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# Lived Experience of Dementia and the Design of Technology

**Peter Worthy<sup>1</sup>, Jacki Liddle<sup>1</sup>, Sarah Matthews<sup>1</sup>, Trevor Hunter<sup>1</sup>, Gladys Chua<sup>2</sup>, Emma Safarova<sup>2</sup>, Minh Tram Tran<sup>2</sup>, Muhammad Al Mahdi<sup>2</sup>, Craig Johnson<sup>2</sup>, David Jeffs<sup>2</sup>, Chuiké Jwahir Nadifa Lee<sup>2</sup>, Ryan Deslandes<sup>2</sup>, Chanon Kachornvuthidej<sup>2</sup>, Ben Matthews<sup>1</sup>, Anthony Angwin<sup>1</sup>, Janet Wiles<sup>1</sup>**  
School of Information Technology & Electrical Engineering  
The University of Queensland, Brisbane, Australia

<sup>1</sup>[p.worthy, j.liddle, s.matthews, trevor.hunter, matthews, a.angwin, j.wiles]@uq.edu.au  
<sup>2</sup>[aik.chua, e.safarova, minhtram.tran, m.mahdi, craig.johnson1, d.jeffs, chuiké.lee, ryan.deslandes, c.kachornvuthidej]@uq.net.au

**Ron Beleno<sup>3</sup>, Dubhglas Taylor<sup>4</sup>, Elieen Taylor<sup>5</sup>, Dennis Frost<sup>6</sup>**

The Florence Project Lived Experience Reference Group  
School of Information Technology & Electrical Engineering  
The University of Queensland, Brisbane, Australia

<sup>3</sup> ron@rb33.com

<sup>4</sup> daatoz@outlook.com

<sup>5</sup> eileentaylor@infodai.com

<sup>6</sup> dennis.frost@bigpond.com

## ABSTRACT<sup>1</sup>

Technology for people living with dementia has been criticised for being technology rather than person centred. Often the design does not sufficiently recognize and respond to the range of

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## KEYWORDS

Design; Participatory Design; Dementia; Lived experience; Things; Infrastructuring; Third-wave HCI

### ***The World Health Organisation's Position relevant to Assistive Technology – A Matter of Human Rights***

*In their Global priority research agenda for improving access to high-quality affordable assistive technology, the World Health Organization identifies people living with dementia as being a key group requiring the development of assistive technology to support their independence and contribution to their communities <http://apps.who.int/iris/bitstream/handle/10665/254660/WHO-EMP-LAU-2017.02-eng.pdf;jsessionid=DD2D9C53293A863A562BA50D9738D29C?sequence=1>.*

*Further, in their Global action plan on the public health response to dementia 2017-2025, the World Health Organisation considers that ensuring accessibility and inclusion in terms of 'policies, plans, legislation, interventions and actions' for people living with dementia is recognised as a human right. <http://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=F36B3D09956C4682950B983F99913A35?sequence=1>*

individual, family and societal forces at play. Where these technologies have fallen short is often on the account of neglecting important dimensions of a thoughtful design process. For this reason, technology is often not accepted by its intended user group, and is therefore not meeting the potential to support independence, wellbeing and quality of life. Required is a process that supports technology development that is considered, flexible, inclusive and broad, centring the person living with dementia both in terms of focus and power. As technology is largely now ubiquitous, this must now be considered as a rights and inclusion issue by those who design and develop that technology. The Florence Project is a long-term project focused on improving communication between people living with dementia and their care partners. This paper reports on a design sprint that is the subsidiary of this much larger project. The design sprint was run as an exploration of design methods that seek to bring discussion around the complex issues surrounding designing technology for dementia and to further inform technology developments recognise and respond to the lived experience of dementia. These activities contributed to the formation of 'Things', took steps towards the establishment of infrastructure and the scaffolding of the project team.

## 1 INTRODUCTION

People living with dementia experience changes in their memory, cognition and participation in a range of activities and roles. Technology has been identified as having great potential to support difficulties related to changes in memory, communication, connection with others and safety [9]. To date, however, there has been poor uptake of specialised technology and everyday technology has been identified as being often inaccessible or unusable. A recent audit of technologies developed specifically for people living with dementia, identified that few took a human centred approach, and fewer evaluated the technology involving intended users using rigorous approaches [7]. Ethical issues relating to technologies including those involving monitoring have been highlighted as requiring further attention for this population [8]. In addition, issues arising from the lack of accessibility of ubiquitous mainstream technology for this group has led to concerns for equity and access to essential services [12]. The impact of gatekeeping and stereotyped beliefs possibly preventing the access of people living with dementia to technologies they may benefit from has also been identified (see sidebar "The World Health Organisation's Position relevant to Technology"). This is more than an issue related to inclusion but is now considered a human rights issue, a fact that must be recognised by HCI.

There is recognition within the HCI field of the need to develop and adopt new approaches considering a diverse range of lived experiences [2], including those related to dementia [10], that centres the person's specific experience and needs. This requires the development of methods and approaches that: recognise the importance of lived experience and of its nature as being embedded within a specific context, connected to specific values and emotions of a person; and, ensure that the design of technology recognises and responds to those experiences. It also requires an epistemological shift within the field particularly in terms of its conceptualisation of disability and

### ***Information used to provide background to developers***

Dennis' video

<https://www.southerndag.org/2018/10/21/ethics-of-design/>



*"Become a Dementia Friend", Dementia Australia,*

<https://www.dementia.org.au/dementia-awareness-month/become-a-dementia-friend>

Ron's video presentation



*"Understanding the Challenges of Dementia Communication", Professor Alison Wray,*

<https://www.youtube.com/watch?v=u6cchefGn2M&feature=youtu.be>

the role of technology [10]. The contribution of this paper is to provide a case study outlining the initial activities undertaken, as part of a larger participatory design ('PD') project that were aimed at ensuring the development of technology *with* people living with dementia. We seek to share our experiences in order to stimulate discussion and future work around how, practically, third-wave HCI might embrace the wholeness of the lives of people living with dementia [2] and take steps towards the epistemological commitments [10] that we outline below.

## **2 WHAT'S REQUIRED FROM HCI?**

Third-wave HCI shifted focus from efficiency to experience and how people made sense of new technologies [2]. Questions still arise regarding the approaches research should adopt as it seeks to understand and account for these experiences in the design of technology [2], particularly within the field of dementia [10]. Whilst some work propose specific approaches [10], there is a critical starting point that must be recognised: in terms of people living with dementia, some people's current experience of technology is that of stigmatisation, exclusion, de-humanisation, and the perpetuation of misconceptions. This paper proposes that HCI must make a deeper shift when seeking to engage with people's experience living with dementia. HCI must accept that it is as much designing for a new future for people living with dementia as it is creating a thing for use. In fact, a failure to recognize this responsibility and respond through action may serve to perpetuate the experiences referred to above. This paper contends that this is one of the epistemological commitments that HCI must make as it designs technology for people living with dementia.

Bödker proposes that the third-wave must "use participatory methods to rethink design" and "embrace people's whole lives" [2]. PD approaches and methods are now more widely used. This is a further shift required of HCI: that the true value of PD extends beyond the production of a thing for market to supporting the establishment of a new future" [5] where all stakeholders are engaged in the design process, working beyond otherwise existing power boundaries to confront issues and towards a future condition where those issues are addressed [1, 3]. Critical to this shift is the recognition of PD's role in the establishment of Things and the infrastructuring of the publics that form around the matters of concern that are the focus of those Things [1, 5] The process adopted for design must ensure that this lived experience is incorporated as a fundamental stratum of a project and must also close the "gap" that often exists between designers/developers and those who hold that lived experience in terms of both understanding and power.

## **3 THE PROCESS**

A core tenet of the Florence project is the importance of lived experience guiding and supporting research activity and the development of technology. Key to this was establishing "Lived Experience Reference Group", people with lived experience in either living with dementia or care partners to someone who is/was living with dementia. This group provide suggestions and guidance of the research throughout the project. The project team included user experience and interaction designers and software engineers (developers) who's role was to develop technology, together with an occupational therapist, a speech pathologist, and a cognitive scientist.



## ***The Wall***



*A wall within the workspace was used as a stage to organize insights identified by the designers throughout the process making these insights and their organization constantly visible. The designers also added an articulation of the underpinning values to those insights. This wall did not remain static: throughout the project the information on the wall was changed. These changes were in response to difficulties experienced by the designers related to the complexity and enormity of the domain as was made visible by the wall. Following one design review discussion the wall was reorganized around the matters of concern that became apparent. This reorganisation originated from a need to identify a specific focus based on the lived experience of a matter of concern rather than attempting to design 'universal technology'. The role of people with lived experience within the design sprint was critical in this regard.*

person living with dementia and that lived experience remained core to the project. For example: in one of the design reviews a statement was made: *'Is technology or are people a better solution for this issue?'* These discussions supported "Thinging" [1], facilitating the expression of matters of concern and providing relationships to allow this expression.

The project sought to create many ways for people with lived experience to become involved. The establishment of the reference group was a commitment of the project to an involvement through the opportunity to guide the research that was conducted. Through initial discussions with the members of the reference group directions, priorities and areas of focus for studies were established. People with lived experience also became involved in the project through their participation in experiential interviews making visible to the project the range of perspectives and concerns about 'technology'. For example, two videos created by people with lived experience about considerations about technology and ethical issues were provided to the project. Further, people with lived experience participated in the dissemination of research findings through authorships and presentations in both academic and industry forums. These many involvements have allowed participation to extend beyond what is often seen within PD processes.

Prototyping required the developers to produce a physical representation of their design concepts making thinking and decisions explicit. The design reviews created a forum for discussion that was nuanced and specific to the design that had been produced but also based on lived experience. Those discussions provided important detail of the matters of concern. For example, feedback on a device designed to provide reminders where those reminders could also be remotely managed by family or caregivers included *"the home for this device may be on the fridge door"*. This signaled the importance of technology fitting within the existing structures of a person's home and the strategies they already used to manage their life. This added meaning to the concerns that technology could be disempowering and the need for a person to maintain their individual identity. More importantly, it was taking steps towards supporting the embedding of lived experience into the research and design process. The iterative nature of the process coupled with design reviews created a process that supported an open expression of matters of concern and ability to re-formulate matters of concern through discussions. The process had supported the design project shifting to a "design Thing" [1]. The process also supported infrastructuring and scaffolding beyond the original aims. A key component of this infrastructure was 'the Wall' (see sidebar "The Wall"). The wall and its construction performed as infrastructure becoming a point of reference throughout the design information generated by the process. It has been stated that scaffolding is a task for designers [4]. In our experience it was multi-directional, recognizing that the condition sought to be addressed involved an interplay of people and technology to which all members of the design project must be scaffolded.

## **5 CONCLUSION AND FUTURE DIRECTIONS**

As HCI struggles to engage with its third-wave and making the epistemological shifts necessary to work within domains such as dementia, it is felt that establishing methods that support engagement with lived experience is critical. This requires re-alignment of participatory

Emerging design  
considerations/implications

*The process should challenge all project participants' understanding and conceptualisation of dementia beyond 'memory problems'.*

*Maintain a focus on the technology experiences and perspectives of the person that the proposed technology is for.*

*Start with an aim of helping a person do something that is meaningful to them.*

*Consider the strengths and interests, not just the difficulties.*

*Understand and retain a connection with the context within which the proposed technology will be embedded.*

*Identify, understand and support sensory considerations that can be individualised.*

*You are designing for people not for dementia*

*Technology must provide options*

*Technology must maintain personal identity and preserve sense of self*

*Simplicity, usability and aesthetics remain important*

*Consent and transparency of how the technology works should be considered*

design to its original ideals. This paper and the processes adopted by the project upon which it is based provide an example of approaches and methods that supported this realignment of participatory design and how it supported a deeper engagement with lived experience. As the project continues, we aim to further explore the effectiveness of these methods. In particular, how well they support infrastructuring as an ongoing process. The aim of the design sprint was to identify design considerations, itself a form of infrastructuring. The process has already identified a number of these guidelines or considerations (see sidebar "Emerging design considerations/implications"). The further development of these as a component of the infrastructuring and to support scaffolding will also be a focus for future work.

## REFERENCES

- [1] Björgvinsson, E., Ehn, P. and Hillgren, P.-A. 2010. Participatory Design and "Democratizing Innovation." *Proceedings of the 11th Biennial Participatory Design Conference* (New York, NY, USA, 2010), 41–50.
- [2] Bødker, S. 2015. Third-wave HCI, 10 years later—participation and sharing. *interactions*. 22, 5 (2015), 24–31.
- [3] Dantec, C.A.L. and DiSalvo, C. 2013. Infrastructuring and the formation of publics in participatory design. *Social Studies of Science*. 43, 2 (Apr. 2013), 241–264. DOI:<https://doi.org/10.1177/0306312712471581>.
- [4] DiSalvo, C., Lukens, J., Lodato, T., Jenkins, T. and Kim, T. 2014. Making public things: how HCI design can express matters of concern. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (2014), 2397–2406.
- [5] Ehn, P. 2008. Participation in design things. *Proceedings of the tenth anniversary conference on participatory design 2008* (2008), 92–101.
- [6] Ethics for Designers: 2017. <https://www.ethicsfordesigners.com/>. Accessed: 2019-01-04.
- [7] Ienca, M., Fabrice, J., Elger, B., Caon, M., Pappagallo, A.S., Kressig, R.W. and Wangmo, T. 2017. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. *Journal of Alzheimer's Disease*. 56, 4 (2017), 1301–1340.
- [8] Ienca, M., Wangmo, T., Jotterand, F., Kressig, R.W. and Elger, B. 2018. Ethical Design of Intelligent Assistive Technologies for Dementia: A Descriptive Review. *Science and Engineering Ethics*. 24, 4 (Aug. 2018), 1035–1055. DOI:<https://doi.org/10.1007/s11948-017-9976-1>.
- [9] Kenigsberg, P.-A., Aquino, J.-P., Bérard, A., Brémond, F., Charras, K., Dening, T., Droës, R.-M., Gzil, F., Hicks, B. and Innes, A. 2017. Assistive technologies to address capabilities of people with dementia: from research to practice. *Dementia*. (2017), 1471301217714093.
- [10] Lazar, A., Edasis, C. and Piper, A.M. 2017. A Critical Lens on Dementia and Design in HCI. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17* (Denver, Colorado, USA, 2017), 2175–2188.
- [11] Le Dantec, C.A., Poole, E.S. and Wyche, S.P. 2009. Values as lived experience: evolving value sensitive design in support of value discovery. *Proceedings of the SIGCHI conference on human factors in computing systems* (2009), 1141–1150.
- [12] Mahoney, D. 2018. DEVELOPING ASSISTIVE TECHNOLOGIES FOR PERSONS WITH DEMENTIA AND THEIR CARERS: THE ETHICS OF DOING GOOD, NOT HARM. *Innovation in aging*. 2, Suppl 1 (Nov. 2018), 51–52. DOI:<https://doi.org/10.1093/geroni/igy023.192>.