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### **The *while* of participation: A systematic review of participatory research involving people with sensory and/or intellectual impairments**

Jonathan Rix, Helena Garcia Carrizosa, Jane Seale, Kieron Sheehy and Simon Hayhoe

#### **Introduction**

This article reports on a systematic study of participatory research practice involving people identified with sensory impairments and/or intellectual impairments. This review was undertaken as part of the ARCHES, an access to Heritage project funded by Horizon 2020. ARCHES involved research groups that included participants who have a diverse range of access preferences. These preferences are frequently associated with the labels of sensory impairments and intellectual impairments. At the outset of the project a broad label was proposed, “people who experience differences and difficulties associated with perception, memory, cognition and communication”; not all the ARCHES participants wished to be defined by this or any other label however. There was a collective agreement early in the project that it would be far more useful in an access to Heritage project to refer to our access preferences. Our use of the deficit labels within this paper exemplifies the manner in which our commitment to voice is compromised when we move into another arena, as does the inaccessibility of some of language in this paper.

At the outset of the ARCHES project we sought reviews which had explored the practices undertaken within the broader participatory framework; however, given their associations with particular user groups or a focus upon specific fields (in particular, health), their applicability seemed limited. There were useful overviews of the field, which provided an excellent insight into the purposes, benefits and methodological issues (eg: Smith-Merry, 2017) or offered a detailed synthesis and analysis of research with particular groups (eg: Aldridge, 2016). In these studies, processes and activities were mentioned in passing as they were neither the focus nor was there an aim to provide an overview of processes and activities.

In the context of our focus population, Duckett and Pratt (2007) updated a previous review undertaken in 1999 looking at emancipatory and empowering research involving people with visual impairment. Both originally and in their update, they noted the lack of this research and the poor quality of that which exists. In contrasting this with other categories of impairment they noted the difference particularly in relation to people with identified with learning difficulties. It was in relation to research involving people with intellectual impairments that two reviews stood out; Stack and McDonald (2014) and Nind (2008). Both are interesting studies; however, Stack and McDonald (2014) had only identified 21 studies, mainly from the UK and US and the majority of studies demonstrated no, low or low-medium levels of participation, whilst Nind’s commissioned report (2008) drew mainly on literature from the UK and was not specific about how this literature was identified or analysed. In light of this it was decided to undertake a wider systematic search and analysis

alongside a thematic review of the literature associated with participatory research involving people with sensory impairments and intellectual impairments.

In undertaking this review, we were interested in identifying activities which research groups have developed to organise and explore experiences, capture and analyse data and disseminate findings. Our concern was the practicalities of effective research processes, but we were also aware of the lack of a theoretical basis to explain the participatory nature of these processes. In seeking these practical and conceptual outcomes, our guiding question was:

*What lessons could be learned from other participatory projects to inform the development of practice in future participatory research groups?*

### **A background to the review**

The end of the twentieth century saw the emergence of a variety of research forms which involved disabled people taking an active role. Swain (1995), for example, identified six approaches that fit within a participatory framework: democratic research (Hall, 1981) which prepares people to be researchers within their own community; critical research (Comstock, 1982) and praxis research (Lather, 1986) drawing upon Freirean action research techniques to raise awareness of the form of the researchers' oppression; emancipatory research (Carr and Kemmis, 1986), which focuses upon the need for research to be accountable and open throughout to a group run by disabled people, with the skills and knowledge of researchers being at the disposal of disabled people (Barnes, 2003); co-research (Shakespeare, 1993) which examines the socio-cultural construction of knowledge through collective and self-reflection; and participatory research (French, 1993) where disabled people are actively involved in the production of research knowledge and also its selection and presentation.

A variety of other terms and forms are in evidence. Participatory action research (Whyte, Greenwood and Lazes, 1989) calls for members of a community to be involved actively in the research process with a professional researcher. In inclusive research (Walmsley & Johnson, 2003) research participants must be treated with respect by the research community and the research must deal with issues that matter to the participants; it should also lead to an improvement in their lives, and draw upon and represent their views and experiences. Perhaps unsurprisingly, Walmsley and Johnson (2003) situate Inclusive Research as encapsulating both emancipatory and participatory research in the learning disability context. The values of inclusive research align with the principles underpinning emancipatory research, which Barnes (2003) suggested describes research that has a transformative aim, through the promotion of disabled people's individual and collective empowerment and through barrier removal. Emancipatory research aims to produce accessible knowledge, using methods that are rigorous and places findings within their environmental and cultural context so as to highlight the disabling consequences of society (United Kingdom's Disabled People's Council, 2003).

Within ARCHES we determined to use the term participatory research to encapsulate our approach. We could not claim to be meaningfully accountable to disabled people (Barnes, 2008), given the funding mechanisms of Horizon 2020 and the involvement of 13 partner institutions with their diverse priorities. We could also could not respond to the call by

Seale, Nind, Tilley, & Chapman (2015) to unify under Inclusive Research, since we were also working with participants other than those labelled with learning difficulties. As Aldridge (2016) proposed, participatory research required our work to be designed with the needs of participants in mind, involving ongoing dialogue and consultation, in relationships based on mutuality, understanding and trust, seeking to enhance the participant voice in all aspects of the project. We would offer clear opportunities for participation as well as being clear about its limitations, whilst being sufficiently flexible to be used within a larger study. We would recognise that vulnerability is not a fixed identity or condition, that transformative outcomes can be in many arenas and that the data can be subject to diverse forms of analysis and interpretation. This paper is in part an exemplar of this participatory approach. The systematic search and thematic review of the literature reported here comes as a response to requests from researchers within the participatory research groups involved in ARCHES. From early on, participants had said they wanted to make sure we were taking advantage of established research and practice whilst avoiding unnecessary duplication of “what was already out there”.

### **METHOD**

The research team drew upon their experience with protocols established by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) to design a systematic search of the literature. Our keyword terms involved a two-level search strategy. Firstly, we used a range of dominant terms from recent decades (disabilities; disabled; disability; impairment; difficulty; difficulties; retard; handicap; deaf; blind). Secondly, we used a range of terms associated with research: (inclusive research; emancipatory research; participatory research), but avoided other terms which have also been applied to participatory research (such as action research, critical research and praxis research) because of their heritage beyond the field of disability studies.

We sought papers in the three main languages associated with the ARCHES project (English, Spanish and German), going back 30 years, 1996-2016. We sought to limit our inclusion/exclusion criteria to maximise the breadth of studies. The following criteria had to met for a paper to be included:

1. Must have a focus upon intellectual or sensory impairment
2. Must involve qualitative or quantitative data collection
3. Must report on inclusive/participatory/emancipatory research
4. Published after 1996
5. In English, Spanish or German

In deciding whether a paper was reporting on inclusive/participatory/emancipatory research we understood this broadly, as research directed to some degree by the participants. We also interpreted position papers, which mentioned data collection but were primarily about a separate issue, as coming under Exclusion 2 (E2).

The search took place between December 2016 and May 2017. We limited our searches to Scopus because:

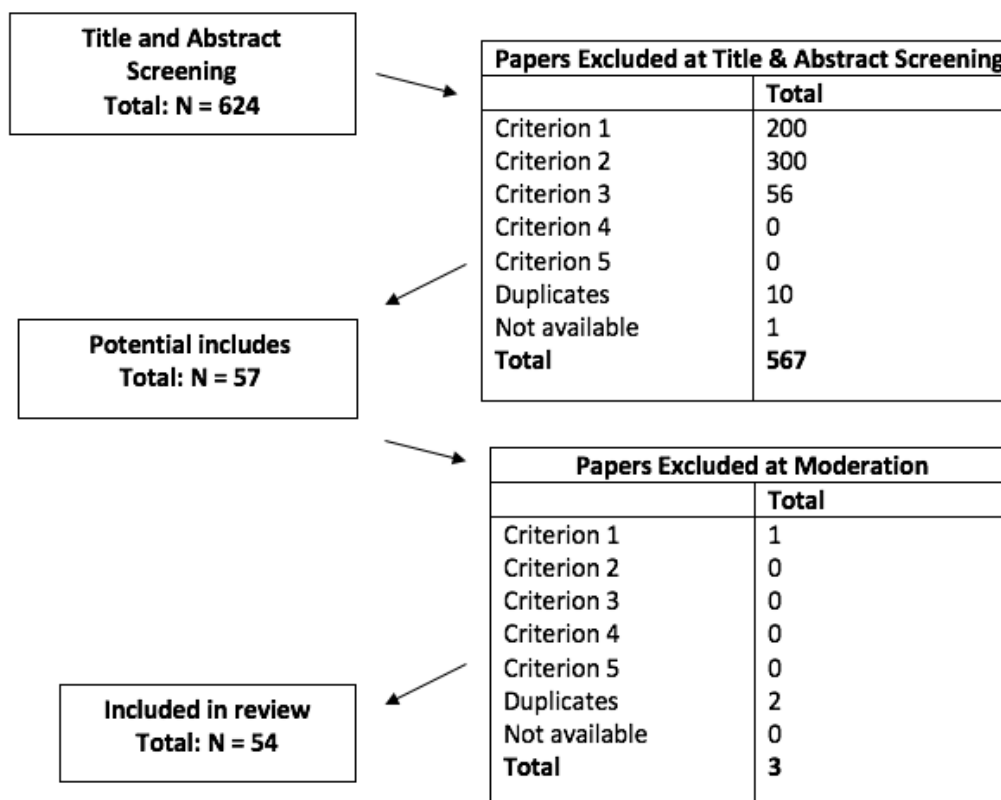
- Scopus covers nearly 36,377 titles from approximately 11,678 publishers, of which 34,346 are peer-reviewed journals in top-level subject fields: life sciences, social sciences, physical sciences and health sciences. It covers: book series, journals, and trade journals.

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- Scopus allowed us to search in different languages.
- Initial searches with Scopus had identified over 600 papers. Stack and McDonald (2014) used similar search terms across a range of databases (including PsychInfo, Medline and Google scholar) as well as 12 international journals. This process identified 110 articles. They then reviewed their reference lists and identified an additional 13 articles.
- We recognised that the 624 papers identified included the names of major figures and projects within the field.
- The time frame of ARCHES was limited and spending additional time on searches unlikely to produce additional studies seemed inefficient.

The search identified 624 papers (see Figure 1). A review of abstracts and titles was undertaken (with a skim read for clarification if required). After removing duplicates and those not meeting the inclusion criteria we had 57 studies in total. We then undertook a moderation process and all 624 papers were evaluated by a second researcher. The decisions were confirmed for 603 articles and questions were raised about 21. These articles were re-examined in detail and discussions held. Three additional papers were included, three excluded and the original decision confirmed on 15. There then followed a more detailed examination of all 57; agreement was reached to reject 3 more articles and to retain a fourth study that contributed 2 papers which examined different aspects of process. The final review included 54 papers (see References).

**Figure 1: Filtering of papers from initial searching to in-depth review**



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A three-part, data extraction and analysis process was undertaken. In phase one an overarching document was created which included all the extracted information from the papers. Information was sought under the following headings, Country, Participants, Duration, Confidence and detail, Level of Participation and Activities. We wished to be able to identify and explore who was involved, for how long and what activities and processes they were involved in during the research. As well as extracting data about the specific activities and process in evidence, we also extracted any discussion or description around them which might inform us of about their nature.

An attempt was made to evaluate the level of participation within each study. We recognised that participatory research can be described on a consultative-consumer led spectrum with an ad-hoc nature to it (Smith-Merry, 2017). We therefore understood that a one-off paper may struggle to capture and represent all that went on and where it might lie on such a spectrum. Any assessment we made on level of participation could only be a reviewer's perception. With this proviso, we presumed that a high level of participation would involve meaningful involvement at all or virtually all stages of a project. A reviewer was allowed to use low-medium, medium and medium-high to facilitate moderation discussions. Projects with a low level of participation, were those where individuals had virtually no control; such as having a group playing a minor advisory role, or participants being targets of a focus group or simply being involved in an externally-organised workshop. An assessment was also made of the level of confidence which the reviewer had in the description of research practices. Here too, judgements were to some degree circumstantial; but confidence was recognised as being closely allied to the level of detail provided. However, it was also understood that some papers could be relied upon with some confidence (for example if it had been written by people with learning difficulties) even though they did not contain a high level of detail.

After the information had been extracted (see Tables 2-4), a thematic analysis was undertaken on the data which reported on the activities and processes, using an approach drawn from grounded theory (Corbin and Strauss 2008). Through open-coding, the data were refined to identify concepts which represented aspects of that data. The relevant evidential quotations were allocated to emergent themes. If a point of saturation was reached in relation to an aspect of a theme, then further evidence was not added to the theme. Repetition, where it existed, was only evidenced if it seemed necessary to capture weight of evidence around a particular issue or if there was a nuanced difference because of the context of the study. Subsequent to the thematic analysis, the extracted information was summarised. This summary document was then further reduced and a numerical representation of the data was undertaken, followed by a re-examination of the summaries to seek patterns and to enable categorisation of findings for write up. This last phase of analysis involved a process of comparison, moving between the different summaries and the original documents to ensure that studies were being accurately represented and that appropriate interpretations were being drawn.

### RESULTS

The papers came from 27 Journals, with 32 (59%) coming from 5 journals. Studies involved 14 countries, with just over half reporting from the UK (28/54) and 9 from countries where English is not the main language. The participatory activity described ranged in length from an afternoon to 21 years. The lack of clarity in relation to duration was noticeable in many papers. Even where there was clarity, there might then be a comment about a participatory output which implied that participation continued beyond the primary study. Studies varied from 1 participant to 85, though there was frequently a lack of clarity, particularly in relation to numbers on advisory groups; there was also inconsistent reporting of demographic details, such that no meaningful summary emerged from the review. Thirty-six studies reported the involvement of participants identified as having learning difficulties, 4 involved participants identified as having a hearing impairment, 2 involved participants identified as having a visual impairment, 9 involved people identified with a mix of these labels and 3 involved an unclear population.

Overall there were 13 papers which represented high levels of participation, 35 which were at a medium level of some kind and 7 papers which were at low levels of participation (See Table 1). One paper (Simmons & Watson, 2015) reported on a study of a person with profound and multiple learning difficulties, but did so in a way which it argued maximises participation for an individual, even though they were not involved in the various stages of research in a way that many researchers would deem to be meaningful. In relation to confidence and detail, 14 papers were identified at a high level of confidence, 33 at a medium level of some kind and 10 at low levels of confidence and detail. Three papers (Flood et al, 2013, Walmsley et al, 2014; Williams & Simons, 2005) created a high sense of confidence but provided a low amount of detail. Overall 6 papers were high in participation, confidence and detail (Flood et al, 2014; O'Brien et al, 2014; Rix et al, 2010; Simmons & Watson, 2015; Walmsley et al, 2014; Williams & Simons, 2005) though two of these also fell into the contradictory categories noted above (Flood et al, 2014; Simmons & Watson, 2015). The majority of papers were below a high level of participation, confidence and detail, so any findings related to the practices and activities undertaken within each project are introduced with a note of caution. The advantage of this review, however is that in synthesising the wide range of studies it is possible to draw together a collective view of practices (See Table 2, 3, 4 – Numbers relate to code given in references).

## The *while* of participation

**Table 1: Level of Participation and Level of confidence in and detail of description of research practices**

	High	Medium High	Medium	Medium Low	Low
<b>Level of Participation</b>	13	12	15	8	7
<b>Papers</b>	9, 11, <b>12</b> , 17, <b>37</b> , <b>41</b> , 42, 43, <b>45</b> , <b>50</b> , 51, <b>53</b> , 54	2, 5, 8, 13, 18, 19, 36, 39, 40, 46, 48, 49	3, 14, 20, 22, 23, 26, 27, 30, 31, 33, 34, 35, 38, 44, 47	1, 6, 7, 7, 15, 24, 29, 32	<b>4</b> , <b>10</b> , 16, 25, <b>28</b> , <u>45</u> ,52
<b>Confidence &amp; Detail</b>	14	5	19	9	10
<b>Papers</b>	<u>12</u> , 14, 15, 18, 26, 32, 33, 37, 40, 41, 45, 47, <u>50</u> , <u>53</u>	2, 9, 21, 44, 46	1, 7, 8, 13, 17, 19, 22, 24, 25, 29, 31, 34, 35, 36, 38, 39, 42, 48, 54	3, 6, 11, 16, 20, 23, 30, 51, 52	4, 5, 10, <u>12</u> , 27, 28, 43, 49, <u>50</u> , <u>53</u>

Table 1 note: Bold within participation is high in participation, confidence & detail or low in both; Underline is a paper which creates a dichotomy and is both high and low in relation to participation or in relation to confidence and detail.

Table 1 & 2 Key: Aldridge, 2007 [1]; Bigby & Frawley, 2010 [2]; Bigby et al, 2014 [3]; Brooks et al, 2013 [4]; Chin et al, 2013 [5]; Cluley, 2017 [6]; Conder et al, 2017 [7]; Cook & Inglis, 2012. [8]; Dias et al, 2012 [9]; Draffan et al, 2016 [10]; Erdtman et al. 2012. [11]; Flood et al, , S., Bennett, 2013 [12]; Fudge Schormans, 2014 [13]; Garcia-Iriarte et al, 2009. [14]; Gates & Waight, 2007 [15]; Greenstein, 2014. [16]; Grundy et al, 2005 [17]; Haak et al, 2015. [18]; Haigh et al, 2013 [19]; Herron et al, 2015. [20]; Higginbottom et al, 2014 [21]; Hodges et al, 2014. [22]; Keyes & Brandon, 2012. [23]; Koenig, 2012. [24]; Kramer et al, 2013. [25]; Kramer, et al, 2011. [26]; Lutz et al, 2016. [27]; MacDonald, 2016.[28]; Malling, 2013. [29]; McKee et al, 2012. [30]; Morgan et al, 2013. [31]; Nicolaidis et al, 2015. [32]; Nind & Vinha, 2016. [33]; Nind & Vinha, 2014. [34]; Noell et al, 2016. [35]; Northway et al, 2014. [36]; O'Brien et al, 2014. [37]; Povee et al, 2014. [38]; Raymond & Grenier, 2015. [39]; Richardson, 2002. [40]; Rix et al, 2010. [41]; Rogers et al, 2016. [42]; Rome et al, 2015. [43]; Schleien et al, 2013. [44]; Simmons & Watson, 2015. [45]; Stevenson, 2014. [46]; Strnadovva et al, 2014. [47]; Tarleton & Ward, 2005. [48]; Tilly, 2013. [49]; Walmsley et al, 2014. [50]; Watson et al, 2014. [51]; Wickenden & Kembhavi-Tam, 2014. [52]; Williams & Simons, 2005. [53]; Young & Chesson, 2008. [54].



## The *while* of participation

**Table 2: Activities undertaken within review, including study in which identified**

Activity Type	Eg: Study	Activity Type	Eg: Study
Activities in context	14	Poetry workshops	22
Action planning	53	Poster development	35
Agenda days	43	Practice questioning	48
Board games	15, 16	Presentations	25, 26, 30, 51
Cycles of sharing skills & knowledge	31	Prioritising flash cards	37
Define questions	37	Problem picture stories	52
Editing dvd	43	Questionnaire trials	7
Exploration of issues in data	42	Question creation	54
Expression through dance	29	Question formation	47
Fictionalised accounts of collective realities	39	Reflections	49
Film clip stimulus	35	Refreshments	15, 18
Finding & scanning photographs	50	Reminiscence materials	9
Group discussions with visuals	35	Role play	51
Group dynamic & open space exercises	24	Round robin	14
Grouping concepts	46	Scenarios	54
Improvised drama	16	Selecting data collection priorities	29
In session analysis	36	Sensory object	32
Interactive activities	43	Session feedback with emoticons	52
Invited experts	18	Some analysis	35
Learned about questionnaires	12	Sorting documents	50
Learning technological skills	50	Standard research development	21
Making models of people and places	16	Survey development	25
Meeting review	32	Tactile circles of closeness	52
Member check	39, 41, 44	Talking mats	52, 54
Memory lane sessions	50	Thematic analysis -importance relative to inner square	37
Observation	31	Thematic data analysis	21, 24, 46
Ongoing analysis	23	Training	37
Oral introductions	33	Training course	9
Paired activities	51	Training for research	48
Participant verification	5, 8, 18, 19, 20, 23, 46	Training for research skills and assistive technologies	47
Participant-observer-led discussion	41	Transcription	9, 37
Pathway representation (wallpaper with blu-tacked targets)	53	Trialing of video & cameras	41
Peer debriefing	39	Turn taking activities	15
Photographs taken by/with participants and discussed.	1, 6, 38, 44	Video recording	16
Photoshop	13	Video scenarios	8
Piloting	37	Video vignettes	15
Playful metaphors	33	Vignettes	45, 52
		Working with artists	39

**Table 3: Approaches to support communication and research**

Aimed at generating ideas and conversation	Aiming to move beyond the constraints of everyday communications	Communication strategies;	
Watching film clips; Undertaking paired activities; Examining photographs; Vignettes; Playful metaphors; Sensory objects problem picture stories; Memory lane sessions; Oral introductions; Expert's presentation	Drama; Poetry; Dance Photography; Working with artists	Pre-meeting activities; Provision of pre-information; Pre-visits or pre-meeting discussions; Preliminary discussions at start of meeting to frame processes; Help cards to express a need for support Help cards to provide reminders; 5-finger clarification; Reading support; Reading aloud	
Approaches to collecting data		Approaches to analysing data	
Focus Groups; Ethnographic study across contexts involving discussion with significant others; Interviews; Biographical interviews; Interviews using photographs (inc Photovoice approach); Questionnaires; Visual questionnaires; Surveys; Likert scales using emoticons (to collate information at the end of sessions); Photography; Video recording; Research diaries		Participant verification of findings as part of the working process; Verification from a critical friend; Questioning frames; Weighting; Sorting; Ranking; Coding; Highlighting; Checking through revisiting experiences, ideas & images.; Transcription;	Participant as transcriber; Frequency analysis; Populating a database; Negotiation; Conversation; Analysis meetings; Discussion of photographic evidence; Sorting documents; Thematically analysing materials; Debriefing; Member checking
Approaches to sharing findings		Alternative outputs	
Traditional research outputs; Conference presentations; Exhibitions; Open days; Final events (including the use of signing support); Easy read, plain English or accessible reports		American Sign Language; Video blogs; Photo novels; Newsletters; Comic strips; i-poems; Video; Photobooks; Dance performance	

**Table 4: Tools, actions and mechanisms to support organisation and access of meetings**

<b>Mechanisms for organising meetings</b>	<b>Tools for managing the process of meetings</b>	<b>Actions specifically targeted at controlling the flow of meetings</b>	<b>Supports for process</b>
Training; Sharing of knowledge; Practising questioning; Trialing equipment; Creating questions or agendas	Graffiti walls; Drawings; Diaries; Lists,; Notes; Photograph records; Public images; Concept mapping; Timelines; Flip charts; Noticeboards; Whiteboards; Notecard; Mind mapping; Post-it notes; Post cards; Slide shows; Video calls; Web; Tele-conferencing; Digital recorders; Microphones; Accessible information and consent documents; Easy to visualise and read materials; Meeting checklists	An agenda; Voting; Planning groups meeting notes/summaries; The use of pacing strategies; A timer; Agreed session etiquette and rules; Themes for meetings; Single idea questions. Identifying people to play particular roles within a session; Circle leaders; Collaborative leaders for a group; Meeting process monitor,; Agreed approach to the involvement of support staff	Visual rules; Visual materials agenda template; Topic guides; A picture consent booklet; Accessible interview booklet; Pictorial interview guide; Analysis sheets; Answer scales and large grids with emoticons; Trigger questions; Workbooks to guide questionnaire production; Facilitators tool kit, photo and picture symbols; Picture based-review sheets; Prompt cards; Prompt questions question frames; Scaffolds; Think aloud protocol; Statement cards; Drawings alongside text; Easy read information and protocols; Large print; Printed and read transcripts.
<b>Tools for collective recording of ideas</b>			
Bullets on a large sheet; Coloured stickers for preferences; Dot scales; Coloured tagging; Flip charts and post-it notes Shared transcripts			

### Organising and supporting process

Within the papers it was hard to clarify the difference between many of the approaches; activities may have looked the same but have been labelled differently or used the same label to describe different practices, or simply not been described in enough detail. However, in synthesising these partial perspectives there was evidently great diversity in research groups' ways of working (see Tables, 2, 3, 4). This diversity posed a genuine challenge to the working processes of the research groups; creating, practical and moral questions that are often absent or are a far lower priority for researchers working with other populations.

The most obvious barrier was that the primary medium for the activities was speech. By its very nature speech is not an access preference for many participants. Papers therefore described processes which were leading to or intended to enable discussion. Across all the studies were a variety of actions to support this communication. Often there was mention of individualised support and support for presentations and at events; rarely did papers talk about the provision of Sign language interpreters or sign supported communication and there was no mention of using Note Takers or Palantypists. There were numerous activities aimed at supporting analysis, discussion and communication (see Table 3). Some sought to generate ideas and conversation, though this also included more passive roles where people simply listened to someone talk. There were also activities seeking to move beyond the constraints of everyday communications, often involving a creative approach. More generally there were activities that focused upon development of skills and capacities and activity related to the analysis of data. This underlined the relative weight of priorities in the research process and the reality of professional privileges. Erdtman et al, 2012 and Haak et al, 2015 reported on the use of idea-circles and research-circles which had the specific intention of generating priorities and outlines for research. A more frequent response was the establishment of a steering committee or some such structure. This provided an advisory overview to the project, offering expertise, helping to frame issues and acting as gatekeepers to the target population. Fourteen papers referred to a group commissioning research, an advisory/steering/reference board/committee/group or a consultation/scoping meeting. However, these papers provided very little to guidance about how best to set up and run such committees, nor ensure representation upon them, so that they reflect the concerns and priorities of the intended participants.

Activity to support two key research processes was particularly apparent in the review: data collection and data analysis (see Table 3). Most data collection processes were qualitative in nature, with far fewer projects sitting within a quantitative paradigm. This reflects the 'nothing about us without us' mantra of many within the disability movement, and a focus upon people's experiences of life situations. The underpinning principle was collective engagement with an issue. From the 54 papers only 2 made no mention of a collective engagement with a group, and one of these was the ethnographic study with a person identified with profound and multiple learning difficulties. However, even though it is fair to say that participatory research involves collective research processes, often it was hard to tell to what degree participants had been involved in the creation and delivery of such approaches. It was also evident that the success of many approaches was partial and very much dependent upon the participants' priorities, whether they matched that of the research, and the degree to which their access preferences were being responded to.

The involvement of participants within data analysis was less in evidence, but once again there was a clear collective approach to the focus upon data. This nearly always involved some kind of thematic analysis. Generally, an academic researcher would undertake a first stage data analysis and the participants would then sort the emergent themes; or inversely the participants would undertake an initial thematic sweep and the academic researchers would then undertake a next stage of analysis. Some papers recognised this partial participation. Those that focused upon this issue, represented it as the consequence of research priorities and resources, alongside participant preferences and skills.

The barrier was evident too in the approaches and outputs involved in sharing of findings (see Table 3). The use of accessible formats was not evident in all studies but was more commonplace than setting the research question and analysing the data or representation of diversity in materials. It was hard to be certain how many of the papers were written by participants or the part which participants played if they were named on the papers, as this was frequently not clarified within the text. Many of the outputs represented the views and experiences of participants, but were not produced by the participants themselves (e.g: accessible reports, I-poems, comic strips or video). Even if these outputs could be accessed by those involved in the research and may coherently re-present their words, ideas or work, it is debatable about whether they represent a participatory output.

The drive to overcome these barriers was evident in mechanisms related to organising the range of research meetings. As well as frequent mention of accessible spaces, there was evidence of many tools, actions and mechanisms intended to support their organisation and accessibility, with a strong focus upon the visual (see Table 4). These were constitutive activities, that created and defined the identity of the groups whilst at the same time being created and defined by that group. They reflected their agency and the nature of their participation in the overall project. These tools played a key role in managing the process of the various types of meetings across the review. But there were also actions specifically targeted at controlling the flow of meetings. These included traditional research and organisational processes, but they also included more nuanced actions clearly directed at resolving the real or perceived challenges of working with a specific set of access preferences when seeking to achieve certain research goals.

### **Emergent Themes**

Three overarching themes emerged from the synthesis of descriptions within the 54 papers of activities and processes. These were: *underpinning tensions*, *meaningful outcomes* and the *component parts* (see Table 5 – numbers relate to codes given in references). The underpinning tensions were representative of issues of *power*, *voice* and *support* within each study. These tensions were evidenced through the meaningful nature of outcomes, which were described as *representing lives*, *moments of learning* and *value to selves*. These emerged through the practicalities of participation, its *component parts*.

**Table 5 – Evidence base for the underpinning tensions, meaningful outcomes & component parts**

<b>Tensions</b>	
<b>Power</b>	1, 2, 3, 4, 6, 7, 8, 11, 13, 14, 15, 16, 17, 18, 19, 21, 22, 24, 25, 26, 27, 29, 32, 35, 38, 39, 47, 41, 42, 53
<b>Voice</b>	1, 7, 8, 15, 17, 20, 22, 24, 25, 26, 32, 33, 35, 40, 41, 43, 50, 52
<b>Support</b>	2, 3, 6, 8, 9, 14, 22, 23, 26, 27, 35, 37, 41, 43, 44, 45, 51, 53
<b>Outcomes</b>	
<b>Value to selves</b>	2, 4, 6, 8, 9, 10, 12, 15, 16, 19, 20, 22, 29, 32, 35, 38, 43, 51, 52, 53
<b>Moments of learning; (General claims)</b>	8, 19, 12, 20, 22, 24, 37, 45, 46, 47, 48, 50; (1, 16, 24, 25, 29, 47, 52)
<b>Representing lives</b>	1, 2, 6, 8, 12, 13, 20, 21, 22, 24, 26, 33, 35, 39, 40, 44, 45, 46, 50
<b>Component Parts</b>	
<b>Time</b>	3, 7, 8, 9, 12, 14, 15, 17, 20, 32, 33, 36, 37, 38, 40, 41, 42, 44, 45, 46, 48, 50, 51, 52, 53
<b>Enjoyment</b>	2, 4, 6, 8, 16, 19, 22, 29, 52
<b>Roles</b>	3, 6, 7, 21, 26, 42, 44, 46, 47, 51, 53
<b>Flexibility</b>	2, 3, 15, 33, 38, 47, 51, 52, 53
<b>Beliefs</b>	1, 2, 5, 9, 10, 13, 15, 29, 31, 40, 44, 47, 52, 53
<b>Adaptation</b>	1, 2, 11, 17, 25, 29, 30, 31, 35, 41, 47
<b>Space</b>	3, 15, 17, 18, 26, 39, 43, 46, 54
<b>Languages</b>	1, 2, 3, 8, 9, 12, 13, 15, 17, 18, 19, 20, 21, 22, 24, 26, 29, 30, 32, 35, 37, 38, 40, 41, 44, 46, 47, 50, 51, 52, 53
<b>Listening</b>	1, 7, 8, 15, 17, 20, 22, 24, 25, 26, 32, 33, 35, 40, 41, 43, 50, 52
<b>Relationships</b>	2, 9, 14, 15, 17, 21, 24, 30, 32, 33, 38, 40, 41, 42, 45, 48, 50

Table 5 Key: Aldridge, 2007 [1]; Bigby & Frawley, 2010 [2]; Bigby et al, 2014 [3]; Brooks et al, 2013 [4]; Chin et al, 2013 [5]; Cluley, 2017 [6]; Conder et al, 2017 [7]; Cook & Inglis, 2012. [8]; Dias et al, 2012 [9]; Draffan et al, 2016 [10]; Erdtman et al. 2012. [11]; Flood et al, , S., Bennett, 2013 [12]; Fudge Schormans, 2014 [13]; Garcia-Iriarte et al, 2009. [14]; Gates & Waight, 2007 [15]; Greenstein, 2014. [16]; Grundy et al, 2005 [17]; Haak et al, 2015. [18]; Haigh et al, 2013 [19]; Herron et al, 2015. [20]; Higginbottom et al, 2014 [21]; Hodges et al, 2014. [22]; Keyes & Brandon, 2012. [23]; Koenig, 2012. [24]; Kramer et al, 2013. [25]; Kramer, et al, 2011. [26]; Lutz et al, 2016. [27]; MacDonald, 2016.[28]; Malling, 2013. [29]; McKee et al, 2012. [30]; Morgan et al, 2013. [31]; Nicolaidis et al, 2015. [32]; Nind & Vinha, 2016. [33]; Nind & Vinha, 2014. [34]; Noell et al, 2016. [35]; Northway et al, 2014. [36]; O'Brien et al, 2014. [37]; Povee et al, 2014. [38]; Raymond & Grenier, 2015. [39]; Richardson, 2002. [40]; Rix et al, 2010. [41]; Rogers et al, 2016. [42]; Rome et al, 2015. [43]; Schleien et al, 2013. [44]; Simmons & Watson, 2015. [45]; Stevenson, 2014. [46]; Strnadovva et al, 2014. [47]; Tarleton & Ward, 2005. [48]; Tilly, 2013. [49]; Walmsley et al, 2014. [50]; Watson et al, 2014. [51]; Wickenden & Kembhavi-Tam, 2014. [52]; Williams & Simons, 2005. [53]; Young & Chesson, 2008. [54].

### **Underpinning tensions**

By looking across the studies it is possible to get a broader sense of what these ways of working might be and the tensions that underpin them. At the heart of much discussion of practice was the issue of power, and the capacity of participants to make individual and collective decisions about the structures, topics and outcomes of what is produced and how it is used. Studies recognised that they were rarely led by participants. But they also questioned how one can 'hand over' power. People need to recognise the potential power they have and be willing, comfortable and have the time and capacity to use it. In this way, power needs to be learned and facilitated. Power negotiation cannot be about a singular action. This points to the need for ongoing questioning, with time being given to developing voice and relationships, and people being honest about their experiences.

At the core of participatory relationships was the need to listen. Talking together and spending time in people's company allows you to hear other perspectives, to see if participants feel represented, respected and have opportunities to participate, as well as hearing those who are saying "no" to research. This is not without challenges. For example, contradictory voices emerged, as did communication differences that caused an impasse, frustration and fatigue. Studies reported a need to continuously evaluate, recognising that those who speak more than listen will lack trust and rapport.

Supporting people to be heard was as important as supporting their understanding and physical access. Support came in many forms, but at its heart was collaboration and mutual support built around peers. Projects recognised they must not underestimate the support that individuals may require, as once underway it could be very challenging to get additional resource. The role of the supporters had to be clear to all. They were frequently interpreters, go-betweens or gatekeepers and so they needed to want to be involved. However, groups needed to be aware that supporter's priorities can clash with participants', and it was not uncommon for them to have limited aspirations and ambitions on behalf of the group. Supporters needed to recognise that the process of learning is not one way, and the importance of having high expectation about what will be achieved.

### **Meaningful outcomes**

The degree to which those tensions of power, voice and support were played out in a positive participatory manner depended upon the meaningful nature of outcomes. Across the 54 studies the dominant outcomes appeared as the value of the project to the participants themselves, the moments of learning which emerged and the capacity of projects to represent the lives of participants. Nearly a quarter of projects talked in some way about payments or reimbursing participants for travel or with food. However, more typically, the development of new skills and a sense of involvement and enjoyment were claimed as primary motivation. The achievement of participation was evident in the understanding which emerges, in moments of learning. This learning may impact upon supporters' or individuals' relationships within the group or beyond. It may be a realisation amongst the organisers about what is emerging or it may be evident in people's agency, their developing skills and ideas, their actions or in the things they produce. It was also closely linked to their capacity to represent the lives of others and those involved within research. It involved asking if perspectives come from the participants themselves, moving beyond description and avoiding using language and ideas that marginalised them. Some

claims were also quite general in nature and were more of a belief about outcome than a conclusion which was based on evidence. People often recognised such limitations in their work, particularly in relation to how participatory it was and in considering its possible future impacts on research and practice.

### **Component parts**

Evident across the thematic analysis were practicalities of participation; these components parts were identified as languages, roles, attitudes, adaptations, enjoyment, relationships, time, listening, beliefs, flexibility and space.

Underpinning nearly all the participatory projects was a focus upon language. Participants had to be attentive and involved in discussion, such that some projects required certain language skills of those involved. There was a belief among some too that participants were limited in their ability to interpret data that had been collected and that the way in which findings were expected to be presented also excluded many participants. To deal with the challenge of language, studies talked of accompanying people on an experience and creating collective records of experience, using imagery and alternative forms of expression, adapting their language and reflecting upon all aspects of one's communication and other people's communication preferences. The tensions between research approaches reflects attitudinal variations across studies. Some projects seemed to feel comfortable defining participants categorically, whilst in other there was also resistance to generalising across a population.

Evidently studies also needed to recognise that people change across the life of a project, in terms of their communication preferences, roles and identities. The need for change also reflected the degree to which a study tried to adapt the researcher or the process. Studies may have required developing particular knowledge and skills but the need to train could disempower a person. Participants may not have shared interest in components of the academics' research; not appreciated the limits of research; or have had bad experiences of research in the past. This is one factor in why studies needed to build relationships within groups and a wider community. These relationships both created and were created by trust, honesty and consideration and developed rapport, respect and commitment, whilst helping engagement with other people's ideas. These characteristics needed to be planned for. Relationships were complex; they were sites of discord and anger as well as harmony. They changed across the life of a project and could absorb significant resources, energy and emotion. This was a key reason for managing the space where people could share and discuss ideas. Evidently this involved places people enjoyed, formal and informal spaces that were familiar and accessible. Access was more than a physical issue; it was an ongoing process that requires flexibility and listening. It involved tolerating uncertainty, sharing control and not being overly wedded to a schedule, topic or approach. There needed to be the space for new ideas to arise from reflective practices in ways that suited all those involved; responding in the moment, not on the basis of presumption. All this took time. Time was important for understanding the background and relationships within a group; allowing for rapport, trust and dispersed power to be established; and allowing for the shifts in involvement that occur across an extended period. Many processes were also time consuming, and the time required limited the amount of real participation and reduced the amount of activity. The need to plan and organise events to overcome these difficulties was



also time consuming. But, it was recognised that organisational issues should not over-ride the need for enjoyment and enjoyment's capacity to reflect accessibility and enhance motivation. For some participants success was measured by the enjoyment of sessions more than the outcome of the project, and the many forms which enjoyment may take.

### Discussion

As noted by Duckett and Pratt (2007), the field of participatory research is dominated by projects involving people identified as having learning difficulties (59%). Perhaps surprisingly, the next most common grouping was people with a wide variety of access preferences (16%), and the least represented was people with a visual impairment. Although English speaking countries dominated, with the UK providing just over half of the studies, there was strong evidence that participatory approaches are being increasingly adopted across countries. Of particular importance given concerns expressed in the review about accessibility to journals, is the extensive list of journals that were willing to publish this methodology, and although 5 journals dominated the list, 22 others had published at least one article in the last 30 years. Papers rarely provided a thorough level of detail in relation to their methods, however; so, whilst one paper gave considerable detail about its sample, it might be light on detail about working processes; and where one gave more detail on process it might give less about its sample or overall project structure.

Stack and McDonald (2014) rated just over 28% of their studies to be high in participation, whilst across this current study the overall figure was slightly lower (24%) but in the same range. A slightly higher percentage (25%) chose to have some kind of advisory group, however there was virtually nothing in the literature discussing how best to set these up and work with them, apart from in relation to idea/research circles. Participatory research is primarily qualitative, involving collective processes and diverse approaches to communication. The dominant form of data collection was focus groups, followed by interviews, with over 75% of studies using imagery as key means of supporting communication. Involvement in data analysis was evident in just under 35% of studies, though nearly half of this related to participant verification, supporting the findings of Nind (2008). Typically, analysis rested with the academic but evidently it did not need to do so. This was a decision made by those research leads. Similarly, the writing up of studies was primarily undertaken by academics, with their lead also evident in alternative forms of output. The recognition of the value of alternative forms of communication were evident across the studies, however the primary medium was still speech, with the alternative forms supporting this medium.

There was inconsistency across the review, in the manner in which activities were described and their effectiveness discussed. There were numerous examples of an activity being listed but not described in any detail. However, in synthesising these partial perspectives there was evidently great diversity in research groups' ways of working, more than might be typically found in other fields of study (see Tables 2, 3, 4). Activities could also serve a variety of functions at the same time or be used for different purposes. Across the 54 studies activities fell into 7 broad categories:

- Accessing information
- Capturing ideas

- Expressing ideas
- Analysing information
- Developing skills
- Building relationships
- Organising process

Practical everyday tools of the kind used in many meeting and teaching situations dominated the activities. Often there was a creative framework around these everyday tools but with little mention of 'special' approaches or materials. The creative approaches generally related to preparatory work and developing simple ways to express and record people's ideas and experiences, particularly in a collective context. This linked to a strong emphasis on working in ways that fitted with people's communication preferences and of creating processes that enabled all of these preferences to have a place within the group situation.

Despite inconsistencies in the practices across these studies, the thematic overview suggested a theoretical understanding of participation within them. The underpinning tensions were representative of issues of power, voice and support within each study. These tensions were evidenced through the meaningful nature of outcomes, which were described as representing lives, moments of learning and value to selves. These outcomes emerged through the ongoing and continuous practicalities of participation, as it is experienced, through its component parts. This overarching explanation can be seen as the *while* of participation.

### **The *while* of participation**

The *while* of participation involves the underpinning tensions around power, support and voice, whose participatory nature are evident in the learning, value and representation which emerge and constructed through the practicalities of participation. These components parts emerge and are constructed though

- shifting language, roles and attitudes
- a capacity to adapt practices and spaces that emerge from and enable relationships
- a recognition of the need for being flexible, taking time, and for people to enjoy themselves.

The underpinning tensions, outcomes and component parts can be seen as multiple interactions which create and are created by participation. They are of the kind evident in an Escher painting (see Figure 2), they lead both upward and downward, inward and outward, forward and backward and may be both positive and negative. These moments and interactions form around each other, but they are also the layers through which we can understand the activities identified within the review and people's experiences of them. They are a wave and a particle, a flow from many directions which means any singular moment is more than a sum of preceding moments.

Figure 2 – The tensions, outcomes and component parts within the *while* of participatory research



The notion of the *while* of participation fits with the recognition of the participatory research space between researchers, people with learning disabilities and practitioners as a “messy space” (Seale et al, 2015). It recognises that participation is a personal trajectory across contexts of social practice (Dreier, 1999). As suggested in Nind and Vindha (2014), when people work together they give preference to formalised or improvised approaches, variously drawing upon plans and rules or in-the-moment responses. We recognised too, the need to consider the moments of participatory research within the context of planned and unplanned responses situated both in the short and long term (accepting their relative nature), constituting and constituted by the components, outcomes and tensions. But planned or unplanned, across the 54 studies, multiple interactions were evident, that were responsive (or not) to the participants’ need. This is the *while* of participatory research. It is the experience that occurs while the group and a participant are in the moment and it defines their experience of that moment; the experience that emerges from and creates the boundaries in which people find themselves. It is both a physical and personal experience, socially created from the collective resources, understandings and interactions. When we consider any activity from the 7 broad categories which emerged from the review, the multiple interactions of participation will be happening *while* the activities are - through them, within them and around them. This perhaps explains how some research undertaken in the name of participation can lack any genuine participatory involvement, despite obvious goodwill and aspiration. It perhaps also explains why other studies can engage fully with various participants whilst reflecting so honestly upon their own limitations. Perhaps it also reflects what Barnes said of emancipatory disability research (2003), that in its widest sense, we need to conceive it as an ongoing process.

### Conclusion

This literature review set out to answer the question: *What lessons could be learned from other participatory projects to inform the development of practice in future participatory research groups?* It examined 54 papers in detail, identifying a range of practices which are prevalent within the field. In drawing upon a wider evidence base than previous reviews it confirms many of their earlier findings, but expands upon them and provides a coherent overview for developing practice. It is the first systematic overview of participatory practice involving people identified with sensory impairments and/or intellectual impairments and clearly explicates its key practices and characteristics, providing an original theorised framework for considering activity within this field of research.

Participatory research literature is dominated by work with people identified as having learning difficulties, which has taken place in English speaking countries, but this must not be seen to define its nature; it largely reflects the priorities of researchers, funders and publishers. Its use is evident across nations, across groups of individuals and across extended periods of time. Despite the access preferences of many possible participants, participatory research is dominated by speech, supported by a use of imagery, and remains largely (but not entirely) under the control of the funders and academics who set up projects. Studies often lack detail but there is an evident mix of practical everyday tools within a creative framework which seek to access and analyse information, capture and express ideas, build relationships and organise process. Participation is experienced as part of the tensions, outcomes and components within the interactions of research. The participatory nature of these research activities is happening *while* the activities are; participation and activity are inextricably linked. Participatory practice is therefore not about activity type but the manner in which all activity is undertaken.

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## The *while* of participation

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