

Co-producing an observational tool for immersive technology use for people living with dementia: An Action Research Study

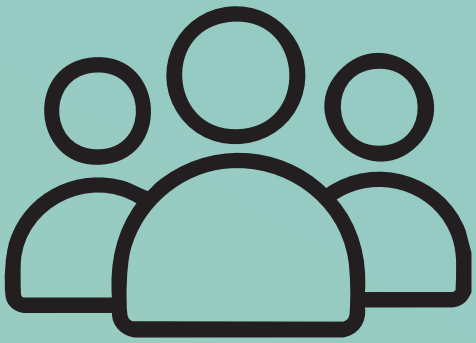
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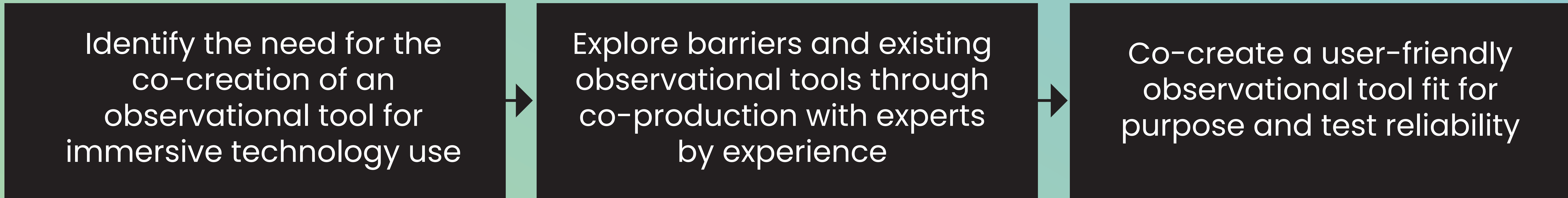
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Background

 944,000 People have Dementia in the UK, expected to rise to 1 million by the end of 2025	 Dementia leads to cognitive decline and is incurable treatments aim to manage symptoms (WHO, 2022)	 Technology has advanced in dementia care, from assessment to well-being support (Astell, 2019; Lorenz et al., 2019; Moyle, 2019)	 Immersive Technology blurs the line between real and virtual worlds and has the potential to enhance the life of people living with dementia (Lee, Shan et al., 2013; Appel et al., 2021)	 64% of people diagnosed with dementia in the UK live at home, many benefitting from user-friendly electronic interventions (Alzheimer’s Society 2021)	 Virtual Reality Technology may reduce symptoms like anxiety and agitation for people living with dementia, but evidence is currently anecdotal	 A robust tool is needed to measure the effects of Immersive VR and VR technology on mood, communication and well-being (Strong, 2020)
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Lay Explanation of Study



1. Systematic Literature Review

Search strategy: CINAHL, MEDLINE, PsycINFO, and British Nursing Index. Study analysed 21 papers from 2002–2021, covering UK, USA, Australia, and other countries. Focus on observational tools in dementia, categorized into:

- Agitation: (4 studies), Well-being (9), Communication (3)
- Quality of life: (2 studies), Engagement (1), Activities of daily living (2)

Diverse methods are being used for observation and assessment aspects of dementia globally. Current observational tools for dementia have useful and positive aspects. Many require training (not all user-friendly) also a lack of co-production with people living with dementia. Co-development with people living with dementia could aid creation of a tool for real world settings for immersive technology use.

2. Interviews

Four interviews were conducted after ethical approval:

- 2 with museum staff using mobile immersive space for dementia care
- 1 with a software designer (immersive technology) for people living with dementia
- 1 Care Assistant from a residential home observing the technology in use
- Data analysed aided by Nvivo software in which six themes emerged: Barriers – Benefits – Engagement – Experience – Mood – Observations

Themes and data discussed with the supervisory team, confirming alignment. Themes to guide the next stage: focus groups

3. Focus Groups & Co-Creation

A total of 3 x focus groups conducted (May–June 2023) with:

- 7 unpaid carers (family/friends of people living with dementia), 2 x technician facilitators, 2 x healthcare professionals (dementia specialist nurses).

The focus group sessions were based on the semi-structured interview themes. Participants evaluated 9 observational tools from the literature review (excluding 2 for ‘trained experts’). Participants provided feedback on user-friendliness, observation categories, and transferability to immersive technology. Key areas for designing an observational tool for immersive technology were identified from the data by the group:

- A simplified ‘user-friendly rating scale’. Maximum of 3 options wherever possible.
- Pre and post intervention rating options.
- Topics within the observations should include social interaction, engagement, attention, mood, agitation, communication (both verbal and non-verbal), reactivity and enjoyment.
- The language used within the tool should be sensitive (empathic).
- A simple scoring system should be added to gain a level of the interventions effects.
- Post-evaluation would be beneficial to assess the level of effectiveness hours after the intervention (7 x areas: mood, appetite, continence, communication, sleep, mobility and socialising).

4. (ITOT Tool) Testing & Final Phase

The ITOT (Immersive Technology Observational Tool) was co-created. Approval from Coventry & Warwickshire NHS Research Ethics Committee received. Tool was then tested with people who can consent to ensure safety and purpose of tool. Observations conducted at three public events by 6 observers – 30 observations completed (15 male, 15 female) using ITOT (Ver.2.0). Scores analysed with Cronbach alpha software, resulting in a score of 0.95. Tool adapted to version 3.0 based on field issues (simplified terms, typo correction). Further ethical approval granted (Jan 2025) for final phase testing with people living with dementia in immersive tech space ‘House of Memories on the Road’ in spring/summer 2025. This phase will be to test the tools adaptability and reliability within the immersive space.

