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Exploring Participants' Representations and Shifting Sensitivities in a Hackathon for Dementia

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Recent HCI research has addressed emerging approaches for public engagement. One such public-facing method which has gained popularity over the previous decade have been open design events, or hackathons. In this paper we report on DemVR, a hackathon event that invited designers, technologists, and students of these disciplines to design Virtual Reality (VR) environments for people with dementia and their care partners. While our event gained reasonable attraction from designers and developers, this paper unpacks the challenges in representing and involving people with dementia in these events, which had multiple knock-on effects on participant's outputs. Our analysis presents insights into participants' motivations, challenges participants faced when constructing their 'absent user', and the design features teams developed to address the social context of the user. We conclude the paper by proposing a set of commitments for collaborative design events, community building through design, and reification in design.

CCS CONCEPTS • Human-centered computing → Human computer interaction (HCI) • Human-centered computing → Collaborative and social computing

Additional Keywords and Phrases: dementia, community, social, hackathon, care, virtual reality

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1 Introduction

Traditional hackathons are sprint-like design events that are a popular approach for researchers and organisations to bring together the public to develop new paths to research, ideate and test software or products. Sprint-like design events are often time-constrained iterative design processes that tackle a business or product problem [79]. Typically, hackathons have been known to target technical students who are willing to offer their time and technical skills in exchange for the opportunity to network with companies and learn new soft skills and new insights into areas they may not have yet explored [89]. In recent years, various domains have adopted hackathons to prioritise to respond to issues beyond the software or hardware skillsets of attendees. For instance, 'civic hackathons' [59] have aimed to improve citizen-government relationships through transparency, open data, and events focused on 'social good' [34]. Within HCI, hackathon research has demonstrated useful cases for participation, learning, building, and connecting people in communities of practice [5, 32, 54, 59, 79, 117]. However, such events pose challenges of longevity [5], compensation [29], accessibility [53], and representation of the area for which attendees are designing [114]. In response, researchers have re-structured and tailored the format to tackle the challenges described above. For instance, Hope et al. [53] leverage feminist and intersectional lenses to suggest pathways to building more inclusive and accessible events. Echoing this, in a recent review of the past ten years of hackathon research, Olesen & Halskov highlight there is often a topical drive that is typically related to an ongoing real-world problem or engaging a particular community [32]. With this in mind, hackathons that invite public engagement into design work within sensitive settings require careful consideration. One challenge lies in how we engage such sensitive topics in HCI while encouraging public engagement, which facilitates opportunities for collaborative learning and awareness around the topic of interest. While it takes time for researchers to become aware of the sensitivities required for working with such population, hackathon formats expect the same sensitivities to develop within a short amount of time – usually a weekend. Therefore, it is not a surprise that prior work has indicated that some design outputs may be unsuitable or feed into stigmatising ideas of the group or topic at the centre of the design event [116]. Prior work has considered ways to sensitise attendees on the event's topic through presentations, workshops [53], and inspiration packs [5] to upskill participants who may hold outdated or stereotypical attitudes. Given the potential challenges of such public design events [5, 53, 62, 115], it is particularly timely to begin to unpack the representations and attitudes that influence attendees and their design outcomes to surface future considerations for organising hackathons within sensitive contexts.

This paper presents a detailed account of DemVR: a hackathon that invited designers, technologists, and students to learn about dementia through the design of VR environments for people with dementia and their care partners. VR was chosen as a focus area due to local interest from local authorities – who were interested by prior VR and dementia work conducted by the first author]. The first stage was a pre-hackathon phase, running over six weeks, where attendees, people with dementia and their care partners, took part in short consultations via an online platform, Ideaboard, to share possible VR ideas. Following this engagement, we organised a two-day hackathon that invited designers, technologists, and other makers to engage with domain experts and people with dementia to develop their ideas further. While we gained reasonable interest from designers, developers and students, our event under-represented people with dementia and their care partners. Our challenges in sufficiently representing people with dementia had multiple knock-on effects on teams' outputs that we describe in our findings.

In response, our research focus on this paper switched to how designers/developers engaged with the topic of dementia, rather than ways they engage with people with dementia. We revisit our structuring of the hackathon to reflect on how our work practices led to a lack of involvement of people with dementia and their care partners. In our analysis of interview and ethnographic data, we provide insight into the motivations for those taking part in hackathons, and an account of how some participants new to the area of dementia conceptualised, operationalised, and designed for an absent user. Our analysis is guided by the following research questions:

- **Research Question One:** How do designers/developers represent people with dementia when solely relying on their own experience (or lack thereof)?
- **Research Question Two:** What considerations for technology do designers/developers prioritise when designing for people with dementia?

- **Research Question Three:** What challenges arose when trying to represent the voices of people with dementia and care partners during the hackathon? What opportunities arose which we may, in time, pursue?

Building on our analysis, we take the opportunity to reflect on our hackathon structure and, using dementia as a case example, propose a series of commitments for HCI and dementia research. These commitments offer insights into how we might mitigate stereotypes in constructing the end-user; ways to improve recruitment for involving marginalised populations in events; and steps to promote more inclusive, community-driven events.

2 Related work

To provide context for our approach to the design of DemVR, we discuss current approaches in designing *for and with* people with dementia and conclude the section by considering the challenges and opportunities of including such populations in public design events such as hackathons.

2.1 Learning about marginalised communities through design

Co-design and participatory design traditions have historically engaged with marginalised communities in order to highlight the agendas and individual needs of members on topics such as rights, benefits, resources, and identity [27, 43, 94, 102]. This work has resulted in design practices that examine the acknowledgement of emotion in our research [1]; give careful attention to researcher-participant relationships [16]; and create safe spaces to support the sharing of sensitive topics [67, 102, 111]. Following this work, the acknowledgement and sensitivity required for participants depends on their desires, needs as a community, and the community's history that we are building on. Prior work has innovated many of our methodological approaches to better fit our participants: for instance, careful navigation of gatekeeping [101], awareness of biases and stereotypes [74], and providing slower, longer-term projects to provide the time to build trust and a relationship between the researcher and participants [38]. Beyond designing for individual needs and desires, working specifically with LGBTQIA*groups [13], refugee and immigrant populations [111, 112], those with mental health conditions [5], older people [97], and reproductive rights advocates [80] has contributed to a more inclusive design that invites *"new ways of doing, making and inhabiting the situation of our world today" (pg.65)[99].* This project focused in particular on designing for and with people with dementia, where dementia is a neurodegenerative condition causing changes to cognitive ability and increasing reliance on social and physical care; it can also bring with it stigmatisation and subsequent social isolation [50]. Moving from an early, medicalised understanding of dementia as a process of decline and memory loss, recent social justice and rights-based responses to the experience of dementia have resulted in a more holistic understanding of the condition [104]. This evolving understanding of dementia is mirrored in social and technological responses in research, which moved from early assistive technologies focusing on bridging a 'cognitive gap' [84], to experience-centred design that fosters creative expressions of personhood [83], to more recent work on supporting wider social engagement with people with dementia [38, 40, 67, 124]. Through understanding best practices for designing *with and for* people with dementia, HCI researchers have developed a range of approaches which centre relational interactions, as opposed to engaging this population solely at the end of the design process, e.g., by inviting participants for 'user testing' or 'user evaluations' [7, 38, 68, 103, 120, 122, 124]. However, by providing a more relational approach in such work, both researchers and participants are faced with different challenges. For instance, Hendriks et al. describes the need for longer-term commitment to projects to support trustworthy relationships between the researcher and participants [48]. Furthermore, the authors draw attention to the implicit decision-making designers and researchers may make because they have certain skillsets or expertise.

In response to an increase in multidisciplinary teams (e.g., encompassing designers, developers, and researchers), designers and developers use toolkits to manage collaborative design and *"understand the design situation and the problem at hand and to explore and experiment with potential solutions*." *(pg.21)[57].* Caraban et al.'s work in developing 'Nudge Deck' [14] supported participants to break their design challenge down into more minor problems and in turn lay out directions for their design. However, the use of design toolkits can face challenges where other cultural contexts and settings interact [92], such as when values, goals and technologies displayed on cards may have little to no meaning within the setting. While one approach is to make toolkits more abstract and open to be applicable for different

settings, Peter et al. suggest tools be more "*consciously culturally-tailored" (pg.20)* [92]. This may require involving audiences in the creation and customisation of the tool. Similarly attending to the practical use of such kits, in a recent review of open-source fairness toolkits, Lee and Singh raise a valuable concern, stating creators of such toolkits should *"remain vigilant to ensure their adoption is aligned to the over-arching goal: to ensure our algorithms reflect our ethical values of non-discrimination of fairness" (pg.12) [70].* In cases like these, the provision of tools that may be freely used and reshaped by a user community requires further thought about the roles of moderation or expertise, particularly when toolkits may be intended for use or application in marginalised settings.

In contrast, other toolkits such as the Compassionate Design Toolkit by LAUGH provides an approach to show designers how they may design for people with dementia by including their interests, life history and opening experience to the senses [118]. While these activities are beneficial in prompting learning and informing user scenarios [121], researchers must be wary that methods such as personas may reduce flexibility and creativity by attempting to fit the technology to a set of *"caricatures" [96],* rather than exploring the ambiguous nature of how people may use the technology. Therefore, while these design activities can offer initial insights into the people we are designing for, researchers should continue to question and explore the challenges and impact such approaches may have for when we are designing within sensitive settings.

Concerned by similar implications arising from design thinking activities [4], researchers have considered novel approaches to undergraduate education to provide budding designers and developers with the skillset and ethics to make more sensitive design choices. In the context of dementia and HCI, this has led to inviting students to collaborate in co-design methods with care home residents by developing life story work [39] and storytelling projects [46]. Hendriks et al. [48] further supports the importance of designers and students building a relationship with the people we are designing for and with in the context of dementia. The authors argue design decisions *"emerge from the relationships designers build" (pg. 3)[48]* . However, while opportunities to work in more non-traditional settings such as care homes may be possible through university classes, these are often limited to a small, selected group of students or courses focusing on healthcare and psychology [63], meaning those who are taught technical or design disciplines through university miss out on opportunities to gain experience with the vulnerable populations that they may end up building for. Finally, developing these types of understandings through intergenerational interactions has often relied on organisations or care homes to provide a community of older adults or people with dementia, both increasing the workload of already pressured social care organisations, and limiting the potential of involving communities or individuals who are not part of those selected organisations. One alternative may be to support collaboration and engagement between the public and people with dementia through online spaces, as we discuss below.

2.2 Dementia and public engagement

Much of the research around social interaction with people with dementia is highly facilitated through family care partners [52, 78, 124], and often positioned in either family homes, or care homes [38, 41, 49]. This work emphasises the importance of relationships, and the potential for design technology to support close and personal interactions. Involving care partners in the home of the person with dementia provides familiarity, inclusion and 'subtle support' for decision-making processes to make involvement comfortable for the person with dementia [35]. However, this approach requires continued engagement and relies on support and time from care partners, volunteers, and the person with dementia [56, 93]. In contrast to this, Lazar and Dixon's work on dementia activism online [67] demonstrates the willingness of some people with dementia to share their experiences in order to change public attitudes, and to present 'real and raw' accounts of life with the condition. Participants' motivation to share their experiences of living with dementia seems to be twofold*:* writing allows a reclamation of social identity through sharing their thoughts and feelings, and second, sharing their experiences helps not only family members, but also the public to look past the diagnosis of dementia by demonstrating life continues to be rich and meaningful post-diagnosis [100].

Sharing lived experiences can also be seen in the recent proliferation of blogs, presentations, and personal books advocating for changes in media and public portrayals of dementia which might in turn counteract dominant misconceptions about, and stereotypes of, the condition [12, 15, 109]. However, careful consideration must be attended to the way technology is appropriated as Lindqvist et al. argues technology can *"be hindering and evoke stress or, in contrast, bring about feelings of control" [71]*. While this creates an opportunity for public engagement, the extent to

which the ‘public’ are engaging with these narratives is underexamined, begging the question: how can these experiences be better positioned for societal change-making? Moreover, such advocacy work, despite its benefits, is often associated with strain, through the *“psycho-emotional consequences of taking action” [2]* where advocates present themselves in an opposing dominant public view. For instance, Christine Bryden, a pioneering dementia advocate, will often show images of her brain scans in presentations to prove she has dementia as several advocates have been accused by medical practitioners of not *“look[ing] or sound[ing] like [they] have dementia” [108].* In these instances, exploring ways to balance between empathy and maintaining an individual’s privacy and dignity is required.

With this in mind, including aspects of public engagement in design work with vulnerable groups such as people with dementia requires careful consideration. One challenge lies in how we engage with such complex (and often stigmatised) topics sensitively while encouraging public engagement, which in turn allows a greater extension of awareness and understanding around the topic of interest. For example, many expert researchers will have years of experience working with people with dementia, and are aware of both the importance of attuning to person-centred approaches [33] and language, but also of the damage negative and stereotypical ideas of dementia can have when used to emphasise a deficit or inaccurate image of life with dementia [125]. Moreover, Niederdeppe et al. highlights the formidable communication challenges faced when inviting a wider public to input on a sensitive topic due to unknown biases, priorities and cultural norms which may run the risk of having stereotypes aired publicly or even perpetuated [87]. In response, Niederdeppe et al. argues that different communication strategies may be required to educate and upskill the public on sensitive topics.

Facilitating broader design engagement creates opportunities for collaborative learning between different communities to provide spaces for refining a more sensitive, nuanced public narrative of dementia, which may then be realised in the products, services, and systems we co-create [19]. This may in turn shape the environments in which we learn about and support those living with dementia. Supporting collaboration and engagement in creating such artefacts through public-facing design events offers us one such opportunity.

2.3 Design events and public engagement: a steep learning curve

Public design events such as hackathons [89], design sprints and workshops, involving as they do interdisciplinary teams interested in innovation, have been said to *“offer new opportunities and challenges for cooperative work by affording explicit, predictable, time-bounded spaces for interdependent work and access to new audiences of collaborators”* [36]. Originating within the tech industry as competitive over-night coding events [60], hackathons are events where designers, developers collaborate over an intensive short period of time (typically a weekend), on software or design projects [86]. Typically, hackathons have been organised and sponsored by businesses or universities to provide undergraduates the opportunity to gain experience and practice new skills, and potentially building connections between the attendee and organisation recruiters or employees. Hackathons are often coupled with rewards and prize money for the winning team as enticement to spend time building a demo and/or presentation [59]. Hackathons have also been adopted as opportunities for co-operative makerspaces focusing on health and other community-based issues: for example, hackathons for women’s health [91], and self-harm [5] have offered key insights into how interdisciplinary teams can come together to shape innovative technical responses to complex topics and wicked problems.

Despite their benefits, hackathon formats can also raise tensions in certain circumstances: Taylor and Clarke [113] note issues in *“explaining what a hackathon is and what it will involve”*, particularly when the audience background is mixed. Additionally, Nolte et al. note that *“participants were able to expand their respective network during a hackathon”* where there is a trade-off between *“trying new goals and skills” and “developing a product” [88]*. Beyond these structural factors, facilitators of design events for public and civic issues are challenged with introducing often sensitive topics, while also encouraging creative and technical responses from participants in a short time frame. While these spaces are encouraging for student makers or as community-building events, the hackathon space expects participants to get 'up to speed’ with contemporary knowledge about the condition, group or topic while simultaneously requiring participants to design and build outputs. It could be argued that, when the focus of the hackathon is on health and/or wellbeing, such open design events require the careful scoping of presentations, workshops [53], facilitation, and inspiration packs [5] to upskill participants who may be drawn by the promise of prizes or creatively fruitful weekends, but who may hold outdated or stereotypical attitudes towards the topic out of a lack of experience. Providing engagement

through interactions and design tools is particularly important where participation is open to the public where participants may lack lived experience.

Given the potential challenges of such public design events [5, 53, 62, 115], but also the increasing prevalence of such modes of public engagement [29, 32, 53, 126], it is particularly timely to unpack exactly how the work of designing for marginalised populations within such settings may be better supported. To gain insight into prior work that reflects our research questions, our literature review has explored: a) ways designers and developers learn and represent dementia through design thinking activities, b) how people with dementia are involved and portrayed in public engagement, and c) the challenges of representing marginalised voices in public engagement settings – in particular, hackathons. This study explores the importance of restructuring hackathons to accommodate and represent the experiences of marginalised population, and the ways in which we provide and support education to those without these experiences, but who find themselves designing for them. The following section describes our event context that provides insights into how hackathons could provide a creative and inclusive space for designers and developers to learn about dementia and VR.

3 Event Context

This project is part of an ongoing long-term study focusing on the inclusive design of evocative VR experiences for families living with dementia. While our previous work extended concepts from experience-centred (ECD) [1, 76, 83] which require working closely with participants, often one-on-one [122], requests for collaboration from both local dementia community groups and local authorities allowed us to contemplate extending this work to larger groups of people. At the same time, work in digital civics for social care [18, 90] as well as interest from local authorities prompted us to explore how inclusive design work might function within the context of larger-scale community events.



Figure 1: Timeline of the hackathon

Drawing these threads together, we organised a hackathon called DemVR, both to generate a set of bespoke VR environments for those with dementia, as well as to consider how developers/designers and people with dementia may collaborate. Inspired by prior work involving marginalised groups in hackathons [5], the hackathon was split into two engagement phases (see figure 1). The first was a six-week pre-hackathon phase: this consisted of the deployment of an online platform (called Ideaboard) to support designers/developers in pitching their potential hackathon ideas and receiving feedback from people with dementia and care partners. The second phase was the two-day hackathon event itself, where participants formed teams to compete for £1,000 & £500 prizes by creating prototypes of VR environments for people with dementia and their care partners. To accommodate funding for venue hire, branding, food and travel, the research team partnered up with several organisations in the city of the university who assisted in the funding and providing expert knowledge on dementia, VR, and running tech-focused events. We acknowledge our project partners in our acknowledgements. In the following sub-sections, we describe the event according to the timeline of the hackathon: 3.1 recruitment; 3.2 pre-hackathon - online platform, in-person workshops, team formation event; and 3.3 the two-day hackathon. Additional details of the schedule can be found in the online appendix A.

3.1 Recruitment

Our initial recruitment process targeted designers and developers through university networks, VR/AR labs across the UK, as well as publishing blog pieces on popular VR websites to invite creators to take part in the two-day event. Upon

registering for the event, participants were sent an email inviting them to sign up for Ideaboard and submit their idea. During the recruitment phase, we attempted to recruit people with dementia and their care partners in multiple ways. The first was through a series of invitations across Newcastle city that consisted of: inviting a local dementia café who we have worked closely with in past projects and sending flyers and posters out to a range of public spaces that are often used for dementia-friendly meetings and gatherings (seen in appendix c). For our work with the dementia café, we set-up in-person workshops at the café to ensure the participants felt comfortable in the space. Further, given Twitter is a popular social media platform for dementia advocates [39], we ran a Twitter account posting tweets to encourage people with dementia and their care partners to sign-up. We also reached out to several dementia networks such as 'World Young Leaders in Dementia' to share the event information on their public newsletter and bulletin boards. During the recruitment phase, we described the event as design focused but required little to no experience with designing, dementia, or VR. In these instances, while we invited people with dementia and care partners to the hackathon, our priority was signing them up to our online platform or to take part in our in-person workshops as the pre-hackathon phase supported longer-term engagement. However, as we have mentioned above, our recruitment processes to involve people with dementia and care partners was challenging, with only one care partner signing up to our online platform. We revisit issues regarding the language used, expectations and the research problem in our discussion when recruiting for people with dementia

Twelve participants (2 women, 10 men) actively signed up to the online platform. During set up, to initiate conversations, the authors added three initial example ideas focusing on shared family VR experiences, personalising the VR headset, and a VR experience that blends the real world and virtual into one. Out of the twelve participants, eight submitted ideas. Of the twelve participants, nine attended the hackathon (see table 1), with two submitting an idea but not attending the hackathon. One participant, a care partner named Denis, was unable to attend the hackathon but actively joined discussions on six of the submitted ideas. Denis was the only person to represent the 'end user' in some capacity. We gained no interest from any other care partners or people with dementia to attend the event. Additionally, while we set-up two in-person workshops described in the *3.2 Pre-engagement phase,* the workshops received no signups resulting in no additional feedback for teams from people with dementia or their care partners. In our discussion, we reflect on why this might have been the case and its implications for public engagement.

For the hackathon, we had 40 participants (18 women, 22 men) in attendance. In our pre-hackathon team formation stage, we had an additional team of four that dropped out due to intellectual property concerns. This resulted in nine teams. Individual demographics of participants within their associated teams are summarised in table 1. Although no participants had the experience of being a care partner or living with dementia, we defined and solicited participants' experience with dementia in the following ways:

- Experienced: Has worked around dementia in a research/industry/care setting/charity.
- Knowledgeable: Has had a family member or friend living with dementia but not necessarily cared for them.
- Limited: Have read people's experiences or recent research in dementia.
- None: Know very little about the topic.

Table 1: Hackathon teams' demographics (gathered on participants' signup)

Team	No. members	Age-range	Background(s)	Experience with dementia	No. members who joined the online platform
Garden Life	7	18-25	Comp-sci undergrad (7)	Limited (1) / None (6)	3
Chatter Bench	2	26-45	History researcher (1) / HCI research developer (1)	Experienced (1) / Limited (1)	0
Augmented World	6	18-25	Comp-sci undergrad (6)	Limited (2) / None (4)	1

VR Hallucinate	6	18-35	Psychology researcher (2) / Developer (3) / Designer (1)	Limited (1) / None (5)	0
Looking VR Back	4	25-45	Marketing (1) / Biomedical researcher (1) / Comp-sci undergrad (2)	Experienced (1) / None (3)	2
Mindful Forest	2	18-25	Comp-sci undergrad (2)	Knowledgeable (2)	0
Sensory Tide	6	26-45	HCI researcher (3) / Developer (1) / Filmmaker (2)	Experienced (2) / Knowledgeable (1) / None (2)	3
World Share	3	18-25	Filmmaker (3)	Knowledgeable (1) / None (2)	0
VR motion	4	18-25	HCI researcher (1) / Developer (1) / Designer (2)	Experienced (1) / Limited (1) / None (2)	0

Expert speakers were also invited to discuss topics on design, dementia advocacy, and experiences of living with dementia. An additional three dementia & HCI researchers, a gerontologist, and the CEO of Silverline Memories, our partner charity, assisted with hackathon facilitation. The facilitators lent their experience by sitting with individual teams throughout the two days to talk through the teams' ideas and thought processes. Our judges consisted of a dementia HCI researcher, the CEO of Silverline Memories, a VR expert, and an accessibility HCI researcher to judge the team's VR ideas.

3.2 Pre-hackathon engagement

We planned and arranged a six-week consultation period, to be conducted via 1) an online participatory platform, and 2) in-person workshops with people with dementia and their care partners. Additionally, we provided a team formation day prior the two-day hackathon to socialise with other participants and form teams if they had not already. Our pre-hackathon stage provided the optional opportunity for future hackathon participants to submit initial thoughts and ideas where experts would provide feedback to give participants insight into the needs, desires, and experiences of people with dementia and their care partners.

3.2.1 Online platform (Ideaboard)

The participatory platform, *Ideaboard* (see Figure 2a, b), was conceptually inspired by participatory platforms such as Kickstarter, GoFundMe, and Indiegogo. The platform also takes influence from work in digital civics and social care – for instance, one inspiration was App Movement [45], a platform that enables users to *"collaborate, design, and deploy community commissioned mobile applications".* Ideaboard similarly offers creative tools and workspaces to support the creation of ideas and collaboration. Here we describe the process users undertake to add ideas to the platform. Our Ideaboard process was split into three components:

1) On Ideaboard, participants were invited to share preliminary ideas that they could develop during the in-person hackathon. The idea consists of the title, summary of the idea, a detailed description, and an option sketch/mock-up. Once their idea was uploaded, participants could then explore and comment on other submitted ideas (see figure 2a).
2) Once participants had submitted their ideas, we invited people with dementia and their care partners to share insights on and critique the submitted ideas on Ideaboard. We hoped that this would allow people who might be unavailable for the hackathon to take part in design ideation and help to shape emerging ideas that might be taken further in two-day hackathon.
3) Hackathon participants could then respond to the expert feedback and begin an open dialogue with other participants, care partners and people with dementia. From here, ideally, teams would have more in-depth and developed ideas that consider the experiences of care partners and/or people with dementia.

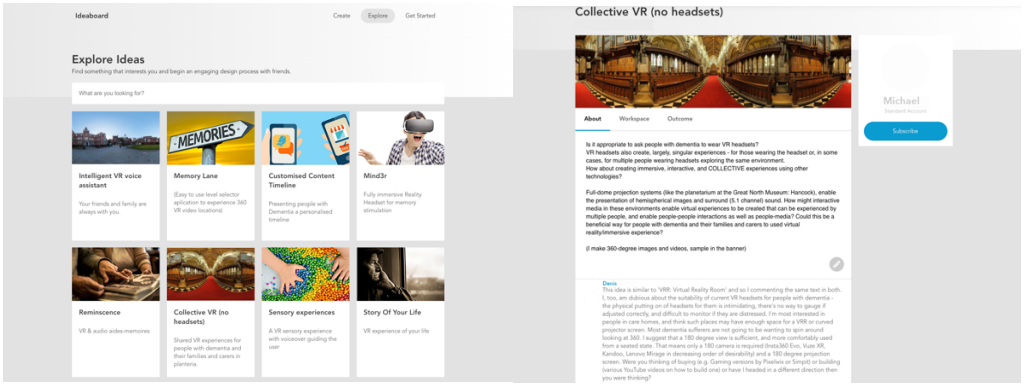


Figure 2: a) Explore Ideaboard ideas, and b) example of 'idea' features (anonymized)

3.2.2 In-person workshops

To further support participation beyond the online platform [93], the first author set up two in-person workshop sessions inviting members of a local dementia café [26]. Working closely with the dementia café on prior VR projects, the team expected to recruit several people with dementia and care partners with established experience of VR. Within the six-week consultation period, the two in-person workshops were organised in the final two weeks to ensure the first author could print off any submitted Ideaboard ideas to share with participants. This workshop was intended to support participants to engage in a set of design activities to illustrate their desired VR shared experiences or build upon the existing eleven ideas posted on Ideaboard. Based on comments and ideas produced in these workshops by care partners and people with dementia, the researchers would then add any additional ideas and comments to Ideaboard. We hoped that this process would allow the designers/developers to have additional time to reflect on comments from people with dementia and their care partners. As stated in our recruitment section, our attempts to involve people with dementia and their care partners was significantly limited to just one care partner's involvement who engaged through our online platform. For both in-person workshops, we had no sign-ups. We explore this in more detail through our findings and discussion.

3.2.3 Team formation

We set up a 2-hour pre-hackathon team formation event on the Friday of the hackathon weekend to ensure participants had organised themselves into teams. During the team formation event, we printed the eleven ideas published on Ideaboard. We placed them on individual tables where participants could add a sticky note to express an interest in the idea. Since submitting an idea on Ideaboard was optional, five teams came prepared with ideas. As a result, only four of the eleven Ideaboard posts were taken into the hackathon. In the online appendix b, we present the origin point of teams' initial ideas. During the hackathon, all teams adapted their original ideas by reflecting on how people with dementia may experience them. They did this through engaging with a series of resources (discussed below), and otherwise used the time to build and design a rudimentary prototype of their VR experience.

3.3 Hackathon event



Figure 3: Hackathon event schedule[1]

Our hackathon took place across one weekend at a local museum in [city]. The venue is centred within the city centre near the University campus and co-exists alongside a Natural History Museum that attendees had access to throughout the two-days that provided space away from 'hacking'. To accompany the large number of teams and space required for VR demos, each team received a demo space, rounded table, and an array of crafting materials. For additional details of the schedule, check out our online appendix A. In terms of equipment, teams had access to eight Oculus Go's, four Oculus Rifts, one HTC Vive, and two VR-ready PC rigs. Teams were encouraged to bring their laptops and VR kit if they wished, and to notify the facilitators before the event if they need any additional technologies.

3.3.1 Day One

The first morning of the event consisted of presentations on dementia, participatory research, and virtual reality by invited speakers. The invited speakers also functioned as facilitators who provided hackathon participants with insight into their areas of expertise. At midday, we organised an online Q&A with Howard, a dementia advocate who shared his experiences living with dementia. This Q&A lasted 15 minutes. In the Q&A, one of the keynote facilitators led the conversation due to having a strong existing relationship with Howard. During the Q&A, participants could submit questions through a WhatsApp group that the facilitator would use. Through the discussion, Howard was asked about his challenges of being diagnosed, the type of technologies and experiences he would find useful, and the social complexities he is currently facing given the stigma of dementia.

After this, teams began to 'hack'. Teams could then ask for additional help or critique from facilitators, either in-person or reaching out to the facilitators in the individually set up WhatsApp team groups. In practice, these online chats with facilitators provided quick and easy links to papers or method approaches that were related to the topic at hand. Furthermore, we used these groups chats as an opportunity to a) ask participants to respond to reflective questions such as *"how have your thoughts about dementia and/or virtual reality changed from the beginning of day one?"* and *"describe your reaction to Howard's Q&A",* and b) invited to detail their project's progression through submitting comments, audio recordings and videos through a dedicated Team WhatsApp group chat, which formed the basis of data collected during the event. For instance, team Sensory Tide shared pictures of team members traveling to a local beach to collect videos and shells to be used in their finalised idea.

Teams were given *inspiration packs* (see figure 4): these consisted of materials that summarised key insights from previously published work on VR and dementia [51, 52]. In addition to the physical inspiration packs, we set up an online shared document that would continue to grow as a resource through the duration of the event. In the end, this consisted of academic papers; speaker slides; dementia guides such as DEEP language and NHS (UK National Health Service) guides; a set of handouts detailing design processes such as scenarios, bodystorming, and 5 Whys; and tips and tricks for what to include in the final presentations. In our findings, the DEEP language guide is drawn upon several

[1] WhatsApp reflection period was when the facilitators sent prompts for teams to submit an audio recording answer. We describe this in more detail in our data collection and analysis stage.

times; it is a three-page document designed by 20 people living with dementia [25]. The key takeaways of the document are a set of standards for accepted or sensitive ways to talk about dementia. During the afternoon, all teams pitched their idea to the rest of the room. This provided an open forum between facilitators and participants to provide additional feedback for the set of ideas. For the rest of the weekend, the teams worked on their ideas with periods built in for breaks and socialisation.



Figure 4: Inspiration packs

3.3.2 Day Two

On the Sunday morning, teams had the entirety of the day to finalise their ideas and presentations and had the opportunity to ask facilitators for feedback on their presentations and demos. Facilitators assisted in helping teams add finishing touches to their demos and provided feedback on their presentations. To maintain consistency, we provided a template with guiding topics such as: title and tagline; who is your user audience; what is your motivation and problem; what was your approach to inform your design challenge; what are the future considerations; and reflection on the hackathon. The event culminated in each team presenting a final ten-minute presentation and five-minute demo that allowed teams to demonstrate their work to the judges. The four judges had the opportunity to explore the demo and ask any further questions about the teams finalised idea. Each team's finalised concepts were rated on the following:

- **novelty of design concept**: *how original are the ideas? Are they backed up with appropriate research? How provocative (yet sensitive) or otherwise promising are they?*
- **clarity of team's vision**: *how persuasive are the presented arguments?*
- **sensitivity to the challenge**: *specificity to issues central to dementia/care; how well were experts' suggestions taken on board; are there any potential negative consequences?*
- **potential for real-world impact**: *given appropriate backing or resource, would this concept make a difference?*
- **strength of VR/AR**: *How far along did the idea development get? Did the teams make good use of the technology at hand? [2]*

At the end of the day, the judges announced the 1st and 2nd place winners who would receive £1000 and £500, and the event ended with a brief overview of the hackathon by the first author. Teams proposed ideas can be found in the online appendix b.

4 Methodology

Following the event, the paper's authors began to reflect on how the event unfolded and the study's potential contribution to HCI research. Although the initial focus of the event was on bridging the gap between the designers/developers and the topic of dementia, given the challenges we faced in representing people with dementia and their care partners, we saw this as an opportunity to provide guidance for future researchers on the potential knock-on effects when designing

for a user group who are missing from the design process. As described in our introduction, we present the following research questions, which guided our analysis:

- **Research Question One:** How do designers/developers represent people with dementia when solely relying on their own experience (or lack thereof)?
- **Research Question Two:** What considerations for technology do designers/developers prioritise when designing for people with dementia?
- **Research Question Three:** What challenges arose when trying to represent the voices of people with dementia and care partners during the hackathon? What opportunities arose which we may, in time, pursue?

4.1 Ethics

Ethical approval was granted by [university]. Upon signing up, each participant was provided with an information and consent form describing the event and pre-hackathon stage. Any participants who then signed up to use our online platform was given additional information about the project. Participants who registered for the hackathon signed a consent form about the hackathon weekend when they came to pick up their lanyard and sign in for the opening day of the hackathon. Participants' and team names have been anonymised for privacy.

4.2 Data and Analysis

In our study, we gathered data from four different sources: 1) the text data of the Ideaboard ideas (I), including additional comments from participants on the ideas; 2) the keynote, Q&A and teams' presentations from the event (P); 3) each team's WhatsApp group's texts (W), images and audio, which were extracted using the built-in Google Drive feature and 4) the first author's observational field notes (F) taken throughout the event highlighting conversations they had with teams and facilitators. Audio recordings collected through WhatsApp were in response to five questions asked over the weekend that we described above. WhatsApp audio recordings were also transcribed and anonymised by UKTranscription. The initials (I, P, W, or F) indicate the source of the data in the findings.

Table 2: Data collection

Stakeholders	Ideaboard (I)	WhatsApp (W)	Presentations (P)	Field notes (F)
Hackathon participants	11 submitted ideas	25 minutes audio recordings + average 25 texts per team	117 minutes	N/A
People with dementia and care partners	One care partner replied to eight submitted ideas	N/A	15 minutes Q&A	N/A
Facilitators	N/A	Average 6 texts replying to each team	40 minutes	11,355 words

Our analytic approach followed a Thematic Analysis (TA) approach set out by Braun and Clarke [8–10]. To make sense of interactions between data sets, the first author used the recorded keynotes, Q&A, and team presentations to structure an organised timeline of the individual sets of data. This approach helped us to decide if it was possible that a certain event, such as a keynote or the Q&A, had influenced a team's design approach, though our qualitative approach is careful in not claiming causality. Second, the first author structured a set of team narratives consisting of the different data sources described above. Structuring the data this way helped to describe the chronological development of each individuals' teams from design ideation through to presenting their final idea and post-hackathon reflections. Once the data was framed chronologically, the first author began to conduct open coding. Four co-authors then had bi-weekly meetings to construct themes and reflect on the patterns evident across the data. Finally, the first author constructed the named themes, which are presented in the next main section.

5 FINDINGS

Our findings comprise of three themes, which have been identified through a semantic approach to analysing the data corpus. Our first theme details participants' motivations for participating in the event. The second theme provides insights into participants' challenges and design techniques, given the absence of crucial stakeholders. Finally, our third theme unpacks the teams' final prototypes to explore their new understandings and considerations for dementia within their design.

5.1 Motivations behind participation

Participants' motivations for taking part in the event ranged from their own personal experiences of loved ones with dementia, seeking a chance to win the cash prize, sharing their voice, and learning about the area of dementia & HCI. This speaks to the varied emotional and technical entry points for our participants. For those with personal experiences, the concerns and needs of family members were central to the teams' ideas. For instance, in team World Share's presentation, one member, Michael, described conversations with their grandmother about his grandfather where *"he may not remember going to the beach that day but he's happy, and it's about the day-to-day quality of life, which is something we're looking to do with [our idea]" (P).* Likewise, David from Chatter Bench, described family connections influencing their involvement where they *"called [his] mum [to talk about his] grandparents who were living with dementia in a home before they died…this informed what was important [to them joining the event]" (P).* Drawing on family history and experience implied a strong personal motivation to take part, with designs informed by the context of a specific user and their needs.

For others who had research experience in the field, their reasoning for taking part was rooted in learning how VR could be a beneficial technology within this space. For instance, one member from *VR Motion* works on *"intergenerational interactions in dementia care" (P)* and came to the event to *"learn how VR and dementia can be linked together" (W)*. Undergraduate teams echoed similar comments where *VR Hallucinate* could learn about *"how technology can help dementia" (W),* or *Garden Life* asking, *"What can I do to help people with dementia?" (F).* In this sense, the teams are seeking out a technical and social knowledge to inform design of appropriate technologies in their work. At the end of *Garden Life's* presentation, they expressed that *"events such as [this hackathon], continue to be ran to deepen our understanding of such issues [to] help alleviate the stigma that caused [negative representations] to happen" (P).* This demonstrates the team's reflections on the value in the learning process through the hackathon. Perhaps unsurprisingly, a sense of competition and prize money were significant motivators for several teams. The first author's field notes described *"how [teams] would come up to the [primary facilitator] and say they're going to win the prize money as their idea is the best" (F).* While this made for particularly enthusiastic participants, in many ways, it could also be seen to hinder collaboration between teams. Moreover, it was also a potential contributor to why there was little uptake from our participants for using the online platform, which would have made participants' budding ideas public knowledge.



Figure 5: Day one of DemVR

For others their motivation to take part clashed with the event goals. For example, a team of VR developers from a game company, dropped out during team formation with concerns of revealing their idea to the extent of questioning *"who owns the intellectual property" (F)* of the idea. During the pre-engagement phase, we made it clear to the teams that the university would not progress or develop any idea, we simply wished to potentially describe their ideas in academic work. However, the team remained hesitant to continue due to *"people could read the paper and steal the ideas and build it themselves" (F).* Additionally, Rachel from *Sensory Tides*, raised similar concern with publication as they wanted to *"build [their] idea into an academic paper"* but felt wary that the *"novelty of the idea may have worn off once the event had published the idea" (F)*. While only one team left, motivation to collaborate or share ideas that could be fleshed out into a commercial product remained relatively scarce between those with expertise knowledge in VR or dementia research.

As described in the event context, there was little motivation to participate in the pre-engagement phase. From the twelve participants in our 'pre-engagement phase', Denis was the only care partner who signed-up and participated with the other designers/developers. Denis was motivated to share his experiences of his father's dementia hoping outputs of the event would provide *"published prototypes [he] can use [with his father]" (I)*. As Denis continued to comment on the Ideaboard ideas, he would identify limitations in people's ideas, saying: *"my father is too old to use social media" (I),* or *"my father wouldn't understand how to navigate in VR" (I).* In these examples, Denis was advocating on his father's behalf to make sure his father's challenges are considered in future VR outputs. Although Denis expressed his motivation in the development of VR technologies for people with dementia, our planned in-person workshops with people with dementia raised concerns for interest when *"no-one signed up to our workshops... CEO of the café just notified me and asked if we should cancel the [the workshops]" (F).* From the first author's field notes, at the time, they felt *"perhaps members [of the café] are no longer interested in VR work anymore" (F)*. Likewise, when the first author reached out to recruit families with dementia from prior VR studies [52], the families themselves expressed disinterest in taking part in more VR research as they felt it *"was too complicated"* for them after having spent significant time using an Oculus Go headset. While they were also uninterested in the hackathon structure, they still expressed going out on *"another day out"* that would be similar to the study they participated in.

From this theme, it is evident that there were intersecting, and sometimes opposing, motivations for taking part in the hackathon, ranging from personal experience, competition, or opportunities to upskill and expand their research/development profile. This diverse range of motivators has implications for event organisers, who may need to consider how the event can attend to emotional, social, and technical support required of the teams. Pre-engagement may be an important time to ask teams to reflect on their motivations for taking part and pre-empt any support needed.

5.2 Constructing the absent user

In response to the 'absent user', ideas were generated and developed over the course of the event through interactions with facilitators, inspiration packs, and Howard's Q&A. We noted that participants often focused on comments made by speakers who discussed their experiences with people with dementia. For instance, during World Share's presentation, Michael described learning from *"some of the expert [facilitators], that dementia is more than focusing on memory loss"* and instead their idea focused on *"designing experiences that are set in the present, inclusive, and can be shared with others that are going to make a connection" (W).* This demonstrates the team's willingness to learn about dementia and incorporate feedback into their design ideas.

The interplay between the stories, resources and conversations scaffolding the event helped to create an initial understanding of what it might be like to live with, and design for, dementia. Due to the lack of people with dementia and care partners involved in the event, several teams drew on Howard's experiences of dementia that he shared in his 15-minute Q&A to understand the potential challenges and opportunities he may want in a VR environment. For those teams, Howard became a pivotal resource, and a somewhat static personality they were designing 'for'. The ways in which teams reacted to Howard's experiences varied. Team *Garden Life* changed their design approach in response to Howard's hobbies and interests: their initial idea centred around *"a journey through the story of your life using different media that links memories with locations'." (I) They stated that "The experience can be customised by family, so that the focus is on either neurological rehabilitation or reminiscence" (I).* In response to Howard's Q&A, the team developed a virtual reality 'garden', with a feature that allowed the user to interact with a virtual dog. In the WhatsApp group chat, the team state that they *"found it interesting [Howard] has a pet dog" (W).* This led to the team reflecting on how people living in a care home may not get that opportunity, but that *"having an animal to care for seems to help people in a lot of ways' (W)'*; and the team felt a virtual dog could help with loneliness (seen in figure 6). Translating Howards experience into features for their design helped the teams to incorporate aspects of Howards lived experience into their design, rather than focusing on dementia and its related symptoms.



Figure 6: Garden Life VR dog companion

As the team developed the garden environment further, they built customisability options: *"you can change its breed, colour and name of the animal" (W).* Similarly, for Mindful *Forest*, Howard's experiences provided an opportunity to expand their current understandings of dementia as they *"realised [they] actually don't know as much [about dementia]"* (W). In response, the team's final idea featured "*family members adding various pictures from holidays when they were young, so it would help in remembering if they forgot about their grandson or grand-daughter" (P).* While the team prioritised their experiences of dementia where *"I still remember the day when my grandma no longer recognised me" (P),* the team were inspired to enhance their social features after being *"surprised that all of Howard's friends left" (W).*

Additionally, teams' design decisions were influenced by conversations with stakeholders before and during our hackathon, such as Howard's Q&A, discussions on Ideaboard, or reaching out to caregivers outside the event's network of people. For example, *Augmented World* designed for AR rather than VR based on advice from a Dementia Advice Centre, which suggested: *"VR might be quite frightening…and with it being a bigger adjustment mentally with them living in a reality they don't know what is real or not" (P).* Similarly, Michael – a team member from *Sensory Tide* - engaged with Denis via Ideaboard to gain a richer understanding of dementia from a care partner's perspective. Denis highlighted ethical and financial concerns for Michael's proposed idea on Ideaboard: this was to create *"full-dome projections" (figure 7a) (I)* as an alternative to *"wear[ing] VR headsets" (I).* The care partner and the designer engaged in conversation on the platform and raised concerns about projection domes' practicality for care homes. The care partner pointed they are *"$13,000 as base price" (I).* The team shifted their course from here, and their final idea was by developing light-weight DIY solutions using Google Cardboard. Here, participants with little experience relied on stakeholder's experiences of dementia to construct their understanding of people with dementia – that provided key design overhauls and subsequently more appropriate designs.



(a) Dome projection tested at the hackathon

(b) Sensory Tide final prototype with Google Cardboard telescope DIY solution

Figure 7: Change in Sensory Tide's VR technology

With that said, even though *Sensory Tide* and *Chatter Bench* won the final prizes, they still highlighted they struggled to construct an understanding of who the user might be. During their final presentation, *Sensory Tide* presented a set of personas to represent the person they are designing for: *"Mary: can often get confused or lost if left alone" (P)* and *"Ben: has anxiety and depression as a result of his diagnosis (P).* Although *Sensory Tide* used the personas to *"help us decide who we are actually designing for" (P),* for reasons similar to *Chatter Bench*, they found it *"hard to figure out what to design because [they] can't ask the user" (W).* This observation highlights the value teams placed on engaging with end-users in the research. Here the absent user prompted critical reflection from the team members and demonstrated key evaluation points where user feedback may encourage teams to pursue their design ideas further.

5.3 Making sense of dementia through design

Throughout our event, the teams design processes opened-up participants ways to reimagine how VR may support the person with dementia. In our pre-hackathon stage, submitted ideas helped us to form an initial picture of how prospective participants viewed dementia. For instance, *Garden Life's* Ideaboard idea wanted to help people with dementia *"feel more independent",* or to *"help calm the mind[s]" (I)* of people with dementia. Although multiple participants used terminology no longer accepted in best practice in dementia, such as 'sufferers', and 'patients' (I), the design ideas uploaded suggest these terms are not intended to stigmatise. For example, a participant from team *World Share* suggested ways for VR to *"guide sufferers through daily basics"* (I) by having VR technology allow them to repeat tasks such as

"basic cooking, making a cup of tea" (I). Although these terms were being used early in the two-day hackathon as well, through engaging in conversations with facilitators, and through introducing resources such as the DEEP Guide [13], participants adopted person-centred terms. In the same vein, many early iterations of participants' ideas promoted 'treatment', 'fixing the disease' and ways for technology to improve a person's memory or other deficits [40]. However, as highlighted in the findings above, many teams' final ideas explore topics that go beyond dementia symptoms and related behaviour and reimagine ways VR experiences may support the person with dementia's relationships with care partners, family, and friends. Below we present two sub-themes: 1) providing comfort and 2) supporting the shared experience

5.3.1 Providing comfort

While our facilitation and topics leaned towards broadening the conversation of dementia away from the biomedical perspective, it is important to not overlook the importance for designing for people's impairments and abilities to use technology. Here, many design ideas took the aspect of providing comfort and educating others on dementia symptoms. For example, for team *VR Hallucinate*, the team reflected on Howard's comments regarding hallucination where they wanted to tackle the *"stigmatising and isolating nature" (P)* of hallucinations. Within their presentation, the team described their VR idea to provide the public, family, and friends with a virtual experience of hallucinations to teach and be empathetic of the challenges faced for people with dementia. In this instance, *VR Hallucinate* begun to see the stigma surrounding dementia as a societal problem where friends and family may contribute to further *"psychological and emotional distress for the person having the hallucination" (P)* when someone *"challenges the situation"* by saying the hallucination is not real, thus drawing on socially constructed experiences of the user. Another team who took a critical approach in their design was *Sensory Tides* who took inspiration form many language guides around dementia and considered what that would mean for the term 'Virtual Reality' (see online appendix b for final idea). Aware of the social challenges that people with dementia may face with defining their reality, and the concerns of a virtual simulation of a reality that may challenge the person with dementia's understanding of reality, the team designed for continued reassurance through the technology. Instead of the term Virtual Reality, they describe their experience as a *"magical viewfinder" (P)* along with giving calm and helpful suggestions of how users may use it: either by leading the experience through the viewfinder or "*lean[ing] back away from the headset and join everyone else relaxing on the [virtual] beach" (P) (seen in figure 7b)*. This demonstrates careful consideration of existing social stigma and the role of design in responding to these existing stigmas rather than permeating them.



Figure 8: Mindful Forest influences from Sweden forest research

Multiple teams began to question some of the more ethical and social challenges of designing for people with dementia's abilities. For *Garden Life*, the team argued that *"people with dementia may be fearful of VR devices" (P),* that they approached through *"easing them into the experience"* by building a real-world space that replicates the VR environment through *"building a comfortable garden room, featuring real plants, grass, smells, and ambident garden sounds*

throughout playing" (P). Additionally, the team built a companion app that provided the care partner to assist in guiding the person with dementia *"in navigating the virtual space" (P).* In the team's final presentation, they described how people with dementia could navigate by saying "*I want to go to the flower bed area" (P)* as an alternative to using the *"complicated VR joysticks" (P).*

In similar vein, team *Chatter Bench* were conflicted regarding *"how [to] represent the person living with dementia [in VR]" (W)*. The team's idea is a 'VR skype call' where both participants would be present in a 360-degree video on a bench in a park. For example, when discussing the possibilities of designing avatars for the VR environment, they worried that *"the other [avatars in the environment] will look like a scary apparition or, some floating smiley head" (W).* To tackle this concern, the team removed the virtual avatars and transmitted the online voices between the two users. This demonstrates the team's consideration for mitigating discomfort for the person with dementia. Likewise, team *Mindful Forest* state that they originally *"planned to add fantasy elements to [their] idea. But due to learning about other symptoms like hallucinations, we, therefore, had to change it to be more realistic, because we don't want to cause any problems for people with dementia" (W).* In both teams, the designers question how to virtually represent environments for people with dementia in retrospect to their potential capacity to navigate and understand the virtual environment.

5.3.2 Supporting the shared experience

One of the key areas of interest from the event was how designers might design shared experiences for people with dementia. Several teams' ideas explored ways VR could provide a shared experience between family members and the person with dementia. Team *Augmented World's* AR app aimed to "*enhance the ability for [real-life] objects to facilitate meaningful social interaction" (P).* In *Augmented World's* demo, the team demonstrated a feature to augment digital media, onto an object at home (i.e., photo frame), where the team's intention was that people with dementia could *"experience stories in a simple way, and promote interactive communication and inclusivity through shared experiences" (P)*.

Here, design ideation expanded to incorporate the social home environment, inviting others into the AR experience. In *Chatter Bench* presentation, the team highlighted concerns of their shared experience may add *"strain on the family and resources" (P)* in order to create the 360-degree worlds that people with dementia and care partners may want to share together – to the point that *Chatter Bench* presented future ideas of more social and community-led curation methods to generate a variety of environments in the *"hope it will scale"* (P). This demonstrates an awareness of issues with extending caregiver duties, a sensitivity that is often overlooked in dementia care technologies. Furthermore, the team stated that if their VR experience was implemented into a care home, then scheduling of the VR 'Skype calls' needs to consider *"fitting into the schedule of the care partner as well" (W)*. Here the team show further awareness of the social context and environmental factors that informed their design. These considerations result in design that values appropriate responses to context over high-intensity VR experiences.

For *Sensory Tide* who envisioned their VR idea being placed within a care home, the team wanted to build an experience that prioritised the relationship between people with dementia and their families and friends who are visiting. In this instance, as the person with dementia controls the movement of the VR headset, this drives the experience for not only themselves, but projects what they are seeing into the outside space of the room for the family to see. The teams reasoning behind adding multiple sensory outputs such as *"sight, sound, smell and touch"* was to *"offer the user a way to engage with nature and provide props for talking points to facilitate, then, further conversation" (P)* between the person with dementia and their family members. Here design decisions were made to support the onboarding for the person with dementia while also drawing in their family while they sit and watch their loved one take control of the virtual shared experience. Sharing new immersive experiences provides opportunity for social and therapeutic activities, thus providing new experiences for the care units.

Similarly, *VR Motion* designed a series of VR activities such as *"songs to sing along to, guess the place, solve the riddle or even share jokes" (P),* and displayed the collaborative experiences needed to ensure continued participation within the care home. This is done through giving the staff member the responsibility as a facilitator to *"pull a lever on a [VR] slot machine, which will show a random task. [Then] people with dementia and the facilitator will work together to complete the task" (P).* These examples within this sub-theme highlight tensions when designing shared experiences that are

controlled or supported by others for the person with dementia. Here a focus on interdependence and the maintenance of reciprocity between family members was core to the design of the technology.

6 Discussion

Below, we map our findings to our three research questions that presents the nature of participation from team members, and the impact of structural factors of the event on design outcomes.

Research Question	Analysis
RQ1: How do designers/developers represent people with dementia when solely relying on their own experience (or lack thereof)?	• Teams would rely on stakeholders' experiences of dementia to construct their understanding of dementia. Those who did not engage with other stakeholders drew on Howard's Q&A to represent who they were designing 'for' *(seen in 5.2)*. • Through the hackathon structure, participants adopted person-centred ideas to dementia through engaging with facilitators, inspiration packs, and resources curated by dementia organisations *(seen in 5.3)*.
RQ2: What considerations for technology do designers/developers prioritise when designing for people with dementia?	• Some teams prioritised ways to mitigate the discomfort of VR by considering ways to navigate, use of language around 'VR', and how to sensitively represent the VR environment *(seen in 5.3.1)*. • Teams' ideas present challenges and considerations needed for the shared VR experience *(seen in 5.3.2)*.
RQ3: What challenges arose when trying to represent the voices of people with dementia and care partners during the hackathon? What opportunities arose which we may, in time, pursue?	• While participants' motivation for taking part ranged from prize money, learning about dementia, and personal experiences, the incentives for people with dementia gave no real encouragement for taking part *(seen in 5.1)*. • Teams highlighted the difficulties in constructing who their user might be - emphasising the importance of engaging with people with dementia and the knock-on effects it had on the final ideas *(seen in 5.2 and 5.3)*.

Overall, these findings raise important considerations for future hackathons and participant involvement. This discussion section will consider our analytic findings considering existing literature on reification in design, collaborative design events, community building, and meeting participants where they are. Within each subsection, we provide three 'commitments' to mitigate stereotypes, improve recruitment processes, and ways to ensure hackathons are more inclusive and community driven.

6.1 Reification, experience & designing with and for stereotypes

The transformation of complex individuals, groups, communities, processes, and systems into manageable constructs to inform design has long been noted in HCI. Such conceptualisations are often referred to as creating or using boundary objects – that are *"entities that enhance the capacity of an idea, theory or practice to translate across culturally defined boundaries" (pg. 71) [42]*, which are adaptable across application areas, but which are also solid enough to represent one 'thing' or meaning across these areas too. Our participants, working with an idea of their own end users, or as those dealing with instrumental cognitive problems wholly aside from the felt experience of their own dementia, were working with a boundary object – the "Person with Dementia" - which was manageable for a weekend's design work, but may have shut down possibilities for greater creativity and wider representation. The irreducibility of individuals' experiences means that designing with a reified idea of what it means to be a Person with Dementia cannot account fully for these values, needs, desires and goals. Following our work, we realised that our participants, who were working primarily from Howard's Q&A, as well as from artefacts and snippets from past research, were working, functionally, from personas, or the sort of data that might be expected from personas. The material provided, like personas as written about by Maarsden & Haag, *'contribute[d] value by informing design, i.e., ha[d] a predominantly prescriptive function … they are meant to open design spaces by connecting the designers with the people they are designing for.'* [75] However, such design tools and methods which abstract from the user are also prone to stereotypes – in fact, are often built to resemble such stereotypes in order to seem more 'real' by appealing to designers' own recognition [22, 75]. By appealing to this sense of recognition, however, they often 'prime' certain problem areas as operationalisable for

designers – for instance, a persona of someone with dementia who wanders may easily prompt a home security system or a personal alarm, where extended engagement with this person may uncover that she simply misses walking a certain stretch of a local riverbank and is content with weekly trips to do just this. Given the challenges we had of involving people with dementia in the design process, we suggest the following commitments to mitigate stereotypes for researchers and designers:

6.1.1 Mitigating stereotyping commitment one: Exploring shared needs

A solutionist approach in HCI has been characterised as finding a set of technological quick fixes that solve social complexities [81]. For instance, *Garden Life 'found it interesting that [Howard] has a pet dog'*, and so go about inscribing this already existing reality into a technological solution – they create a VR dog interaction where the user *'can change its breed, colour, and name'*. This virtual representation of an enriching human-animal relationship is in stark contrast to existing research on technological approaches to designing animal companionship for older people by Lazar et al [69]. In this study, older people express a need for comfort and companionship through 'cuddling and petting live pets' and wanting a pet that was 'warm, soft'; which promotes social opportunities for getting out and about; and a reciprocal relationship. This isn't to say that *Garden Life's* idea was unsuitable, or that VR experiences cannot at all provide these sorts of qualities; but that our participants were disadvantaged by time and by lack of engagement with 'real' participants – and as such, were able to provide only a shallow exemplar which might have been much richer. Alternatively, we might want to look towards Pullin's 'resonant design' [95] approach which starts out with designing for those who are marginalised, to then explore how these needs coincide with a broader set of users. Similar to the event where participants did not have access to iterating their ideas with the end users, designers might initially look towards designing for shared characteristics of that population, and then provide their potential users with a range of other characteristics that may not be related to their dementia. For instance, *Sensory Tides* redesign of the VR headset to a seaside viewfinder to accommodate a person with dementia's potential inexperience with VR, could also open potential avenues for redesigning VR headsets to be less bulky and personalised to appeal to the owner. For designers working in this space, considering a broader set of shared needs might balance the tensions between designing for abilities associated with dementia and the more diverse individual identities, to offer creative and accessible technologies that inspire new thinking rather than propose solutions. Inspired by D'Ignazio et al. work on designing postpartum technologies [28], one design approach to collecting a variety of shared needs could be through crowdsourcing. Within the authors work, they describe the overwhelming interest mothers had in sharing their challenges with breast pumps which generated a shared understanding of the communities' needs. However, to ensure this approach considers the needs of the community the researchers are designing for, they must consider the type of resources to make communication successful. What are the outputs of crowdsourcing exploration? What do participants get out of sharing their needs?

6.1.2 Mitigating stereotyping commitment two: Revising language used in design for marginalised groups

From reviewing the Ideaboard pre-engagement ideas, the lack of training regarding language might have contributed to a disinterest from people with dementia. For instance, terms such as 'patient', 'demented' and 'sufferer' were used in submissions, and descriptions were tech-heavy in terminology. In these examples, our pre-engagement did not provide a comfortable space to allow people with dementia to open and share their stories. McGovern et al. suggests that to build a meaningful and safe space, researchers should accept diversity; adopt language that represents the community; and use language and images that represent the community during recruitment, whether in information sheets, marketing materials or leaflets [77].

As the event went on and participants engaged with the expert facilitators, participants recognised the importance of how they speak about dementia, with terms such as 'patient', 'demented' and 'sufferer' rarely used. Barlett and O'Connor draw on the power of language in which they state, *"both oral and written - reflects systems of assumptions, values and beliefs" (pg. 52)[3]*. Despite the knock-on effects that we describe regarding the lack of people with dementia in our event, participants adopted person-centred terms through the way the facilitators and structure of the hackathon positioned people with dementia (in terms of use of language).

Similarly, Dalton's paper on the neurodiversity movement reports on making HCI aware of the growing movement that encourages researchers to think and see neurodiversity differently [24]. Through this work, the author stresses

researchers *"must conduct research in a way which is aware, responsive, and critical of what's considered 'normal'"*. Bartlett and O'Connor [3] further argue that when working in the area of dementia, we must look beyond the welfare context, and instead, see all the different social identities a person with dementia might have. For instance, Chatter Bench were worried about the 'strangeness' of bodily representation in VR as they felt the unfamiliarity of VR was enough to heighten the person with dementia's anxiety. Similarly, Mindful Forest decided against adding fantasy elements to their design response for fear of triggering hallucinations. Our intention here is not to devalue the team's priority in safety and comfort, nor is it to suggest this is problematic as we design new technological responses. A heightened focus on risk might quash creativity, remove any room for individual differences in user experience, and further limit the expressive and aesthetic potential of the technology itself. When designing in sensitive settings, researchers must continue to engage with a broader understanding and ways of thinking about abilities.

6.1.3 Mitigating stereotyping commitment three: Disseminating research outputs

One-way researchers and designers might mitigate stereotypical perspectives is to start disseminating research into less 'static' ways to offer participants new explorations into ethical and embodied topics within sensitive settings. In the context of dementia, we have seen a gradual shift in disseminating dementia work, such as the theatre play Cracked that follows a person with dementia and their family on a journey to see beyond the diagnosis. Gray et al. [64] designed this one-hour play that tells the story from diagnosis, through to the person with dementia moving to a long-term care home. The families in the play, demonstrate the changes in relationships and struggles that a diagnosis of dementia presents. Throughout the play, the director creates an immersive space for the audience to question and reflect on their assumptions, sharing and refining a more sensitive, nuanced narrative of dementia. This recent work resonates with the ongoing drive towards using film for public health and cultural awareness in educational programmes to elucidate in-class discussions [6].

Through our event, we documented the team's design processes through WhatsApp group chats, audio recordings, field notes, final idea presentations, and demos. Initially, the first author intended to publicly make the data available to disseminate the design processes and prototypes. However, this became challenging due to unfinished prototypes and the 'messiness' of design process data. While we live tweeted the event on Twitter and gained reasonable attention in terms of likes and retweets, Smith et al. argues that leveraging social media can be difficult as online interactions will often just be in 'academic filter bubbles' primarily between other academics [106]. Alternatively, hiring designers/filmmakers to design outputs inspired by the team's final ideas might have disseminated the context of the event to a wider audience. Furthermore, Zheng et al.'s work on tackling stigma among Chinese Americans stresses the disseminating information needs to be *"culturally sensitive and tailored toward the values of [the] specific ethnic group"* to ensure that the message is set in a familiar setting and the audience can easily sympathise [127]. Therefore, to get the public to engage with the more sensitive and complex topics, researchers should consider taking more creative approaches to present their work. This may be through film, theatre, zines, and other creative arts to provoke similar understandings that researchers aim to gain from collaborating with people in marginalised communities.

6.2 Facing actual reality: Unplatforming and participant disinterest

As described in our event context and findings, our hackathon configuration gave rise to certain challenges. Prime among these was the extent to which people with dementia were meaningfully engaged in the event itself. As noted above, we tried to involve people with dementia (and their care partners) in three ways: 1) through planning workshops through a community partner with whom we've worked several times, 2) as full participants during the day itself, and 3) as participants on our online platform, Ideaboard. The former two routes failed, as no person signed up through our community partner; the latter route saw some engagement, but ultimately much less than we had hoped. Late in the planning process, we invited Howard to share his experiences and engage in a Q&A with our participants, to ensure that our attendees had an opportunity to engage with at least one person living with the condition around which the event was centred.

Our use of Ideaboard, a participatory platform for group ideation, deserves some consideration. Part of a suite of participatory platforms launched as part of a wider research initiative aimed at including citizens in the development of services and systems for their own locality, Ideaboard took inspiration from App Movement, a similar platform which

allowed limited co-design of community-commissioned apps [45]. However, App Movement was critiqued in a paper published in 2017 which focused on the co-design of apps for dementia services; the commissioning platform was described as "*not yet nuanced enough to capture and represent aspects of the complicated experience of caring for someone with dementia or living with the condition itself"* [82]. Although Ideaboard was not created solely for older users (whom we envisaged as the people living with or caring for dementia who might be interested in our hackathon), it is true that more familiar technologies might have been used in soliciting the views and opinions of participants with experiences of dementia. To mitigate these challenges in recruitment, we offer a set of commitments for recruiting and involving marginalised populations in future work:

6.2.1 Recruitment commitment one: Meeting your participants where they are

When planning recruitment processes, researchers must follow appropriate language and terminology that suit the communities they are reaching out to. For example, we followed common terminologies such as 'participants' and 'experts' in our recruitment flyers, social media and Ideaboard text when recruiting for people with dementia [21]. One approach we might have adopted to improve recruitment was to deliver more personalised strategies for the communities we wanted to engage with. For instance, providing sessions/presentations to community audiences can promote confidence and trust where community members can get to know the research team [11]. Furthermore, it is crucial in these in-person conversations to use non-technical language and explain the value of participating in research.

In addition, instead of designing additional online platforms, we suggest asking participants what platforms they would like to use for engagement. Not only does this reduce development costs, but this also provides the opportunity to understand the communication processes with which participants are familiar. One approach we might have adopted would be an 'Unplatformed' approach to the design of the pre-hackathon experience and recruitment stage. Unplatformed design is a model for the appropriation of social media technologies, that pays particular attention to the implications of the individual features of social media in respect to coordinating participation in specific contexts [66]. We might have reduced barriers to engagement and ensured better representation of the views of our participants by coordinating participation on the technologies that they were already comfortable with (e.g., Twitter, Facebook, and other media platforms). Although we knew that some members of the community whom we would have liked to have reached used these platforms, we were seeking an additional 'string to our bow' by piloting the use of the Ideaboard platform. Nevertheless, in this case, it hindered rather than increased participation.

However, it should also be noted that utilising solely digital methods to facilitate recruitment and engagement could be limiting for some participants facing significant marginalisation. For instance, Lazar et al. describe how even inclusive initiatives centred around the involvement of people with dementia may silence voices that offer less "polished stories" or those who are nonverbal [67]. Dai & Moffatt describe that while online interactions provide an enjoyable and beneficial interaction for the person with dementia [23], it contributes to a burden and the need for the care partner to provide *"responsive, continuous, and knowledgeable support*" (pg. 46:24) [56]. Moreover, when collaborating with marginalised communities, we should involve their friends, family, and other individuals who support that community in the research process, to help ensure agendas are more closely aligned with stakeholders' priorities and desires. To this extent, participant-led research may offer understandings into new, more impactful ways our research could be of benefit to communities beyond academic publications.

6.2.2 Recruitment commitment two: Fostering participation through relationships and topic training

Within our hackathon participant recruitment, most attendees had, to some degree, technical, design and/or research skills. While we did invite care partners, social workers and practitioners, the high-level expectation of building demos or lo-fi prototypes for virtual reality environments could have intimidated those with less technical backgrounds from participating resulting in a *"limiting difference among participants" [58].* Additionally, the technology-oriented event may have contributed to the lack of interest from people with dementia and care partners. For instance, Hwang et al. recommends researchers should provide a longer-term learning and facilitating process with people with dementia to promote inclusion and learnability [56]. Furthermore, the author highlights that, if the learning process for engagement evokes *"frustration, anxiety, or sense of vulnerability (pg. 46:26)* [56]*,* then the person with dementia may resist engaging with that particular technology.

In this way, we are guilty of many of the shortcomings levied against researchers who claim participatory work yet don't involve their participants from the ground up, and don't schedule in regular check-ins to ensure interests and priorities haven't shifted. In contrast, our hackathon provided developers and designers with guides, resources, and expert facilitation on the topic of dementia that supported the building of their bespoke VR environments. Alternatively, future hackathons that invite diverse communities, should consider ways to facilitate collaborative learning that would require clear indication of community outcomes to ensure participants could weigh up if the time dedicated to supporting and training is worthwhile [47].

6.2.3 Recruitment commitment three: Supporting the ecology of care within the research topic

As previously mentioned, although the hackathon was centred on shared experiences for people with dementia, the topic lacked any primary focus on care partners, families, and friends – those who make up the ecology of care for the person with dementia. Kaziunas et al. report that designers and researchers must consider not only formal healthcare institutions in behavioural health management, but also the informal systems in community settings that are often seen as invisible forms of care, such as local faith communities, friends, and neighbours. In hindsight, undermining care partners desires and interests may have contributed to the struggle in recruitment. When looking back at the hackathon, teams' ideas that emphasised care partners typically came from facilitators' feedback instead of the introductory presentations or Howard's Q&A. For instance, *Chatter Bench* describes a facilitator *as "opening up their eyes" (W)* to the potential burden to care staff if the technology requires significant assistance.

Moreover, Dai and Moffat [23], recent insights into a community-based social group for people with dementia highlight the unintentional complexities in care partners mediating social cues and communication for the person with dementia. The authors draw attention to the strain and potential "burdening" that this can cause, despite the benefits of people with dementia sharing their experiences and partaking in activities. Given the progression of dementia means that the individual's role within the family structure can change, as they become the care receiver, it is no surprise that several studies describe care partners who want to promote their agendas and perspectives in the domain of technology and dementia. When collaborating and navigating diverse stakeholder interests, Kendall et al. suggests having steering committees containing various stakeholders who then organise, guide and structure interactions within a conversation [61]. Coulson and Shaw [20] describe the importance of understanding the skills and necessary resources in effectively undertaking a moderation role. Drawing from this literature, we expect that such an envisioned future may require training and developing long-term relationships between a group of developers, designers, researchers, and the ecology of care in order to recognise the necessary shared work of collaborating together. Here, researchers must consider how they can design tools and methods to promote conversation and include the voices of a diverse set of stakeholders to ensure we are designing technologies that pay attention to both the desires and interests of the person with dementia and their ecology of care.

6.3 Towards a new economy of collaboration for design events

Olesen and Halskov [32] differentiate between research with, and research on hackathons, and outline a series of benefits and challenges for both: some of which have already been discussed in our account of our hackathon. One which deserves some consideration due to its frequency in other papers [5, 53, 59] is that hackathons have 'limited sustainability and implementation of hackathon outcomes'. This paucity of workable outcomes is in stark contrast to the resources that are often ploughed into hackathons – for example, our hackathon, which drew on public funds and involved the labour of highly skilled individuals over several months, cost £5,000 to hold. While Olesen and Halskov note that such events target 'real-world' problems, "facilitate new research projects and publications", and help to *"[imagine] citizenship in new ways"*, they also note that *"it can be difficult for peer researchers to evaluate and build upon hackathon outcomes if the circumstances in which the outcomes were created are not well-documented.*" [32]

This is not to say that the hackathon itself did not offer any remuneration for participants – we budgeted for their travel, their meals, and their accommodation, as well as offering a prize of £1000 and £500 which could be invested in developing their solution to a higher standard. In fact, the fast-paced nature of the hackathons, along with their high opportunity cost and valuing of technical skills over 'softer' skills, belies their starting point in Silicon Valley [58], which remains to this day in the structure of the events, which has been described as patriarchal, capitalistic, and

competitive [30]. When such events are predicated on ‘making things better’ for marginalised communities with no clear pathway to actually do this; with limited participation and high barriers of engagement for these communities; with budget and university pathways to compensate the designers and developers but not the population themselves; when these events overwhelmingly focus on the problems, discrimination and indignities faced by people undergoing significant challenges: then marginalised people become the currency with which we trade. Here, we offer three commitments to promote more inclusive and community-driven events:

6.3.1 Hackathon commitment one: Analysing the value of your event

When applying for a grant, designing a study, or creating an event, analysing the cost-benefit, ideally with community partners, may provide insight into the events contributed value to the community. Reflecting on the lack of output our hackathon provided, preparing our event with the community may have offered us additional insights into understanding the topics of interest and the type of technologies that may be of use. For instance, while our VR hackathon stemmed from local authority interest across several years, the use of VR contradicts prior work on acknowledging technology needs to be cheap, widely accessible and be easily adapted and tailored to fit the ever-changing needs of someone living with dementia [72].

Similarly, collaborating with the community earlier in the organisation process might have highlighted the potential challenges of people with dementia participating in a hackathon requiring quick iterative processes. Given Namageyo-Funa et al. reports *“participants are less likely to enrol in a research study if the location is not convenient" [85]*, placing the hackathon in the city centre might have been inaccessible for those who struggle with public transport. In the context of dementia, the event location could have been more flexible, adopting a walking interview approach to building connections between the teams and families with dementia. Kullberg and Odzakovic suggest that a walking interview approach provides a less stressful surroundings, where participants may describe what they are seeing and how they are feeling, and there is even the potential for memories and experiences to be triggered by varying triggers from their senses [65]. Moreover, providing activities instead of a sit-down interview promotes improvement in health and wellbeing. It allows people with dementia to control pace, direction, and topics through conversation. In this way, walking around a location puts less strain on verbal communication than the expectation to participate that people with dementia might feel in a sit-down interview or workshop.

Working with the community may have provided other alternatives for a hackathon. While this study intended to understand hackathons in the dementia context, the funding for this opportunity could have been used to support engagement between schools and care homes or contribute to funding to maintain dementia communities that are perhaps doing more for dementia than a public hackathon. As such, we encourage researchers to analyse the cost of a project with community partners, as this may provide a) an understanding of the type of technology the community uses, and b) gain the interest of the public who have experiences and insights into the cheaper and more accessible technologies – resulting in a greater interest in public engagement across the hackathon.

6.3.2 Hackathon commitment two: Appropriate incentives for all

Within our findings, teams expressed a gradual change in their motivation once they had more experience with dementia [44]. For instance, *VR Hallucinate* were motivated by the stark contrast of Howard’s experiences where the team thought a diagnosis of dementia would bring support from *“friends and [relationships] would be a lot closer…instead, there is a lot of loneliness surrounding it”*. Similarly, Foley et al. work on student engagement with residents at a care home, describes students *“sense of purpose and the determination”* as their role became more supportive [39].

As teams gained insight into the experiences of people with dementia, *Garden Life* described being motivated by a desire to continue to *“deepen [an] understanding of these issues”* in hope to *“help to alleviate the stigma”* that contributes to misrepresentations of dementia. Furthermore, while we described the prize money hindered the sharing of resources and knowledge between teams during our event, the two winning teams did use that money for initial exploratory studies whether that was in a dementia care home, or for *Chatter Bench* who trialled their prototype technology within a heritage setting [119]. While prize money was a strong incentive to spark people’s interest, it was apparent from our findings that multiple teams had additional pro-social motivations for spending their weekend ‘hacking’ away together.

Alternatively, incentive could be provided by emphasising the common purpose, and meaningful benefits of sharing and contributing to a shared interest. For instance, Colusso et al. describes the importance of research being translated into

important and digestible content for practitioners to improve their designs. Through this work, the authors describe a series of innovative tools to promote dialogue via 'Ask Me Anything' sessions on Reddit, or providing automated bots to make community members aware of academic research [17]. In these instances, the incentive is driven by learning more about an area and to promote the potential collaboration between different members of communities. As such, researchers should not be put off from creating opportunities for people with dementia to learn new skills. Ward et al.'s recent work on innovative practice in Denmark demonstrated the valuable opportunities for people with dementia to return to schools to attend woodcraft, art, music, and cognitive training sessions. In this study, participants describe the opportunities to go to school to *"sustain their mental resilience and wellbeing and maintain their cognitive abilities for longer" [123].* Additionally, people with dementia who take on advocacy roles, have seen value in teaching roles for nurses specialising in dementia care; researchers and organisations looking to develop technology with marginalised populations might do the same - where the community takes on a more equal role to the researchers by facilitating the expertise knowledge [105].

6.3.3 Hackathon commitment three: Drawn-out phases for hackathons

Within DemVR, it was our intention to provide a set of phases that would provide a longer and drawn-out process to provide people with dementia and care partners to engage with the event. Originally, we envisioned these engagements as providing an opportunity for designers and developers to gain expert feedback and potentially collaborate with care partners and people with dementia. For instance, hackathons that are centred on a particular marginalised population may provide the space to be a learning context for not only designers and developers, but also a space for those marginalised to take part in a learning context. Rosenberg & Nygård [98] describe the challenges people with dementia face with a diagnosis where opportunities to learn technology (such as through work), due to being retired or being no longer able to work. The authors highlight that people with dementia can learn together with others to help with learning how to use technology and realise they are *"not alone in being challenged by technology"* which may offer *"strength, comfort, and confidence".* Drawn out hackathons may mirror positives seen in Game Jams where month-long cycles allow for *"playtesting and refinement that short jams are not able to support" [31].* In this way, the technology built in a hackathon does not end post-weekend, but instead, leans towards hackathons being a longer-term project that is done in the designer/developer's spare time where commitment to the project is driven by the relationships and learning between the communities that promotes the growing of loosely coupled, companion 'communities of practice'.

For design research for older age or in dementia, the idea of partnering communities together – for instance, partnering a cohort of design or technology students together with a community of older people, and having both learn from one another in a mutual way – may hold promise. The UK-based 'FixEd' [37], FixED, has introduced a scalable learning programme called 'Fixperts' that targets schools and universities to engage their students in creative problem-solving that is rooted in the communities around them, which might provide an opportunity for people with dementia to be involved in the different phases of technology development. From Suijkerbuijk et al. review, the involvement of people with dementia varied significantly through the stages of technology development [107]. The authors reported that in HCI studies, the participation of people with dementia in the evaluative phase is unsurprisingly prevalent, this is, the stage where prototypes are evaluated, and iterative development occurs. This is due to the evaluative phase not requiring people with dementia to reflect on their experiences or provide feedback on the type of ideas they may require. To involve people with advanced stages of dementia, Foley et al. reported on taking a two-year ethnography within a care home to understand the ways in which technology and design can enrich their lives [38]. Here, the authors drew on recognition theory to support collaborative actions and sense-making through the design process. This could be using a participant's individual items with person meaning, such as a participant and their scarf; or the designing of tools or probes to encourage and support conversation. From collaborating closely with the members at the care home, the authors developed a conversational aid game called Printer Pals, a media-centred print-based quiz game [40]. By partnering communities together, a student might engage with an older neighbour to innovate simple solutions that fit into their current lives, which help them get out of a car; or another student might work with someone experiencing a time-limited disability or injury to help them navigate their college campus in a safe manner. By drawing out the interactions over a longer period, relationships could be formed where people with dementia can be part of the exploratory phase while iteratively contributing to the prototyping stages by testing the DIY solution.

Capitalising on the ingenuity and availability of design, technology and engineering students looking for meaningful application areas, such programmes deliver small-scale, bespoke fixes for potentially large numbers of people. Similar ideas are seen at work in programmes such as TimeBanking [55], and even within studies previously cited such as Reuter et al's work [97], which made use of the resources a university is often rich in (e.g., technical competence, A/V equipment) to innovate within a radio programme for older people, leading them to encourage researchers 'to consider participatory action research as a method of assistance in itself, complimented by technical innovation to facilitate processes in this space'. Finally, given the interest in dementia as an area of interest for design and technology students, for HCI and CSCW, as well as for industry more widely, researchers should consider ways to facilitate and promote different communities to 'partner-up' to share knowledge and skills.

7 Limitations of the work

It is worthwhile to highlight the limitations of the study. Within the participant recruitment, only one care partner participated in the event through the pre-engagement phase. While our paper highlights the knock-on effects this created for attendees' final design ideas, the facilitators (who are the authors of this paper) guided and answered the teams' questions throughout the event, which likely influenced the final ideas presented at the end of the hackathon. Our orientation towards how we view dementia influenced the hackathon's framing by encouraging participants to take a more creative, well-being-focused approach to their design instead of concentrating solely on cognitive decline instead of the biomedical model [73]. While carefully selecting presenters and facilitators with similar framing to ours was intentional, we must acknowledge our view of dementia significantly impacted the teams' final prototypes and potentially limited the potential of groups who sought to develop more biomedical-led design approaches. As such, our commitments leverage the author's expertise on dementia to frame the discussion on dementia and improve the involvement of marginalised populations in public-facing events.

8 CONCLUSION

This paper presents a detailed account of DemVR; a hackathon aimed to design novel VR environments in dementia supportive contexts. Our event consists of two stages: a six-week engagement phase to support participants in proposing and refining initial ideas online; and a two-day hackathon inviting designers and domain experts to develop their ideas further. While we gained reasonable interest from designers, developers, and students throughout both phases, the representation of people with dementia and their care partners was limited. We examine the structure of the event and the role this played in our struggle to involve people with dementia and their care partners. Our data analysis presents insights into participants' motivations, design approaches to accommodate the absent user, and the design ideas that the teams developed to address the social context of the user. Against a background of the extant literature on reification in design, collaborative design events, and dementia, our discussion provides a series of commitments for HCI and dementia research. The commitments offer insights into how we might mitigate stereotypes in constructing the end-user; ways to improve recruitment for involving marginalised populations in events; and steps to promote more inclusive, community-driven events. Finally, we conclude our discussion to look beyond hackathons to examine the role of community building to bring different communities to 'partner-up' in hopes to share skills and knowledge to reduce stigma and provide opportunities of co-developing technical DIY products that are tailored to the person with dementia and care partner's needs.

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