
HCIxDementia Workshop: Engaging People Living with Dementia

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Abstract

Increasingly, HCI researchers are recognizing the challenges and opportunities of designing with and for people living with dementia. Recent critiques have highlighted the limited ways people with dementia are engaged in the research and design process. The second CHI HCIxDementia workshop will focus on engagement with and by people living with dementia. Through interactions with local community organizations and people living with dementia, workshop attendees will explore design possibilities. Building on open questions from the CHI 2017 workshop, this workshop will address how HCI researchers can support people living with dementia in engaging as leaders and with research, industry, and the community.

Author Keywords

Dementia; citizenship; agenda-building; human-centered design; engagement.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

Background

As the population ages, the percentage of people living with dementia is growing worldwide. Accordingly,

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CHI'18 Extended Abstracts, April 21–26, 2018, Montreal, QC, Canada
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ACM ISBN 978-1-4503-5621-3/18/04.
<https://doi.org/10.1145/3170427.3170613>

dementia is increasingly a focus for researchers, policy makers, and healthcare systems across the globe. In HCI, research on aging and dementia is undergoing a radical shift. Researchers are acknowledging how aging has been framed in terms of decline and deficit [1,3,5,9], and that products aimed at older people are often designed “for” rather than “with” and very rarely “by” individuals in this population [8]. This passive and potentially negative positioning is particularly prevalent in work relating to dementia. Recent studies have emphasized the potentiality and abilities of people living with dementia to contribute to research and called for a re-envisioning of how we think about dementia in HCI [4,7].

Technology, Design, and Dementia

CHI 2017 hosted the inaugural “HCIxDementia Workshop: The Role of Technology and Design in Dementia” [6]. This workshop offered a way to index existing research and to establish an agenda for HCI-related research involving people living with dementia. It also set up a network of international, interdisciplinary researchers working in this area. Twenty-five researchers shared research findings and perspectives on design and dementia in HCI. Themes discussed included the importance of understanding local and cross-cultural experiences; the role of creativity; and personhood and citizenship in relation to living with dementia. Over the two-day workshop, attendees engaged with local members of the community in the Denver area, including individuals involved in dementia care, dementia-friendly community initiatives, and organizations promoting involvement in meaningful activities for people with dementia. Open questions that emerged during the workshop included:

- How can alternative innovative and creative modes of engagement be established that focus on potential and possibility?
- How do researchers take into account changes in physical, cognitive, communicative, and perceptual functions and engage ethically and promote dignity with people at all stages of dementia?
- How can design support normalcy in the spaces of daily sociability of everyday life for people living with dementia, such as in leisure activities and public transport use?
- How do researchers navigate the complexity of needs, preferences and rights of both people living with dementia and the often-opposing needs and actions of family members, health care providers, and care staff: such as supporting autonomy, offering protection, and negotiating risk aversion?
- How can technology and design support social and cultural engagement that focuses on current and changing needs and preferences of people with dementia and facilitates access and inclusion in society at all levels?

Workshop Themes

Building on the themes and questions raised during last year’s workshop, and in line with the CHI 2018 theme “Engage with CHI,” this workshop will explore differing perspectives on engagement in relation to dementia. Attendees will explore the complexities of dementia and investigate how existing approaches in research and design (e.g. inclusive and person-centered design) can facilitate greater engagement in the design process for people with dementia. This will be examined through four perspectives: engaging with research, engaging with industry, engaging as leaders, and engaging with the community. Including individuals outside of the CHI

community is essential to developing these perspectives and so Montreal-based companies, non-profits (e.g. Alzheimer's Society), and individuals with dementia have been invited and are committed to attending the workshop.

Engaging with Research

HCI research is moving from designing *for* people with dementia to recognizing people with dementia as equal partners in design and research. As this shift occurs, there is a need to reconsider existing approaches to how we engage, interact with and refer to research participants [10]. This workshop will explore alternative methods for engaging people with dementia in HCI research, such as drawing on creative approaches used in other fields, acknowledging the importance of embodied interactions and experience, and reflexively considering the role of the facilitator or researcher in the process. Participants will be invited to work alongside people living with dementia to address how interaction might occur between researchers and people living with dementia to further the design and development of technologies that meet real needs and preferences.

Engaging with Industry

Research and design findings gain impact as they are made available and translated to industry. Researchers in academia have been developing strategies to engage people with dementia in the design process, but this is still less common in industry. Industry strengths lie in the ability to concretely impact the lives of large segments of the population through engaging locally, nationally and globally, and with national organizations, such as the Alzheimer's Society. At times the goals of academia and industry conflict. For example, current

research in relation to design for dementia promotes personalization and customization and recognizes individual wants and needs. In contrast industry has often seen, a "one size fits all" approach as a more feasible strategy. More work is needed to fully understand these seemingly different and contradictory perspectives. Furthermore, a greater understanding is needed to balanced and map these perspectives to allow for knowledge translation and transfer to occur between people with dementia, HCI researchers, and industry practitioners [2]. Through discussion with industry attendees from the local area, participants will identify tensions that arise when reconciling the potentially contradictory goals of academia and industry research and development. Strategies to navigate these tensions will be shared and discussed.

Engaging as Leaders

Many of the initiatives in design for dementia have been led by researchers, designers, and technologists setting up projects and engaging with dementia communities and stakeholders. However, even as we work to engage people with dementia in research and industry projects, we must also recognize that individuals with dementia may wish to lead their own research or design projects. As incidences of dementia increase we will see more people who *are* designers, technologists, artists and activists living with dementia themselves. These individuals may use their experience to engage as project leads as opposed to partners in coproduction. Facilitating this kind of engagement has the potential to provide important insights into the design priorities of people living with dementia. How can we design tools and platforms to enable people with dementia to be more engaged as leaders of the design and development process?

Engaging with the Community

The concept of citizenship in dementia extends design beyond the supporting of individual physical, cognitive, and emotional needs to supporting individuals to be an active engaged member of their communities [1]. Research shows engagement with the community is associated with a high quality of life and aligns with moves within the broader population to make civic engagement accessible and democratic as shown through a push to online engagement and recent work in HCI on digital civics. For example, social media technologies are used by many groups to organize social movements online. Work is needed to understand the tensions that such approaches can bring about when they interact with approaches to dementia that aim to protect (e.g. maintain privacy and anonymity, proxy decision making) compared to those that aim to support autonomy (supporting full agency of people with dementia). Workshop participants will explore concrete ways that technology can both support and limit the involvement and active participation of people with dementia in the community, how tools are currently being used by people with dementia, and how might these tools be made more suitable.

Organizers

Amanda Lazar is an Assistant Professor in the College of Information Studies at the University of Maryland in College Park. Her research focuses on the ways that technologies position and support individuals with dementia.

Austin L. Toombs is an Assistant Professor in the Department of Computer Graphics Technology at Purdue University. He studies the impact that digital technologies have on how communities develop, are

maintained, and foster (or not) the development of strong interpersonal relationships, including how those technologies are implicated in explicit and implicit forms of care.

Kellie Morrissey is a Career Research Fellow at Open Lab at Newcastle University, where she leads the Digital Social Care theme. Her research explores how the collaborative and sensitive design of new technologies can uncover tensions at the intersection of health and politics, particularly in ageing and dementia.

Gail Kenning is a Researcher at the University of Technology Sydney (UTS); Design United Research Fellow at University of Technology, Eindhoven (TU/e), Netherlands; Honorary Reader in Design for Ageing and Dementia at Cardiff Metropolitan University, Wales, UK; and Visiting Fellow at the Museum of Applied Arts and Sciences, Sydney (MAAS). She has published in journals including *Continuum*, *Media International Australia*, *Textile: Cloth and Culture* and *Leonardo*. Her research explores creative inclusive approaches to design for dementia and how technology can support older people and people living with dementia.

Jennifer Boger is an Assistant Professor in the Department of Systems Design Engineering at the University of Waterloo and the Schlegel Research Chair in Technology for Independent Living at the Research Institute for Aging. Jennifer is engaged in the collaborative creation of a wide variety of technologies that support independent aging, well-being, and quality of life, with a focus on supporting people living with dementia and their care partners.

Rens Brankaert is an Assistant Professor in the Department of Industrial Design at the University of Technology Eindhoven. His studies revolve around design (research) for active and healthy ageing, with a specific focus and interest for dementia. In this research, he focuses on inclusive design processes, suitable (interaction) design and multi-stakeholder involvement. He aims to perform research as much as possible in the field, by applying Living Lab methodology.

Community Attendees

In order to move this agenda on dementia, design, and technology forward, it is essential to include a number of groups outside of academia. An important element of last year's workshop which attendees reported as beneficial was interacting with local experts including the Alzheimer's Association (Denver chapter) and "Dementia friendly Denver". This year, engagement with people living with dementia and local care and industry organizations is a key aspect of the workshop and will directly impact the form of the workshop. The workshop organizers have secured a commitment from several organizations to be involved in the workshop and offer applied and lived perspectives on dementia and the role of technology and design.

Pre-Workshop Plans

In the months preceding the workshop, we will promote the workshop through a number of listserves, including one that we formed with last year's participants. We will populate our website hcixdementia.umd.edu with a workshop structure and call for papers. We will work continuously with the attendees from the local community to ensure the workshop structure is

appropriate for their needs (e.g., activities may need to be structured in open ways to allow for the comfortable participation of people with dementia), and to arrange a suitable venue.

Workshop Structure

The workshop will be structured as follows:

Day1

9:00-10:30 Welcome and introductions

10:30-11:00 Coffee Break

11:00-12:30 Group discussions about position papers.

11:30-1:00 "Engaging with research" theme

1:00-2:30 Lunch

2:30-4:00 "Engaging with industry" theme

4:00-4:30 Coffee break

4:30-5:00 Synthesize discussion and identify open questions and next steps

Day 2

9:00-10:30 "Engaging with the community" theme

10:30-11:00 Coffee break

11:00-12:30 "Engaging as leaders" theme

12:30-2:00 Lunch with community attendees

2:00-3:00 Consolidate discussion from all workshop themes and identify open questions and next steps

3:00-3:30 Coffee break

3:30-5:00 Workshop evaluation and discussion about workshop outputs

5:00-7:00 Dinner with attendees and community representatives (optional)

Post-Workshop Plans

The primary output from this workshop will be a co-created research agenda which will be informed by a) critical examination of extant research literature, b)

discussions centered around the four workshop themes, and c) documentation of concerns from community members and people with dementia with specific regard to work that has already been done. This will be disseminated in a special issue of a journal, where the agenda from this workshop will foreground individual submissions from workshop attendees, as well as from a wider research community. Additionally, industry and academic articles will examine the engagement between researchers, industry, community organizations, and people living with dementia during the workshop. Community partners will mutually benefit from their participation in the workshop through the co-creation of a resource that responds to discussions in the workshop.

Call for Participation

Dementia has increasingly been a topic of interest for the HCI community. Recently, there have been calls to attend to the ways by which researchers engage with people with dementia. This two-day workshop brings together HCI researchers, industry researchers, community groups, dementia-focused organizations and people living with dementia. Attendees will discuss extant research and experiences in relation to engaging people with dementia in research, industry, as leaders, and in the community. The goal of this workshop is to consolidate existing research within the area in order to co-create – with community members – a research agenda for the future which responds to real life challenges and opportunities brought about by a diagnosis of dementia. More details regarding the workshop can be found at our website: hcixdementia.umd.edu.

We invite researchers interested in participating to submit 2-4 page position papers (ACM Extended Abstract format). Papers should respond to at least one of the themes of the workshop. Submissions should be sent to lazar@umd.edu in .pdf format. Position papers will be reviewed based on relevance to the workshop and the potential for contributing to discussions on the research agenda to be developed during the workshop. At least one co-author of each accepted paper should attend the workshop and one day of the conference.

Important Dates

Submission Deadline: February 2nd 2018

Notification: February 22nd 2018

Workshop Dates: April 21st-22nd 2018

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