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Neurodivergent participatory action research for Virtual Reality (VR)

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Participatory research entails the formation of active and deliberate partnerships between academics and stakeholder groups, particularly in the decision-making components of studies (Cargo & Mercer, 2008; Jivraj et al., 2014). These approaches do not mandate a particular methodology or data analysis technique. Instead, they revolve around the meaningful inclusion of participant groups (e.g. autistic people) throughout the entire research process, from project planning to dissemination (Cornwall & Jewkes, 1995). Such collaborative investigatory methodologies effectively hand control of research onto stakeholders within the community, an approach which has been particularly advocated in the field of autism research (Chown et al., 2017; Fletcher-Watson et al., 2019; Jivraj et al., 2014; Milton, 2017). While less established in other areas of research on neurodivergence, many of the same principles and debates still apply.

Participatory research studies remain sparse in the field, and even where neurodivergent people have been included in the process, their degree of involvement is often limited and/or undefined. A common means of visualising this degree of involvement is the ladder of participation from Arnstein (1969), which originally described the differing distributions of power between citizens and governing institutions, but can also be applied to research. At the bottom of this ladder is the non-participation of citizens (e.g. pathologizing individuals), followed by degrees of tokenism (e.g. informing and consulting), and peaking at citizen power (e.g. partnership and delegated power). The model itself has been critiqued and developed to include more nuance around the goals and non-linear benefits of increased participation (Titter & McCallum, 2006). However, the key premise, that increasing community participation is ethically and materially beneficial, remains intact (Ocloo & Matthews, 2016).

Crucially, there is a noticeable disconnect between the priorities of academic researchers and the priorities of the neurodivergent communities in which they are studying (Pellicano et al., 2014a). This disconnect has been widely criticised by autistic stakeholders and can be observed in the allocation of research funding, especially in the prominence of basic biological research (den Houting & Pellicano, 2019) which is not a priority for autistic people (Roche et al., 2021). Similar concerns have also been raised in ADHD research (Jacobson et al., 2016).

There are a few different reasons for this disconnect. First among these is the prominence of the medical model of disability within neurodivergence research. This model compares any given individual against the standard of a ‘typical’ archetype. Any deviation from this archetype is a deficit and should be the target of an intervention to bring back to baseline (Akhtar & Jaswal, 2013). By studying neurodivergence entirely through this lens, the neurodivergent experience becomes
something undesirable and it is appropriate to explore preventative strategies as a method of public health (Dinishak, 2016). The highly individualised thinking has also placed all of the responsibility for these deficits on the individual, rather than on the social structures and environments that have been developed for neurotypical people (Pellicano & den Houting, 2021).

Moving beyond the medical model, concerns have also been raised about how well non-autistic researchers understand autistic people. The common conception is that autistic people struggle to communicate and integrate socially. The double-empathy problem (Milton, 2012) restates this problem to be that autistic and non-autistic people struggle to understand each other socially, such that the responsibility for difficulties lies with both participants. This is supported by evidence showing that non-autistic people struggle to interpret autistic people’s behaviour and autistic people’s deep and meaningful interpersonal relationships (Crompton, Ropar, et al., 2020; Crompton, Sharp, et al., 2020; Davis & Crompton, 2021). These difficulties mean that it should not be assumed that autism researchers are innately aware of the research needs of the autistic community.

Even as researchers are producing research about autistic people, the community is unable to access that research process and its outputs, leading to further dissatisfaction with the research establishment (Gowen et al., 2019; Pellicano et al., 2014b). This distance is not likely caused by differences in neurology, but instead represents fundamental issues in the dissemination of academic work experienced by most laypeople. Examples of barriers include inaccessible language, paywalls, inexperience with research methods, and ableism (Fletcher-Watson et al., 2019; Pickard et al., 2022).

The final proposed reason for the research disconnect here is that the needs of the researcher and researched are inherently different. Autistic participants are acquiring lived experience continuously, being affected by autism issues daily, and their lives during non-working hours are likely engaged in non-research activities. Researchers, on the other hand, face institutional pressures to be continuously producing research to maintain and/or advance their positions (Pickard et al., 2022).

Participatory Research has been suggested as a partial solution to improve the relationship between academia and the autistic community. That is not to say that the process of co-production is straightforward. Pickard et al. (2021) found that limited time, funding, and institutional support are the main barriers faced by early career researchers to effectively implement participatory methods. As these are primarily systemic issues, reform to funding processes would be key for supporting autistic people to lead research based on autistic people’s priorities (Gowen et al., 2019; Milton, 2014).

There are many resources and articles covering the best practices of co-production and participatory research (Fletcher-Watson et al., 2021). For example, Redman et al. (2021) recommend several mechanisms to ensure that participatory research is implemented, with the caveat that what works at a given time and in a given situation may not replicate in another circumstance. They argue that co-production requires trust, shared power, and respect for differences in expertise. It also relies on clear communication and honesty regarding what is and is not feasible. Gillespie-Lynch et al. (2017) and Gowen et al., (2019) similarly note that transparent communication practices can resolve misunderstandings between research partners. In these frameworks, the authors support methods that proactively familiarise partners with their research team and the exact processes that will be undertaken on a project (as well as the specific goals that it is likely to achieve). By bringing neurodivergent people on board as meaningful collaborators in research projects, whether as fully-fledged researchers or as an oversight board, research projects can avoid issues such as stigmatising language or analyses (Gernsbacher, 2017). Going further, researchers can connect with
neurodivergent-led organisations and communities like the Participatory Autism Research Collective (Milton et al., 2019), allowing for a larger selection of neurodivergent people to have a leadership role in choosing research directions (Chown et al., 2017).

Undertaking any of these steps can improve the quality and appropriateness of research, yet the prevalence of participatory action approaches is relatively sparse in VR-based studies and investigations. Accordingly, the section below will consider the unique advantages of participatory methodologies in VR research, so that more effective and inclusive methodologies can be developed within this growing scientific field.

**Why is Participatory Action Research Important for VR projects?**

The term Virtual Reality (VR) has been used to describe a breadth of technologies placing the user in virtual environments. The key distinguishing features between the technologies relate to whether the user can move in the physical space, rotate their view, and the extent to which the user is fully immersed (Mandal, 2013; Savickaite, McDonnell, et al., 2022). The dominant, though not exclusive, technology at the current time is the Head Mounted Display, a screen placed in front of the eyes projecting two different images to the eyes (Grand View Research, 2022).

VR is still a young technical platform compared to many of the devices that we increasingly use throughout our lives. Unlike other technologies, very few standards have been agreed upon between different manufacturers. A subset of these potential standards is the presence of accessibility features. There has been some movement on the hardware side from manufacturers (Mott et al., 2019), but without mature operating systems for that hardware, software accessibility remains an area of concern. This lack of standardisation means that the responsibility for implementing accessibility features lies with the developers of applications. The user experience of Extended Reality is so novel that many potential barriers and solutions will have yet to be identified, further increasing the challenge of developing inclusive and accessible technology in the field.

PAR methodologies offer a promising practical approach through which high-fidelity VR systems can be created. Indeed, by involving neurodivergent stakeholders throughout a project’s development, PAR can intuitively cater for heterogeneous user preferences and behavioural characteristics. For instance, to increase psychological fidelity, one may be able to identify and remove informational cues that are potentially adverse or disruptive to autistic individuals. Such features could take the form of visual or auditory stimuli that are unpleasant for those with sensory hypersensitivities, or seemingly minor visual idiosyncrasies that are readily detected by individuals with high ‘attention-to-detail’ (Savickaite, McNaughton, et al., 2022). Furthermore, potential differences relating to anxiety (White et al., 2009), emotion regulation (Mazefsky et al., 2013), and motor coordination (Fournier et al., 2010) can be examined by stakeholders who have lived experiences of these issues, to evaluate a system’s affective and/or ergonomic fidelity. Together, these adaptations could ultimately allow users to interact with VR environments in a more compelling and naturalistic manner.

A consideration for developers and researchers alike is that their project is likely to be among the first times, if not the first time, that a user has experienced VR. The technology has plenty of benefits for people, both now and in the future. However, these benefits arise from offering a radically different user experience than people are used to. To make the most of these benefits, users need to have sufficient buy-in to learn a new set of technical skills. If someone has a negative first experience, they may lose that buy-in and be put off from using any other form of Extended Reality. This is particularly relevant for neurodivergent people who may be more likely to develop automatic adverse reactions from single events (King, 2010). As such, developers have an ethical responsibility to avoid discouraging people from what could be a vital platform.
Virtual environments are often designed to replicate key aspects of the real world. VR training developers, for example, will typically try to make user interactions look and feel authentic to increase skill transfer and learning (Harris et al., 2020). Furthermore, realistic psychological and emotional responses are commonly targeted within immersive research and/or gaming programmes (e.g., excitement, stress, fear; Moghimi et al., 2016). The extent to which simulations achieve these aims and create ‘lifelike’ virtual conditions, is referred to as system fidelity. This construct not only concerns how realistic a simulation looks or appears; it also relates to the affective states, cognitions and behaviours that a simulation produces (Gray, 2019; Perfect et al., 2014). In effect, this means that a system’s fidelity fundamentally relies on how individuals perceive and interact with the world around them. As such, it is important to consider the wide-ranging differences that are shown by neurodivergent populations when processing sensory information and performing physical actions.

Overall, by bringing participatory design and research into VR development, researchers and developers will be able to improve the quality and accessibility of their applications. Furthermore, for applications which are specifically designed for use with neurodivergent populations, involving neurodivergent people should help ensure that the priorities of their communities are being taken into account and avoiding programs which have little uptake.

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