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Emergent analysis and dissemination within participatory research

By

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Introduction

It is widely recognised that within participatory research projects in which disabled people are the focus they are excluded from most data analysis and much of the dissemination. This article reports on theoretical understandings which emerged from four participatory research groups in three countries (Austria, Spain & the UK), and a systematic literature review which arose from this project. It identifies that within most participatory research the dominant processes of analysis and dissemination have inherent in-research access barriers that work against participation, however an alternative approach is also evident. This paper explores an emergent participatory process of analysis and dissemination which was evident in both the projects and the systematic literature review.

Background

This paper reports on findings which emerged from XXXXXX, a Horizon 2020 funded project involving heritage and technology partners across Europe, which established four participatory research groups within the UK, Spain and Austria. These groups were created as part of the aim to enhance museum accessibility. Over 150 people have attended these groups, with regular attendance of between 15-25 in each. These research groups involved participants who have a diverse range of access preferences (cite Helena's paper). These needs 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 to subsequently refer to us as having access *preferences* (eg: audio-description, signing, subtitles, easy-read, sensory objects). 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 the language in this paper. As we will discuss later, this is a funneling effect.

Participatory research emerged at end of the twentieth century, amongst a variety of research forms which involved disabled adults taking an active role. Swain (1995) talked of six approaches that fit within a participatory framework. He discussed democratic research (Hall, 1981) which prepares people to be researchers within their own community; critical research (Comstock, 1982) and praxis research (Lather, 1986) which raises awareness of the form of the researchers' oppression; emancipatory research (Carr and Kemmis, 1986), which focuses upon research that is accountable and open throughout to a group run by 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. Other terms and forms are also in evidence, for example participatory action research (Whyte, Greenwood and Lazes, 1989) which calls for members of a community to be involved actively in the research process and

inclusive research (Walmsley & Johnson, 2003) which encapsulates both emancipatory and participatory research in the learning disability context.

Within XXXXXX project we determined to use the term participatory research. As Aldridge (2016) proposed, our work was 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 sought to 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.

Analysis and dissemination in participatory research

Just as the term by which a project defines its research methodology is open to interpretation, so too is the nature of the participation within the project. What might be anticipated as evidence of authentic participation with jointly undertaken analysis and dissemination of data (Richardson, 1997 p1117) or a collective analysis of the research problem (Cocks & Cockram, 1995, p32) is very rarely evident in practice. Stack and McDonald (2014) for example explored 21 action research projects involving people with developmental disabilities, mainly from the UK and US. The majority were no, low or low-medium levels of participation, with only 6 projects being on high levels. Three-quarters of these studies had discussed challenges they had faced. Issues included making the research project accessible and engaging for everyone, particularly data organisation and analysis. Challenges also emerged because of academic ways of working, particularly in relation to payment and authorship and ethical approval.

Nind's commissioned review (2008), looking at research with people with learning disabilities mainly in the UK, showed how little had been written about the process of data analysis compared to other aspects of participatory research. Even basic participant validation (member checking) was little in evidence. She also identified literature which highlighted the struggles of involving participants with learning disabilities in data analysis or generation of theory. Nind (2011) also recognises that the challenges involved are particularly under-explored and need to be investigated, giving examples of informal and formal, unstructured and structured, trained and untrained, explicit and implicit approaches. She sees authentic reciprocal learning as a potential benefit of participatory analysis, describing "an evolving process of interaction" (p356); giving as examples, the narrative lifestory work of Atkinson and Walmsley and Meininger.

Similar findings were evident in a wider systematic review undertaken as part of XXXXXX Project. Unlike earlier studies, this review was focused across the population of disabled people, drawing upon a wider range of international studies, in the context of an applied research project which sought to undertake practical research of immediate relevance to the range of participants in the project (Hammersley, 2000). This review sought an in-depth analysis of participatory research practice involving people with sensory and intellectual impairments (████████████████████). These studies needed to provide detail about what went on in research sessions. We sought 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. The review included 54 papers.

Involvement in data analysis was evident in just under 35% of studies. Of these, nearly all linked to thematic analysis and nearly half related to participant verification. Across this review, there was mention of weighting, sorting, ranking, coding, highlighting, negotiation, conversations, meetings and checking, as well as ongoing analysis and revisiting of experiences, ideas & images. There were 2 examples of participants being involved in processes frequently associated with the quantitative paradigm, in particular frequency analysis (Tarleton & Ward, 2005) and populating a database (Kramer et al, 2013). 11 studies made some link to collective analysis in some ways (Bigby & Frawley, 2010; Chin et al, 2013; Conder, J., Milner, P., Mirfin-Veitch, 2011; Dias et al, 2012; Haigh et al, 2013; Higginbottom, Rivers & Story, 2014; Koenig, 2012; Morgan, Moni & Cuskelly, 2013; O'Brien, McConkey & Garcia-Iriarte, 2014; Rix et al, 2010; Stevenson, 2014). 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. 9 studies described a process of participant verification of findings as part of the working process (Chin et al, 2013; Cook & Inglis, 2012; Haak et al, 2005; Haigh et al, 2013; Herron, Priest & Read, 2015; Keyes & Brandon, 2012; Raymond & Grenier, 2015; Richardson, 2002; Rix et al, 2010; Schleien et al, 2013; Stevenson, 2014). 1 study sought verification from a critical friend (Haigh et al, 2013). Some papers recognised the partial participation evident in their research. Those that focused upon this issue, represented it as the consequence of research priorities and resources, alongside participant preferences and skills.

To facilitate data analysis, there were example of what could be described as easy read summaries of results, as well as questioning frames and research draft findings to facilitate discussion. The use of transcription was evident in a number of papers, but it was frequently hard to tell if this was available to participants or was merely a tool for the academic researchers. The sharing of findings in an accessible format was not evident in all studies but was more commonplace than analysing the data. There were mentions of exhibitions, conference presentations, an open day and final event including the use of signing support, as well as easy read, plain english or accessible reports. 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. There were a few alternative outputs identified too, (including American Sign Language (ASL) video blogs, photo novels, newsletters, comic strip, i-poems, a video, photobooks, and a dance performance). Many of these outputs however were not produced by the participants themselves (e.g: accessible reports, l-poems, comic strips or video) and so though they could be accessed by those involved in the research and may re-present their words, ideas or work, it is debatable about whether they represent a participatory output.

Developing a participatory approach to analysis and dissemination

Typically, across the studies in the review, analysis rested with the academic(s) but we propose that 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 focus upon traditional research roles and processes was dominant, and so it was perhaps inevitable that skill development was implicit in many studies and explicitly discussed in 9 studies (Morgan, Moni, Cuskelly, 2013; Flood et al, 2013; Walmsley et al, 2014; Conder, Milner, Mirfin-Veitch, 2017; O'Brien, McConkey, Garcia-Iriarte, 2014; Dias et al, 2012; Tarleton & Ward, 2005; Strnadovva et al, 2014). There was one example, where training was framed around the needs of all those involved including academics, but even here (perhaps quite reasonably) only part of the academic team was involved (Strnadovva et al, 2014).

A few studies moved beyond traditional research analysis, recognising the evolving nature of the “messy space” (Seale et al, 2015). They looked beyond skills and training, to build upon the strengths of participants already have. Richardson (2002) explored in-session analysis where stories were created from the data for discussion. Northway et al (2014) used a process of group discussion, priority setting and voting, in defining questions for research, where the outcomes of the discussion become the outcomes of the research. Bigby et al (2014) talked of a “broad shared purpose” where the focus is the self-advocates life histories, but academics frame the self-advocates’ idea of doing their history as research. They approached analysis through Flexible Adapted Research Methods, for example moving from formal approaches at co-analysis when they proved unsatisfactory to more open discussions of interview summaries. Keyes & Brandon, (2012) talked of data analysis as a continual process, with multiple opportunities for those taking part, including varied and accessible presentation of themes with outputs of the project being developed with interactive feedback and evaluation sessions. They worked with participants to develop the idea of Mutual Support, in a project which saw knowledge as being co-constructed in the interaction between researcher and participants.

In looking across the 54 studies (██████████), multiple moments of interaction were evident, that were responsive (or not) to the participants’ need. This allowed us to identify the component parts, outcomes and tensions which were in evidence in the participatory research projects. It allowed us to describe the *while* of participatory research. As Heidegger (1996) recognised, being is defined by its historicity and beings are ‘always already together’ (p99). Things show themselves by being within the world and turning their attention to aspects of that world. Being-in is not a quality which being sometimes has and sometimes does not have, nor is it a sum of momentary realities. Things show themselves by being within the world. Only experiences in the actual now are really real. Participation happens in the moment, while you are doing something. It defines the person’s experience of being within that moment; it is the experience that emerges from and contributes to the ‘they’ within which we all are; it is where we can discover our understandings of our separateness and of our boundaries. It is both a personal and physical experience, socially created from the collective resources, understandings and interactions.

Perhaps this echoes what Barnes said of emancipatory disability research (2003), that in its widest sense, it needs to be conceived of as an ongoing process. It certainly echoes Seale, Nind, Tilley & Chapman (2015), who explored the nature of participatory research within a seminar series with inclusive researchers, in which the insider perspective was allowed to come to the fore. An emergent notion was of participatory research as a shared space. They

saw the boundaries between groups of participants defined by common objects and shared interests. Following on from Star (2010) and Star & Griesemer (1989) they saw the boundaries as enabling the production of knowledge and as an essential means of communication.

Nind, Chapman, Seale, and Tilley (2016) went on to explore the outputs from the seminar series. They identified seven models of training and capacity building (TCB) which emerged through these discussions. The most commonly experienced models (The apprenticeship, lifelong learner, challenging inequality, addressing deficits and formal) all support the continuation of traditional approaches. However, as they note, training away differences loses the variability in dialogue we seek. This is why they concluded that we need:

to develop new methods together that work to form a good fit to the research needs, and that require collaborative thinking rather than transfer of skills and knowledge from expert to novice (Nind et al, 2016, p549) .

This where they suggested the two other models come into play; Inclusive immersion and dialogic. Such models respond to theories of empowerment and social justice evident in other participatory research involving particular groupings. For example, Nicholls (2009) concludes from research with Indigenous participants that a reflexive process of collaborative ‘sense- making’ is “a theoretically consistent tool within participatory methodology” p124), and requires not just being open to new socially situated ways of understanding, but also ceding control of research into data collection, analysis and distribution.

Table 1: Models of TCB (based on Nind et al, 2015)

Model of TCB	Characteristics
Apprenticeship	Novice working alongside more experienced researchers who model and mentor
Lifelong learner	Novice managing own need for ongoing training negotiating formal and informal opportunities to keep developing skills
Challenging inequality	Researchers with and without learning disabilities perceived as in need of TCB and learning together in equal footing
Addressing deficits	Novice seen as having skills or experience gaps and in need of training to address these
Formal	Novice taught by a teacher following a curriculum
Inclusive immersion	Aspects of inclusive research are learned through an immersion in the research environment and its particular challenges within the distinctive context of the extra accountability and political. There is no expert for the novice to learn from, just problems to learn through.
Dialogic (based on the seminar series)	Inclusive researchers seek to learn through engaging with each other and testing each other’s contributions to knowledge.

Developing an emergent model within XXXXXX

The notion of immersion and dialogue goes beyond training and capacity building. It is at the root of all knowledge development. Knowledge and learning is inextricably linked to participation. It arises within the *while of participation* (). However, these understandings of participatory practice set up contradictions in relation to data when we

choose to adopt traditional approaches to analysis, and undertake its analysis within a different context, outside of the initial *while*:

- As Heidegger (1996) suggested, being understands itself by the nature of its own world. The retrospective activity will by its nature create a new source of participation, a new source of knowledge and learning, a new source of data. The analysis will be data, within its own experience of participation. It sets up a never-ending shortfall.
- The retrospective process privileges particular kinds of knowledge and particular capacities and thereby calls for mediation of the data. This mediation compromises both the nature of the participation and the 'reality' of what is being presented to participants. This is not to say that such retrospective examination does not have a role to play. As Heidegger also suggested, the essence of experience will be partially concealed, and what is readily apparent may be a semblance. To more fully understand the *while* we therefore need to see it from a distance; to attempt to look upon it as 'there' so we might better reveal the nature of the participation and explore its authenticity.

Since knowledge and learning is our data within the research context then analysis which is under the control of the participants must be within the *while*. Data will be emergent; and so their analysis must be emergent too. This emergence is a contextual phenomenon which involves dissemination of knowledge and learning, firstly within a project and then beyond. Within the *while* of participation, all activity is underpinned by tensions between power, support and voice (██████████). We recognise these tensions in the outcomes of a project, in how it represents lives, in its moments of learning and its value to selves. These are essentially processes of analysis and dissemination, the way in which participants are heard. The multiple views and boundaries of participants [see Figure 1) can be brought together and shared, in an inward process, leading to a point of collective experience. As part of this inward process, ideas spread through the group like a ripple (See Figure 2). Ideally, ripples of knowledge subsequently turn outwards beyond the project; however, projects also work within the constraints of institutional cultures and at the mercy of gatekeepers. This creates a funneling effect which can have profound influence on inputs and outputs to and from the group (See Figure3).

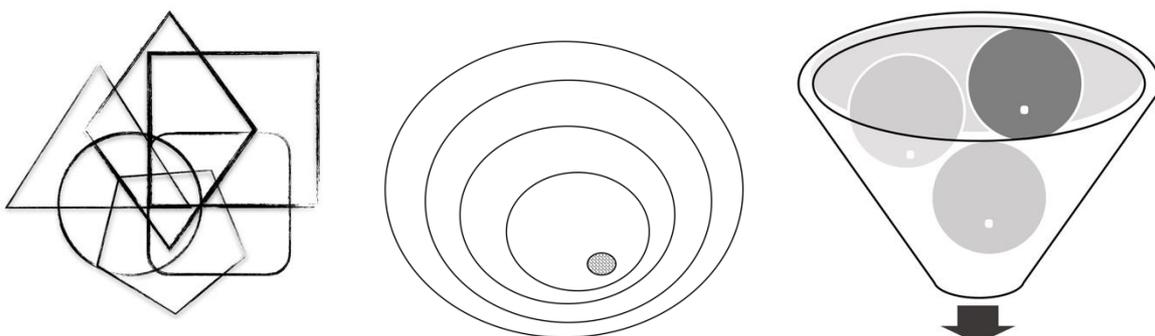


Figure 1: Bringing together Figure 2: The spread of ideas Figure 3: A funnel of control

In order to build on the possibilities created by contradictions in relation to data within and outside the initial *while* and minimise the marginalisation they may precipitate, XXXXXX developed an emergent approach to data analysis, using ongoing participant verification

and participant representation of data. Retrospective analysis, using more traditional observational and interview processes, was only used to assess the validity of the participatory process overall. This was the verification of the *while*.

An experience of emergent analysis and dissemination

Within XXXXXX, we were focussing upon data for three distinct purposes.

- Evaluation of technologies leading to recommendations to technology partners
- Evaluation of activities and sites leading to recommendations to museums
- Evaluation of process & method leading to recommendations in EU reports

From a research perspective, these were our primary funnels of control. We had to produce evaluations which fell under these headings. We needed to create the ripple of ideas as well as delivering on specifics. However, each funnel had a series of internal restrictions too; funnels within the primary funnels. The participants from the technology companies, museums and universities came with their own pre-established intentions, expectations and aspirations, just as all those who joined the groups. These funnels, implicit or explicit, acted variously to constrain or foreground the formats and forums through which outcomes were expressed, and the agency of particular voices within specific contexts, and could be fossilised structures hidden from our inspection.

From the outset, we had a wider conceptualisation of the participants, beyond the single groups who met in individual cities. We understood participants to include all those who visited or communicated with these groups in any regular manner. In this way, as a minimum, we all had a commitment to a collective relationship. We encouraged this with visits from the technologists and providing them with recordings of activities aimed at answering questions they had. Various partners produced their own ways of working documents. This helped us recognise that all participants would come with skills and experiences which could lead us in different directions. As Nind (2011) and Bigby, Frawley & Ramcharan (2013) described, it makes sense for people to undertake a role within the group for which they have pre-established resources and motivations.

Across the two years the Exploration groups evaluated their own ways of working, devised 'rules', decided how they wished to be represented (for example in demographics) and fed back their views of the project and how it was being run (including presenting on this at a conference). A whole range of in-museum activities have emerged, including access audits, relationship building, exploring access preferences, trialling access ideas, and advising on and developing tours and multisensory resources. The ideas for these activities been initiated by, and followed up by, regular attenders and the less regular. People have come and gone and left ideas behind them which have continued to spread.

Within the sessions we established a routine. People would have an experience, reflect upon the experience, share understandings and insights from that experience, summarise those experiences, record them and then share them with other participants for clarification and verification. This emergent ongoing analysis typically happened shortly after an experience had occurred, but it could also take a longer view (for example across one of the group's projects) providing snapshots on the way to producing a final artefact or a representation of that experience (for example: video reports on museum visits sent to the Director, a tapestry representing the highs and lows of participation, a PowerPoint

presentation on a museum website shown to the museum, a keyring of creative activities to enhance a museum visit, and feedback to a technology partner).

In nearly all these projects there were competing priorities, funnelling our ways of working and what could be achieved with the output. In all instances it was, and is, up to the institutions to decide what to do with them, but the primary funnel (alongside our three distinct purposes) was the overall project funding, which paid for the group meetings and for the costs of buying in technical skills. Beyond this, we would suggest that an emergent analysis and dissemination, a spread of ideas, was in evidence throughout the project. Here are three examples:

- *Feeling my way project* emerged early on within the Vienna Exploration Group. During a session, it was suggested and agreed that the museum needed a tactile map. Over five sessions the participants decided what was relevant to show, to what detail and at what size, they worked with a designer to revise and re-design the map mock-ups, then wrote and recorded the audio description to go with it and tested it.
- *The QR Code project* was developed in London and emerged from a variety of conversations, sparked by a collective desire to focus upon accessing ideas, by one participant's enthusiasm for QR codes and by another's suggestion (recognising the failings of previous uses of QR) that you could have a book in each room for different access preferences, with links to accessible, updatable information. The participants decided to create a single example. They chose an object in the collection, agreed headings for information, interviewed a curator, wrote a script, recorded the script, filmed the sign language interpreter, selected images for a video, worked with an editor who produced the short videos which would be accessed through the QR codes (see Figure 4). The suggestion for this project came early on, and the project emerged in small bursts. One or two participants stayed with it the whole way through, but nearly all the London Exploration Group was involved in its development at different times.

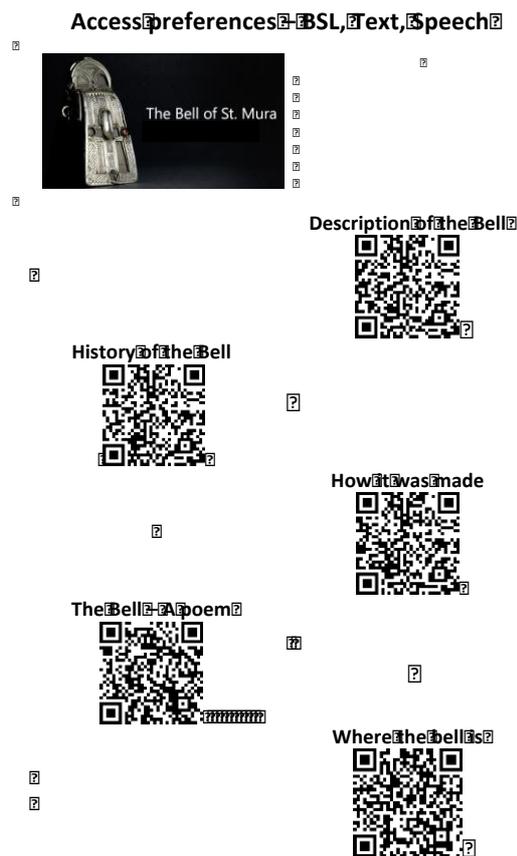


Figure 4: An example of a QR code page used for testing

The Welcome to our Museum project was developed by the Madrid Exploration Group. This emerged when participants got into groups of interest to consider what they might focus this shared interest upon. The people interested in navigation around the museum, recognised that access is not something that begins when you walk through the door of the museum, nor simply about standing in front of works of art when you are there. The group decided to produce a video to enable potential visitors to find out about the different resources available to them, and how to navigate around the museum space to find basic amenities. The Exploration Group decided on content for the video and accessibility aspects, they worked with a local video company on the script, which they approved and presented. The video is intended for the museum webpage but also in other places such as the entrance of the museum or with specific apps such as those being produced by the technology partners.

There were a wide variety of other outputs which responded to our three distinct purposes for focussing upon data. These included a How-to-Guide from Museums to Museums, with comments on activities from all the participants, a range of technology outputs and a manifesto of access. Through this diverse set of outputs, we sought to use the multiple funnels available to us, in the hope that we create an outward spread of ideas.

Conclusion

The process of emergent analysis and dissemination apparent in XXXXXX and some other research, is evidence of a project that seeks to build upon the groups' collective network of life experiences in all aspects of the project. 'Valid' participation is not situated in a singular space. It is based on continual negotiation; participants need to move to where others are. If this is to be a democratic, equitable process, this movement must be in the direction of all the participants and be supported by the participants. There is as much reason, if not more, for research processes to move toward the participants as there is for participants to absorb research practices and discourse. Emergent analysis and dissemination shifts the balance from the funnel to the ripple and enhances the validity of the *while* of participation.

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