaking.
- We will respect each other’s different opinions and views.
- We will use ‘reactions’ on Zoom – to clap or raise our hand.
- We will print our cards to hold up if anything isn’t clear or we don’t agree, or when we are happy or agree with something.
- We will use the mute button when we are not speaking.
- We will all encourage others to speak to make sure everyone has a chance to have their say.
- We will record our sessions (video, audio and chat) but these will only be shared between us.
- Everything that is discussed stays within the group, although if there is a safeguarding issue this will need to be raised. We will talk about confidentiality at the time, if and when tricky discussions come up.

- If we need to talk about other people in the research as examples, we will keep them anonymous.

- If Bev needs to talk to her supervisors at the university about our groups, she will talk generally about our progress and she will keep everyone’s names and details private.

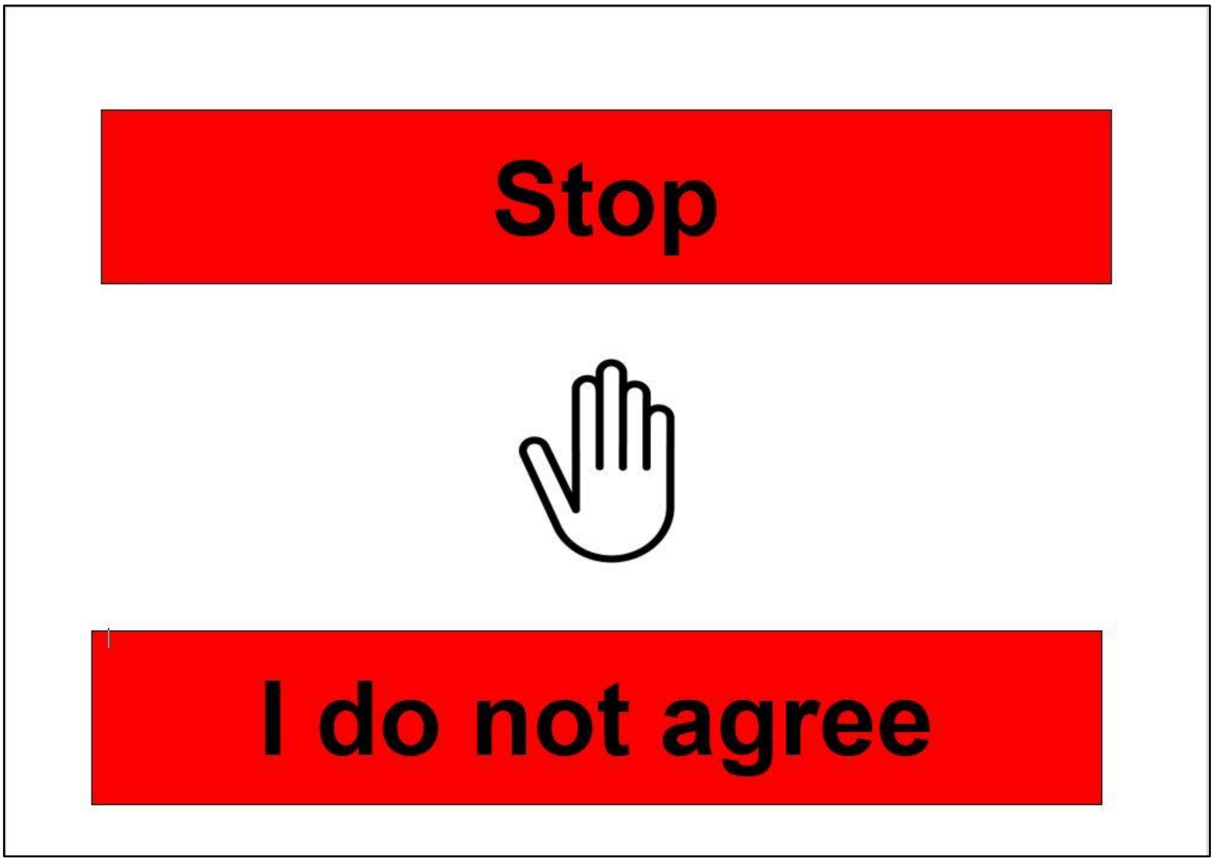
- Ros at Hertfordshire Disability Sports Foundation is a trusted contact if anyone wants to talk to her generally about the research (but not with specific details or people involved.

- We will use a private University of Essex Box folder to share information between us. Everyone is aware that they may be able to see each other’s email address.

- We will meet monthly, for two hours with two 10-minute breaks.

Appendix 5.13: Our skills and experiences

Appendix 5.14: Co-researcher discussion group communication tools for virtual meetings



Stop

I do not agree

I would like to speak

please

Slow down

please

OK

I agree

Appendix 5.15: Our Definitions

Disability

Our co-researchers describe and experience disability and impairment in different ways. In this project, we use both person-first language ‘person with disability’ and ‘disabled person’, which considers the social model of disability. We use these terms to mean anyone who has a physical, learning disability, sensory impairment or mental health condition or illness, that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities.

This includes, but is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear.

Physical Activity

Physical activity is any body movement that uses your muscles and needs more energy than resting. Walking, pushing in a wheelchair, running, dancing, swimming, yoga and gardening are a few examples of physical activity.

Physical Inactivity

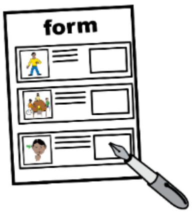
1) Someone who does not engage or participate in physical activity that uses body movements, muscles or extra energy and spends

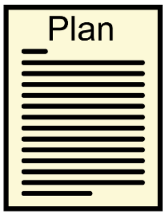
the majority of their time sitting still.

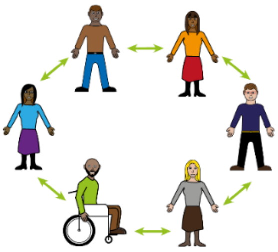
2) Someone who does less than five 30-minute sessions of physical activity a week; physical inactivity is not engaging in body movements that need more energy than resting.

Appendix 6: Our Research Proposal

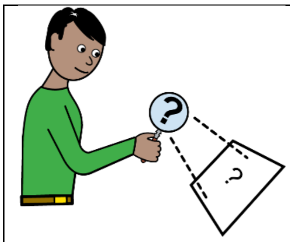
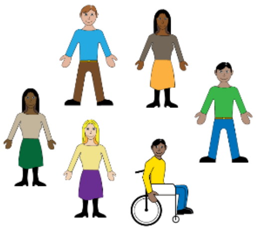
Research proposal: This research proposal is made up from discussions and decisions taken by a group of co-researchers. We have designed our research project together and this is the plan for our research.	
	**This research proposal has been designed to be accessible to everyone involved in co-designing our research project.**
Project title The name of our research project	**'Nothing about us without us'**: Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity
Who do we mean by 'disabled person'?	There are many ways of describing disability but within this project, co-researchers have decided to use the term 'disabled person' to refer to anyone who has a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities. This includes, but

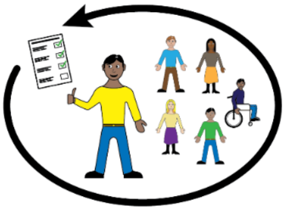
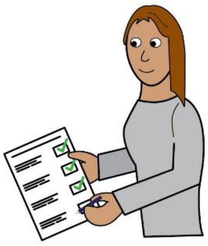
	is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear. This definition might change throughout our work.
Project purpose and aims What is this research about? 	Surveys and questionnaires that are used to evaluate disabled people’s participation in sport and physical activity are not easy to use by and with disabled people. They are not relevant to the activities they are taking part in.
What do we already know? 	Smaller numbers of disabled take part in sport and physical activity than people who are not disabled. But it is difficult to know how many disabled people take part or want to take in sport and physical activity. These numbers are collected using surveys. But these surveys are difficult to use by and with disabled people.

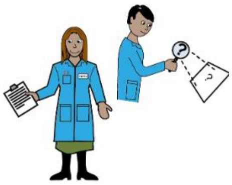
	These surveys are also supposed to be used by people who run sport and physical activity programmes to show funders how they used their money.
What do we want to know? 	We want to know what funders want to find out about disability sport and physical activity when they provide funding. We also want to know what it is about physical activity that matters to disabled people.
What do we want to do? 	By finding this out, we want to make evaluation of disability sport and physical activity more person-focused and accessible, while meeting the needs of both participants and funders.

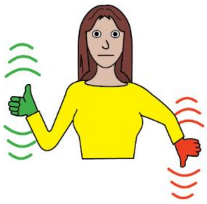
	We want to explore how funders can evaluate things in a way that's meaningful, useful and relevant to disabled people.
Research team Who is involved in this research? 	We are a group of 7 co-researchers, including 5 disabled people and one family carer, facilitated by PhD student Beverley Goodman. Beverley Goodman recruited all co-researchers via two disability sport and physical organisations. All but one co-researcher was recruited with the help of a gatekeeper. All co-researchers received written and video information (including Easy Read where needed) about the project and had an individual conversation with Beverley Goodman before their first meeting. Six co-researchers met for the first and second discussion group. A seventh co-researcher was then recruited after group members asked to have another male in the group.

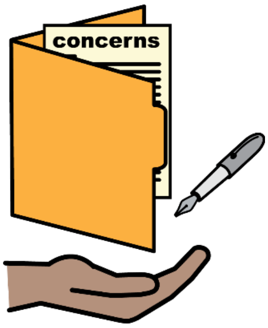
Background What has happened so far? 	Using a Participatory Action Research approach, we have held 6 out of 8 planned co-researcher discussion groups to plan our research project. We have met online using Zoom for 1.5 hours (1 meeting) and 2 hours (5 meetings). We have talked about: • How we will work together • Our skills and experiences for this research • Who this research is for • What participation means • What evaluation means • Who we need to involve in our research • What we are trying to find out: our research questions We have now split into two groups: • one group is working on our research with disabled people • the other group is working on our research with funders and related organisations.
Research questions What are we trying to find out?	How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders?

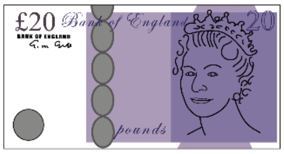
	g) What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part? h) What do funders want to know about disabled people's participation in sport and physical activities? i) How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?
Research participants Who will we invite to be involved in our research? 	We have chosen two groups of participants: **1) Users (participants) and non-users of disability sport and physical activity** **2) Funders and related organisations** • Large funding bodies • Other organisations that may provide funding • Grassroots projects that receive funding.
Recruitment How will we get people involved in our research?	One of the strengths of our research group are the contacts and networks we have.

	We will use a purposive approach to identify potential participants. This means we will choose people who we think will be best able to answer our research questions. For users and non-users of disability sport and physical activity, we will use our contacts with gatekeepers to invite potential participants. For funders, we will use our extensive personal contacts within the three levels of organisations.
Methods How will we collect information to answer our research questions? 	We have developed two sets of questions for: 1. users and non-users of sport and physical activity 2. funders and related organisations Although our preference would be to ask these questions face-to-face, we are restricted by the Covid 19 pandemic. For the first group, we will use these questions in a range of formats, including online and paper questionnaires, supported by Easy Read images, interviews by telephone or Zoom and Zoom focus groups. We want to make the

	research as accessible as possible to people with a range of different impairments. For the second group, we will conduct interviews by Zoom or telephone but may also send questions by email or in survey format.
Analysis How will we make sense of the information we collect? 	At the end of each data collection session Beverley will have a debrief with the co-researcher(s) involved. This will allow them to talk about what was shared, what they saw, heard and think. This will be used by Beverley as she completes the first stages of reflexive thematic analysis. This will involve getting to know the data, labelling it (coding) and organising it into themes. Top-level themes will be presented back to co-researchers for deeper analysis and discussion about next steps. Data will be stored in our shared Box folder.

Validation How will we check our findings? 	As co-researchers, we will: • Talk about what we saw/heard/thought during interviews/groups • Talk about key themes as a group • Check our findings and themes back with participants from both groups (participants and funders) to see what they think
Sharing our findings 	We will explore accessible and inclusive ways to share our findings, including Easy Read, Plain English articles and video formats. Co-researchers have given verbal consent (recorded on Zoom) to provide anonymous feedback at the end of the project on the process of its co-production, so that we can share our learning with others. This may be undertaken by anonymous survey or interview with a third party.
Ethical issues	

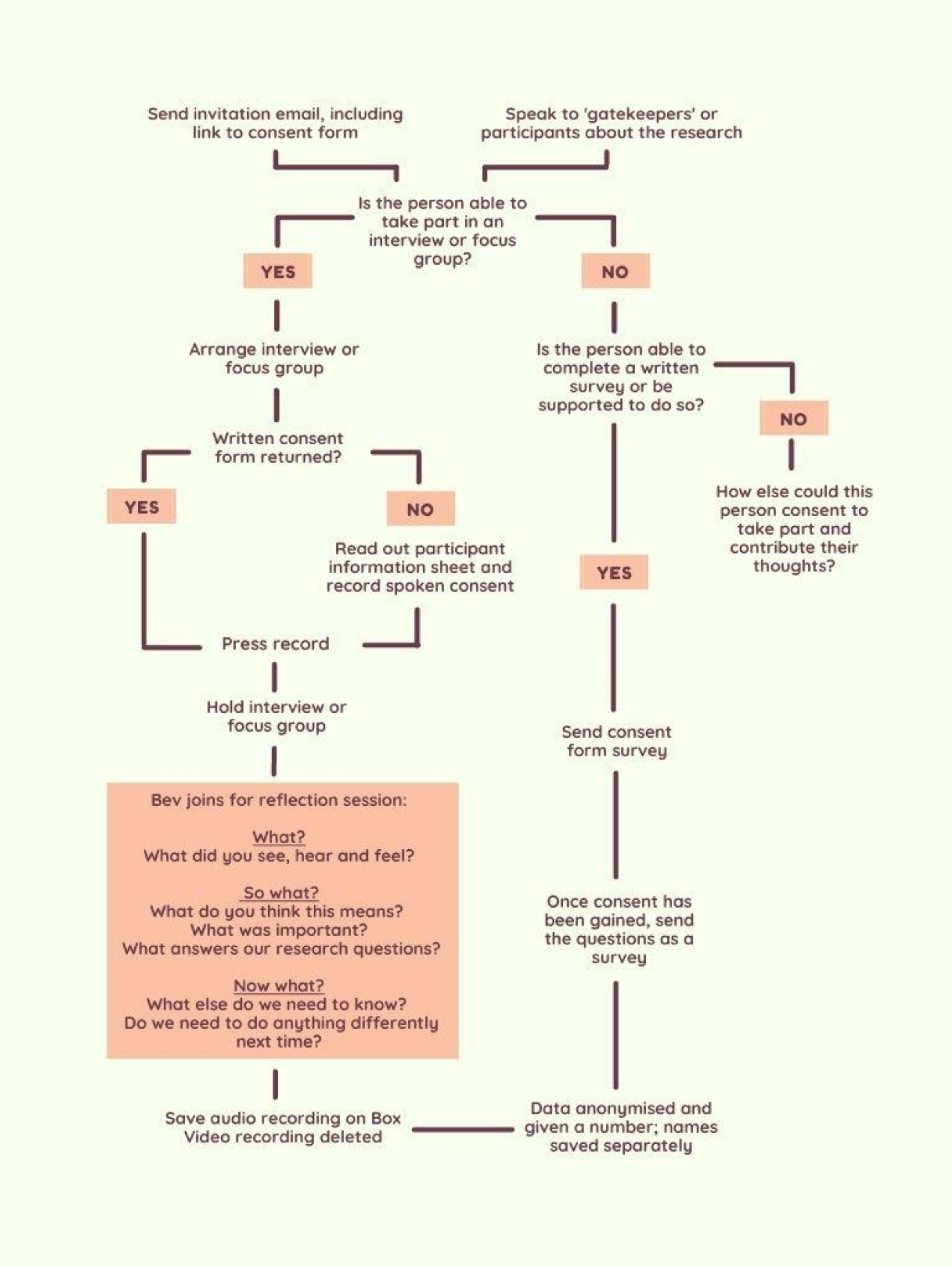
Ethical approval 	This project has been designed by people with lived experience of disability and inclusive sport and physical activity, to make sure it is relevant to disabled people who take part, or want to take part, in sport and physical activity. Co-researchers have been designing this project but are not participants providing data. Ethical approval was not sought for their involvement, but steps were put in place to make sure they were able to provide informed consent to be involved. Co-researchers have, however, given verbal consent to provide anonymous feedback at the end of the project on the process of its co-production, so that we can share our learning with others. We want to get ethical approval before collecting data from participants. The information and consent process for participants has been designed by co-researchers, to make it more relevant, useful and accessible to participants.

Ethical issues Autonomy and informed consent 	We have produced Easy Read information for people with learning disabilities, but will also share this information in video, audio or verbal format if required. If spoken consent is required, we will read through the consent form and record this consent using the recording function on Zoom. We are offering different methods for data collection to capture information from people with a wide range of impairments.
Ethical issues Involvement payments 	Participants will not receive payment for their involvement. In line with best practice in co-production and following advice from the organisation Shaping Our Lives, external funding has been obtained to provide co-researchers with an involvement payment. Co-researchers have been given the option to claim an involvement payment for each discussion group they

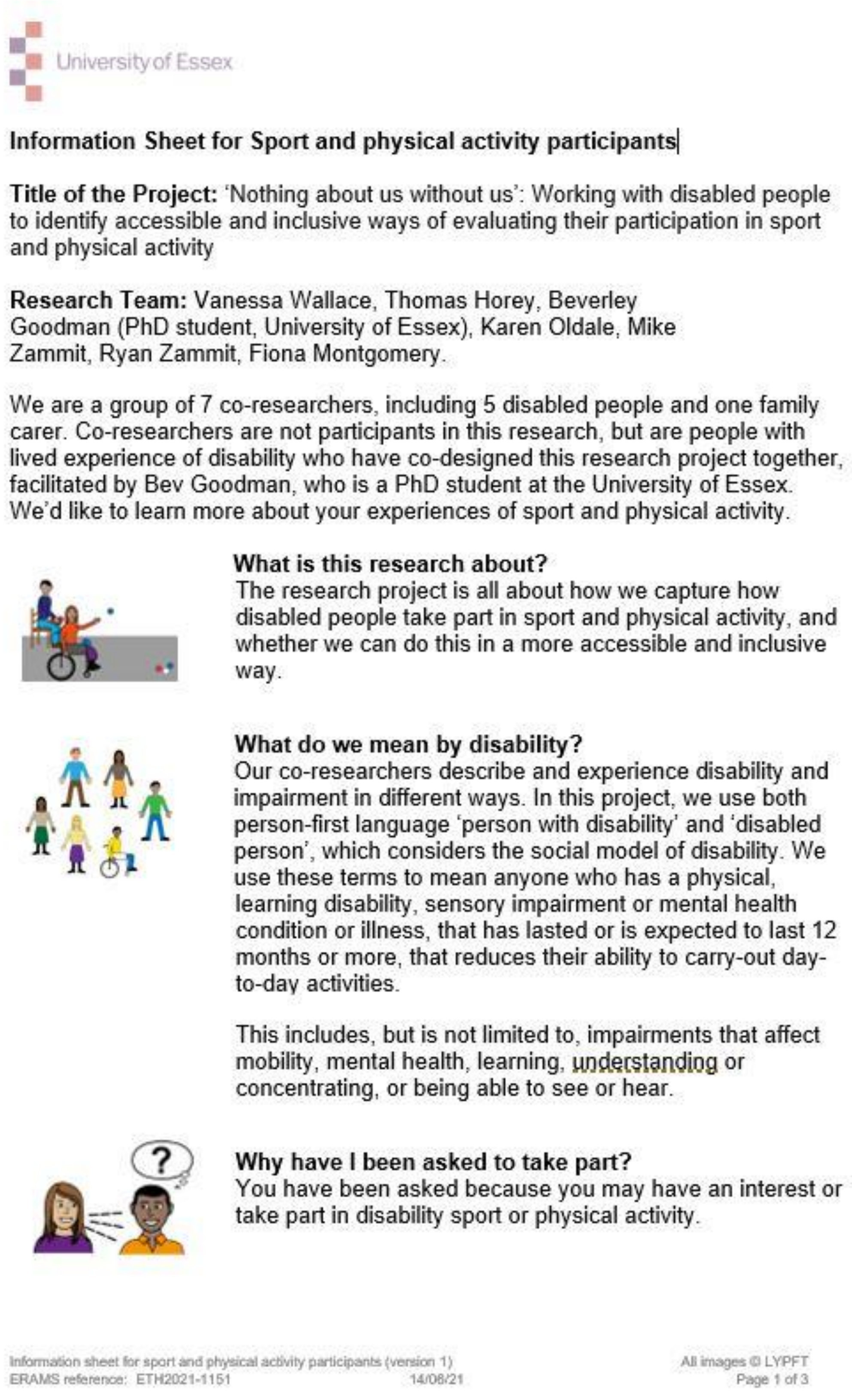
	attend, which can either be in the form of a gift voucher or donation to a registered charity or user led organisation.

Appendix 7: Data collection phase

Appendix 7.1: Our Data Collection Process



Appendix 7.2: Strand 1 Information sheet for users and non-users of disability sport and physical activity



University of Essex

Information Sheet for Sport and physical activity participants

Title of the Project: 'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity

Research Team: Vanessa Wallace, Thomas Horey, Beverley Goodman (PhD student, University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery.

We are a group of 7 co-researchers, including 5 disabled people and one family carer. Co-researchers are not participants in this research, but are people with lived experience of disability who have co-designed this research project together, facilitated by Bev Goodman, who is a PhD student at the University of Essex. We'd like to learn more about your experiences of sport and physical activity.

What is this research about?
The research project is all about how we capture how disabled people take part in sport and physical activity, and whether we can do this in a more accessible and inclusive way.

What do we mean by disability?
Our co-researchers describe and experience disability and impairment in different ways. In this project, we use both person-first language 'person with disability' and 'disabled person', which considers the social model of disability. We use these terms to mean anyone who has a physical, learning disability, sensory impairment or mental health condition or illness, that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities.

This includes, but is not limited to, impairments that affect mobility, mental health, learning, understanding or concentrating, or being able to see or hear.

Why have I been asked to take part?
You have been asked because you may have an interest or take part in disability sport or physical activity.

Information sheet for sport and physical activity participants (version 1)
ERAMS reference: ETH2021-1151 14/06/21

All images © LYPFT
Page 1 of 3

What will participants be asked to do?
You will answer a list of questions for us. This could happen on the phone or on Zoom. You might be on your own or part of a group. It should not take more than one hour. If you prefer, you can complete an online survey.

Are there any risks to taking part?
We **do not** think there will be any risks to you from taking part in this research, but we will respond quickly to any issues that come up.

Will there be any benefits to taking part?
Yes. We hope that our research will improve the funding and range of activities that you can take part in. You also might get the chance to meet like-minded people and make friends.

Where will my information be kept?
All of your answers (transcripts and audio recordings without your name) will only be seen by co-researchers involved in the project. They will be safely stored in a University of Essex Box folder, which is a secure way for co-researchers to save and share project information between us. Any video recordings made by Zoom will be destroyed straight away after our discussion. Anything that has your name or other personal information will be kept in a separate University of Essex Box folder. This information may be kept for up to 10 years before it is destroyed.

We may also share research findings to support future research, without using your name or other personal details. The Data Controller for this research is the University of Essex and the contact for this is the University Information Assurance Manager (dpo@essex.ac.uk).

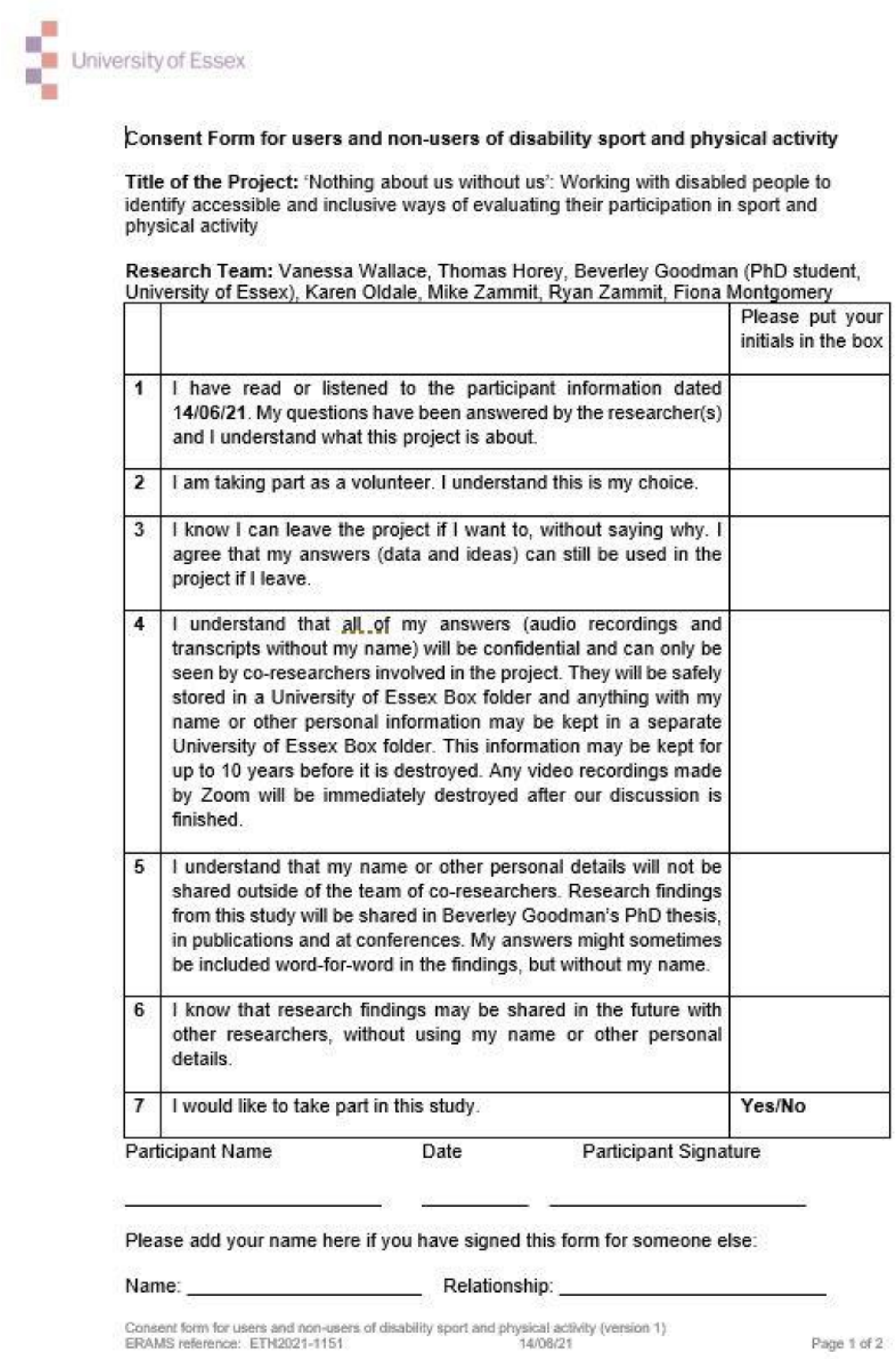
Where will the research findings be shared?
After the project, Beverley Goodman will write about it for her degree and we may share our research in publications, conferences and in other ways decided by co-researchers.

Do I have to take part?
You do not have to take part in this research if you do not want to. It is your choice. You can also leave the project at any time if you want to, without having to give a reason and without penalty. However, it will not be possible to withdraw any information given before this time.

How do I find out more?
If you want to talk to someone to find out more, please tell the person who gave you this information. You can ask any questions you want to before deciding whether to take part. Or, contact Beverley Goodman on bg16905@essex.ac.uk

What if I have a problem with the research?
If you have any problems with this study, please contact Beverley Goodman. If you are still concerned, please contact Dr Camille Cronin, Director of Research and Impact for the School of Health and Social Care on camille.cronin@essex.ac.uk

Appendix 7.3: Strand 1 Consent form for users and non-users of disability sport and physical activity



University of Essex

Consent Form for users and non-users of disability sport and physical activity

Title of the Project: 'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity

Research Team: Vanessa Wallace, Thomas Horey, Beverley Goodman (PhD student, University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery

		Please put your initials in the box
1	I have read or listened to the participant information dated **14/06/21**. My questions have been answered by the researcher(s) and I understand what this project is about.	
2	I am taking part as a volunteer. I understand this is my choice.	
3	I know I can leave the project if I want to, without saying why. I agree that my answers (data and ideas) can still be used in the project if I leave.	
4	I understand that all of my answers (audio recordings and transcripts without my name) will be confidential and can only be seen by co-researchers involved in the project. They will be safely stored in a University of Essex Box folder and anything with my name or other personal information may be kept in a separate University of Essex Box folder. This information may be kept for up to 10 years before it is destroyed. Any video recordings made by Zoom will be immediately destroyed after our discussion is finished.	
5	I understand that my name or other personal details will not be shared outside of the team of co-researchers. Research findings from this study will be shared in Beverley Goodman's PhD thesis, in publications and at conferences. My answers might sometimes be included word-for-word in the findings, but without my name.	
6	I know that research findings may be shared in the future with other researchers, without using my name or other personal details.	
7	I would like to take part in this study.	**Yes/No**

Participant Name ________________ Date __________ Participant Signature ________________

Please add your name here if you have signed this form for someone else:

Name: ____________________ Relationship: ______________________

Consent form for users and non-users of disability sport and physical activity (version 1)
ERAMS reference: ETH2021-1151 14/06/21 Page 1 of 2

Appendix 7.4: Strand 1 Invitation email to users and non-users of disability sport and physical activity

Subject: Invitation to take part in a research project

We would like to invite you to take part in a research project.

We are a group of co-researchers who have lived experience of disability, facilitated by Bev Goodman, who is a PhD student at the University of Essex.

We are researching how we capture how disabled people take part in sport and physical activity, and whether we can do this in a more accessible and inclusive way.

The research will involve us asking you a list of questions. This could happen on the phone or on Zoom, whatever is easiest for you. You might be on your own or part of a group. It should not take more than one hour. If you prefer, you can complete an online survey.

We have included an information sheet about the project with this email, but please let us know if you need this information in a different format or would like to speak to one of us.

We would be happy to answer any questions you have about the research.

If you would like to take part, please complete our consent form here: Nothing about us without us - Consent Form

Appendix 7.5: Strand 1 Questions for users and non-users of disability sport and physical activity

Questions for users and non-users of disability sport and physical activity

1. Do you have a disability or impairment?

   Yes or No

If yes, please choose all that apply to you:

- Vision (for example blindness or partial sight)
- Hearing (for example deafness or partial hearing)
- Mobility (difficulty walking or unable to walk)
- Dexterity (for example lifting and carrying objects, using a keyboard)
- Learning or understanding or concentrating
- Memory
- Mental health
- Stamina or breathing or fatigue
- Autism Spectrum Disorder (ASD), Asperger's or Attention Deficit Hyperactivity Disorder (ADHD), or anything else that may affect behaviour or social skills
- Other (please specify)
- Prefer not to say

For the following questions, please think about the activities you would usually do before the Covid 19 pandemic.

2. What sports or physical activities do you take part in? Please name them all.

If none, please go to question 7.

3. How often do you take part in these?

Every day

2-3 times a week

Once a week

Other – please say how often:

4. a. Please name all the things you enjoy and that matter to you most about the sports or physical activities you take part in

b. Is it important for you to get out of breath or raise your heart rate when doing sport or physical activity?

Prompt: please explain

5. What helps you to take part in sports or physical activities?

6. What makes it hard for you to take part in sports or physical activities?

7. Have you ever been asked to tell someone before about your experience of sport or physical activity?

Yes – if so, please describe what you had to do _______________________
a survey or questionnaire

a video

focus group

interview

Something else –

No

8. What is the easiest way for you of sharing your experiences of taking part in sport or physical activity? (Tick list with options, including easy-read pictures)

a survey or questionnaire

a video

voice note or recording

focus group

interview

sticker or tick chart

diary

Photographs or pictures

Anything else? Please give your own ideas

Thank you for taking part

Appendix 7.6: Strand 1 Qualtrics survey for users and non-users of disability sport and physical activity

Survey for users and non-users of disability sport or physical activity

Q1 Title of the Project: ‘Nothing about us without us’: Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity. Research Team: Vanessa Wallace, Tom Horey, Beverley Goodman (PhD student, University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery.

Thank you for your interest in our research project. It is all about how we capture how disabled people take part in sport and physical activity, and whether we can do this in a more accessible and inclusive way. We’d like to learn more about your experiences of sport and physical activity.

We are a group of 7 co-researchers, including 5 disabled people and one family carer. Co-researchers are not participants in this research, but are people with lived experience of disability who have co-designed this research project together, facilitated by Bev Goodman.

If you have not already seen it, please view the Participant information sheet

Completing this survey should take 15-20 minutes. You do not have to take this survey if you do not want to. It is your choice. You can also leave the survey at any time if you want to. However, it will not be possible to withdraw any information after the survey has been submitted.

If you would like to take part, please make sure you've completed the Consent Form

Q23 Please click on the "I agree" button if:

You have read the participant information sheet and the information above, and you understand it

You are at least 18 years of age

You would like to take part

You have completed the consent form

○ I agree (1)

Q2 What is your age group?

○ 18 - 24 (11)

○ 25 - 34 (12)

○ 35 - 44 (13)

○ 45 - 54 (14)

○ 55 - 64 (15)

○ 65 - 74 (16)

○ 75 - 84 (17)

○ 85 or older (18)

○ Prefer not to say (20)

Q3 What is your gender?

○ Male (24)

○ Female (25)

○ Non-binary (26)

○ Prefer to self-describe (please state): (28)

____

○ Prefer not to say (27)

Q4

Do you have a disability or impairment?

○ Yes (1)

○ No (3)

○ Prefer not to say (4)

Display This Question:

If Do you have a disability or impairment? = Yes

Q5 If yes, please choose all that apply to you:

☐ Vision (for example blindness or partial sight) (1)

☐ Hearing (for example deafness or partial hearing) (2)

☐ Mobility (difficulty walking or unable to walk) (3)

☐ Dexterity (for example lifting and carrying objects, using a keyboard) (4)

☐ Learning or understanding or concentrating (5)

☐ Memory (6)

☐ Mental health (7)

☐ Stamina or breathing or fatigue (8)

☐ Autism Spectrum Disorder (ASD), Asperger's or attention deficit hyperactivity disorder (ADHD), or anything else that may affect behaviour or social skills (9)

☐ Other (please specify) (10)

____

☐ Prefer not to say (11)

Q6 For the following questions, please think about the activities you would usually do before the Covid 19 pandemic.

Q7 Do you take part in sports or physical activities?

○ Yes (21)

○ No (22)

If Do you take part in sports or physical activities? = No

Q8 If you don't, please tell us why?

Skip To: Q14 If Condition: If you don't, please te... Is Displayed. Skip To: What helps or would help you....

Q9 What sports or physical activities do you take part in? Please name them all:

Q10 How often do you take part in these?

○ Every day (1)

○ 2-3 times a week (3)

○ Once a week (4)

○ Other: please say how often (5) ____

Q11 Please name all the things you enjoy, and that matter to you most about the sports or physical activities you take part in:

Q12 Is it important for you to get out of breath or raise your heart rate when doing sport or physical activity?

○ Yes (1)

○ No (3)

Q13 Please explain your answer:

Q14 What helps, or would help you, to take part in sports or physical activities?

Q15 What makes it hard for you to take part in sports or physical activities?

Q16 Have you ever been asked to tell someone before about your experiences of sport or physical activity?

○ Yes (23)

○ No (24)

○ Unsure (25)

Display This Question:

If have you ever been asked to tell someone before about your experiences of sport or physical activ... = Yes

Or have you ever been asked to tell someone before about your experiences of sport or physical activ... = Unsure

Q17 Please describe what you had to do:

○ A survey or questionnaire (1)

○ A video (2)

○ An interview (3)

○ A focus group (4)

○ Something else - please describe what you had to do: (5)

____

Display This Question:

If Please describe what you had to do: = A survey or questionnaire

Or Please describe what you had to do: = A video

Or Please describe what you had to do: = An interview

Or Please describe what you had to do: = A focus group

Or Please describe what you had to do: = Something else - please describe what you had to do:

Q18 Were you able to share what was most important to you about taking part in sports or physical activities?

○ Yes - please explain: (1)

____

○ No - please explain: (2)

____

Q19

What is the easiest way for you of sharing your experiences of taking part in sport or physical activity? Please choose as many answers as you like:

☐ A survey or questionnaire (1)

☐ A video (2)

☐ A voice note or recording (3)

☐ A focus group (4)

☐ An interview (5)

☐ A written diary (6)

☐ A sticker or tick chart (7)

☐ Photographs or pictures (8)

☐ Something else (9)

Q20 Please share your own ideas:

Q22 Please let us know about your experience of completing this survey and anything that could be changed or improved:

Q19 All images © LYPFT

ERAMS reference: ETH2021-1151 with amendment ETH2122-0130

Appendix 7.7: Strand 1 Qualtrics survey for carers of users and non-users of disability sport and physical activity

Q1 Title of the Project: ‘Nothing about us without us’: Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity. Research Team: Vanessa Wallace, Tom Horey, Beverley Goodman (PhD student, University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery.

Thank you for your interest in our research project. It is all about how we capture how disabled people take part in sport and physical activity, and whether we can do this in a more accessible and inclusive way. We’d like to learn more about your experiences of sport and physical activity.

We are a group of 7 co-researchers, including 5 disabled people and one family carer. Co-researchers are not participants in this research, but are people with lived experience of disability who have co-designed this research project together, facilitated by Bev Goodman.

If you have not already seen it, please view the Participant information sheet

This survey has been designed for carers and/or family members of people who take part in disability sport and physical activity. It has been designed for you to answer on a person's behalf, if they are unable to complete their own survey. Within the survey questions we describe them as 'the person you care for'.

Completing this survey should take 15-20 minutes. You do not have to take this survey if you do not want to. It is your choice. You can also leave the survey at any time if you want to. However, it will not be possible to withdraw any information after the survey has been submitted.

If you would like to take part, please make sure you've completed the Consent Form

Q23 Please click on the “I agree” button if:

You have read the participant information sheet and the information above, and you understand it

You are at least 18 years of age

You would like to take part

You have completed the consent form

I agree (1)

Q2 What is the age group of the person you care for?

18 - 24 (11)

25 - 34 (12)

35 - 44 (13)

45 - 54 (14)

55 - 64 (15)

65 - 74 (16)

75 - 84 (17)

85 or older (18)

Prefer not to say (20)

Q3 What is the gender of the person you care for?

Male (24)

Female (25)

Non-binary (26)

Prefer to self-describe (please state): (28)

____

Prefer not to say (27)

Q4 Does the person you care for have a disability or impairment?

Yes (1)

No (3)

Prefer not to say (4)

If Does the person you care for have a disability or impairment? = Yes

Q5 If yes, please choose all that apply to them:

Vision (for example blindness or partial sight) (1)

Hearing (for example deafness or partial hearing) (2)

Mobility (difficulty walking or unable to walk) (3)

Dexterity (for example lifting and carrying objects, using a keyboard) (4)

Learning or understanding or concentrating (5)

Memory (6)

Mental health (7)

Stamina or breathing or fatigue (8)

Autism Spectrum Disorder (ASD), Asperger's or Attention Deficit Hyperactivity Disorder (ADHD), or anything else that may affect behaviour or social skills (9)

Other (please specify) (10)

____

Prefer not to say (11)

Q6 For the following questions, please think about the activities the person you care for would usually do before the Covid 19 pandemic.

Q7 Does the person you care for take part in sports or physical activities?

Yes (21)

No (22)

Display This Question:

If Does the person you care for take part in sports or physical activities? = No

Q8 If they don't, please tell us why?

Skip To: Q14 If Condition: If you don't, please te... Is Displayed. Skip To: What helps, or would help you....

Q9 What sports or physical activities does the person you care for take part in? Please name them all:

Q10 How often does the person you care for take part in these?

Every day (1)

2-3 times a week (3)

Once a week (4)

Other: please say how often (5) ____

Q11 Please name all the things the person you care for enjoys, and that matter to them most, about the sports or physical activities they take part in:

Q12 Is it important for the person you care for to get out of breath or raise their heart rate when doing sport or physical activity?

Yes (1)

No (3)

Q13 Please explain your answer:

Q14 What helps, or would help the person you care for, to take part in sports or physical activities?

Q15 What makes it hard for the person you care for to take part in sports or physical activities?

Q16 Have you or the person you care for ever been asked to tell someone about their experiences of sport or physical activity?

Yes (23)

No (24)

Unsure (25)

Display This Question:

If Have you or the person you care for ever been asked to tell someone about their experiences of sp... = Yes

Or Have you or the person you care for ever been asked to tell someone about their experiences of sp... = Unsure

Q17 Please describe what you had to do:

A survey or questionnaire (1)

A video (2)

An interview (3)

A focus group (4)

Something else - please describe what you had to do: (5) ____

Display This Question:

If Please describe what you had to do: = A survey or questionnaire

Or Please describe what you had to do: = A video

Or Please describe what you had to do: = An interview

Or Please describe what you had to do: = A focus group

Or Please describe what you had to do: = Something else - please describe what you had to do:

Q18 Were you able to share what was most important to the person you care for about taking part in sports or physical activities?

Yes - please explain: (1)

____

No - please explain: (2)

____

Q19 What is the easiest way to share the experiences of the person you care for in taking part in sport or physical activity? Please choose as many answers as you like:

A survey or questionnaire (1)

A video (2)

A voice note or recording (3)

A focus group (4)

An interview (5)

A written diary (6)

A sticker or tick chart (7)

Photographs or pictures (8)

Something else (9) ____

Q20 Please share your own ideas:

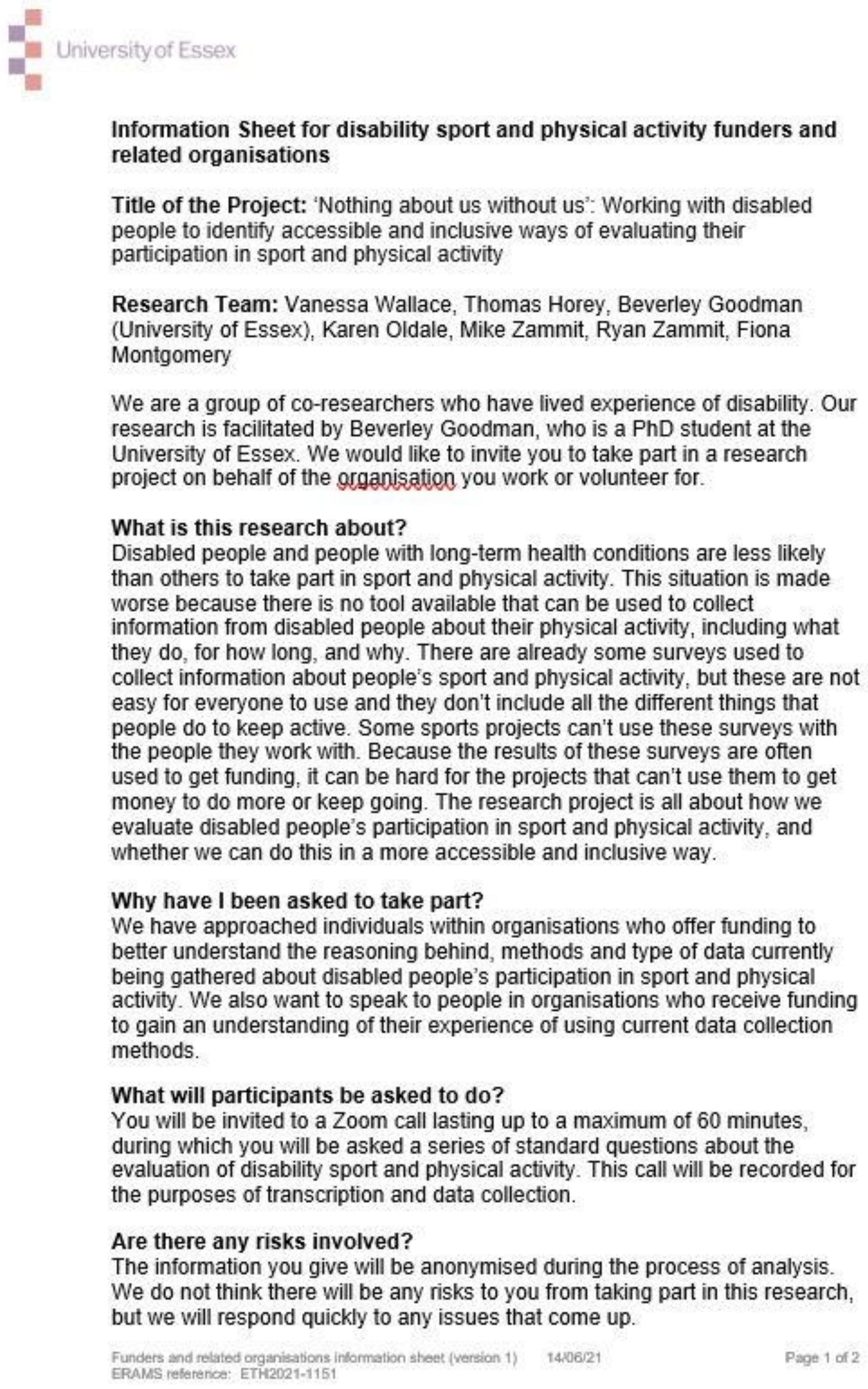
Q24 This question is for you, rather than the person you care for or support. How do you like to share your own experiences of taking part in sport and physical activity?

Q22 Please let us know about your experience of completing this survey and anything that could be changed or improved:

Q19 All images © LYPFT

ERAMS reference: ETH2021-1151 with amendment ETH2122-0130

Appendix 7.8: Strand 2 Information sheet for funders and related organisations



University of Essex

Information Sheet for disability sport and physical activity funders and related organisations

Title of the Project: 'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity

Research Team: Vanessa Wallace, Thomas Horey, Beverley Goodman (University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery

We are a group of co-researchers who have lived experience of disability. Our research is facilitated by Beverley Goodman, who is a PhD student at the University of Essex. We would like to invite you to take part in a research project on behalf of the organisation you work or volunteer for.

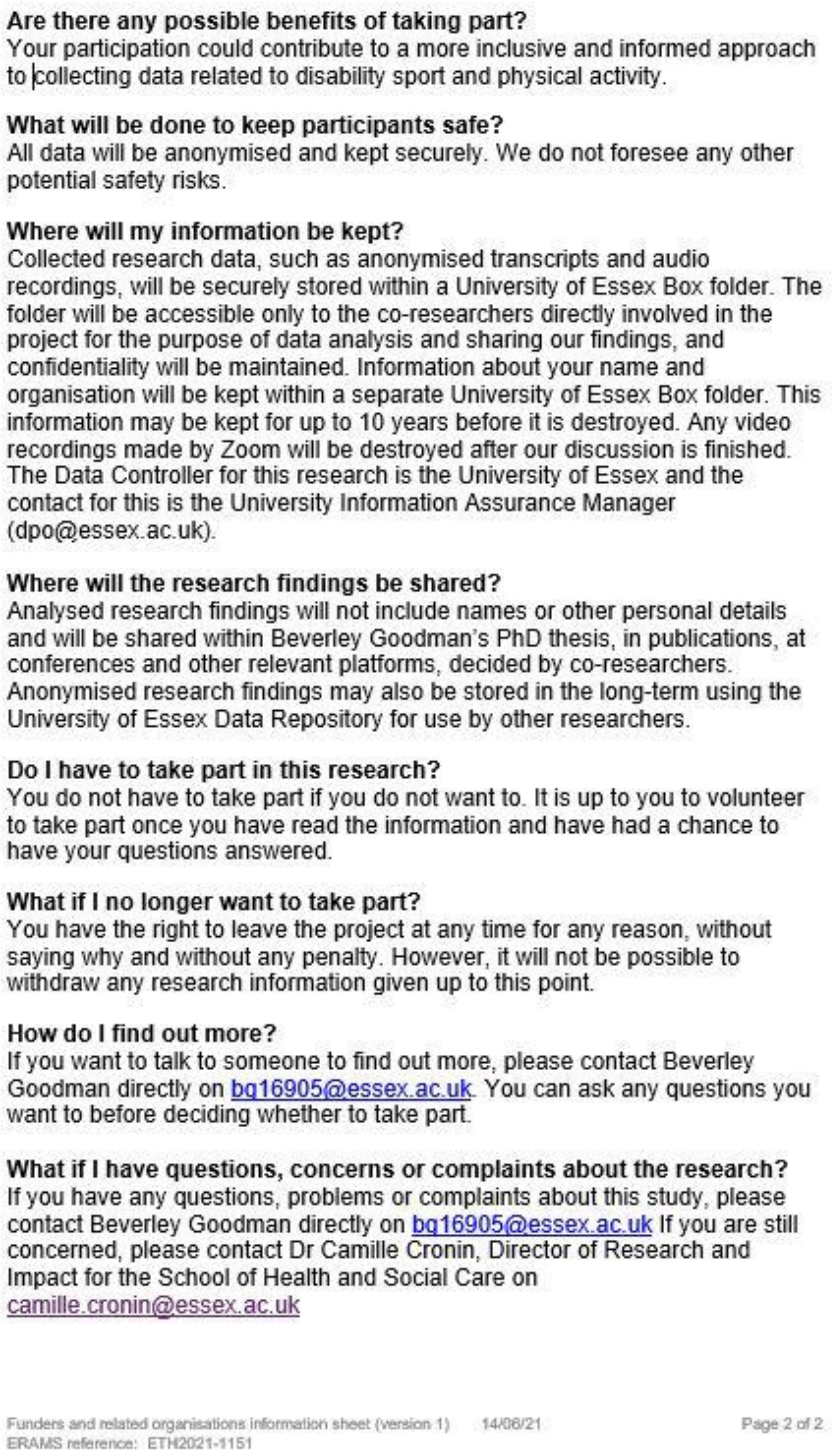
What is this research about?
Disabled people and people with long-term health conditions are less likely than others to take part in sport and physical activity. This situation is made worse because there is no tool available that can be used to collect information from disabled people about their physical activity, including what they do, for how long, and why. There are already some surveys used to collect information about people's sport and physical activity, but these are not easy for everyone to use and they don't include all the different things that people do to keep active. Some sports projects can't use these surveys with the people they work with. Because the results of these surveys are often used to get funding, it can be hard for the projects that can't use them to get money to do more or keep going. The research project is all about how we evaluate disabled people's participation in sport and physical activity, and whether we can do this in a more accessible and inclusive way.

Why have I been asked to take part?
We have approached individuals within organisations who offer funding to better understand the reasoning behind, methods and type of data currently being gathered about disabled people's participation in sport and physical activity. We also want to speak to people in organisations who receive funding to gain an understanding of their experience of using current data collection methods.

What will participants be asked to do?
You will be invited to a Zoom call lasting up to a maximum of 60 minutes, during which you will be asked a series of standard questions about the evaluation of disability sport and physical activity. This call will be recorded for the purposes of transcription and data collection.

Are there any risks involved?
The information you give will be anonymised during the process of analysis. We do not think there will be any risks to you from taking part in this research, but we will respond quickly to any issues that come up.

Funders and related organisations information sheet (version 1) 14/06/21 Page 1 of 2
ERAMS reference: ETH2021-1151



Are there any possible benefits of taking part?
Your participation could contribute to a more inclusive and informed approach to collecting data related to disability sport and physical activity.

What will be done to keep participants safe?
All data will be anonymised and kept securely. We do not foresee any other potential safety risks.

Where will my information be kept?
Collected research data, such as anonymised transcripts and audio recordings, will be securely stored within a University of Essex Box folder. The folder will be accessible only to the co-researchers directly involved in the project for the purpose of data analysis and sharing our findings, and confidentiality will be maintained. Information about your name and organisation will be kept within a separate University of Essex Box folder. This information may be kept for up to 10 years before it is destroyed. Any video recordings made by Zoom will be destroyed after our discussion is finished. The Data Controller for this research is the University of Essex and the contact for this is the University Information Assurance Manager (dpo@essex.ac.uk).

Where will the research findings be shared?
Analysed research findings will not include names or other personal details and will be shared within Beverley Goodman's PhD thesis, in publications, at conferences and other relevant platforms, decided by co-researchers. Anonymised research findings may also be stored in the long-term using the University of Essex Data Repository for use by other researchers.

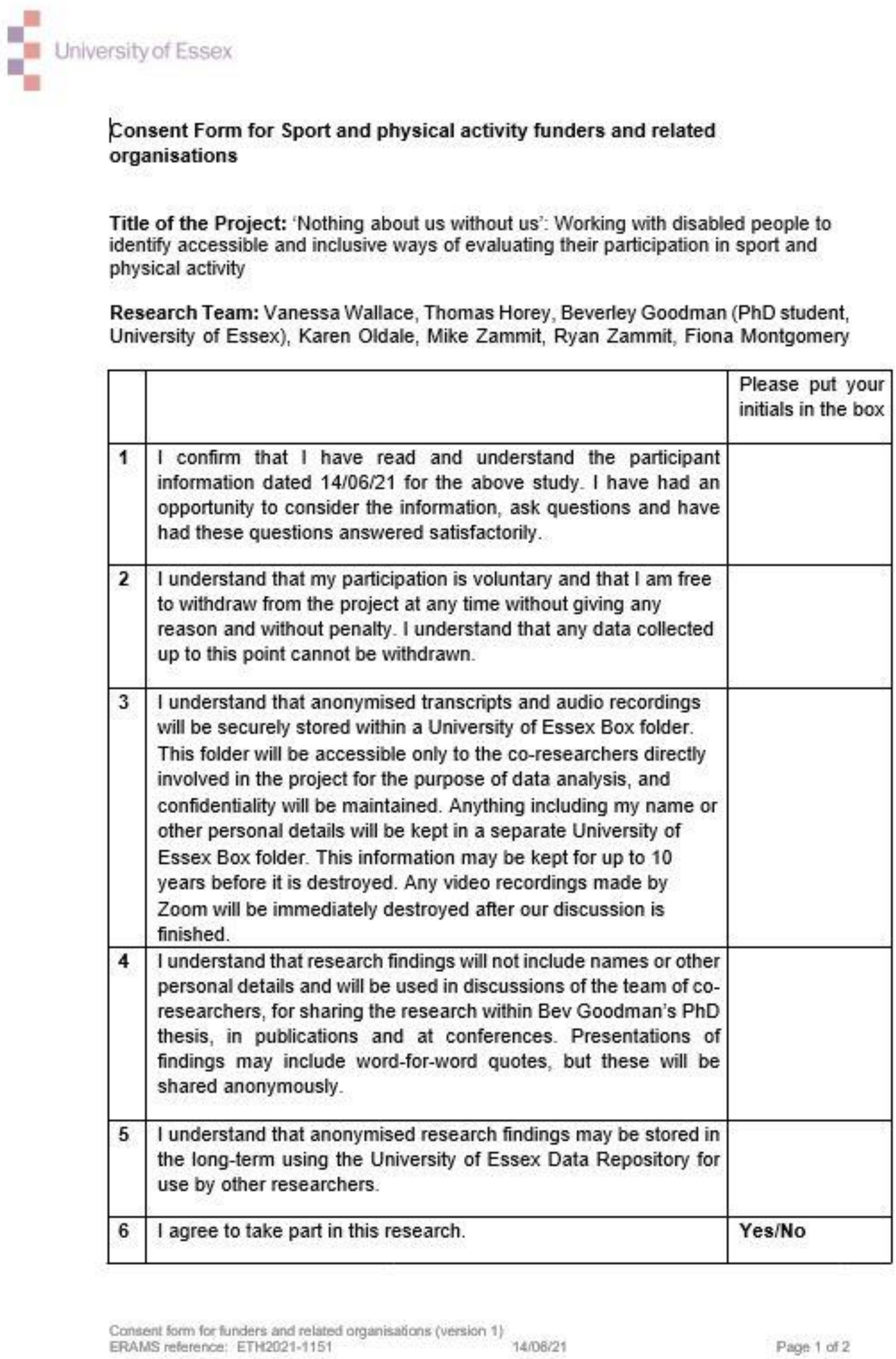
Do I have to take part in this research?
You do not have to take part if you do not want to. It is up to you to volunteer to take part once you have read the information and have had a chance to have your questions answered.

What if I no longer want to take part?
You have the right to leave the project at any time for any reason, without saying why and without any penalty. However, it will not be possible to withdraw any research information given up to this point.

How do I find out more?
If you want to talk to someone to find out more, please contact Beverley Goodman directly on bg16905@essex.ac.uk. You can ask any questions you want to before deciding whether to take part.

What if I have questions, concerns or complaints about the research?
If you have any questions, problems or complaints about this study, please contact Beverley Goodman directly on bg16905@essex.ac.uk If you are still concerned, please contact Dr Camille Cronin, Director of Research and Impact for the School of Health and Social Care on camille.cronin@essex.ac.uk

Appendix 7.9: Strand 2 Consent form for funders and related organisations – Word and Qualtrics versions



University of Essex

Consent Form for Sport and physical activity funders and related organisations

Title of the Project: 'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity

Research Team: Vanessa Wallace, Thomas Horey, Beverley Goodman (PhD student, University of Essex), Karen Oldale, Mike Zammit, Ryan Zammit, Fiona Montgomery

		Please put your initials in the box
1	I confirm that I have read and understand the participant information dated 14/06/21 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected up to this point cannot be withdrawn.	
3	I understand that anonymised transcripts and audio recordings will be securely stored within a University of Essex Box folder. This folder will be accessible only to the co-researchers directly involved in the project for the purpose of data analysis, and confidentiality will be maintained. Anything including my name or other personal details will be kept in a separate University of Essex Box folder. This information may be kept for up to 10 years before it is destroyed. Any video recordings made by Zoom will be immediately destroyed after our discussion is finished.	
4	I understand that research findings will not include names or other personal details and will be used in discussions of the team of co-researchers, for sharing the research within Bev Goodman's PhD thesis, in publications and at conferences. Presentations of findings may include word-for-word quotes, but these will be shared anonymously.	
5	I understand that anonymised research findings may be stored in the long-term using the University of Essex Data Repository for use by other researchers.	
6	I agree to take part in this research.	**Yes/No**

Consent form for funders and related organisations (version 1)
ERAMS reference: ETH2021-1151 14/06/21 Page 1 of 2

Appendix 7.10: Strand 2 Invitation email to funders and related organisation

Subject: Invitation to take part in a research project

We would like to invite you to take part in a research project on behalf of the organisation you work or volunteer for.

We are a group of co-researchers who have lived experience of disability, facilitated by Bev Goodman, who is a PhD student at the University of Essex.

Our research project is all about how we evaluate disabled people’s participation in sport and physical activity, and whether we can do this in a more accessible and inclusive way.

You will be invited to a Zoom call lasting up to a maximum of 60 minutes, during which you will be asked a series of standard questions about the evaluation of disability sport and physical activity.

We have included an information sheet about the project with this email, but please let us know if you would like to speak to one of us: we would be happy to answer any questions you have about the research.

If you would like to take part, please complete our consent form here:

Funders and related organisations - Consent Form

Appendix 7.11: Strand 2 Questions for funders and related organisations

At start of interview:

- Have you had the chance to read the project information?
- Do you have any questions?
- Are you happy to proceed and to be audio recorded?

Key: questions for funders in black; other organisations in green.

1. Are you representing a funding body or an intermediary organisation – can you briefly explain the role of your organisation and the steps you're involved in? What role does your organisation play in the delivery of PA/sport for disabled people?

2. What sorts of disability sport and physical activities do you fund? What sorts of disability sport and physical activities do you deliver?

3. What size range of funds do you give? What funds have you accessed previously? what size grants were these? If not accessed funding previously, why not?

4.Why do you give funding to disability sport/physical activity projects?

and what are the factors that do and don't make you continue to support a project?

5. What information do you require during the application process? What information have you been required to provide in previous funding applications?

6. At what intervals does evaluation information need to be provided? And why? At what intervals have you been required to provide evaluation previously?

7. What information do you require successfully funded organisations to provide following the completion of their project/having spent the money? What information have you been required to provide at the completion of projects previously?

8. What tools do you currently use to evaluate disability sport or physical activity projects/groups/organisations? Why do you use this tool? What tools have funders asked you to use to evaluate your projects previously?

9. Why is evaluating funded projects an important process for you as a funder? Why do you think evaluating funded projects is an important process for funders?

10. Do you believe the quality of insight you currently receive from evaluation of funded disability sport projects is of a good standard? Do you believe the quality of insight you currently provide through evaluation of funded disability sport projects is of a good standard?

11. Why is the specific information you ask for important to you as a funder? Why do you think funders ask for the specific information they do?

12. Do you allow flexibility around how this evaluation is supplied to you? Why do you take this approach? In your experience do funders allow flexibility as to how you supply evaluation?

13. Would you be open to using further adapted forms of evaluation that may be more inclusive to those with a wide variety of disabilities? (e.g. case studies, storytelling, videos? Would this work for you or not?) Should funders be open to using further adapted forms of evaluation that may be more inclusive to those with a wide variety of disabilities? What formats would work best?

14. Do the evaluation methods you currently use elicit adequate information on the outcomes you want to measure? Do the evaluation methods you are currently asked to use by funders allow you to demonstrate the outcomes you want to show?

15. Do you consider the evaluation tools you currently use to be in an inclusive format for use by those with a wide range of disabilities? If not, why not? Do you

consider the evaluation tools you are currently asked to use to be in an inclusive format for use by those with a wide range of disabilities? If not, why not?

16. Do you believe there are currently adequate tools available to evaluate disability sport/physical activity? If no, what evaluation tools or methods are needed to enable you to better understand the impact your funding is having on disability sport/physical activity? Do you believe there are currently adequate tools available to evaluate disability sport/physical activity? If no, what evaluation tools or methods are needed to enable you to better demonstrate the impact the funding is having on disability sport/physical activity?

17. Do you have any other thoughts on how evaluation of sport and physical activity for disabled people could be changed or improved to be more useful and meaningful for your organisation, for organisations that are funded and for disabled people? Do you have any other thoughts on how evaluation of sport and physical activity for disabled people could be changed or improved to be more useful and meaningful for your organisation, for organisations that are funded and for disabled people?

Appendix 7.12: Strand 2 Breakdown of organisation types and data collection method

	Organisation description	**Category and question list used**	**Method**
1	Disability sport and physical activity provider (various UK locations)	Provider	Zoom
2	National UK disability charity with a sport and physical activity programme	Provider	Zoom
3	Active partnership for a specific English county with a limited disability sport and physical activity remit	Funder (intermediary)	Zoom
4	Active partnership for a specific English county with a large disability sport and physical activity remit	Funder (intermediary)	Zoom
5	National funding body for sport and physical activity	Funder (national)	Zoom
6	Disability sport and physical activity provider for a specific English county	Provider	Face-to-face
7	Evaluation company working predominantly with charity and voluntary sector	Related organisation	Zoom

Appendix 7.13: Co-researcher interview tips, created by co-researcher Karen

Tips when interviewing or conducting surveys for research based on my experience.

Apologies, I am sure these are obvious, and you would do these anyway.

They are only my thoughts.

1. Before the interview - Preparation, Preparation, Preparation

- We have tried to develop robust (strong) questions that are easy for everyone to understand, but if you find people are struggling or you have to explain things, we can change them.
- If it's a survey to be completed by a participant, make it as attractive, short and simple to complete as possible while ensuring you can still gain all the information you require.
- Practice our questions on others beforehand.
- We will mostly be doing our research on Zoom and need to remember to press record at the beginning. If for some reason we can't use Zoom, we will need to plan how to record the answers.
- You can use the introduction in our information sheet to introduce the research. You might want to talk to participants about why the survey, focus group or interview matters, and how in the future this research might help the participant and others.
- Check whether the person has read the information sheet and ask if they have any questions about anonymity confidentiality and data storage.
- On the day, make sure you have everything that you will require.

2. The interview or survey

- If a person has not been able to return a written consent form, we will need to read out the information sheet and get their spoken consent to take part.

- Treat others as you would wish to be treated yourself.
- Allow enough time.
- Always be professional, confident and reassuring.
- If relevant, find a suitable, quiet, private place to speak to someone on Zoom, and check whether the person being interviewed is also in a quiet, private place.
- Try to develop a rapport, be friendly and smile (the interviewee may be nervous.)
- If a written survey, ask how the participant would like to complete this – by themselves or with your help. If so, what help?
- Do remind participants if they have any questions - please ask.
- Our questions are just a starting point. They can also change for future interviews or focus groups if there is anything that is not clear.
- If interviewing or completing a questionnaire on someone’s behalf, it’s always important to listen carefully.
- Try to make sure you record as accurately as possible what the person says. If you’re not sure you understand what someone is saying, check by repeating what they say back to them.
- Try to avoid giving your own opinions during the interview or focus group. If an answer is unexpected and you don’t agree, respect what is being said and carry on.
- If taking information from an interviewee where a parent/carer is answering on their behalf, always try to include (speaking, looking etc) the person you are surveying in whatever way you can.
- If someone starts to talk a lot and go off the point, gently and politely try to keep them on the question being asked.
- If someone doesn’t answer a question, their answer isn’t clear or you’d like more information, it is ok to prompt them to give more information or to explain what they mean.

- If working with a group, try to ensure everyone has a chance to speak on each question. Ask each person in turn whether they would like to speak.

3. At the end:

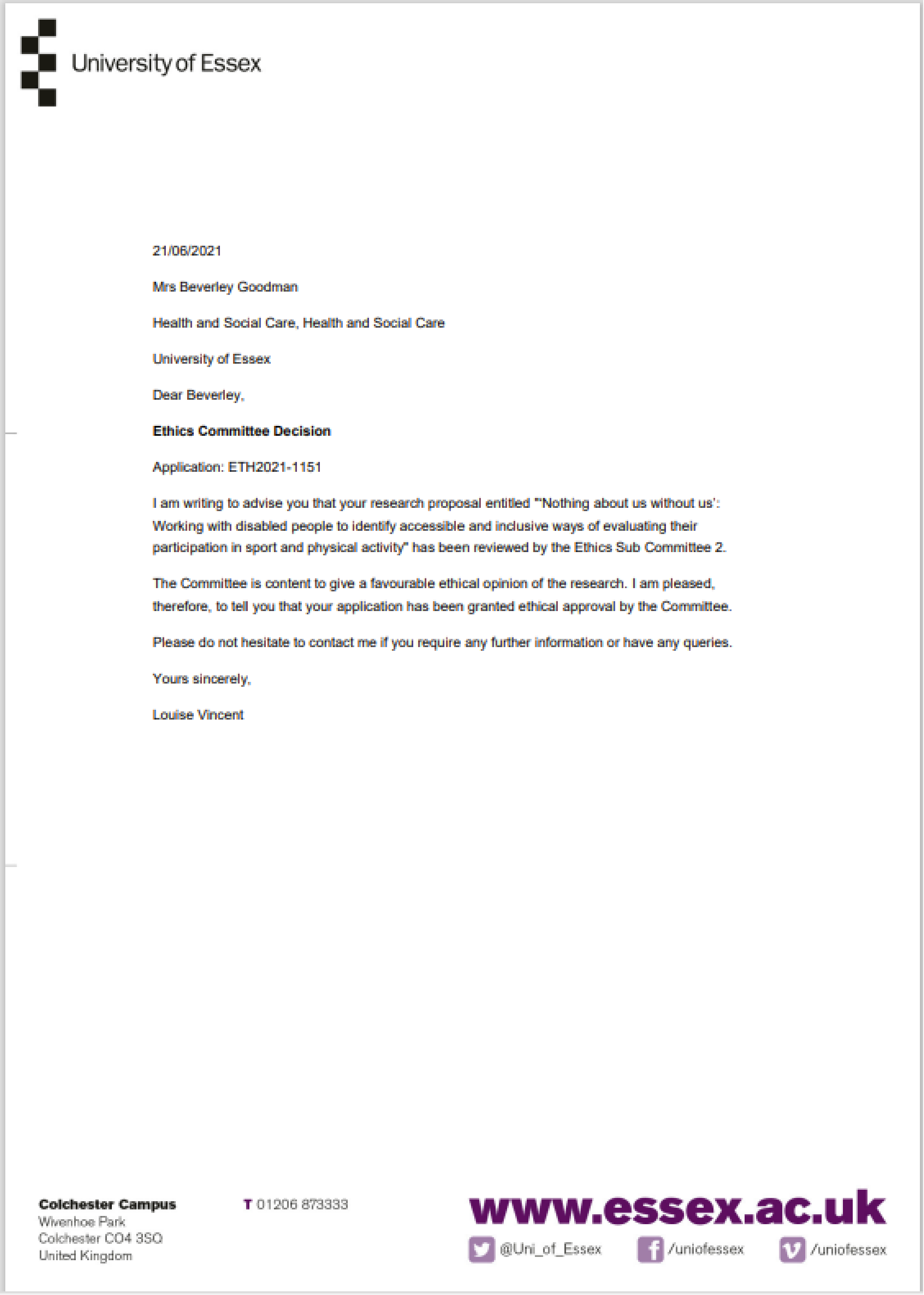
- Once finished, quickly check that you have completed all the information and asked all your questions before anyone leaves.
- Ask if there are any questions or if they would like to add anything that hasn't been covered. Don't stop recording until people have left!
- If relevant, reassure of confidentially and, if relevant, visibly remove all paperwork into a secure place.
- Thank the person and explain what happens next. Provide information if the person would like to be kept updated

4. Afterwards

- If relevant, transcribe information as soon as possible. After each interview or focus group, Bev will join you to reflect on what happened during the session. We will then save the audio recording from Zoom to Box.

Appendix 8: Ethical approval

Appendix 8.1: Confirmation of ethical approval - original application ETH2021-1151



University of Essex

21/06/2021

Mrs Beverley Goodman

Health and Social Care, Health and Social Care

University of Essex

Dear Beverley,

Ethics Committee Decision

Application: ETH2021-1151

I am writing to advise you that your research proposal entitled "'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity" has been reviewed by the Ethics Sub Committee 2.

The Committee is content to give a favourable ethical opinion of the research. I am pleased, therefore, to tell you that your application has been granted ethical approval by the Committee.

Please do not hesitate to contact me if you require any further information or have any queries.

Yours sincerely,

Louise Vincent

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

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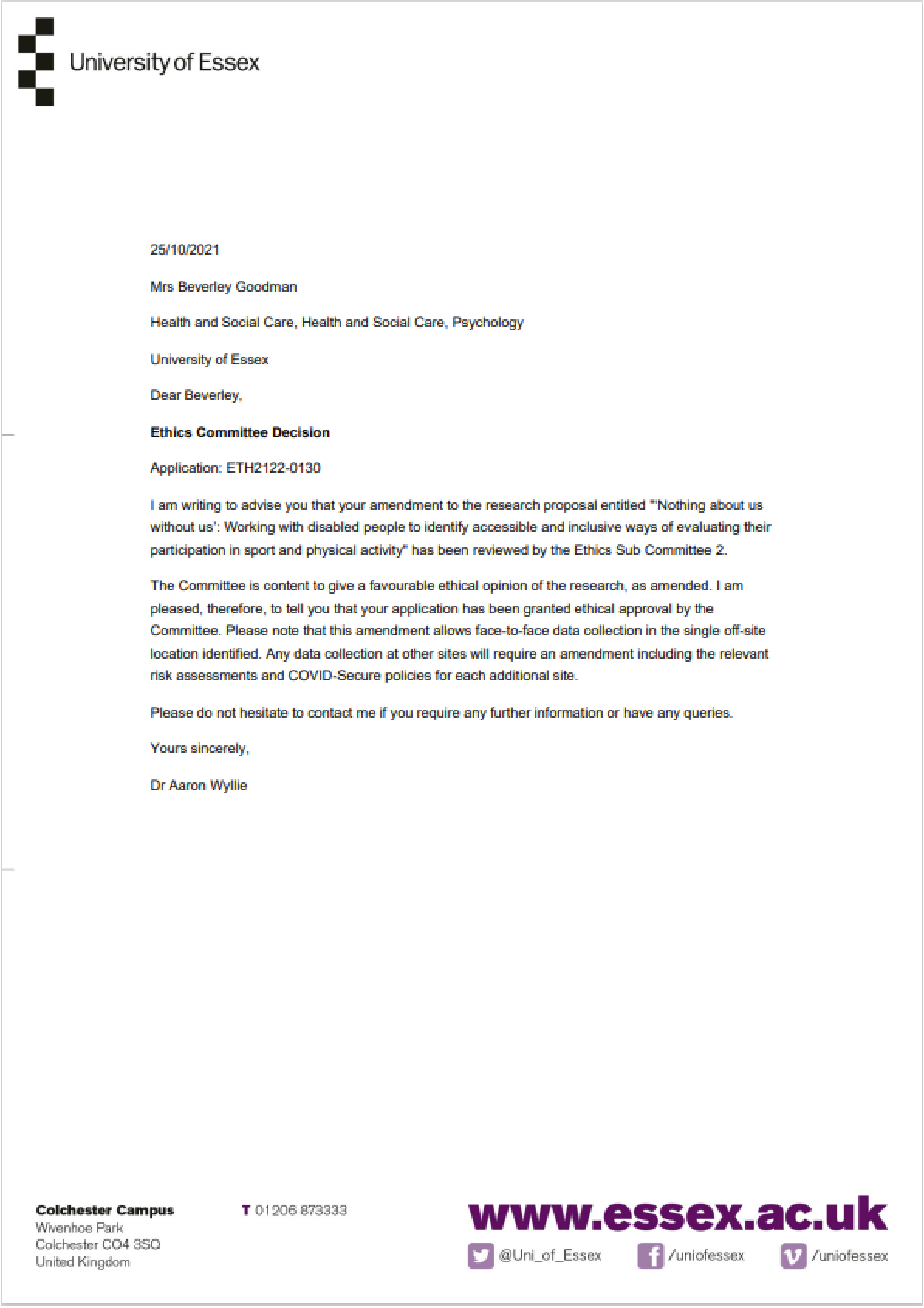
Appendix 8.2: Confirmation of ethical approval – amendment for face-to-face data collection ETH2122-0130



University of Essex

25/10/2021

Mrs Beverley Goodman

Health and Social Care, Health and Social Care, Psychology

University of Essex

Dear Beverley,

Ethics Committee Decision

Application: ETH2122-0130

I am writing to advise you that your amendment to the research proposal entitled "'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity" has been reviewed by the Ethics Sub Committee 2.

The Committee is content to give a favourable ethical opinion of the research, as amended. I am pleased, therefore, to tell you that your application has been granted ethical approval by the Committee. Please note that this amendment allows face-to-face data collection in the single off-site location identified. Any data collection at other sites will require an amendment including the relevant risk assessments and COVID-Secure policies for each additional site.

Please do not hesitate to contact me if you require any further information or have any queries.

Yours sincerely,

Dr Aaron Wyllie

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Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

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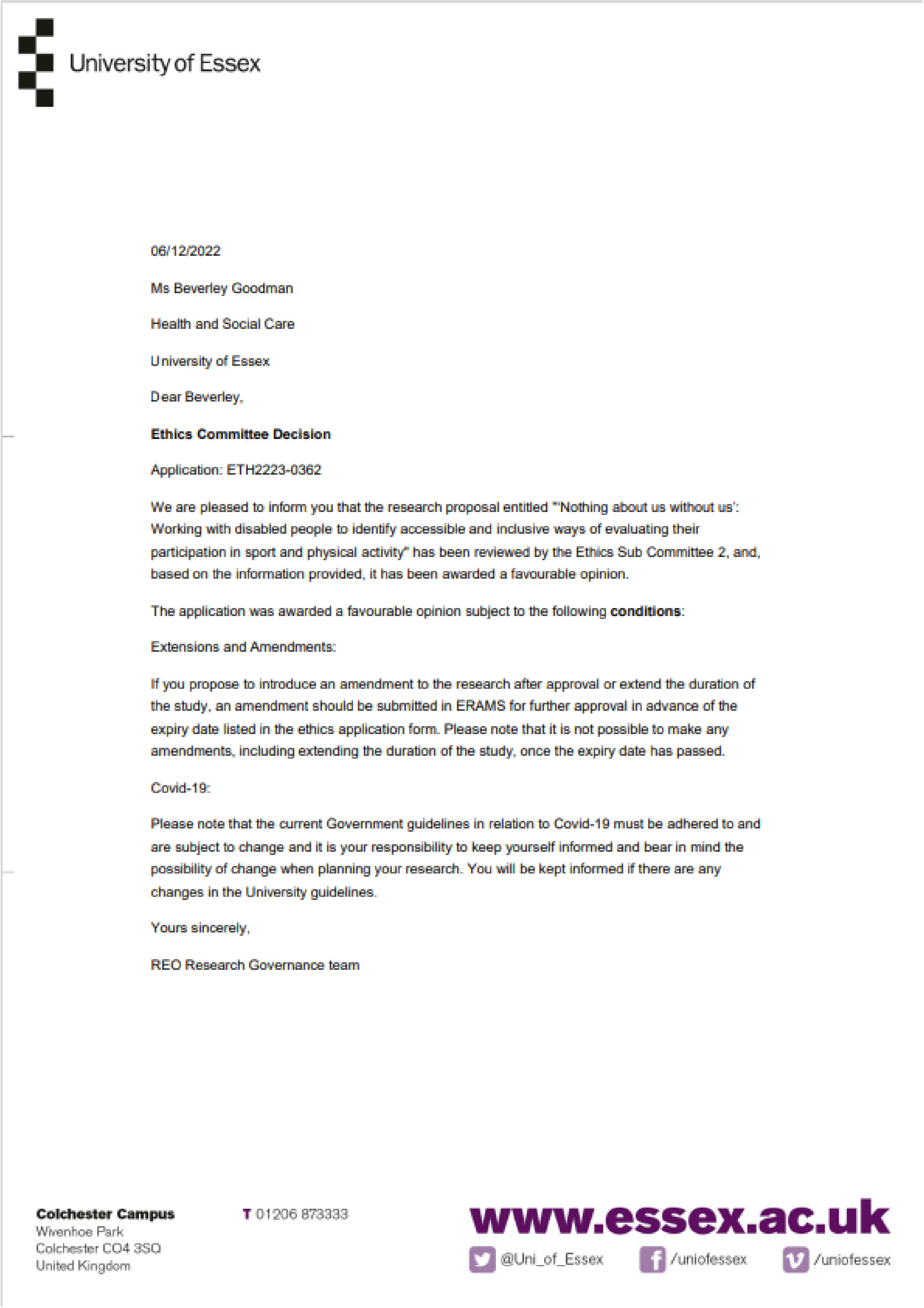
Appendix 8.3: Confirmation of ethical approval – project extension ETH2223-0362



University of Essex

06/12/2022

Ms Beverley Goodman

Health and Social Care

University of Essex

Dear Beverley,

Ethics Committee Decision

Application: ETH2223-0362

We are pleased to inform you that the research proposal entitled "'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity" has been reviewed by the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance team

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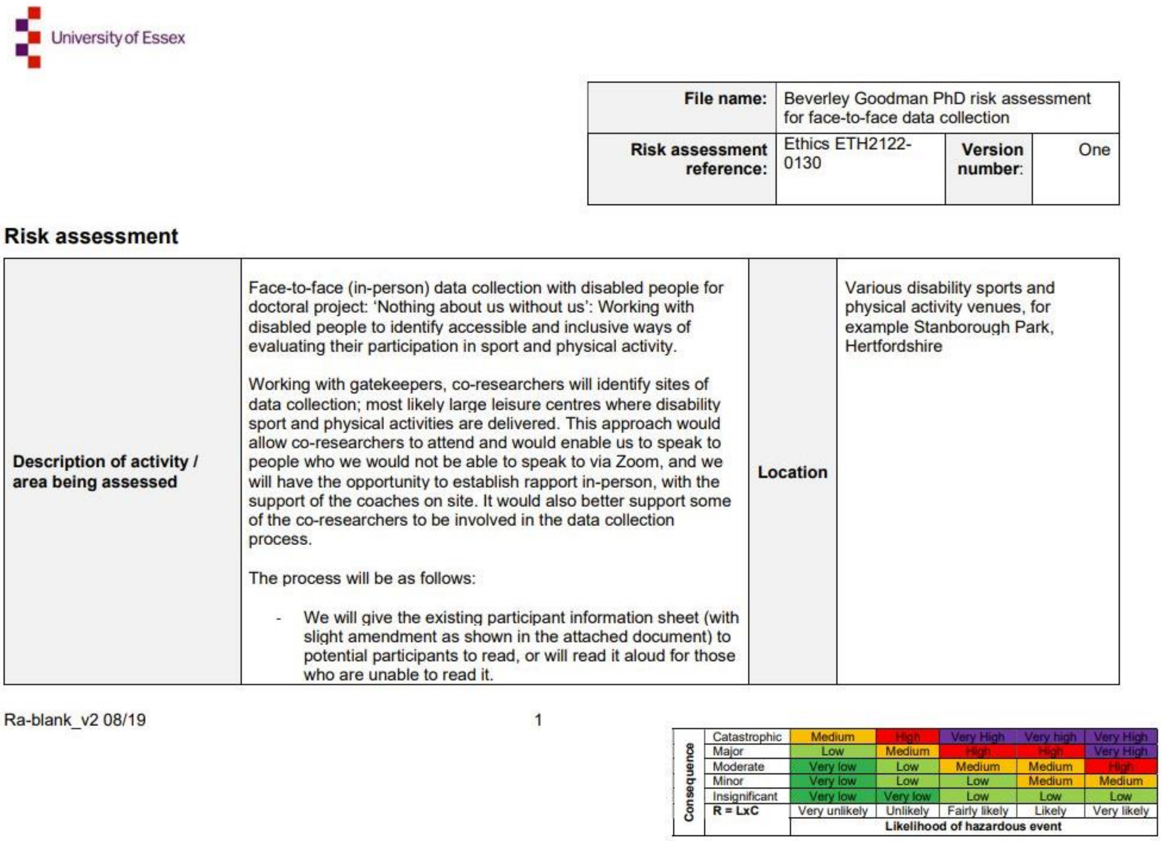
Appendix 8.4: Risk assessment for in-person data collection activity



University of Essex

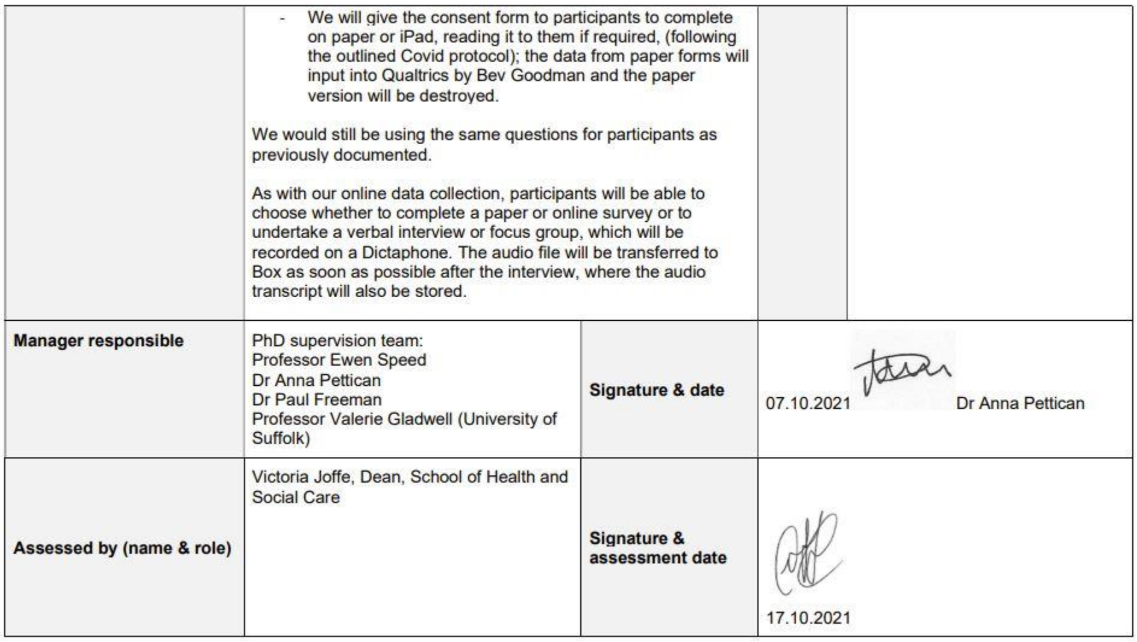
File name:	Beverley Goodman PhD risk assessment for face-to-face data collection		
Risk assessment reference:	Ethics ETH2122-0130	**Version number:**	One

Risk assessment

Description of activity / area being assessed	Face-to-face (in-person) data collection with disabled people for doctoral project: 'Nothing about us without us': Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity. Working with gatekeepers, co-researchers will identify sites of data collection; most likely large leisure centres where disability sport and physical activities are delivered. This approach would allow co-researchers to attend and would enable us to speak to people who we would not be able to speak to via Zoom, and we will have the opportunity to establish rapport in-person, with the support of the coaches on site. It would also better support some of the co-researchers to be involved in the data collection process. The process will be as follows: - We will give the existing participant information sheet (with slight amendment as shown in the attached document) to potential participants to read, or will read it aloud for those who are unable to read it.	**Location**	Various disability sports and physical activity venues, for example Stanborough Park, Hertfordshire

Ra-blank_v2 08/19 1

Consequence						
	Catastrophic	Medium	High	Very High	Very high	Very High
	Major	Low	Medium	High	High	Very High
	Moderate	Very low	Low	Medium	Medium	High
	Minor	Very low	Low	Low	Medium	Medium
	Insignificant	Very low	Very low	Low	Low	Low
	R = LxC	Very unlikely	Unlikely	Fairly likely	Likely	Very likely
		Likelihood of hazardous event				



	- We will give the consent form to participants to complete on paper or iPad, reading it to them if required, (following the outlined Covid protocol); the data from paper forms will input into Qualtrics by Bev Goodman and the paper version will be destroyed. We would still be using the same questions for participants as previously documented. As with our online data collection, participants will be able to choose whether to complete a paper or online survey or to undertake a verbal interview or focus group, which will be recorded on a Dictaphone. The audio file will be transferred to Box as soon as possible after the interview, where the audio transcript will also be stored.		
Manager responsible	PhD supervision team: Professor Ewen Speed Dr Anna Pettican Dr Paul Freeman Professor Valerie Gladwell (University of Suffolk)	**Signature & date**	07.10.2021 Dr Anna Pettican
Assessed by (name & role)	Victoria Joffe, Dean, School of Health and Social Care	**Signature & assessment date**	17.10.2021

Hazard (H) hazardous event (HE) consequence (C)	Who might be harmed	Current controls	Current risk LxC=R	Additional controls needed to reduce risk	Residual risk LxC=R	Target Date	Date achieved
Research activities at the host organisation **Hazard:** Visiting and/or working at another organisation during the Covid-19 pandemic. **Hazardous event:** Infection with Covid-19. **Consequence:** Illness and at least 7 days off work.	Staff Vulnerable persons People with a disability	Example control measures: • Hand Washing, Equipment cleaning (iPads) before and after each participant • Surgical mask worn by researcher and participant, 2m+ Socially distanced where possible but may require short breaches in order to set up equipment. • Existing one-way systems will be utilised, and gaps are arranged before and after sessions, to avoid a build-up of people. • Before any participants arrive, the activity environment will be prepared to reduce the contraction/transmission of Covid-19. • All surfaces/equipment/data collection aids must be cleaned and wiped with an anti-bacterial sanitising wipe or 1% Virkon solution. • Room layout - chairs/couches must be moved to maximise space to maintain good social distancing (2m where possible) • Where relevant windows will be opened to increase ventilation	Unlikely x Major = Medium	In all cases the risk assessments and associated practices of each venue visited will be abided by.			
Transport **Hazard:** Travel for business during the Covid-19 pandemic. **Hazardous event:** Infection with Covid-19. **Consequence:** Illness and at least 7 days off work.	Staff Vulnerable persons People with a disability	All co-researchers, including Bev Goodman, will be travelling individually by private car to the site of data collection. Where taxi or public transport needs to be taken, control measures will include: • All passengers to carry hand sanitiser and use after touching surfaces. • Surgical masks to be worn. Avoid peak times for travelling.	Unlikely x Major = Medium	Individual private transport used whenever possible.			
Emergency procedures/medical requirements **Hazard:** Requiring medical assistance	Staff Vulnerable persons	Generally co-researchers will not be in the specific public community locations (listed above) alone and they will always be there with the awareness and approval of	Unlikely x Major = Medium	In all cases the risk assessments and associated practices of each			

Hazard (H) hazardous event (HE) consequence (C)	**Who might be harmed**	**Current controls**	**Current risk LxC=R**	**Additional controls needed to reduce risk**	**Residual risk LxC=R**	**Target Date**	**Date achieved**
when visiting and/or working at another organisation during the Covid-19 pandemic. **Hazardous event:** Infection with Covid-19. **Consequence:** Illness and at least 7 days off work.	People with a disability	staff from the community setting when conducting the data collection activities in these locations. Co-researchers will identify their local exit routes and follow the local emergency arrangements.	🟨	venue visited will be abided by.			
Injuries, slips, trips and falls **Hazard:** Injuries, slips, trips and falls. **Hazardous event:** People (participants and others), might sustain an accidental injury during data collection activities. **Consequence:** injury	Co-researchers	The co-researcher will stop the data collection and inform necessary parties (e.g. first aider on site) and make a decision about whether they can continue to work, which is then communicated to the evaluation team.	Unlikely X minor LOW RISK	No further controls needed	Unlikely X minor LOW RISK		
Participant welfare: **Hazard:** Participants are asked questions about their life and health. **Hazardous event:** Participant may feel impacts their social standing and/or causes mental distress (for example, if being recently bereaved is connected to them being less physically active). **Consequence:** Potential implications for participant mental health.	Research participants	Participant information sheet makes clear that participants can withdraw at any point during data collection. Data collection is also anonymous.	Unlikely X moderate LOW RISK	No further controls needed	Unlikely X moderate LOW RISK		
Fire, first aid and local emergency arrangements **Hazard:** Co-researchers not familiar with the emergency arrangements. **Hazardous event:** Harm escalates due to their delayed response or incorrect emergency action. **Consequence:** potentially major, potential fatalities.	Co-researchers Participants and others	Generally co-researchers will not be in the specific public community locations (listed above) alone and they will always be there with the awareness and approval of staff from the community setting when conducting the data collection activities in these locations. Co-researchers will identify their local exit routes and follow the local emergency arrangements.	Very unlikely X major LOW RISK	No further controls.	Very unlikely X major LOW RISK		

Appendix 9: Data analysis phase

Appendix 9.1: Reflective matrices to guide initial analysis and theme generation

FUNDERS, PROVIDERS AND RELATED ORGANISATIONS

More inclusivity needed, but unclear what this means in practice; a sense that change is coming, but not sure what this looks like	Innovative ideas for evaluation, e.g. gamification, visual methods.	Non-sport outcomes that aren't always measured can be the most important e.g. social contact, isolation, loneliness; fitness is less important/a by-product?	Freedom and flexibility Vs Standardisation and comparison; the value of qualitative data	Issues with the format of standard/ standardised tools	Funder awareness levels of lack of inclusivity - are they aware of the issues? Funders need to see what's happening in action	Different tiers/ levels of evaluation	The necessity of proxy report with some clients. Not necessarily a negative if there is a trusted person who can enable a true as possible response - preferable to no response at all	The actors involved: who is the evaluator, who delivers evaluation, and who is providing evaluation information? The crucial role of the facilitator; the use of agencies; the ultimate funders (government)	When should evaluation take place? Timing?	Examples of good practice? Evaluation as learning

USERS AND NON-USERS OF DISABILITY SPORT AND PHYSICAL ACTIVITY

Everyone is put together in one group when our disabilities are very different; different views on what disability means	Evaluation needs to cater to a wide range of individual needs	Fitness is important to some people but only one part of what people get out of taking part. Different outcomes of significance for different people: mental health, social contact	The importance of the social aspect of sport and physical activity - even more so to disabled people; a socially welcoming space for participation	The importance of support and encouragement to participate and the different it makes to experience	The importance of the evaluation facilitator and their understanding of participants' needs; someone that takes the time to consider this; flexibility to adapt in the moment	Ideas for making information and evaluation more accessible

LEARNING ON EVALUATION IN OUR PRACTICE

Physical and environmental considerations for evaluation (weather, noise)	Adapting questions in the moment	Potential issues with asking questions, particularly about abstract ideas (e.g. loneliness; what evaluation is and whether people had previously done it)	Replication of bad evaluative practice?	People's perception/understanding of their own disability; whether they use diagnostic terminology or labels (does this matter?)

Appendix 9.2: Plan for co-researcher analysis and findings day

Exploring more inclusive and accessible evaluation of sport and physical activity: Co-researcher analysis and findings day

When?	Sunday 14th April 2024
What time?	10am – 4pm
Where?	[redacted]
Who will be there?	Bev, Fiona, Karen, Nessa, Tom

What are we going to talk about? How can we find out what disabled people get out of sport and physical activities in a way that meets the needs of disabled people and funders?	
10 – 10:30	**Gathering, catch-up and cake**
10:30 – 11:30	**Themes in the data for research question a)** What are the things about sport and physical activities that matter to disabled people? Why do disabled people take part or not take part?
11:30 – 12:00	**Break, with cake**
12:00 – 13:00	**Themes in the data for research question b)**

	What do funders want to know about disabled people's participation in sport and physical activities?
13:00 – 13:30	**Lunch, with more cake**
13:30 – 14:30	**Themes in the data for research question c)** How can we give everyone the chance to share their experiences of disability sport and physical activities, in a way that funders can use?
14:30 – 15:00	**Break, with even more cake**
15:00 – 15:50	**What should we do with our findings?**
15:50	**Next steps, and making a date for podcast 4**

Appendix 9.3 Initial themes shared with co-researchers for discussion

Research question A – findings for co-researcher analysis and findings day

Doing

Concerning participation in an activity. "Doing is the medium through which people engage in occupations, and the skills and abilities needed for doing accumulate across time. Doing involves engaging in occupations that are personally meaningful, but not necessarily purposeful, healthy or organized." (Hitch, Pépin and Stagnitti, 2014)

Doing a range of different activities

Disabled people participate in a range of different activities. Some have been designed specifically for disabled people. Some are traditional sports that have been adapted for participation.

Doing as a gateway

Doing as a gateway to further activity. Being in involved in one activity can lead to another. Participation might build confidence to take part in other activities or subsidiary activities alongside the main activity, such as social activities or other sporting activities with teammates. Participation as a gateway towards productive activity and employment.

Doing in a way that works for me

Adaptations that support participation and enable inclusivity. Feeling supported when someone takes the time to adapt their approach.

Being

"Being is the sense of who someone is as an occupational and human being. It encompasses the meanings they invest in life, and their unique physical, mental, and social capacities and abilities." (Hitch, Pépin and Stagnitti, 2014)

Being free

Feelings of freedom and independence in participation. Freedom in the environment, in the water, being outdoors. Freedom from reality, an escape. Freedom from physical constraints, from mobility devices. Free from fear and being judged by self and others.

Being happy, finding enjoyment in participation

Participating for the enjoyment of it, having fun. "If I've enjoyed it then I'm happy". Not enjoying is reason enough to stop participating.

Being me

Everyone is put together in one group when our disabilities are very different; different views on what disability means. Experience and understanding of disability is individual, sometimes self-determined. Evaluation needs to cater *to a wide range of individual needs. Being accepted for who I am, being enabled to participate regardless. Consideration of my individual needs. Everyone has their own reasons and goals for taking part or limitations for not taking part. Motivation and self-determination.*

Being limited by physical or mental health

Recognising that aspects of physical impairment or mental health make it more difficult to participate. Mental health can affect motivation to participate but an awareness that participation could lead to improvement in this.

Being supported to participate

Having the right conditions in place for participation. The importance of support and encouragement to participate and the difference it makes to experience. Particularly support from a provider/person who encourages participation and understands individual needs. Activities that happen at the right time, as regularly as desired, in accessible places at reasonable cost. Having transport to get there. Having the equipment needed. Being able to participate when I want to. Knowing what activities are out there.

Becoming

Related to the outcomes, self-transformation, and what the activity leads to for the individual. Fitness is important to some people but only one part of what people get out of taking part. Different outcomes of significance for different people: mental health, social contact, challenge. "The perpetual process of growth, development, and change that reside within a person throughout their life. It is directed by goals and aspirations." (Hitch, Pépin and Stagnitti, 2014)

Becoming accomplished

Building skills, being challenged, getting better, getting good, a sense of achievement, competing. Giving things a try and building confidence as a result. Learning something new. Developing skills and capacity to support the participation of others - becoming an expert (generosity in volunteering to share passion and skills with others).

Becoming stronger

Becoming fitter, becoming stronger, often as a bonus of taking part. Fitness is not always the main driver. Being able to maintain ability, to become stronger and more capable for everyday functional activities.

Belonging

The importance of the social aspect of sport and physical activity - even more so to disabled people; a socially welcoming space for participation. "Belonging is a sense of connectedness to other people, places, cultures, communities, and times. It is the context within which occupations occur, and a person may experience multiple belongings at the same time. Relationships are essential to belonging, whether they be with a person, place, group, or other factor." (Hitch, Pépin and Stagnitti, 2014)

Feeling at home

Feeling at home when participating. Having friends and a team that feels like family. Being familiar and knowing how things work, knowing the rules.

Feeling you don’t belong

Groups that are inclusive are not always inclusive to all. Challenging to make everyone feel included. People living with mental health issues may not realise they can access some opportunities in disability sport or physical activity. Not belonging alongside non-disabled children in school, not belonging alongside people with different types of disability.

People to take part with

Participating alongside others as one of the most enjoyable aspects. Making and seeing friends. Friends and family who support participation. Being part of the social side can support confidence and motivation. Having enough people *to participate with, to compete against, building numbers. Working and bonding as a team.*

Research question B – findings for co-researcher analysis and findings day

Disconnect

There is tension from funders being removed from beneficiaries, so they do not have an understanding of the issues or the complex needs of participants. There is not a standard approach. Disconnect between the desire and possibilities for measuring outcomes.

Issues with standardisation

There are issues with using standardised tools that are common to all audiences, for example people can just tick any box for ease.

Inaccessible

Evaluation not in accessible formats for disabled people, leads to skewed data as only those who can use the tools can participate. Falling at the first hurdle in providing valuable data. Numbers and quotes are easy, but questions on attitudinal changes can be particularly difficult to understand. Standardised tools most often cannot be adapted.

Inappropriate

Questioning inappropriate for the audience. Particular issues with people with *learning disabilities or cognitive impairment, introducing concepts they may not associate with their participation. Asking about loneliness, suicide. Asking wheelchair users how much time they spend sitting or walking. Providers not wanting to ask these kinds of questions of their participants.*

Lacking sensitivity

Tools may not be sensitive enough to show change or improvement in disabled people's participation. May not take account of the complexity of external variables, barriers, and enablers to participation.

Reliance on data as a disadvantage

Disability sport and physical activity providers often can't provide the quantitative data required for an economic assessment, so can lose out on funding. Reliance on participant numbers means that smaller organisations miss out on funding to recruit further participants – a Catch 22 situation.

Complexity

Standardised tools do not reflect the realities of physical activity for disabled people. Disabled people's lives are infinitely more complex than can be accounted for in a measurement tool. There are additional barriers to participation. Just an activity being available can be a big step. People will participate in diverse and inconsistent ways. Standardised tools are not sensitive enough to show change in this picture of complexity. Influence of external variables on evaluation: enjoyment of activity can *be affected by reasons outside of the activity.*

Variability

Inclusive activities cater to people with varying conditions and varying needs. The definition of physical activity may be variable across different impairments. Organisations will access a range of funding streams, sometimes according to different impairment groups. Evaluation requirements will be variable and complex across that. Outcomes may be different according to different organisations and individuals.

Change

A sense that change is coming and being encouraged. Change in approach to funding sport and physical activities to tackle inequalities, change to evaluation approaches.

Recognition of a need for whole system change

Change required throughout the system, in both delivery and evaluation. Recognition of the need to do things differently.

Tackling inequalities

Sport and physical activity being used as a vehicle for tackling social change, to tackle social inequalities and encourage inactive people to become more active.

Sustainability

The approach to funding activities is changing. A move from short-term *funding to a more sustainable approach for change. Sustainability in provision and in evaluation approach. Lack of sustainability limits participation.*

Providers want to prove value

Delivery organisations want to have proof of the value that they see anecdotally, to have evidence to ensure their ongoing sustainability.

Drivers of change

Covid response: enabling flexibility

Flexibility was seen in provision and in funding in response to the pandemic

Recognition of evaluation issues

Measurement and evaluation challenges are widespread and frustrating. Comparative approaches are impossible. There is a need to think differently and potential for a more accessible approach. Beginning to see the value in qualitative data.

Learning to create change

Encouraging a move from accountability-focused evaluation towards a learning approach that supports change. Working with organisations as learning partners. Co-producing with disabled people to develop co-designed evaluation approaches. Moving to evaluate the why and how as well as the what.

Barriers to change / Resistance

What is holding back change?

Control

Funders have control over how sport and physical activity is evaluated. Funder strategy determines evaluation approach. Government has ultimate control over most sport and physical activity funding.

Tension

Tension between the aim of tackling inequalities and being more accessible, and accountability to funders of sport and physical activity.

Accountability

Funders still want evidence of effectiveness, with focus on outputs and value for money. Money goes where things appear to be working. A need to prove and evidence what is really happening on the ground.

An alternative approach needs evidence

Need a collective call for a new approach, to demonstrate the value of creative evaluation. However, evidence is required to demonstrate the issue and the need for an alternative approach, as some are not aware. Support for an alternative approach will require it to be based on evidence.

Research question C – findings for co-researcher analysis and findings day

Enabling access

Consideration of specific needs for accessing evaluation, including level of cognitive understanding, physical ability, and sensory impairment, such as visual impairment.

Level of cognitive understanding

Level of cognitive impairment affects the ability to understand the question and response. May be some repetition of preceding question or answers, difficulty with abstract problems and with understanding complex questions, including around personal experiences of disability. Evaluation facilitator may need to adapt questions in the moment. Requires facilitator/proxy to support and find meaning. Need to consider responder's mental capacity and how this is assessed for the provision of valid data.

Personal perception of disability

People's perception/understanding of their own disability; whether they use diagnostic terminology or labels (does this matter?) But accurate recognition of specific impairment (by self or others) enables participation in some activities and connected funding.

Sensory impairment

Evaluation tools and approaches must be accessible for people with sensory impairments.

Exploring creative approaches

Looking outside of standard approaches to meet accessibility needs. Approaches that help people with communication difficulties to share their experiences. Going beyond a standard tool or tick box to show the impact. Enabling people to have a voice and to be heard.

A toolbox

Need a variety of tools, a toolkit or toolbox, a combination of approaches that work for the different people participating. Mixed methods. A single tool will not work. Needs to be a range that is suitable for lots of different people.

Change-based approaches

Evaluation approaches that recognise and reflect change. Most significant change – what was the most important outcome for that person. Theory of change, as a process and outcome.

Demonstrating action, demonstrating value

'A picture says 1000 words'. Being able to see the action, to demonstrate what is going on and demonstrate the value. Talking or presenting to people in person, providing feedback, presenting photos and videos as physical evidence. Recording a video diary in private, not in front of others. Recognising that some people are not comfortable with appearing in photos or videos. Images and visuals are not accessible to people who are visually impaired.

Different levels of evaluation

A tiered approach to evaluation. Evaluation approaches that are proportional to the amount of funding given, the size of the project and the organization, and their capacity to undertake evaluation. Recognising the burden of evaluation.

Evaluating through talk

Informal, verbal conversation can be more accessible for some and potentially easier to facilitate after activity. Or it might be over a phone call or a chat over Zoom, or recording a video diary, although with potential technical challenges. Focus groups can be difficult in ensuring everyone has their say. Speaking in a group might be preferred but not everyone likes this. Talk might be used to create a podcast. Not limiting like written forms - you can cover a lot, and they can select what they need.

Gamification

There is potential for more innovative approaches; gamification has been trialled with young people to explore to what level they have enjoyed sessions.

Observational approaches

The necessity of proxy report with some clients. While the preference would be for the person to respond themselves, this is not always possible. Not necessarily a negative if there is a trusted person who can enable a true as possible response - preferable to no response at all. Using objects of reference and observing response. Recognising that some people do not like to be observed and feel uncomfortable when being watched.

Tech-based approaches

Accessing evaluation online, using iPads or computers. Using file formats and software to enable accessibility, for example using magnification for visual impairment.

Write or type a rhyme, a poem, draw a picture

Written formats such as surveys, questionnaires or diaries might be preferable to some. Writing an article about experiences, which could be shared. Do not need to be physically written, could use iPad or computer to type. Although for some, diary formats might seem onerous or silly. Offering a whiteboard at the end of a session to capture ideas, images, pictures, text.

Recognising the burden

Recognising the burden of evaluation for providers and for participants. Coaches and deliverers may not have the experience, capacity, or capability to collect and interpret data. Some organisations can afford evaluation support, but smaller organisations may not be able to do this. For some participants, the need to complete evaluation may be off-putting, when they are there to take part. It can be more challenging to demonstrate the how and why using qualitative responses than the what, often using numbers.

Capacity and capability

Collecting data is an administrative burden. Coaches and providers are experts in the delivery of activity, not in evaluation. May not have skills in evaluation. Evaluation needs capacity to collect and then analyse and interpret data. Some organisations may not have experience with previous funding or evaluation requirements. Larger organisations can hire additional support and expertise. Some organisations hire evaluation companies, but they can be removed from beneficiaries.

Prioritising participation

It can be a burden and off-putting to participants to complete evaluation when they are there to participate.

Showing why and how

It can be more challenging to show why and how rather than what - finding *value in qualitative data can take more time. It can be more challenging to demonstrate the how and why using qualitative responses than the what, often using numbers. Participatory approaches create an administrative burden on organisations.*

Physical and environmental considerations affecting data collection

Physical and environmental considerations for evaluation (weather, noise) affect the provision of evaluation in practice. For example, traffic noise, losing papers in the wind, or rain affecting technology used in evaluation, such as iPads.

Working together

Developing a learning evaluation partnership to work more collaboratively. Listening and understanding the audience and where they are coming from. A conversation can enable understanding. Discussions, sharing with other organisations, partnership working, learning from each other. A partnership between funders and providers towards more sustainable interventions, improving understanding of challenges, working flexibly so that evaluation can be adapted to individual needs as these are identified. Co-production and co-design.

Participatory and co-produced evaluation

Co-design of evaluation, with the end user. Inclusive and collaborative, opening up to alternative methods, including peer research. Enabling more participatory forms of evaluation for control and independence. Individuals as experts in their contexts, building their capacity and elevating voice.

Evaluation doesn't currently abide by the principle of 'Nothing about us without us'. But these approaches create an additional administrative and financial burden for organisations and take more time.

People supporting evaluation

The importance of the person delivering the evaluation: facilitator supports progress throughout, using supportive techniques such as clarifying communication challenges, being flexible to adapt or rephase questions in the moment, helping to explain concepts, using visual prompts and answering on behalf of someone else (proxy report) according to individual needs and level of cognitive understanding. Using own contextual understanding to explain or clarify concepts discussed.

Responding to leading questioning

How a questions or prompts are phrased can affect the answer given. Sometimes people will respond by repeating ideas from the question or prompt. Limits the potential for further explorations of a topic if such answers are accepted without further probing.

Appendix 10: Collaborative dissemination

Appendix 10.1: Invited presentations

Date	**Event**	**Co-researchers involved**
17/06/2021	Disability Physical Activity Impact Collective Co-Production Workshop	KO, TH, VW, BG
26/10/2022	Sport England interview on co-production and innovation	TH, VW, FM, BG
17/10/2022	Sport for Confidence team meeting	KO, BG
03/11/2022	Sport England co-production group session (follow-up from interview on 26/10/2022)	TH, BG
06/11/2022	Video/audiocast recording session	TH, VW, FM, BG
07/11/2024	Video/audiocast recording session	TH, VW, FM, BG

Appendix 10.2: Co-production workshop for the Impact Collective

Overview

The session is an introduction to co-production as a principle for good practice. The session will give participants the opportunity to discuss, debate, feedback experiences and knowledge.

Participants will have the chance to talk through what co-production means to them and highlight their own experiences of various approaches to involve beneficiaries/participants/clients etc.

Participant outcomes

- Increased knowledge of the principles of co-production, what it is and what it is not.
- Increased understanding of how principles of co-production can apply to own practice and practice of partners.

Session plan

Length: 2 hours

Session Plan	Training aids/tools	Time/facilitator
Introduction		
Introductions/icebreaker	A chance to find out more about people in the room (relationship building is a key part of co-production!)	**Liddie** 10 mins

Introduction to session and outline agenda		**Liddie** 5 mins
Ways of working/ground rules		**Bev** 5 mins
Main Session		
Present definitions of co-production and the importance of it being used/the benefits	PowerPoint presentation.	**Liddie** 10 mins
Present the key principles and values of co-production.	PowerPoint presentation	**Bev** 10 mins
Present the co-production ladder/spectrum to further develop understanding – learning what it is and how it is different to consultation, participation, and involvement.	PowerPoint presentation Discussion	**Liddie** 10 mins

Break		10 mins
Co-production in practice - What helps you and others to be involved in co-production, what works and what doesn't?' (TBC)	Discussion with Bev's group	**Bev** 15 mins
Working with diverse groups and sharing our experiences	Break out discussion with group	**Bev** 20 mins
Membership discussion – who isn't in the room?	Group discussion	**Bev** 20 mins
Conclusion		
Reflective round	Group discussion	**Bev** 5 mins

Our discussion points

Challenges

1) Nessa: Lack of certainty of the whole project and where it is going: cake and cupboard! - It is broad Pro: could choose own way Con: difficult for those who need project defined

2) Tom: Diminished responsibility of group work

3) Karen: Virtual meeting - not knowing the other people involved, who to listen to on certain subjects, harder to build relationships

4) Tom: People dominating within the group - encourages uncertainty, leads to inefficiency, aren't as many natural ways to intervene as when you are face to face

5) Karen: Not knowing where things are stored and when they have been updated

6) Nessa: Anxiety around pre-conceptions and previous experiences of group work

Pros / positives

1) Tom: Working collectively as a group rather than an individual, the benefits of working together. A space to share your expertise but allows for your thoughts and questions to be challenged in a safe space

2) Nessa: Diverse group of co-researchers gives extra credibility to the content of the project

3) Karen: Virtual meetings, practicalities, splitting tasks, more people could attend, using breakout rooms, not having to travel

4) Tom: Listening skills, mutual respect, an opportunity to be equally included

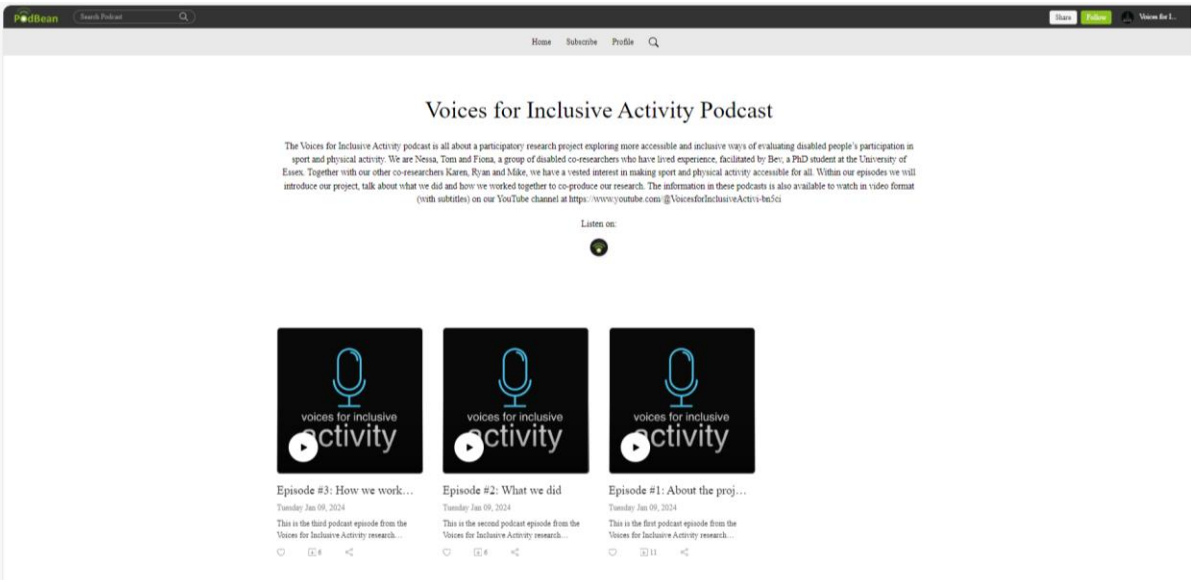
5) Karen: Having the right facilitator and how it makes a difference.

6) Nessa: Practicalities and scheduling helped involvement

Appendix 10.3 Voices for Inclusive Activity podcast series

Audio versions

Voices for Inclusive Activity on Podbean: Voices for Inclusive Activity Podcast | Voices for Inclusive Activity (podbean.com)



Voices for Inclusive Activity Podcast

The Voices for Inclusive Activity podcast is all about a participatory research project exploring more accessible and inclusive ways of evaluating disabled people's participation in sport and physical activity. We are Nessa, Tom and Fiona, a group of disabled co-researchers who have lived experience, facilitated by Bev, a PhD student at the University of Essex. Together with our other co-researchers Karen, Ryan and Mike, we have a vested interest in making sport and physical activity accessible for all. Within our episodes we will introduce our project, talk about what we did and how we worked together to co-produce our research. The information in these podcasts is also available to watch in video format (with subtitles) on our YouTube channel at https://www.youtube.com/@VoicesforInclusiveActivi-bn5ci

Listen on:

Episode #3: How we work…
Tuesday Jan 09, 2024
This is the third podcast episode from the Voices for Inclusive Activity research…
6

Episode #2: What we did
Tuesday Jan 09, 2024
This is the second podcast episode from the Voices for Inclusive Activity research…
6

Episode #1: About the proj…
Tuesday Jan 09, 2024
This is the first podcast episode from the Voices for Inclusive Activity research…
11

Episode #1: About the project | Voices for Inclusive Activity Podcast (podbean.com)

Episode #2: What we did | Voices for Inclusive Activity Podcast (podbean.com)

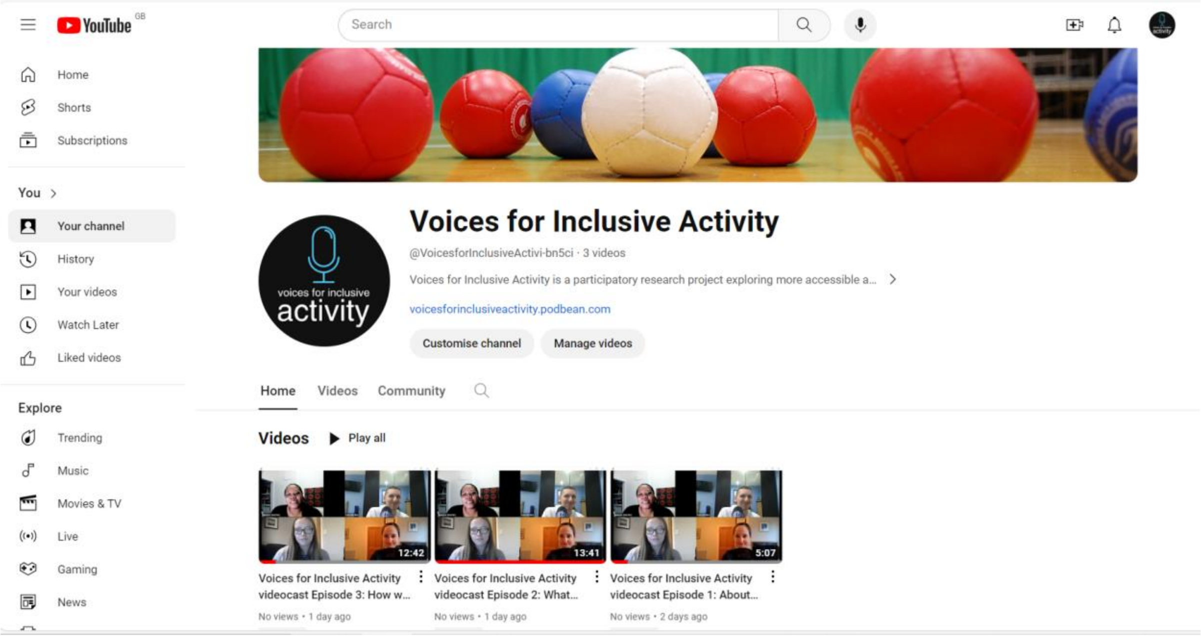
Episode #3: How we worked together | Voices for Inclusive Activity Podcast (podbean.com)

Episode #4: What we found out | Voices for Inclusive Activity Podcast (podbean.com)

Video versions

[Voices for Inclusive Activity videocast Episode 1: About the project (youtube.com)]

The Voices for Inclusive Activity YouTube Channel: [Voices for Inclusive Activity - YouTube]



Voices for Inclusive Activity

@VoicesforInclusiveActivi-bn5ci · 3 videos

Voices for Inclusive Activity is a participatory research project exploring more accessible a...

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[Voices for Inclusive Activity videocast Episode 1: About the project (youtube.com)]

[Voices for Inclusive Activity videocast Episode 2: What we did (youtube.com)]

[Voices for Inclusive Activity videocast Episode 3: How we worked together (youtube.com)]

[Voices for Inclusive Activity videocast Episode 4: What we found out (youtube.com)]

Appendix 10.4: Co-production case study for Disability Rights UK

The Voices for Inclusive Activity Project: working together to co-produce our research project

About the project

Voices for Inclusive Activity is a co-produced research project involving a group of disabled co-researchers who all have lived experience and a vested interest in making sport and physical activity accessible for all. The project is facilitated by Bev Goodman, an occupational therapist, and the project sits at the heart of the PhD she is doing at the University of Essex. For the past four years we have been working together to explore more accessible and inclusive ways of evaluating disability sport and physical activity.

Who was involved

We originally began with five disabled people and one family carer, facilitated by Bev. Although our membership has changed in the four years since we started meeting, four disabled people have been involved throughout: Karen Oldale, Vanessa Wallace, Tom Horey and Fiona Montgomery.

Key learning & outcomes

- At the moment, there are not the tools available to capture disabled people's views of taking part in sport and physical activity, because there isn't one method that would work for everybody.
- Collaboration is needed for a solution - evaluation tools that come out of this need to be developed with others to ensure they are appropriate and can be adapted.

- Collaboration has been extremely useful to help us gather a range of viewpoints, information, and to discuss topics in detail.

- Disabled people are often asked for their assistance and expected to give their expertise on projects for free. They should be recognised for the value they add to any project and reimbursed accordingly. Co-researchers in this project have been offered involvement payments as vouchers or charity donations.

- It has been a good way to bring people together and enabled us to bring the project different skills, experience levels and contacts.

Challenges

- Co-production can be difficult logistically to organise getting everyone together; especially when we started in the pandemic. The use of Zoom as a tool helps to make sure that disabled people can be involved with the project and removes any barriers associated with travel and distance. This has meant that momentum within the project has kept going.

- Involving people with different types of disabilities, e.g. learning needs. Although we tried to include everyone, the topic was difficult to maintain engagement and perhaps was a little too academic for some. It’s vital to ensure the process is enjoyable, engaging and that people’s contributions feel valued.

- Time constraints can mean that some people may be put off from being involved with the project. Support workers may be unsure/wary of getting involved. Some people can support participation; others may have different requirements. The right person, who gives the right support, can be vital to maintaining engagement.

- Having a big group, finding convenient times for everyone to get together can be challenging. Picking a regular time and sticking to it worked for us.
- Motivation: payment, reward, reimbursing - more like a job.

Advice to others

- We worked with a community gatekeeper to ensure there was a mixed group of service users to gain their views.
- Listen to others and encourage people to give opinions.
- Make use of everyone’s contacts built up in chosen subject area.
- Allow an adequate amount of time (and prepare for it to be extended).
- Don't be afraid of uncertainty - embrace it and try to think about the end goal. Clarity will be reached over time.
- Try and look around for different co-production activities throughout the research process, it’s not just a 'tick box' exercise.
- Richness of insight and bonds you make with others (sense of belonging) illuminate the projects.

Appendix 11: Funding received

Date	**Funder**	**Award**
2019 – 2024	University of Essex	Provision of fees and stipend
2019	School of Health and Social Care, University of Essex	Awarded funding towards initial scoping exercise.
2020	School of Sport, Rehabilitation and Exercise Sciences, University of Essex	Awarded funding towards initial scoping exercise.
June 2020	Elizabeth Casson Trust	Grant of £2,000 awarded towards the involvement of co-researchers, including involvement payments and expenses.

January 2022	School of Health and Social Care	Awarded £XXX to cover accommodation and travel costs for attendance at WFOT Congress 2022.
January 2022	Elizabeth Casson Trust	Conference Award of €470.00 received to cover registration for WFOT Congress 2022.

Appendix 12: Conference contributions and teaching sessions

<table>
<tr><th>Date</th><th>Organisation or event</th><th>Achievement</th></tr>
<tr><td>October 2019</td><td>University of Essex Occupational Therapy Symposium</td><td>Presented jointly with Dr Anna Pettican</td></tr>
<tr><td>July 2020</td><td>Qualitative Research in Sport and Exercise Conference, Durham</td><td>Poster accepted for presentation (conference postponed)</td></tr>
<tr><td>June 2020</td><td>HSC staff student research conference</td><td>Joint 3rd place in poster competition</td></tr>
<tr><td colspan="3">


A scoping review of the accessibility and inclusivity of tools used to evaluate disabled people’s participation in sport and physical activity

Beverley Goodman
Supervisors: Dr Anna Pettican, Dr Ewen Speed (HSC); Dr Valerie Gladwell, Dr Paul Freeman (SRES)

Introduction
A scoping review was undertaken to identify existing methods of evaluating disabled people’s participation in sport and physical activity, to explore whether existing tools are accessible to complete and inclusive, both in their relevance to disabled people and their form of participation.

Methods
The review, conducted October 2019 – February 2020, utilised a participatory approach through engagement with key stakeholders, including 5 local and national sports bodies, 6 disability sports projects, 4 national charities and 2 evaluation companies.

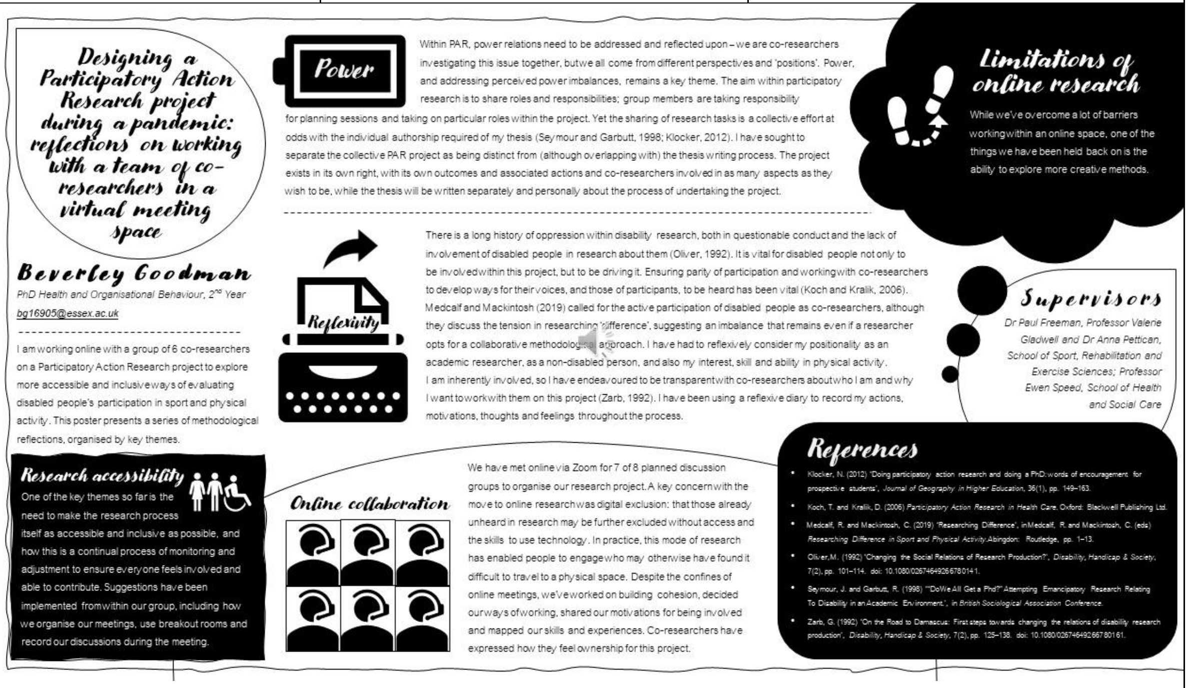
Tools used to evaluate disabled people’s participation in sport and physical activity are not accessible or inclusive

Images: Sport for Confidence

Findings
Existing tools that evaluate participation in sport and physical activity, including standardised and validated tools, are often inaccessible for disabled people to complete. For example, tools may not be in suitable formats for people with sensory impairments or learning disabilities.

Discussion
Impact is very difficult for inclusive sport and physical activity programmes to demonstrate with tools that are inconsistent, inaccessible and not inclusive. This is a disadvantage in competing for funding, which can affect sustainability, replication and growth, and result in reduced access to sport and physical activity for disabled people. This perpetuates inequalities in disabled people’s participation in sport and physical activity and has consequences in terms of health and wellbeing.

Conclusion
Suitable tools need to be identified or developed that can help inclusive sports and physical activity projects to demonstrate their impact.
</td></tr>
<tr><td>3 September 2020</td><td>British Sociological Association Sport Studies PGR Forum</td><td>Abstract accepted and presented 3-minute video followed by 3-minute Q&A</td></tr>
</table>

October 2020	University of Essex Occupational Therapy Symposium	Presentation given on 'My journey into research and innovation'
February 2021	School of Health and Social Care	Appointed as Part-time Lecturer in Occupational Therapy
22nd June 2021	HSC staff student research conference	1st place in poster competition
		
24 June 2021	British Sociological Association Postgraduate Forum: Critically Exploring Co-production Approaches	Part of 4-person ECR panel discussion opportunities and challenges in doing co-production research.

Designing a Participatory Action Research project during a pandemic: reflections on working with a team of co-researchers in a virtual meeting space

Beverley Goodman

PhD Health and Organisational Behaviour, 2nd Year

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I am working online with a group of 6 co-researchers on a Participatory Action Research project to explore more accessible and inclusive ways of evaluating disabled people's participation in sport and physical activity. This poster presents a series of methodological reflections, organised by key themes.

Power

Within PAR, power relations need to be addressed and reflected upon – we are co-researchers investigating this issue together, but we all come from different perspectives and 'positions'. Power, and addressing perceived power imbalances, remains a key theme. The aim within participatory research is to share roles and responsibilities; group members are taking responsibility for planning sessions and taking on particular roles within the project. Yet the sharing of research tasks is a collective effort at odds with the individual authorship required of my thesis (Seymour and Garbutt, 1998; Klocker, 2012). I have sought to separate the collective PAR project as being distinct from (although overlapping with) the thesis writing process. The project exists in its own right, with its own outcomes and associated actions and co-researchers involved in as many aspects as they wish to be, while the thesis will be written separately and personally about the process of undertaking the project.

Limitations of online research

While we've overcome a lot of barriers working within an online space, one of the things we have been held back on is the ability to explore more creative methods.

Reflexivity

There is a long history of oppression within disability research, both in questionable conduct and the lack of involvement of disabled people in research about them (Oliver, 1992). It is vital for disabled people not only to be involved within this project, but to be driving it. Ensuring parity of participation and working with co-researchers to develop ways for their voices, and those of participants, to be heard has been vital (Koch and Kralik, 2006). Medcalf and Mackintosh (2019) called for the active participation of disabled people as co-researchers, although they discuss the tension in researching 'difference', suggesting an imbalance that remains even if a researcher opts for a collaborative methodological approach. I have had to reflexively consider my positionality as an academic researcher, as a non-disabled person, and also my interest, skill and ability in physical activity. I am inherently involved, so I have endeavoured to be transparent with co-researchers about who I am and why I want to work with them on this project (Zarb, 1992). I have been using a reflexive diary to record my actions, motivations, thoughts and feelings throughout the process.

Supervisors

Dr Paul Freeman, Professor Valerie Gladwell and Dr Anna Pettican, School of Sport, Rehabilitation and Exercise Sciences; Professor Ewen Speed, School of Health and Social Care

Research accessibility

One of the key themes so far is the need to make the research process itself as accessible and inclusive as possible, and how this is a continual process of monitoring and adjustment to ensure everyone feels involved and able to contribute. Suggestions have been implemented from within our group, including how we organise our meetings, use breakout rooms and record our discussions during the meeting.

Online collaboration

We have met online via Zoom for 7 of 8 planned discussion groups to organise our research project. A key concern with the move to online research was digital exclusion: that those already unheard in research may be further excluded without access and the skills to use technology. In practice, this mode of research has enabled people to engage who may otherwise have found it difficult to travel to a physical space. Despite the confines of online meetings, we've worked on building cohesion, decided our ways of working, shared our motivations for being involved and mapped our skills and experiences. Co-researchers have expressed how they feel ownership for this project.

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1st November 2021	Research, Brew and Discuss: Methodology	
11th November 2021	University of Essex Occupational Therapy Symposium	Presentation given alongside Dr Anna Pettican on
25th November 2021	Newcomers Presents…	
2nd March 2022	University of Essex MSc Occupational Therapy HS895 Mastering Occupation	'Research project in a morning' workshop facilitated alongside Dr Anna Pettican, involving Service User Reference Group members
6 June 2022	HSC staff student research conference	Verbal presentation: Nothing about us without us': the challenges and opportunities of collaborative approaches to data collection and analysis
14-15 June 2022	Royal College of Occupational Therapists Annual Conference	Poster presentation: Learning from the Voices for Inclusive Activity (VIA) Project: Using digital methods to facilitate

		inclusive and accessible research
August 2022	World Federation of Occupational Therapists Congress	Research Institute 3 Minute Thesis presentation: ‘Nothing about us without us’: Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity
Goodman B (2022) *Research Institute 3 Minute Thesis presentation: ‘Nothing about us without us’: Working with disabled people to identify accessible and inclusive ways of evaluating their participation in sport and physical activity*; World Federation of Occupational Therapists Congress (Paris), 30/8/2022		

Appendix 13: Invited Collaborations

Date	**Event**	**Organiser**	**Role**
17 June 2021	Co-production workshop	Disability Physical Activity Impact Collective (DPAIC)	Worked with Lydia Bone from Disability Rights UK to co-develop and co-deliver a Co-production workshop for DPAIC members, featuring a session co-produced by three co-researchers
10th January 2022	Disabled people in sport and physical activity network event	Dr Chris Whitaker	Invited to be advisor on using co-production approaches
18th January 2022	Disability Data Sector Roundtable	UK Active	Invited as contributor

Appendix 14: Publications

Pettican A, Goodman B, Bryant W, Beresford P, Freeman P, Gladwell V, Kilbride C and Speed E (2022) ‘Doing together: Reflections on facilitating the co-production of participatory action research with marginalized populations’ *Qualitative Research in Sport, Exercise and Health* 15(2): 202-219

Goodman, B, Pettican A, Speed E, Gladwell V and Freeman P (2022) ‘Learning from the Voices for Inclusive Activity (VIA) project: using digital methods to facilitate inclusive and accessible research’ *British Journal of Occupational Therapy* 85 (suppl 8): 47-48

Goodman, B., Lera, D., Shanks, K., & Alrashidi, M. (2021). Newcomers presents... Inclusive evaluation of physical activity; Forming the next generation of sustainability hospitality leaders; Nature therapy & recovering from domestic abuse; Culture representation in EFL classes. University of Essex. https://doi.org/10.5526/newcomers_00032134

Appendix 15: Training Record

Date	Training	Provider
21/10/19	Literature search session	Subject librarian, Greg Cadge
30/10/19	What Should a Literature Review Do?	UEA/SeNSS Online Training
6/11/19	Writing effectively	UEA/SeNSS Online Training
13/11/19	Academic publishing	UEA/SeNSS Online Training
13/11/19 and 14/11/19	PhD Thesis Writing 1	Proficio
20/11/19	Writing and Structuring an Effective Thesis	UEA/SeNSS Online Training
2/12/19 and 3/12/19	NVivo workshop (second day to be repeated in March due to illness)	Proficio
6-10/1/20	Attendance at nine Newcomers research training sessions	Proficio/University of Essex library
8/01/20	Preparing impactful research proposals and grant applications	UEA/SeNSS Online Training
Autumn-Spring term 2020	HS948 Qualitative Health Research	School of Health and Social Care
22/1/20	Politics of Participation conference	Shaping Our Lives/University of Essex
24/1/20	Managing and sharing research data for transparency and fairness	UK Data Service/Proficio
30/1/20	Using Word to Build Your Thesis	Proficio
26/2/20	Co-production conference	Involve
4/3/20	A comparison of qualitative methods	UEA/SeNSS
11/3/20	Qualitative Interviewing	UEA/SeNSS
18/3/20	Analysing qualitative data	UEA/SeNSS
April/May 2020	University Time to Write 'bootcamp' sessions	Proficio
30/04/20	Participated in QRSE ECR journal club	QRSE

5/5/20	Participated in OTalk Twitter chat on research in a pandemic	OTalk
12/05/20	Virtual Co-production: is it actually possible?	from UCL Centre for Co-production
10/06/20	Undertaking Qualitative interviews in challenging circumstances	Proficio
16/06/2020	HSC staff student research conference	HSC, University of Essex
26/06/20	SRES staff student research conference	SRES, University of Essex
29/06/2020	Reaching under-represented public members in a virtual world: Session 1	Wessex Public Involvement Network
6-10/07/20	Setting up online interactive workshops quickly and productively Gather the people: an exploration of co-production and complexity Forming a co-production board In conversation with Co-production Champions	Co-Production week 2020
07/07/20	How to run an accessible online meeting (pre-recorded webinar)	Ability Net
14/07/20	Accessible Design for a Competitive Edge	Ability Net
14/07/20	UCL Virtual Co-production	UCL Centre for Co-Production
15/07/20	How to Get Published	SRES (Dr Ruth Lowry)
03/09/20	British Sociological Association Sport Studies PGR Forum	British Sociological Association Sport Studies
03/09/20	Qualitative Research Methods Symposium	UEA
29-30/09/20	NCRM Advanced Research Methods Training - Co-producing Research with Communities: Lessons from the Productive Margins Programme	NCRM

21/10/2020	Working in Partnership	National Co-ordinating Centre for Public Engagement
22/10/2020	European Conference on Adapted Physical Activity Lite	EUCAPA
Autumn term 2020	Auditing of SE768 Disability, Sport and social change	Dr Andrew Hammond
10-13/11/20	Qualitative Methods: Innovative Approaches; including a one-to-one Tutorial session with Professor Fiona Jane Dowling	University of Copenhagen
16/11/20 onwards for 4 weeks	Introduction to Co-production virtual module	Wrexham **Glyndwr** University
19/11/20	Introduction to Teaching in Higher Education	Proficio
24-26/11/20	PhD Thesis Writing 2	Proficio
25/11/20	Online lecture by Professor Dan Goodley: Thinking with Disability in a Post-Trump era	iHuman, University of Sheffield
25/11/20	Elizabeth Casson Virtual Lecture by Dr Jenny Preston: Re-engineering truth and certainty in occupational therapy	Royal College of Occupational Therapists
23/02/21	Creativity in Research webinar featuring Helen Kara	Policy Press
02/03/21	Inclusive research post COVID-19: Making it different	East of England ARC
02/03/21	Making the most of your supervisor session	Proficio
17/03/21	Participatory Ideology book launch event	Policy Press
06/04-09/04/21	Attendance at QRSEH ECR conference via Microsoft Teams	QRSEH
12/04/21	Getting the most out of your research participants	Proficio
19/04/21	Introduction to Qualtrics	Proficio
17/06/21 23/06/21 01/07/21	“Doing” PAR in Leisure Studies Virtual Webinar Series	Leisure Studies Association / Brunel University

23/06/21	Who lives and who dies? What the pandemic has taught us about health inequality	Policy Press
12 – 23 July 2021	Qualitative Data Analysis: Methods for analysing Text and Talk	ESS Data Summer School
16/11/21	Thematic Analysis: in conversation with Virginia Braun & Victoria Clarke	Sage Publications
23/02/22	Lost voices: Including adults with capacity & communication difficulties in ethically-sound research	Project ASSENT - Dr Karen Bunning & Dr Florence Jimoh
03/03/2022	Innovative methods for researching disability and Covid-19 in the Global South	University of Birmingham/Disability Under Siege
20-21/04/22	Participatory Action Research: Equitable Partnerships and Engaged Research	NCRM, facilitated by Kim Ozano and Laura Dean from Liverpool School of Tropical Medicine.
20/04/22	RCOT EDB Insights: Practising what we preach: disability and inclusion	Dr Wendy Bryant
14-15/06/22	RCOT Annual Conference	Royal College of Occupational Therapists
06/07/22	Impact Academy: Public Engagement 101	University of Essex
10/05/24	Preparing for the Viva (1:1 session)	University of Essex