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It soon became clear – Insights on technology and participation

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Abstract

This paper explores the experience of working with different conceptualisations of participation and participatory practice. It does this through an examination of the involvement of a technology company within a multinational, 3-year participatory research project, involving 13 partners and over 200 disabled people. This paper provides a case study, narrative account of a range of activities undertaken within the project, presenting a rare and much-needed explicit insight into the emergence of participatory ways of working and the reasoning and tensions behind them. Through the case study gaze of one of the technology companies involved, it explicates the underpinning processes of the participatory approach and how these challenged the notions of various partners. This paper shows how engaging in meaningfully participatory research creates profound institutional challenges for technology developers. The subsequent need to make hard decisions and compromises throughout disrupts traditional ways of working and anticipated outcomes. However, it also reveals opportunities for delivering unanticipated and transformatory outcomes, highlighting the need for greater flexibility in funding research that aims to be participatory.

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Introduction

The involvement of disabled people in participatory research is frequently partial at best (Rix et al, 2020; Stack and McDonald, 2014) and the challenges it presents is little explored (Nind, 2011). It is tempting to simply put this down to the dominance of the traditional grammars of research; but it is also evident that different participants often have different roles, and priorities (and funding) as well as varying conceptualisations or understandings of the research process (Cronholm & Goldkuhl, 2004). This was our experience on the ARCHES project, a Horizon 2020 project which aimed to enhance access to heritage for all, through technology and the development of multisensory activities (Garcia Carrizosa *et al*, 2019). This paper presents a perspective from technology partners within this participatory research project. It explores the challenges, which different conceptualisations of participatory research presented, and the opportunities, which subsequently emerged from shifting perceptions. It examines the tension for one of the technology partners between delivering specific outcomes for which they were funded with the need to design their work with the preferences of the participants in mind, in order to be true to the project's underlying participatory principles.

Background to the project

Between October 2016 to December 2019, four participatory 'exploration groups' were established in London, Madrid, Vienna and Oviedo. These groups involved over 200 disabled people, working alongside friends, family and other supporters. These included practitioners (some of whom would also identify as disabled) from six museums, five technology companies, two universities and one cultural education company. Membership and numbers attending the groups varied across the project, with people coming and going across the weeks, with a regular attendance of 15-25 for each session. These exploration groups met weekly or bi-weekly undertaking activities of their own design or in response to requests from the various participant partners. At the outset, the project was divided into three phases. The first phase was developing new technological resources and multi-sensory resources, (such as avatars, 3-d models, and online or offline games and resources) in conjunction with participatory research groups. The second phase aimed to test the technology and resources with those groups. The third phase involved the technology partners finalising the resources, ready to share with the public.

The participants had a diverse range of access preferences (Garcia Carrizosa *et al*. 2019a), which are frequently associated with the labels of sensory impairments and intellectual impairments. Within ARCHES, our understanding of participatory research situated us within the emancipatory tradition. This tradition focuses upon the need for research to be accountable and open throughout to a group run by disabled people. It calls for the skills and knowledge of researchers to be at the disposal of disabled people, promoting individual and collective empowerment and barrier removal (Barnes, 2003). Our work built upon Aldridge's (2016) description; it was designed with the needs of participants in mind, involving ongoing dialogue and consultation, in relationships based on mutuality, understanding and trust. We sought to enhance the participant voice in all aspects of the project, recognising that transformative outcomes can be in many arenas and that the data can be subject to diverse forms of analysis and interpretation.

Drawing upon an extensive literature review, we understood our approach to the research as being within the *while* of participation (Rix et al, 2020). As one of the participants explained when discussing the review: "It's simple. Participation happens while you are doing things". The *while* is the experience of being which emerges from and gives form to the boundaries that people find themselves within. It is the multiple interactions that create and are created by participation. These interactions form around each other; they are moments in time and across time. Participation therefore emerges as a flow from many directions and is more than a sum of any preceding

moments. Within the *while*, we experienced multiple interactions that involved underpinning tensions around power, support and voice, evident in the learning, value and representation which emerged from and were constructed through our shifting language, roles and attitudes. They also emerged and were constructed through our capacity to adapt practices and spaces to enable relationships that were flexible, that took their time and in which people could enjoy themselves.

Our work was also strongly influenced by the ideas underpinning the social model (Oliver, 1983) recognising that it is social responses which construct disability. We were alert to this not only in relation to issues of museum access and our collective discourses, but also in our approaches to research, our uses of technology, and our understandings about relationships, identities and practices. All of these could serve as barriers to and facilitators of participation. We recognised too the value of approaches such as Universal Design and disability sensitive practices. These encouraged us to seek multiple means of representation, action, expression and engagement, whilst recognising the diversity of the people with whom we were working. These values were laid down and shared at the outset of the project in a Ways of Working Document and our principles of participation, consent, security and privacy.

From the outset, we also recognised that there are common approaches to including users in the research and design of technologies. Some are not developed specifically with disabled users in mind, such as User-centred Design (UCD), Participatory Design (PD) and Human-Centred Design (HCD) and some encourage disability sensitive practices through adopting principles of Universal Design, Design for All, Accessible Design or Inclusive Design. Although in theory similarities and differences exist between these approaches, in practice designers confuse them, which often means they might think there are doing participatory design, but actually are not (Seale *et al*, 2019). This confusion in practice is exacerbated within the literature because designers do not fully define, articulate or justify what it was they were doing when they publish papers. They rarely give explicit rationales as to why they use a particular approach or evaluate its success in any meaningful way. This need for projects to make their decision-making process more explicit and to share and evaluate details of their approach, is one motivation for writing this paper.

There is a long history too of participatory action research in the development of technology (Whyte, Greenwood and Lazes 1989). This calls for members of a community to be involved actively in the research process with a professional researcher. Within participatory action research projects though, it has been noted that the level of control the community have and their intentional influence on structures, topics and outcomes depends on the type of supports available and the manner in which supports are provided; these could be variously under the control of ‘advisors’, under shared control, or directed by participants with support (Garcia-Iriarte *et al*, 2009). In a systematic review of research in the development of technology, undertaken within the ARCHES project (Sheehy *et al*, 2019), despite a growing recognition of the need for participation of end users, it was evident that the ‘community’ were largely passive ‘subjects’ within the technology-focussed research or absent from it. The majority of studies were consultative at best, but tended towards experiment or review of a proposal.

The tension around partners understandings of participatory and design process, also echoed our experience at the start of the ARCHES project and findings from other ARCHES systematic reviews; our technology partners were used to focussing their products and research upon specific impairment categories (Rix *et al*, 2020) and to have a more quantitative, quasi-experimental expectation of participation (Sheehy *et al*, 2019). This created a clear dichotomy for the project in light of how it had been designed, funded and the ways in which the exploration groups worked. Given the wide range of access preferences and a collective, participatory understanding of our ways of working an emergent approach came to the fore (Rix *et al*, 2020b). The emergent process was a

‘messy space’ (Seale *et al*, 2015) which soon drew us in different and competing directions. It focussed our experiences upon and within the boundaries between personal and professional background. We learned through immersion in the research environment, with its accountable and political nature, where there were problems to learn through, rather than experts to learn from (Nind and Vinha, 2016).

The project had a wider conceptualisation of the participants, beyond the single groups who met in individual cities or people identified as disabled. We understood participants to include all those who visited or communicated with these groups in any regular manner, even though it was hard for some partners to envisage themselves as participants (Garcia Carrizosa *et al*, 2019). 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. Technology partners and university partners produced their own ways of working documents, as did the museum-based Exploration groups. 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 (2014) described, it makes sense for people to undertake a role within the group for which they have pre-established resources and motivations.

Within the sessions we established a routine, involving all those present. 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 providing snapshots on the way to producing a final artefact or a representation of that experience. In nearly all these activities there were competing priorities, funnelling our ways of working and what could be achieved with the output.

From the outset our 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. This was not just a matter of there not being time and support for the exploratory groups to come together prior to the project in order to submit a bid, (Cook, 2012). It also reflected our collective belief that our application would not benefit from pushing “beyond traditional social science conventions” (Maclure 1990, p18). We did not believe we could simply provide, as Maclure suggested:

- a) The context of proposed projects.
- b) A broad identification of all participants and the manner of their engagement.
- c) Proposed processes of project identification and planning.
- d) Proposed processes of participation.
- e) The applicants’ commitment to the improved wellbeing of the participating communities.

This paper seeks to explore the experience of being drawn in different and competing directions from the perspective of a technology partner. The importance of this voice reflects the project’s recognition of the multiple voices within the group and our aspiration to acknowledge and provide equal value to the experiences being shared; in particular, but not solely, those who have experience of ongoing oppression. This multi-voiced approach to lived experiences holds the promise of creating a richness of contextual data (Portelli, 2003) and to reveal hidden histories (Tilley *et al*, 2012). We aimed to tease out meanings, emotion and thoughts as well as actions and choices (Thompson & Bornat, 2018). In an echo of the life history approach, we were seeking a nuanced interpretation, allowing individuals to recount their lived experiences in their own way, with their own priorities and meanings (Yow, 2005). These lived experiences were our data out of which our understandings emerged. In this context it seems entirely appropriate that participants from a participating

technology company should share their tales. These are presented as a case study narrative, which aims to focus upon the personal perspectives of those involved (Stake, 1995), in order to provide rich insights into phenomena (Robson 2002) and to reveal how events emerge to create different outcomes (Opie, 2004).

What follows is the perspective of three researchers permanently involved in the project, one male and two female, in the age range from 25 to 40. They worked together full time on the project in their roles as developers and also undertook all the project management tasks for their part of ARCHES between the three of them. Every one of them traveled to other locations, visited Exploration groups on different occasions and took part in conducting and designing the exploratory user surveys concerning the technology they were developing. The impressions shared in this paper represent their combined experiences.

The view from a technology company perspective - Our starting point

VRVis is Austria's leading research institution in the field of visual computing. We aim to present data, contexts and issues in the best possible visual and interactive forms. We started working on projects concerning the accessibility of 2D works of art and the computer-aided design of tactile models for people who were blind or had a visual impairment in 2010. (Reichinger, Maierhofer & Purgathofer, 2011; Reichinger *et al*, 2012). In a project called Tactile Paintings we cooperated with local museums and special interest groups of people who were blind or had a visual impairment, who evaluated the tactile materials we produced. This approach placed the users at the very end of development, only allowing additional materials to be produced when the original ones were not comprehensible in their original layout. From this work one vital aspect of user feedback led to our next project: Audio description of tactile materials was deemed a necessity to ensure utmost comprehension by our target group. As part of a subsequent project, DeepPictures (2013-2016) funded by FWF (P24352-N23), which aimed for the semi-automatic generation of tactile reliefs, we started to develop a finger-tracking prototype. This led to an interactive, gesture-based audio guide for 2.5D tactile materials (Reichinger *et al*, 2016a) and the idea of temporary tactile reliefs produced by the means of a new technology we called a relief printer, which we already prototyped in the project AMBAVIS (Reichinger *et al*, 2016b). These formed the basis for our involvement in the ARCHES project.

When joining the consortium of the ARCHES project, we had a series of proposed tasks:

1. The integration of existing prototype applications into one single software platform for tactile relief modelling and further development of our design tools
2. The production of a mechanical prototype for the relief printer concept introduced in AMBAVIS as well as the adaption of our first prototypes of the proposed relief printer medium
3. Development and improvement of a “context-sensitive” tactile audio guide, especially the improvement of touch and gesture recognition as well as of the affiliated content authoring tool
4. The production of tactile reliefs for evaluation (one relief for each participating museum)

We anticipated an iterative development process (including the use of rapid prototyping and mock-ups), providing constant improvements and proposing new features, as well as receiving creative input from the groups for new features in an ongoing development process focused on the tasks proposed in the intended outcomes. Because the groups were meeting in four different cities all over Europe, VRVis' researchers would not have the possibility to attend a large number of sessions in person. At the outset we anticipated that researchers from our partner universities, The Open University and Bath University, would design the test setups and questionnaires and would conduct the testing.

Learning anew

Our previous research had not been within a user-centered research approach or the framework of participatory research. It soon became clear to us that the inherent nature of a traditional funded research project is contradictory to the core idea of participatory research (as there has to be a clear vision of project outcomes in the proposal). Having predetermined goals works against the creative process of arriving at proposals for new technologies, applications and features within the participatory research framework.

It was also new to us to work with groups consisting of people with all kinds of access needs and therefore having to adopt a design-for-all approach. Our experiences of working with one group of disabled people with rather homogenous access preferences also did not prepare us for working with groups with a wide range of access preferences. Nor did it prepare us for dealing with cultural differences between the groups from different countries. But, because collectively the technology partners had previous experience with working with specified disabled people in different contexts, there seemed no need for special workshops building expertise in this field at the beginning of the project. At the outset we were reassured by the setup and timeline, which was designed to allow us to develop participatory ways of working.

As a result, new ways of working had to emerge for us as the project progressed. For example, all of the evaluation of the technology was being done under the guidance and supervision of museum staff, so in line with our traditional experiences we developed a range of quantitative and qualitative questionnaires in cooperation with an external expert from the University of Vienna. We soon came to realise though, that user interaction with our prototypes and technology had to be additionally documented by other means like videos, pictures and audio taping. This decision emerged from the participatory experience, where a member of VRViss recorded a session exploring why gesture recognition did not work for some people. Subsequently, we found video was a far more reliable way of understanding what had gone on.

Interactions always carry a sense of the distribution of power between the people involved. The idea of our participatory research was to have all the participants (users, developers, caretakers) meet as equals and have an equal say. As technology companies, we were probably being perceived and therefore judged by other participants as enabled, power-holding experts, yet we frequently felt at loss too. This was partly because we felt very dependent upon receiving a positive evaluation of our work from the four Exploration groups. Over the course of the project it also occurred to all of us as researchers, that we were not only participants through our participation in the project, but that we were also all experiencing disempowerment, frequently in ways we had not anticipated. We all had limited possibilities of communication and ways of making ourselves understood with other participants. We all had to rely on translators and other intermediators to convey our surveys and our ideas. We also came to recognize, how disability is frequently related to hidden characteristics and ones which emerge at different points in people lives, and that how a person is perceived due to their social status may differ from their actual needs and abilities.

An example of these tensions emerged for us just weeks after the project finished when one of the tech-company researchers was diagnosed as being on the autism spectrum. This colleague played a central role without their particular access preferences being noted within the Exploration groups or at other meetings. We wondered whether, had this been known, this person would have been perceived differently (albeit being the exact same person). Would other people have sought to have made adjustments? It underlined too, the value of looking beyond impairment categories. We cannot know what everyone's access preferences and needs are at all times; these things can change; and so we must not make any presumptions about people. Being perceived as holding a

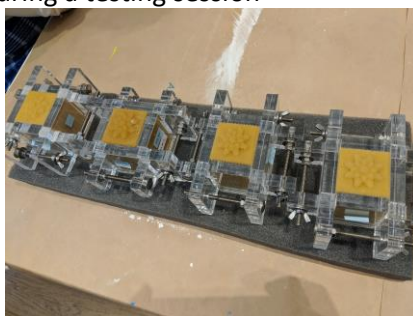
position of "power" within such a group did not mean people did not have different access preferences and needs. Moreover, the needs of this person did not change due to their diagnosis. The needs would have been there the whole time, only nobody knew.

Identifying a common viewpoint

During the development process we were also aware of frictions amongst the participants, concerning the lived reality of a group with mixed access needs. There seemed to be a divide between people who believed the Exploration groups (with their wide range of access-preferences) would ensure a true design-for-all approach and those who feared specific needs would be less well met (when tools were to be developed that did not focus on people from a specific impairment category but rather took a broad approach to the issue of access needs). Museum staff, caretakers and even the users themselves seemed to have differing opinions on this topic. This made it harder for the tech companies, which were still adapting to the participatory framework of the project, to stand by the design-for-all principle during development and testing.

One example of the issue around 'focused special interest' versus 'design for all' was evident in the communication problems that emerged around the adaption of a medium for our proposed printer for temporary reliefs. VRViss produced seven different versions of a possible medium for the printer. These mediums consisted of pins held together by a frame, so that the pins could be pushed upwards to form different tactile materials. The prototypes we built for our purposes had pins of varying shape, diameter and materials. (See **Error! Reference source not found.**) What we wanted to find out was which combination of shape and diameter would be best to achieve a high-resolution tactile relief with possibilities of depicting all kinds of edges and round surfaces.

Figure 1: Pin frame prototypes during a testing session



We had several evaluation sessions with the Exploration groups. To CCCs' researchers attending these sessions, it seemed like people with very limited or no vision had a much more sophisticated approach to evaluating touch materials, while sighted people would be influenced by the materials' colours. The testing was a slow process too, (one test set with the seven prototypes could take up to forty minutes) which made it a very strenuous activity for all participants. In addition, the questionnaire developed by the University of Vienna had to be translated into English and Spanish from German. For people whose access preferences were sign languages these questions had to be interpreted in their respective sign language and their answers translated back and written down. The questions also proved to be hard to perceive for some people who preferred easy read text. So staff had to interpret the questions in various ways, rephrase them in different settings and translate the answers back to us. The participants could also remain anonymous, so, as intended, there was no way to match access needs with evaluation outcomes. Consequently, we could not say if the group of people who would have identified as blind and visually impaired (BVI) alone would have produced different results to the group of people with diverse access preferences.

The participatory dividend

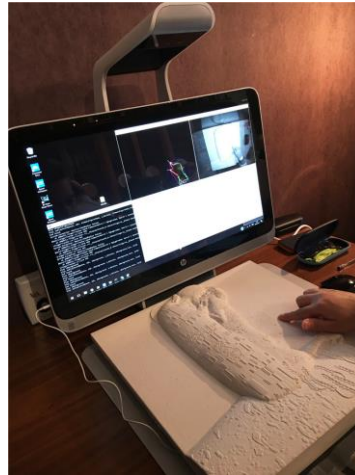
Despite the challenges identified above, the true idea behind participatory research did emerge, revealing itself in unexpected ways. This was particular evident in the development of the “context-sensitive, tactile audio guide”. The intended technical layout was just to have a depth camera positioned above the relief of an artwork to track hand gestures that would then trigger audio content. (see Figure 1) When doing routine testing of the setup, a number of participants expressed interest in the operation of the test screens that we used for the gesture recognition. As we had only be testing with BVI people before, it had not occurred to us to add a touch screen as a fixed part of our setup. Highlighting segments and therefore giving visual feedback of the finger tracking turned out to be a useful feedback for many people with all kinds of access preferences.

Figure 1: Original hardware setup for testing the context sensitive tactile audio guide for works of art – tactile relief on the right hand side, depth camera positioned above, laptop with debug screen on the left hand side.



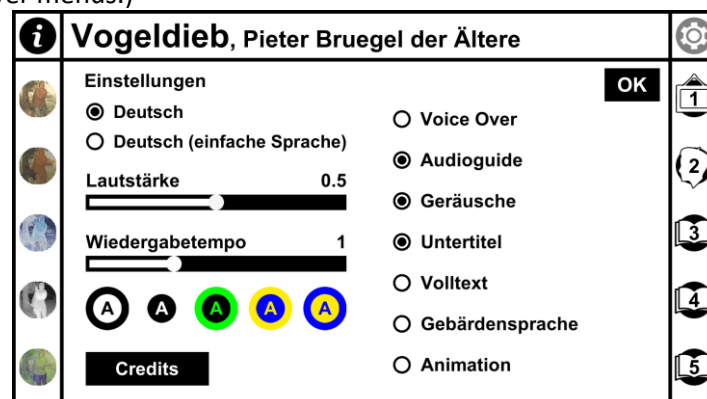
The influence of working with diverse access preferences continued as we responded to this interest in a screen. For instance, the original finger-tracking software relied upon the user’s hand signals. We used fingers (pointed-out from thumb to pinkie) to sign the numbers 1-5 to call up further information about the artwork. When first implementing this feature, in an earlier project, our group of test users did not have any sensory impairments, nor did any have fewer or immobile fingers. Now we had these kinds of experiences to draw on. As a result of having added a touch screen, we had the possibility to drop some of the gestures and could shift the functionalities to on-screen buttons (see Figure 3). We also came to recognise that this made the technology more culturally responsive, as the signing of numbers by using fingers follows different patterns in different cultures. Once again, the functionality we added on popular demand in the group made it possible to solve another problem, which we had not anticipated.

Figure 2: New hardware setup with HP Sprout featuring a touch screen, built in depth-camera and projector (screen in debug mode).



As a result of our willingness to respond positively to suggestions, requests for features started flowing in. The range of functionalities grew at a pace. Having a touch screen added to the setup gave us the possibility to add more features for enhanced accessibility. The artwork itself in its original form could be displayed as a picture (in addition to be projected onto the relief) or even as an animated version. We could showcase UV scans, line drawings and other additional material that was to be found in the museum's collection of material. The audio guide could be accompanied by subtitles or even full text display. Videos with sign language versions of the textual information could be shown on screen. Adding these features meant producing a massive amount of content and developing a storage structure that could hold it and call it up in real time. It also meant, that our setup needed an access preferences settings menu, where users could choose if they wanted information in e.g. audio version, textual version, or sign language. So, we started designing this menu, based on the experiences of one of the partner tech companies in designing a similar menu for their app (See Figure 4). Having this menu lead to adding more access preference settings, like various high contrast colour schemes, controllable audio volume and audio speed. Textual information and verbal information in audio files also needed to be translated into easy read versions.

Figure 4: Middle part of screen: Access preferences settings menu in German (also available in English and Spanish). Options: German/Easy read German, Volume, Playback Speed, Five different colour schemes, Voice Over, Audio Guide, Sound scape, Subtitles, Full text, Sign language, Animations. (The menu changes slightly, if the voice over feature is activated, as sliders are not suitable for voice over menus.)



The cost of being flexible

We were now designing a full graphical user interface (see Figure 4) for a technology that had been meant to be entirely gesture-based and had been designed with blind people and people with a

visual impairment in mind only. This meant we had to add a whole new task to our task list that had not been initially agreed upon. This was no small task either. In a very short time, it became a main focus point of our work and one of our colleagues was working full time on this part of the project. To be able to finish our part of ARCHES we dropped some functionalities of the modelling software we were developing, which was meant for our own use and to help automatize generating the tactile reliefs for our setup. We felt that in the spirit of participatory and publicly funded research we should invest our resources in functionalities directly beneficial to the users instead of in software for internal use.

Our willingness to be flexible was not always enough on its own though. There were a variety of practical problems to be faced. For example, because there were no defined requirements in the research agreement for this work, and participants kept coming up with new ideas, they continued to add wishes to their list while project runtime and project capacity remained unchanged. As the development of such a software never had been intended, there was no money for such things as content production. It was not always clear where the responsibility for production lay. As a consequence, the production of such things as content (e.g. sign language videos, easy read text) were often delayed for a long time. This caused particular frustration for people who wished to experience and test an aspect of the technology, including ourselves. It also meant people felt their wishes were being ignored.

We also found that ways of working which might resolve these issues were not welcomed by many participants. So called *agile* methods, which provide an iterative and incremental framework, overthrowing the idea of sequential product development might sound very suitable as an environment in which participatory research could happen, but there were two barriers. Firstly, in this model the evaluating user that requests the changes is also the paying customer, which means trade-offs and costs can be negotiated directly. Secondly, rapid prototyping approaches common in software development use visual representations, like paper prototypes for graphical user interface layout and interactions, and these were rejected by the groups. Many participants did not find them intuitive to use and felt they did not meet their varied access preferences.

Perhaps the most frustrating realisation was when the newly designed Interactive Multi-Media Guide for our tactile reliefs first came together. There was a moment when we realized that now, after months of work, the setup was only partly accessible to the people we set out to help in the project prior to ARCHES: blind people and people with a visual impairment. Unfortunately, the software framework we used did not bring a full voice-over functionality like some other developing frameworks or operating systems (like iOS). As a consequence, we had no features that would make a touch-controlled and screen-based software accessible for people with visual impairments. We had to invest more work in making the new graphical user interface fully accessible for blind people and people with a visual impairment via new voice over features and various kinds of audio feedback.

Everything is different but it's not

When we finally came to the end of the allotted time for the project, the timetable and the milestones (as laid out in the grant agreement) did not apply to the reality of the project anymore. We could not simply tell the participants that we now had reached the agreed upon status of development. For some of them, therefore, the project probably still felt unfinished. This seemed a significant issue for combining the participatory approach with the framework of an EU-funded project. As funds are given to very specific proposals that are written down in detail on sometimes hundreds of pages, deviating from these not only leaves researchers running the risk of losing their funding, but it also leaves reviewers with the complex task of deciding if the deviating outcomes of a project are better or at least equal to what was proposed in the grant agreement. Our reviewers

were very complimentary, but throughout we were aware that their measure of success could be constrained by what was promised at the outset.

Conclusions

The tension for the technology partners within ARCHES was that they were funded to deliver specific outcomes, but in order to be true to the underlying participatory principles they had to design their work with the needs of participants in mind, seeking to enhance the participant voice in all aspects of the project (Aldridge, 2016). They had to ensure that disabled people were actively involved in the production of research knowledge and also its selection and presentation (French 1993). As a result, they had to work within a ‘messy space’ which created openings for analysis, through disagreements, differences in ideas and ethical concerns (Seale *et al*, 2015). It was out of this messy space, the *While* of participation, that the ways of working and research goals emerged, alongside the relationships in which everyone was involved (Rix *et al*, 2020). This tension between an emergent and more traditional approach was experienced as a challenge of working with varying conceptualisations or understandings of the research process (Cronholm & Goldkuhl, 2004). In particular this emergent approach was set against the technology companies’ prior understandings of participatory research and their focus upon traditional, quantitative approaches which tend to position participants as largely passive or absent ‘subjects’ (Sheehy *et al*, 2019). It also seems likely that participants’ understandings of participatory practices were influenced by their design backgrounds (for example the focus on iterative processes) and that this reflected the wide variations across the literature (Seale *et al*, 2019).

The technology partners arrived with a confident self-image of themselves as researchers and in their understandings of the research process. What is clearly evident from the narrative above is that their previous experiences of what they understood to be participatory approaches had not prepared them for the challenges of working in a project where multiple voices were given equal weight, where roles were disrupted and status was negotiated. Everyone in the project had to look beyond the typical boundaries associated with disability categories, professional expertise and research processes and to do so in a diverse mix of institutional, national and community cultures. The technology partners therefore had to transform not only their ways of working but also their understandings of participation and their own sense of self, both professionally and on occasion personally. A particularly salient aspect of the narrative relates to the different perceptions that people brought to the project about expertise and where power lay, and also about the nature of impairment and disability and how these should be supported and responded to. The narrative presents how these differences emerged in various forms and from across the body of participants.

The primary conceptualisation that everyone was a participant, not because they were a disabled person but because they were attending and engaging with the exploration groups was both disruptive and enabling. The narrative suggests that the reality of this transformation could not be understood from the outset however. Evidently, the presentations and documentation made by the university academics at the outset were not enough to prepare people. It had to be experienced and engaged with, in order to be appreciated. It is also very clear that the disruptive experience that emerged from the *while* of participation was both a productive and troubling one. It enabled new relationships and conceptualisations to emerge, new ways of understanding technologies and their audience, but this of itself generated unanticipated costs and challenges in people’s capacity to deliver outcomes. It also met with resistance from other participants who did not travel the same distance as others, who did not wish to move their boundaries of the possible. Our commitment to engage in an emergent, messy *while*, created a marked tension in relation to the projects social model aspirations and engagement with principles of universal design. Delivering a participatory experience is not just about removing barriers; it throws up a myriad (perhaps new) ways to marginalise and disable. Seeking multiple means of engagement in all its forms requires an ongoing

responsive dialogue. It shifts across cultures and contexts. What works in one moment may not work in the next. When we seek the universal it can feel as if we are seeking the infinite. We therefore have to be willing to embrace the risks, the positives, the negatives and the in-betweens.

In the case of ARCHES, traditional research understandings brought the technology developers into direct conflict with the participatory nature of participatory research, and with the particularly diverse group of users involved within this project. In recognising and responding to this conflict they immediately put themselves at odds with the underpinning principles of the funders, who by the nature of their bidding processes had largely constrained the possible nature of the outputs and the time frame in which they could be delivered. This challenge was one which became increasingly clear to the technology developers as they moved through the project, recognising how their values aligned with the other participants, but feeling the intense commercial pressures associated with product development and funding agencies. The multi-disciplinary nature of the project further added to this tension, creating a range of different spaces in which data collection and relationships between researchers were being mediated, involving people and practices from across sectors. New ways of working had to be developed, which involved taking risks in terms of the nature and quality of outputs and in terms of the relationships between participants (Rix et al, 2020c).

This case study allows us to see how engaging in meaningfully participatory research created profound institutional challenges for the technology developers. It required them to move beyond seeing funding and the length of project as a barrier to the participants directing processes (Garcia-Iriarte *et al*, 2009). This meant they were caught between their obligations to the funders, the users and their own economic and workload reality. Hard decisions and compromises had to be made throughout, frequently without reference or recall to their partners, and often placing them in a dilemma between their sense of what was right or what was necessary. They also had to find ways to deliver, knowing that people were unlikely to have exactly what they hoped for, whilst trying to work alongside other people's timetables and capabilities. Perhaps hardest of all they had to come to terms with ideas upon which they had based their plans not always being welcomed and their initial aspirations for the project not being met.

If organisations wish to support genuinely participatory research, they need to develop funding streams and timetables, which reflect the broad principles outlined by Maclure (1990) in the introduction. They should not require the definition of an output prior to funding being given and the pre-establishment of the participatory group who will submit the bid. This is not so say that some funders do not already evaluate participatory projects on this basis (though this has not been the experience of people working on ARCHES), but rather that funders need to be explicit about this possibility if they are to enable this practice, reassuring applicants, that they can seek to fully engage with the principles of participation.

It would seem from the narrative above, that participatory research which seeks to be genuinely participatory will tend towards delivering unanticipated outcomes. It will also find itself in conflict with many established practices and traditional perspectives. In some ways this equates to its transformative aims (Barnes, 2003). It is aiming to promote disabled people's individual and collective empowerment and the removal of barriers in their lives; but in order for this to be possible it requires a transformation of research and development practices in the first place. Transformation is a pre-requisite for participatory practice to happen, even if the participatory experience is itself a compromised and flawed space. This seems an important message both to those who design participatory research and those who fund it.

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