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To cite this article: Jonathan Rix, Helena Garcia-Carrizosa, Simon Hayhoe, Jane Seale & Kieron Sheehy (2021) Emergent analysis and dissemination within participatory research, International Journal of Research & Method in Education, 44:3, 287-302, DOI: [10.1080/1743727X.2020.1763945](https://doi.org/10.1080/1743727X.2020.1763945)

To link to this article: <https://doi.org/10.1080/1743727X.2020.1763945>



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Published online: 04 Jun 2020.



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Emergent analysis and dissemination within participatory research

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ABSTRACT

Authentic participation involving jointly undertaken analysis of data and dissemination of findings is rarely evident in participatory research involving disabled people. This paper examines analysis and dissemination which offers greater participation, providing a theoretical underpinning for this approach. This conceptualization arises from ARCHES, a museum education and access research project involving over 200 disabled people and a systematic review undertaken as part of this project. A few studies, including ARCHES, have moved beyond traditional research analysis to recognize the evolving nature of the 'messy space' and how this may inform approaches to data and dissemination. This paper frames this space as the *While* of participation, a concept which emerged from the systematic literature review and from working within ARCHES. It explores how the *While* of participation is experienced in practice, in relation to analysis and dissemination. In particular it focuses upon its emergent nature. Within this project and occasionally elsewhere in the literature, data analysis and dissemination are not retrospective or separated activities, but arise as part of the ongoing participatory process, where immersion and dialogue are at the root of all knowledge development and sharing.

ARTICLE HISTORY

Received 24 June 2019
Accepted 24 March 2020

KEYWORDS

Participatory research; data analysis; dissemination; theory; emergent

Introduction

It is widely recognized 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 and a systematic literature review. 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 in evidence. Drawing upon Heidegger amongst others, this paper explores an emergent participatory process of analysis and dissemination. This process was evident within the four participatory research groups and was also identified within some other studies in the systematic literature review.

Background

This paper is based on findings which emerged from ARCHES, a Horizon 2020 funded project involving heritage and technology partners across Europe, which established four participatory research

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groups within four cities (London, Madrid, Vienna and Oviedo). The aim was to enhance access to heritage for all, through technology and the development of multisensory activities. Within the project we were focussing upon the analysis and dissemination of 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

Partners within the project included disabled people, six museums, five technology companies and a range of supporters. These groups met weekly or bi-weekly across a thirty-month period undertaking activities of their own design or in response to requests from the various participant partners. Over two hundred people attended these groups, with regular attendance of between fifteen and twenty-five in each. Sessions ran for between two and half hours and five hours. These research groups involved participants who have a diverse range of access preferences (Garcia Carrizosa et al. 2019a). These preferences are frequently associated with the labels of sensory impairments and intellectual impairments.

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 and Johnson 2003) which encapsulates both emancipatory and participatory research in the learning disability context.

Within ARCHES we determined to use the term participatory research. In line with Aldridge (2016), 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 recognize 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.

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 (e.g.: 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.

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) or a collective analysis of the research problem (Cocks and Cockram 1995), 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 U.K. and U.S. The majority had no, low or low-medium levels of participation, with only six 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 in relation to data organization and analysis. Challenges also emerged because of academic ways of working, particularly in relation to payment, 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. In addition, she identified literature which highlighted the struggles of involving participants with learning disabilities in data analysis or generation of theory. Nind (2011) also recognized that the challenges involved were particularly under-explored and needed to be investigated, giving examples of informal and formal, unstructured and structured, trained and untrained, explicit and implicit approaches. She saw authentic reciprocal learning as a potential benefit of participatory analysis, describing 'an evolving process of interaction' (356); giving as examples, the narrative life-story work of Atkinson and Walmsley and Meininger.

Similar findings were evident in a wider systematic review undertaken as part of ARCHES Project (Rix et al. 2019). The overarching question for this review was *What lessons could be learned from other participatory projects to inform the development of practice in future participatory research groups?* (see Table 1). 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 that project (Hammersley 2000).

The review included 54 papers (see Table 2 below). It 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. After this information had been extracted, there was a re-examination of tabulated data to seek patterns and to enable categorization of findings. This was followed by a thematic analysis of the data which reported on the activities and processes, using an approach drawn from grounded theory (Strauss and Corbin 1998). 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.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Must have a focus upon intellectual or sensory impairment	1. Does not have a focus upon intellectual or sensory impairment
2. Must involve qualitative or quantitative data collection	2. Does not involve qualitative or quantitative data collection
3. Must report on inclusive/participatory/emancipatory research	3. Does not report on inclusive/participatory/emancipatory research
4. Published 1996 and after	4. Published before 1996
5. In English, Spanish or German	5. Not in English, Spanish or German

Table 2. Thematic evidence base (for the underpinning tensions, meaningful outcomes & component parts of the *While* of participation).

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

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

The findings from the review were used as points of reflection about our own practice within the participatory groups and enabled the development of a theorized understanding of our ways of working (for detailed findings see Rix et al. 2019).

Across these studies it was evident that the primary medium for the activities was speech. Papers described processes which were leading to or enabling discussion and a range of activities which were aimed at generating ideas and conversation. There were also activities seeking to move beyond the constraints of everyday communications and everyday mechanisms related to organizing various types of meetings and maintaining their flow. A range of practical tools were in evidence (which may also be seen as constitutive activities) as well as a range of communication strategies and specific actions to support communication. Within the papers it was hard to clarify the difference between many of the approaches and activities, with labels and descriptions often providing too little detail to enable clarification.

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 two examples of participants being involved in processes frequently associated with the quantitative paradigm, in particular frequency analysis (Tarleton and Ward 2005) and populating a database (Kramer et al. 2013). Eleven studies made some link to collective analysis in some ways (Bigby and Frawley 2010; Chin et al. 2013; Conder, Milner, and Mirfin-Veitch 2011; Dias et al. 2012; Haigh et al.

2013; Higginbottom, Rivers, and Story 2014; Koenig 2012; Morgan, Moni, and Cuskelly 2013; O'Brien, McConkey, and Garcia-Iriarte 2014; Rix et al. 2010; Stevenson 2014).

Generally, if participants were involved in an analysis, an academic researcher would undertake the first stage 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. Nine studies described a process of participant verification of findings as part of the working process (Chin et al. 2013; Cook and Inglis 2012; Haak et al. 2015; Haigh et al. 2013; Herron, Priest, and Read 2015; Keyes and Brandon 2012; Raymond and Grenier 2015; Richardson 2002; Rix et al. 2010; Schleien et al. 2013; Stevenson 2014). One study sought verification from a critical friend (Haigh et al. 2013).

Some papers recognized 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. As a consequence, it was perhaps inevitable that skill development was implicit in many studies and explicitly discussed in nine studies (Morgan, Moni, and Cuskelly 2013; Flood et al. 2013; Walmsley 2014; Conder, Milner, and Mirfin-Veitch 2011; O'Brien, McConkey, and Garcia-Iriarte 2014; Dias et al. 2012; Tarleton and 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).

To facilitate data analysis, there were examples 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, i-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 whether they represent a participatory output.

Typically, across the studies in the review, analysis and the writing up rested with the academic(s) but we propose that it did not need to do so. This was a decision made by those who led the research.

Developing a participatory approach to analysis and dissemination

A few studies moved beyond traditional research analysis, recognizing the evolving nature of the 'messy space' (Seale et al. 2015). They looked beyond skills and training, to build upon the strengths of participants. Richardson (2002) explored in-session analysis involving the discussion of stories created from the data. Northway et al. (2014), in defining questions for research, used a process of group discussion, priority setting and voting, where the outcomes of the discussion become the outcomes of the research. Bigby, Frawley, and Ramcharan (2014) talked of a 'broad shared purpose' where the focus was the self-advocates life histories, but academics framed the self-advocates' ideas as research questions. 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 and Brandon (2012) talked of data analysis as a continual process, with multiple opportunities for those taking part. This included

varied and accessible presentation of themes, with outputs of the project being developed through 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 (Rix et al. 2019), three overarching themes emerged. These were: *underpinning tensions, meaningful outcomes and the component parts* (see Table 2). This helped with a conceptualization of the participatory process. 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 framed as *representing lives, moments of learning and value to selves*. These outcomes emerged through the practicalities of participation, its *component parts*. These components parts were identified as:

- 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.

These tensions, outcomes and component parts are descriptive of the *while* of participatory research (Rix et al. 2019). When we consider any activity, the multiple interactions of participation are 'being' *while* the activities are – through them, within them and around them. The *while* of participation is the relational experience that occurs while the group and a participant are in the moment and it defines their experience of being at that moment; it is the experience that emerges from and creates the boundaries in which people find themselves.

As Heidegger (1996) recognized, being is defined by its historicity. Beings are 'always already together' (p99). Things show themselves by being within the world and by turning their attention to aspects of that world. This 'being-in' is not a quality which being sometimes has and sometimes does not have, nor is it a sum of momentary realities. Only experiences in the actual now are really real. Participation therefore 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 et al. (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 and Griesemer (1989) they saw the boundaries as enabling the production of knowledge and as an essential means of communication.

The challenge of traditional approaches within the *while* of participation

As Heidegger (1996) suggested, being understands itself by the nature of its own world. Knowledge and learning is inextricably linked to the tensions and component parts of participation, of being within. Knowledge and learning arise as part of 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. Traditional approaches remove the analysis to another context, outside of the emerging *while*.

If we expand our construction of the original participatory moment to include this separated analysis, the analysis itself will be a new source of data (in need of analysis). It sets up a never-ending shortfall. However, if we do not expand our construction, the processes of traditional analysis

will privilege particular kinds of knowledge and particular capacities. These rarely arise from being within the *while* under analysis. Their being is established beyond, in an alternative arena, in a different experience of participation. This knowledge and capacity from beyond the *while* will mediate the data within its own constructs. This mediation compromises the representation of the participation and its 'reality'.

Traditional approaches can also be seen as retrospective processes. It is analysis being-within an alternative arena, undertaken beyond the original participatory site. The retrospective activity by its nature will create a new source of participation, it will be a new source of knowledge and learning, which is applied to the original *while*. 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. However, this retrospective analysis is a perspective from beyond the participation which it seeks to represent.

Within ARCHES we undertook a retrospective analysis in the final months of the project, with university researchers interviewing over 50 participants using a validities framework adapted from the International Collaboration for Participatory Health Research (2013). This was to assess the validity of the participatory process overall, as required by the funders and our ethics protocols. This was regarded as the verification of the *while* (Seale et al. 2019). The technology companies also undertook retrospective analysis upon the data provided by the four Exploration groups as responses to requests for information, this data was itself usually a result of analysis which had arisen within the *while*.

Developing an emergent model within ARCHES

Drawing upon this understanding of the *while* of participation, ARCHES can be seen to have developed an emergent approach to data analysis and dissemination, using ongoing participant verification and participant representation of data. Since knowledge and learning was our data within the research context then analysis which was under the control of the participants had to be within the *while*. From this perspective, data was emergent; and so their analysis had to be emergent too. This emergence was a contextual phenomenon fundamentally associated with the dissemination of ideas and experiences. Our questions, thoughts and insights had to be developed and shared internally (within and between the participatory research groups) in order to generate data and undertake its analysis. They also needed to be shared externally (beyond the participatory research groups) in order to achieve the three distinct formal purposes for data collection. Being within the *while* meant that much of this internal and external dissemination was emergent, but as with the analysis there were occasions when this dissemination was being-beyond and retrospective, such as this paper.

This notion of emergence was evident from the outset of ARCHES and how we conceptualized ourselves as participants within the project. Our notion of participation was context dependent. A person's presence within the *while* situated them within the emergent processes; by being at a session they were being a part of what was going on. However, from the outset, we also had a wider conceptualization of 'participant', and went beyond being a member of one of the single Exploration 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, but we also created a space for alternative perspectives to emerge. We encouraged this with visits from the technologists and by providing them with recordings of activities aimed at answering questions they had. Technology partners and university partners produced their own ways of working documents, as did the museum-based Exploration groups. This helped us recognize that all participants would come with skills and experiences which could lead us in different directions. As Nind (2011) and Bigby, Frawley,

and Ramcharan (2014) described, it made sense for people to undertake a role within the group for which they had pre-established resources and motivations. However, it also made sense to recognize that people may well have resources and motivations of which others are unaware, and which are revealed within the evolving context of the groups and their activities.

Within ARCHES, building upon notion of the *while* of participation, we came to recognize that the outcomes (representing lives, moments of learning and value to selves) had to be inherently linked to the research processes of analysis and dissemination; as the way in which participants were (and are) heard. But we also recognized that analysis and dissemination can be emergent and retrospective. In attempting to conceptualize this process three visual metaphors emerged. These arose as part of a training session involving the academic team and the museum coordinators. They emerged as a way to reflect upon the challenges we faced in representing and working with the multiple views and boundaries of participants (see Figure 1). We recognized that these views and boundaries had to be shared, in an inward process, leading to a point of collective experience. It was suggested that as part of this inward process, ideas needed to spread through the group like a ripple (See Figure 2); however, to be true to our emancipatory goals, ripples of knowledge also needed to turn outwards beyond the project. This however was constrained by institutional cultures and our relationship with gatekeepers. This created a funneling effect which can have profound influence on inputs and outputs to and from the group (See Figure 3) and how they might be represented.

The three purposes of data collection within the project (outlined in the Background section) were not emergent; they provided parameters within which had to operate. 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; and the same was true of all the individuals who joined the groups. As is evident in the presentation of the four projects in the next section, 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. However, they could also be fossilized structures hidden from our inspection.

Four experiences of emergent analysis and dissemination

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 emerged, including access audits, relationship building, exploring access preferences, trialling access ideas, and advising on and developing tours and multisensory

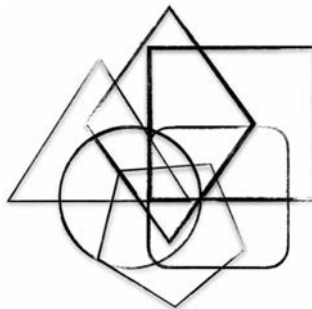


Figure 1. Bringing together.

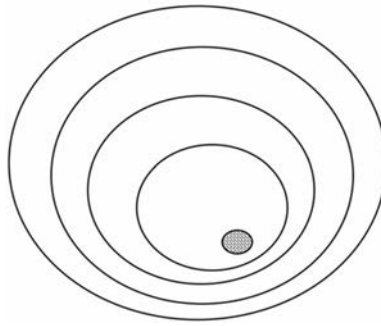


Figure 2. The spread of ideas.

resources (for details of our ways of working see Garcia Carrizosa, Diaz, and Sisinni 2019b). The ideas for these activities were initiated by, and followed up by, regular attenders and the less regular. People came and went and left ideas behind them which continued to spread and have an influence.

Within the sessions we established a routine. People would have an experience (for example; trialling a piece of technology, visiting a gallery, exploring an access preference); they would then reflect upon the experience, share understandings and insights from that experience, summarize those experiences, record them and 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 of an evaluation of 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 and within activities undertaken within the Exploration groups, there were competing priorities, funnelling our ways of working and what could be achieved with the output. From the outset, activities were constrained and enabled by the overall project funding, and therefore by the goals and practices of the institutions involved in applying for this funding and what we had said the overall project would achieve. Beyond this, however, we would suggest that an emergent analysis and dissemination was in evidence throughout the project. Here is an example from each group, which encapsulates our experiences of this approach to analysis and dissemination.

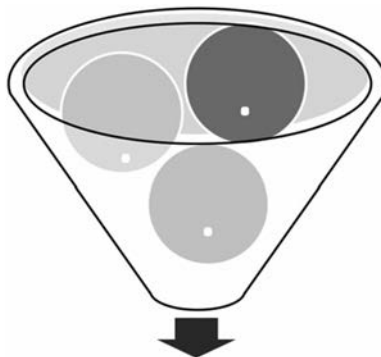


Figure 3. A funnel of control.

The *Feeling my way project* emerged early on within the Vienna Exploration Group. During a session, a group of participants who had a visual impairment took part in a brainstorm session. The emergent notion was that the museum needed a tactile map. This idea was shared across the group and agreed to as a collective goal to work towards. Over five sessions the participants who had identified the opportunity, collectively analyzed the situation and what was possible, deciding what was relevant to show, to what detail and at what size. The need to reflect the museum's design ethos, led the group into working with a designer to revise and re-design the map mock-ups. The group then wrote and recorded the audio description to go with it and began to test it in an ongoing emergent manner. This ensured that it met both their needs as well as those of the museum, passing through the funnels created by the participants' and institution's priorities. At the time of writing the final version is waiting to pass through to final approval prior to being made available to the wider public.

Within the Oviedo Exploration group, a variety of challenges were identified within the context of the museum as a historic building. Early in the project three practical concerns emerged from within the group:

- the need for Wi-Fi to be available throughout the building;
- an inability to communicate through visual means with people trapped in the lift if there was an incident;
- and the use of verbal communication to signify the museum was closing.

The first issue was identified by the museum coordinator working with technologically aware participants. The second two issues emerged through discussion amongst participants mainly from the d/Deaf community, when reporting back after an early tour around the site. The museum worked within considerable constraints due to planning and building regulations and because of the nature of its physical structure all three issues were initially funnelled by what was presumed to be possible within the institution; the sense of frustration associated with these constraints rippled through the group. This ripple reached the museum director, an essential gatekeeper, through the external academic from the UK. This opportunity was itself, emergent, an informal opportunity which presented itself; however, this allowed the ideas that had emerged from the participants' discussions to be heard. Subsequently, Wi-Fi was introduced throughout the museum, plans were developed to include cameras and screens in the lifts and it was decided that the closure of the museum at the end of the day would be announced both verbally and by raising and lowering the lights.

In London, the *QR Code project* emerged from a variety of conversations, sparked by an analysis of the access constraints the group faced on visiting the two museums concerned. From this analysis emerged a collective focus on 'accessing ideas', which rippled through the wider group and their discussions. This collective focus was directly linked to:

- one participant's suggestion to use QR codes to pass on accessible information;
- and by another's suggestion (recognizing 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.

But this focus also came to reflect the ideas of people from across the group. The participants decided to create a single example. Another wave of focussed data collection took place. Out of their discussion emerged a single selected object from the collection and agreed headings for information. It was evident to the group that they could use the knowledge of the institution and so they interviewed a curator and selected what should go into the script that they subsequently developed. At this point the ripple hit the funnel of their own technical inexperience and the financial constraints within which they were working. Access to resources became the constraint, but after some delay the museum partners were able to identify an editor who could work with the group and the university partners were able to organize funding for this work. The group recorded the script, filmed the sign

language interpreter, selected images for a video, and worked with an editor who produced the short videos which would be accessed through the QR codes (see [Figure 4](#)). Designs for the sheets were produced by one of the academics concerned and these were then tested and redesigned on the basis of the emergent analysis of the group. The suggestion for this project emerged early on, and other aspects of the project emerged in small bursts over a two-year period. 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, as it rippled across many sessions. Whether this idea is picked up further will now depend upon gatekeepers within the institutions and institutional priorities as well others beyond this project recognizing its value and wanting the ripple to spread.

The Welcome to our Museum project was developed by the Madrid Exploration Group. As in London the group considered their experience of visiting the museum. In this instance, an emergent conclusion was a need to focus upon navigation around the museum and to recognize that access is not something that begins when you walk through the front door, nor is it simply about standing in front of works of art when you are there. The group concluded from the evidence of their collective experience that they should produce a video to enable potential visitors to find out about the different resources available to them, and prior to their visit learn something about how to navigate around the museum space to find basic amenities. The emergent intention was for this video to be used on the museum webpage and in other places such as the entrance of the museum or with

Access preferences – BSL, Text, Speech



Description of the Bell



History of the Bell



How it was made



The Bell – A poem



Where the bell is



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

specific apps such as those being produced by the technology partners. Once again, the ambition of the Exploration Group was funnelled through economic and technical constraints and an institutional need to have a particular standard of output. In this instance, the decision making was also influenced by a local video company. The Exploration group decided on content for the video and accessibility aspects, as well as serving as presenters, writing the script and choosing the actors/voices and giving final approval, but the film was produced by the company for them.

Discussion and conclusion

At the outset of ARCHES we had three distinct purposes for collecting data, however the nature of participation and our ways of working within this context meant we were able to look beyond the constraints of these purposes. Our understanding of the outcomes of participation gave us possibilities beyond these formalized goals. We recognized that the tangible outputs had to have value to all those involved, in terms of what the outputs represented and how they represented the participants. The emergent process were by their nature open to interpretation and operated in a manner akin to theoretical saturation (Strauss and Corbin 1998), but they also needed to be democratic and negotiated. This meant the process was not one of ongoing equanimity. People did not always agree. Some people left the project (sometimes) in frustration, whilst others returned as they saw what was emerging. Our emergent way of working, however, allowed for a collective, participatory approach to analysis and dissemination evident in few other projects which identify as participatory.

As a project we have been able to produce a range of publications which have emerged from a retrospective analysis situated beyond the *while* of participation experienced within the group sessions. This paper falls within that description, but it enables us to make a clear link between the development of theory both within the literature and as it is experienced in practice. It provides a means to explore why participation and participatory research in particular is not a neat process. It is underpinned by tensions which arise from being within the *while*, and which are situated beyond it. In any moment of participation we can be giving consideration to experiences of where power sits, whose voice is being listened to, and how those involved are being supported; but each of these tensions is not an issue in isolation. Issues of support are also issues of power and voice; whilst issues of voice are also issues of power and support; and issue of power are issues of voice and support. There is a constant interweaving which may reflect a wider series of issues but is emerging (for better or for worse) in that moment of participation.

The wider series of issues will often reflect local values and the differences between cultures, with funnels rooted in the historicity of experience. For example, the emergence of 'access preferences' as the means by which demographic data was to be collected and as a means by which we identified and referred to our individual and collective needs. This was a concept which emerged from the group in London at the outset of the project and was established in all the other groups as they were set up. The strength of the concept and its capacity to encourage positive practice was welcomed by the vast majority of participants, but nearly everyone involved (including in London) still continued to use the plethora of labels associated with their own identities and with notions of impairment and disability. Our understanding of its usage was (and is) an ongoing process. It reflected the role of boundaries and their exploration as enabling knowledge production and facilitating communication (Nind et al. 2016; Star 2010; Star and Griesemer 1989). The same, perhaps, can be said for all the outputs from ARCHES. Their emergent nature reflected our wider participation in which we are 'always already together' and came to better understand our situation by looking from another perspective, a distant 'there' (Heidegger 1996).

Following the seminar series mentioned above, Nind et al. (2016) suggested the need to develop new models of training and capacity building. In an inclusive immersion model, aspects of research are learned through immersion in the research environment, with its accountable and political nature, where there are problems to learn through, rather than experts to learn from. In a dialogic

model, people learn through testing each other's contributions to knowledge as they engage with each other. Such approaches go beyond training and capacity building, however. Immersion and dialogue are at the root of all knowledge development. Such models respond to ideas of empowerment and social justice evident in ARCHES and 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' (124), 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.

Such an approach to the analysis and dissemination of data sets participatory research on a different path to the majority of qualitative and quantitative approaches. Whereas most research paradigms are rooted in notions of expertise and dependent upon approaches akin to 'technical rationality' (Schön 1983), participatory approaches must recognize the relational and uncertain nature of participation. The process of emergent analysis and dissemination apparent in ARCHES 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 or neatly defined space. It is based on continual negotiation, with participants needing to move to where others are; shifting the balance from the funnel to the ripple. 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 rather than being constrained by previously established, top-down research practices and discourse. Emergent analysis and dissemination is a response to this reality, reflecting the nature of the *while* of participation and enhancing its validity.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by European Union's Horizon 2020 Research And Innovation Programme [grant number 693229].

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