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## **Embracing community-based participatory research in Media Accessibility**

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### **Research statement**

The video essay 'Embracing Community-Based Participatory Research in Media Accessibility' is intended as a tool for self-reflection on the scope of established research practices in our field. Both the video and the present statement aim to act as a form of epistemological introspection. This critical assessment takes the form of a call for an approach to research that has gone unnoticed in Media Accessibility (MA) thus far: Community-Based Participatory Research (CBPR), also known as Participatory Action Research. From the three shifts defined by Greco (2018) — from a particularist account to a universalist account of accessibility, from maker-centred to user-centred approaches and from reactive to proactive approaches — this essay focuses on proactive approaches in MA research. More broadly, this is an open invitation to examine the worldviews we are currently adopting whenever we do research *about* access users, and to bring the transformative research paradigm to our MA table.

### **1. Criteria**

Firstly, the proposal outlined in the essay was prompted by several impactful readings. The works of Udo and Fels (2010), Kleege (2016), Di Giovanni (2018), Greco (2019a), Romero-Fresco (2019), and Chottin and Thompson (2021), among others, convinced me that truly accessible products or services require the involvement of users at different stages of its design. Upon deeper reflection, the parallel between most of our research and traditional 'post-hoc' access services was made apparent: users — more precisely, participants in MA reception studies — are arguably not involved in the definition of research questions and hypotheses, in the selection of methodologies, in the decision of the most appropriate publication avenue, etc., unless, that is, they are academics and users all at once of the access service at hand (Cavallo 2015; Kleege 2016)<sup>1</sup>. They enter the picture only to answer our questionnaires, to attend focus groups, and to react to our stimuli. Often, they are also not paid for participating in these studies.

Second, an interest in mixed methods intended for my doctoral dissertation and which later materialised in a devoted journal article (Hermosa-Ramírez 2022), led me to the exploration of the different worldviews or paradigms MA has adopted thus far. Positivist (and postpositivist), constructivist, and even pragmatist worldviews have established themselves in MA, as I exemplify later in this statement, yet there is a fourth worldview that our field has not yet embraced: the transformative paradigm<sup>2</sup>, closely related to CBPR as it "seeks to change the politics so as to confront social

oppression and improve the social justice in the situation” (Kivunja and Ahmed 2017: 35). This is surprising, given that neighbouring fields have largely delved into the CBPR approach, with Disability Studies being one example. The combination of the cited circumstances brought me to the realisation that CBPR is a very tangible possibility and perhaps a necessity in MA. In the following subsections I outline the research questions for this essay, contextualise a number of neighbouring experiences with CBPR, present a number of methodological considerations in pursuing CBPR, and conclude with the intended outcomes of this essay.

## **2. Research questions**

How can we replicate the logic of involving users in the creation of accessible services or products in our own research? If MA scholars are advocating for user involvement in industry practices, do we also not have the instruments to apply a user-led framework to our own research processes? As I found CBPR to be one possible solution to the current shortcomings of user involvement in MA research, as illustrated by the social media example in the video essay, the next logical question is how this framework can be applied to MA. Following the tradition of initiating CBPR with ‘how’ questions (Leavy 2017), how can we pursue research that is mutually beneficiary and culturally relevant? In the video essay, I provide a practical example of the application of CBPR to MA. In this research statement, I wish to include more context and expand on my arguments.

## **3. Context**

A vast array of user-centred methodologies has been applied in MA with the aim of inquiring about user preferences and needs. These range from experimental studies applying psychophysiological instruments (Orero *et al.* 2018) to qualitative studies that focus on the idiosyncrasies of the individual (Romero-Fresco 2021). In mixed methods studies combining subjective and objective measures, a pragmatic stance has often been taken. An example could be Ramos’s studies (2015, 2016), which are dedicated to the physiological elicitation and the self-perception of emotions as users are exposed to different audio-described stimuli. Nonetheless, as presented at the beginning of the statement, there is arguably one worldview missing in our field: the transformative paradigm. It may therefore be advisable to seek inspiration for CBPR in other disciplines, and to recognise some steppingstones from our own field: user-led research, action research, and some pedagogical reflections on MA.

As introduced earlier, user-led research does already exist in MA, though it has often come from authors from outside the Translation Studies framework. Cavallo (2015), Kleege (2016), and Thompson (Chottin and Thompson 2021) are some notable examples. Hiring service user researchers in leadership and decision-making positions is, in itself, a practice increasingly advocated for in the fields of Psychiatry and Mental

Health (Callard and Rose 2012). If we apply this logic to MA, the academic expertise of service user researchers, together with their knowledge derived from 'lived experience' can very much help us evade, for instance, occularcentric practices in research.

Action Research is also a growing approach in MA (see, for instance, Dawson 2020; Barnés-Castaño *et al.* 2021). Avison *et al.* (1999) define action research as a combination of theory and practice where researchers and practitioners engage in problem diagnosis, reflective learning, and action intervention. Action research resonates with CBPR in that it involves a cyclical design (Cravo and Neves 2007), as supported in the Methods section, and in that it aims to not only generate knowledge, but also to foster change. Action research, however, may involve MA practitioners, and not necessarily end users, who typically belong to an unrepresented community, albeit not always. Within an MA CBPR approach, accessibility service users are and should be the community of interest. Furthermore, in action research the research topic is not necessarily defined by the community, unlike in CBPR. Lastly, the present vindication of CBPR is, in some ways, a product of what Greco (2019b) has called a pedagogical reflection on critical learning spaces (in his case, regarding university courses dealing with Accessibility Studies, in my case as an Accessibility Studies doctoral researcher doing the 'critical learning').

## **4. Methods**

CBPR offers a wide range of methodological possibilities. In this section, I briefly reflect on the main methodological properties of this approach, the most common methods applied to it thus far, and some ethical considerations to be borne in mind when embarking on such research.

### **4.1. Key principles in CBPR**

Israel *et al.* (2008) propose nine principles of CBPR, out of which eight are applicable to MA<sup>3</sup>: (1) recognising community as a unit of identity, (2) building on strengths and resources within the community, (3) facilitating collaborative and equitable partnership in all research phases (and assessing social inequalities through a power-sharing process), (4) promoting co-learning and capacity building among all partners, (5) integrating a balance between research and action for the mutual benefit of all partners, (6) developing a cyclical and iterative process, (7) disseminating findings and knowledge to all partners and involving them all in the dissemination process, and (8), committing to both a long-term process and sustainability.

### **4.2. Qualitative methods**

Although CBPR can apply any methodology, qualitative methods are often applied to at least one stage of the research process. Stacciarini *et al.*

(2011) conducted a literature review of CBPR on the topic of mental health in minority populations and found that the most commonly applied methods were case studies, surveys, focus groups, and field work observations, together with less conventional approaches including authors' reflections and descriptive studies based on minutes from meetings. Additionally, mixed methods can integrate further quantitative data, and involving a research team in community-based participatory art projects may also be a possibility in MA. Dokumaci's (2018) research-creation video using stop-time as a technique for audio description in collaboration with end users is an example of the latter.

### **4.3. Ethical issues in CBPR**

The Durham Community Research Team (2011) points to several ethical issues that MA researchers should also acknowledge before partaking in CBPR. As relationships of power become more intricate in CBPR, maintaining partnerships and dealing with blurred boundaries in anonymity may require an additional effort from the researcher. Furthermore, academic calendars, funding timelines and community needs may not always align throughout the process, and institutional ethical review committees assume frameworks that are not generally aligned with CBPR, such as a clear distinction between the researcher and the researched, or a predictability of processes.

## **5. Outcomes**

The desired outcome from this essay is first and foremost to invite MA researchers to (at least sometimes) open up our research processes to more direct user participation, favouring community-identified needs. Within the current framework, we researchers may have acted as gatekeepers of knowledge production. To amend this, I conclude by arguing that CBPR has the potential to become a fruitful research framework for applying the social model of disability in MA.

According to Levitt's (2017) updated definition of the social model of disability, disability can be shaped by society's failure to remove social, economic, and environmental barriers (instead of focusing on the individual and their rehabilitation, as in the medical model of disability). To eliminate the social conditions that cause disability, the Union of the Physically Impaired against Segregation (1976: 3) advocated that "disabled people should, with the advice and help of others, assume control over their own lives, and [...] that professionals, experts and others who seek to help must be committed to promoting such control by disabled people." Indeed, most research papers in our field position themselves within the social model of disability, yet users of accessible services often do not have any control over the research that is conducted on them. In this regard, researchers may need to be open to the fact that they may be working with communities that want to challenge the social model of disability.

With this reflection on the social model of disability in mind, the video essay and this statement make a call for CBPR to be developed in MA in the years to come, for an approach that is impactful, and which invites the 'traditional expert' to delegate agency. I wish to point out the fact that we can be more radical in our 'user-centredness', as the disability motto 'Nothing about us without us' also applies to scholarly work. Throughout both the video and the present statement, a number of theoretical and methodological tools have been provided to push such ideas forward. On a final note, the public funding of a CBPR proposal as described in the video would set an important precedent in our field.

Shifting the focus back to the video essay, the vindication of the CBPR approach deploying an innovative format within Translation Studies and MA has aimed to underline the transformative potential of CBPR. Though this research statement is mainly theoretical, the results of a CBPR study do not necessarily need to be depicted in an academic journal article. The second intent was to present the information in an accessible manner, in the sense that it is provided in different formats (an 'open' audio-described video with subtitles, a transcription of the video, together with the accompanying research statement). A 'sequel' to this video will ideally be a collective presentation of the results of a CBPR study in MA.

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## Biography

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## Notes

<sup>1</sup> Advocacy for the "collaboration between autistic and non-autistic academics" as an approach to overcome old attitudes to autism is increasingly widespread in some areas of Disability Studies (Chown *et al.* 2017: 271).

<sup>2</sup> The transformative potential of translation has been discussed by authors such as Alam (2019), Ashcroft (2008), Campbell and Vidal (2019), and Heinisch (2021).

<sup>3</sup> Israel *et al.* (2008: 51) include a ninth principle specific to their own field of expertise, Public Health: "CBPR emphasizes public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease."